Rumors and Realities: Making Sense of HIV/AIDS Conspiracy Narratives and Contemporary Legends

Jacob Heller, PhD

The social context of the early HIV/AIDS epidemic in the United States provided fertile ground for rumors about transmission. Today, however, rumors about HIV/AIDS persist only within the African American public. Focus group and public discourse data reveal the content and distribution of HIV/AIDS origin and conspiracy rumors. Rumor and contemporary legend theory allows reinterpretation of rumors as a measure of trust between the African American public and health professionals, not as evidence of ignorance or of historical racial oppression. To improve public health results in the African American community, HIV/AIDS efforts must acknowledge the sources and meanings of rumors, include rumors as a measure of trust, and address the underlying distrust that the rumors signify. (*Am J Public Health.* 2015;105:e43–e50. doi:10.2105/AJPH. 2014.302284)

Despite major advances in knowledge about the HIV virus, modes of transmission, and treatments that can reduce viral load and extend life, the spread of HIV among African Americans, especially African American men who have sex with men, has remained stubbornly resistant to interventions. As of 2006, 48.1% of new HIV infections in the United States were attributable to male-to-male sexual contact; African Americans had an HIV prevalence rate of 1715.1 per 100 000 (2388 per 100 000 for men and 1122 per 100 000 for women), whereas the rate for Whites was 224.3 per 100,000 (394 per 100 000 for men and 62.7 per 100 000 for women).¹ These persistent high rates among African Americans run counter to the experience of most populations in the United States, for whom better knowledge about HIV/AIDS has led to reductions in morbidity and mortality, as shown in the following diagram:

scientific knowledge \rightarrow education \rightarrow behavior changes \rightarrow reduced infection rates

These relationships, however, work only if people trust the sources of official information. This applies equally to prevention and treatment: no HIV/AIDS program that requires action by the public—however valid or well-originated can succeed when people distrust the program's sponsors or the sources of information about the disease. Understanding the forces that cause and sustain distrust among African Americans is essential to reducing rates of HIV infection, and this requires recognition of the role of HIV/AIDS rumors—their origins, spread, and capacity to resist contrary information.

Initially, AIDS rumors were widespread, because the social context provided what rumor theorists have identified as fertile ground for the growth and persistence of rumors: a dearth of trusted information in conjunction with high levels of social anxiety.^{2,3} Furthermore, the trust and knowledge networks that support rumors are typically bound by the same elements of social stratification that constitute racial and ethnic identities and subgroups; people circulate stories to people they know and trust, and only retell stories with meaning or resonance.3,4 Rumors about HIV/ AIDS proliferated throughout US society: only gay people can get AIDS⁵; you can catch it from a doorknob, a toilet seat, or a swimming pool; flying insects can transmit it; women are tricking men into having sex with them so they can give them AIDS⁴; AIDS was developed by the Central Intelligence Agency (CIA) to kill off African Americans and gays⁶; it's not caused by a virus at all.⁷ As the emerging HIV/AIDS crisis forced scientists and health professionals to change their habits and practices, partly

because of the science of the virus but largely because of effective social activism by AIDS-affected lay groups,⁸ those same groups invested their faith in the health professions community. They demanded action commensurate with the health crisis: scientific knowledge to replace fears, ignorance, and uninformed suppositions. And they succeeded; as solid, official information developed, general anxiety about HIV/AIDS slowly receded, and so did the stories-most HIV/AIDS rumors have disappeared.9 Within the African American community, however, specific rumors continue to persist, rumors that understand HIV/AIDS as a genocidal government plot against African Americans. Moreover, these HIV/AIDS rumors do more than indicate distrust, they reinforce distrust by positing an explanation that assigns responsibility so explicitly: an illness that can be traced to an intentional (and familiar) actor, instead of a social and health problem that is part of an impersonal modernity with complex causes that can leave the individual feeling helpless and hopeless.¹⁰

I collected data from a systematic survey of public discourse and from a series of 6 focus group interviews that I conducted, organized by race/ethnicity among members of a college community, to examine the ways in which HIV/AIDS rumors distribute themselves in some groups—but not others—and serve to sustain distrust. My goals were (1) to establish the uniqueness and pervasiveness of HIV/ AIDS rumors within the African American public, (2) to connect those rumors to the distrust that contributes to continued high HIV infection rates, and with that knowledge, (3) to inform best practices to contend with the distrust and possibly destabilize the rumors.

Experts no longer dispute the facts about the causes and modes of transmission for AIDS; as a direct result, we know how to stop HIV from spreading: through such measures as safe sex,

clean needles, regular testing, and a screened blood supply, although not everyone follows these practices. People who live with HIV (i.e., who are HIV positive) can have productive, long, and relatively normal lives. The scientific consensus about the origins of HIV/AIDS has fewer practical applications, but that consensus carries profound consequences for how information about best practices will be received. Persistent HIV/AIDS rumors and contemporary legends that center on a government-led conspiracy or on genocide theory to explain its origins undermine the acceptance of behaviors that can prevent infection.

Rumors may encourage behaviors that appear ignorant, but the source of conspiracy theory rumors about the origins of HIV/AIDS within the African American community, as with any rumors, is not ignorance, but distrust combined with high social anxiety. To understand the meaning and importance of genocide-conspiracy rumors, one must answer the question of why there are different levels of trust across racial/ethnic groups. The sources of the trust gap may be connected to the lack of sustained and effective funding for and attention to the general health of African Americans, the history of health professions' abuses against African Americans, and the persistence of HIV/ AIDS among African Americans (as the focus group data suggest, some African Americans see the very mention of high infection rates among African Americans as "blaming," which reinforces the sense of distrust). These rumors are simultaneously evidence of a local situation (the level of distrust by one group in the context of one issue) and indicators of the larger social context in which that distrust occurs. The content of rumors about HIV/AIDS is related to the fraught historical relationship between African Americans and mainstream (White) society, and the perceptions of the health professions as agents of White power. Understanding the rumors (and perhaps dispelling them) first requires an understanding of the different roles that collective memory and rumors play in the creation of distrust.

Collective memory research looks at how groups "know" things and sustain memories of traditions and historical events from generation to generation without formal histories or institutional education.^{11–13} Part of the explanation for distrust of health professions and health initiatives stems from the collective memory of racism and discriminatory abuse in US society, a heritage regularly reaffirmed in everyday experience. Collective memory studies fail, however, when it comes to the question of how alternative stories (such as HIV/AIDS conspiracy accounts) might be conveyed. Rumors are not collective memory; they thrive in the absence of commemorative events, memorials, and rituals. There is no evidentiary foundation for the story of the disease as part of a US government or CIA plan to exterminate African Americans.

Although HIV/AIDS transmission rates continue to fall among many demographic groups,¹⁴ rates of new cases within the African American community remain at tragically high levels. The present study found a similar pattern for rumors—declining rapidly among Whites while stubbornly persisting within the African American public. Just as HIV/AIDS has followed different epidemiological courses within different subpopulations, rumors and stories woven around HIV have also covaried by subpopulation with a correlation across group identity, rumors, and HIV prevalence.

METHODS OF DATA COLLECTION

This analysis relies on 2 sources of data. (1) I performed a qualitative review of the public discourse about HIV/AIDS in the "Black Press," on the Internet, and in other public arenas. (The Black Press, which dates to 1827 in the United States, continues to be a media sector that originates in, caters to, and represents the ideas and issues of the African American community.^{15–17} African Americans invest higher levels of trust and research in the Black Press than in the mainstream press; despite large overlap between the two,¹⁸ this suggests that African Americans and Whites in the United States constitute separate audiences.¹⁹) (2) I conducted a series of 6 race/ ethnicity-segregated focus group interviews populated according to the self-identified race/ ethnicity of participants: 2 each for Whites, Hispanics, and African Americans. I identified the public discourse on rumors regarding HIV/ AIDS by tracking down such stories wherever they appeared. This "discursive snowball sampling" led from large searchable databases, newspaper articles, and magazines to advertisements, television shows, and standup comedy

routines—any kind of public reference to HIV/ AIDS rumors or conspiracy stories. Once new sources began reliably referring back to ones already located, it became clear that the search had reached an important level of closure.

I collected focus group data in a series of 6 focus group interviews over a 2-year period with members of a college community in the northeastern United States. Participants ranged in age from 18 to 53 years and skewed heavily toward women, reflecting the population from which they were drawn; 29 individuals participated, and focus groups ranged in size from 3 to 9 participants. I solicited participants by using posters, social networks, and in-class announcements; I organized the individual groups on the basis of sign-ups by prospective participants into 1 of the 3 race/ethnicity groups: African American, Hispanic/Latino, or White. At the conclusion of each interview, participants had an opportunity to ask questions and make additional comments off the record. They also received my contact information for follow-up questions and a 2-page information sheet detailing the "best knowledge and practices" about such topics as what HIV is, the origins of HIV, the evidence connecting HIV and AIDS, how to prevent transmission, and ways to get tested. I recorded digitally and transcribed the interviews.

Participants were prompted to relate, discuss, mention, or retell stories that they had heard; when the discussion lagged or did not develop rumors, as the focus group moderator I used prods, such as "What have you heard about needle exchange programs?" or "Have you ever heard strange stories about who might have been responsible for HIV/AIDS?" Confidentiality was assured (all participants signed consent forms), and no personal information or medical histories were solicited.

THE CONTEXTS FOR ANALYZING RUMORS

According to the Centers for Disease Control and Prevention, the most important variables associated with continued high HIV transmission rates are

 likelihood of having unprotected sex with someone who is either infected with HIV or at high risk for infection,

- 2. injection drug use,
- 3. having another sexually transmitted disease,
- 4. unknown HIV status,
- social stigma associated with being a man who has sex with men, and
- 6. socioeconomic factors that contribute to poor health care.²⁰

All of these address behaviors, however, not social status or attitudes toward health care. Public health research cites 3 explanations for African American "exceptionalism" to HIV/ AIDS prevention efforts. First, the African American community finds itself on the wrong end of a constellation of variables associated with high transmission rates: education, motivation, recognized self-worth, and access to condoms.^{21,22} The second stresses aspects of interpersonal, group, and status-based relationships (e.g., "sex on the down low," describing men who identify as heterosexual but secretly engage in sex with men, even while in relationships with women) that interfere with a host of well-established preventive measures.^{23,24} The third has to do with deep and abiding distrust for the institutions and intentions of Western (US) medicine and public health.²⁵⁻³⁴ Of the 3 explanations, the problem of distrust might seem the easiest to address.

Conventional wisdom posits that education opens the mind, dispels misconceptions, and can change behaviors-a formulation that is generally valid. But to be effective, education efforts require trust. For this reason, using knowledge-"education"-to defeat distrust has been, and is likely to remain, unsuccessful as long as there are high levels of distrust within the African American community.35,36 Distrust reflected and reinforced by cultural narratives-stories, rumors-cannot easily be displaced by information.² Public health efforts to slow the rate of HIV transmission among African Americans cannot succeed without an understanding of how rumors that begin in an environment of distrust develop, persist, and influence behavior.

Distrust based on experience might be addressed by better behavior, promises of future actions, or the simple passage of time. But one of the most problematic features of a distrust based on rumors is that, as narratives, rumors are relatively impervious to falsifiability: you cannot disprove a story told and

retold by a "friend of a friend"-it's "just a story." Recent scholarship argues that conspiracy rumors can no longer be dismissed as the result of a "paranoid style,"37 but should be seen as strategies used by the disempowered to reconceptualize, contend with, or resist mainstream worldviews that contradict lived experiences.^{10,38-40} These interpretations validate conspiracy theory rumors as legitimate discourse, and provide a basis for understanding the power of HIV/AIDS rumors within the African American community. Discounting conspiracy rumors, by contrast, is an example of what Paul Farmer described as unilaterally establishing "the underlying rules and conventions that determine whether [an] account is received as true or false, by whom, and with what material consequences."41(p229) It is better to interpret the information encoded in HIV/AIDS rumors as a form of meaningful "counter-knowledge."40 We need to use the knowledge of how narratives and rumors work as discursive forms to inform our understanding of how best to respond to the very real-not at all discursive-situation in which people's beliefs can interfere with public health efforts.

RUMORS OF GENOCIDE AND DISTRUST IN THE DATA

Evidence of distrust is clearly visible in stories about the origins of HIV/AIDS. The 4 quotations in Table 1 (arranged chronologically) illustrate the range of accounts about the origins of HIV/AIDS and the extent to which different rumors exist among different groups. Two come from the public discourse and 2 from focus group interviews. The first and third quotations, from 1992 and 2012, instantiate the consistent theme found in both public African American discourse and among African American focus group participants. To find a rumor faithfully repeated after 2 decades demonstrates remarkable durability. Substantively, the 2 quotations implicate the government, the main institution responsible for contending with HIV/AIDS, and ascribe intentional, genocidal motives for the creation and epidemiology of the epidemic. Who, finding such stories even mildly plausible, would trust a government agency or program that declares it is working "to help"?

The quotation from 2001 is not a rumor; it is a mainstream press presentation of the consensus scientific findings on the origins of HIV; it contradicts the other 3 quotations. For most people, this explanation is the "authoritative" story of the origins of HIV/AIDS (in some form). White and Hispanic/Latino focus group participants reliably reported it, though sometimes with minor alterations (no one specifically mentioned "the hunting or preparation of meat," for example).

The fourth quotation is an HIV/AIDS rumor that is prevalent among US Whites (it appeared in both White group interviews), and, like many rumors, relates something "I heard"—"a funny story." Like the conspiracy rumors, this story distorts the scientific finding, but it places responsibility for the origins of the epidemic on "somebody who had sex with a monkey"—in Africa. An HIV origin rumor that blames bestiality among Africans comes from a very different relationship to the health professions than one that blames doctors, researchers, and the US government, and also has little effect on the group's status or response to public health advice; it becomes a "funny story."

Dave Chappelle has a comedy routine that satirically calls Africans having sex with monkeys the "scientific explanation" for the origins of HIV/AIDS.⁴⁴ Humor can be effective at mentioning and dismissing rumors, as in this quotation from the NBC comedy *30 Rock*, scripted to be uttered by the sole African American character (played by Tracy Morgan):

Affirmative action was designed to keep women and minorities in competition with each other to distract us while White dudes inject AIDS into our chicken nuggets. $^{\rm 45}$

This is a typical mainstream public rendering of the AIDS genocide rumor; it acknowledges and dismisses the genocide rumor in one succinct statement, turning persistent rumors about US efforts at genocide against African Americans into a punch line. Group social position affects community status and power; it also privileges the presentation (and dismissal) of rumors.⁴¹

The public discourse and focus group findings reveal that an umbrella narrative about HIV/AIDS exists within the African American community: a United States government plot (sometimes spearheaded by the CIA, the military, or health research and public health

Year	Quotation	Source
1992	"I'm convinced AIDS is a government-engineered disease. They got one thing wrong, they never realized it couldn't just be contained to the groups it was intended to wipe out. So now it's a national priority. Exactly like drugs became when they escaped the urban centers into White suburbia."	Spike Lee, in an advertisement for Benetton, in <i>Rolling Stone</i> magazine ⁴²
2001	"People eat chimpanzees," Dr. Hahn said. "We expect that transmissions occurred through the exposure to blood through hunting or preparation of meat."	Excerpt from a <i>New York Tim</i> es article by Gina Kolata ⁴³
2012	"I heard that [the government] took people, Black people, gay people, and made them do research experiments, and said, 'You guys will get paid for this' and actually they're given the virus."	A woman in a focus group interview with Africa American participants
2014	"This is probably not true, but when I was young I heard that somebody had sex with a monkey who had it, yeah-not that I believe it, just a funny story."	A man in a focus group interview with White participants

Note. The 6 focus group interviews were conducted by the author in 2012-2014, with members of a college community in the northeastern United States. The interviews were segregated according to the self-identified race/ethnicity of the participants: 2 interviews each for Whites, Hispanics, and African Americans.

institutions) to invent, plant (or release) the virus, cause an epidemic, and thereby complete the racist project to eradicate African Americans.46 This idea of intentional genocide is the unifying thread running through almost all of these rumors. US celebrities as mainstream as Bill Cosby (in 1991 in the New York Post)47 and Will Smith (in 1999 in Vanity Fair)48 voiced their opinion that the HIV/AIDS epidemic could well be the result of intentional actions, either by the US government or others. The Reverend Jeremiah Wright, who gained national attention as the controversial pastor of Barack Obama's church, railed against the racist power structure in the United States, asserting that "The government lied about inventing the HIV virus as a means of genocide against people of color. Governments lie!"49 In 1990, Essence magazine ran an article entitled "Is It Genocide?" that described the widespread genocide stories about HIV/AIDS and attempted to debunk them, although it also acknowledged that "our whole relationship to [Whites] has been that of [their] practicing genocidal conspiratorial behavior on us . . . from the whole slave encounter up to the Tuskegee study."50(p78) This is a version of the collective memory explanation, but researchers have not found that distrust is correlated with knowledge about the Tuskegee syphilis experiment⁵¹; in focus group interviews, only 1 African American participant was aware of Tuskegee, whereas all were familiar with the genocide rumors.

The genocide rumors have a long history within the African American public. Some of the earliest reports of HIV/AIDS-as-genocide conspiracy rumors appear to have been disseminated by associates of the Nation of Islam (which also sold an alternative AIDS therapy called Kemron, since dismissed by mainstream scientists as useless).⁵² In the early 1980s, rumors circulated within the African American community in Atlanta, Georgia blaming health researchers for the disappearances and killings of young African American boys, purportedly used in experimentation; James Baldwin published a book on the case.⁵³ In 1988, Steve Cokely, then Chicago's coordinator for special projects, pronounced that Jewish doctors were infecting African American infants with HIV.54 The mainstream press eventually picked up on the circulating rumors; in 1990, a New York Times article reported the comments of a rap musician on the Arsenio Hall Show that

AIDS was part of a "clean-up America campaign" intended to hit "target markets" of homosexuals and racial minorities: "I think they definitely have the cure already and I think it was definitely created by some sick person."⁵⁵

These conspiracy rumors have made only rare appearances in the public health literature on HIV/AIDS. A 1991 study examining HIV/ AIDS rumors about transmission vectors (whether it is possible to catch AIDS from a swimming pool, for example) found—and then dismissed as too obscure—a rumor that the AIDS virus had been invented at a US military laboratory; they felt it was too "esoteric" for college students to have heard of it.⁵ The rare studies that have focused on genocide rumors among African Americans have found their impact to be meaningful.^{34,36} Other origin rumors that implicated health professionals enjoyed brief popularity in mainstream discourse (e.g., the *Rolling Stone* article asserting that AIDS was the accidental result of vaccine testing in Africa⁵⁶) and received widespread attention and careful refutation in the professional literature.^{57,58} The audience (and source) for these rumors was the mainstream US population, however.

The data in the present study show the strong connection between distrust, rumors, and behaviors. We know that initiatives that might be uncontroversial with other populations (needle exchange programs, condom availability, sex education) have been met with higher levels of distrust and suspicion among African Americans, and therefore with greater resistance.59-62 In public discourse, programs to slow the spread of HIV have been seen as the equivalent of a "genocidal campaign,"⁵⁹ or, as Calvin O. Butts, III, pastor of the Abyssinian Baptist Church in Harlem, put it, as "cooperating with the devil."^{52(p26)} Here, the conspiracy narrative interprets the stated goal of reducing HIV transmission as a blind designed to do active harm by encouraging injection drug use. Part of this discourse is that drug dealing, generally, is a conspiracy against the African American community's young people-a modified genocide conspiracy.63,64 One African American focus group participant (woman #5)

commented about drug users getting brandnew, clean needles:

How do you know? You see, it goes back to the whole idea of they're purposely spreading this. How do you know they didn't drop some HIV into those needles?

Nearly the same thought came from a participant in a Hispanic group interview (woman #3), who identified herself as African American during the course of the conversation:

I wouldn't trust it. The government has a history of, like, using people as "subjects," in their little experiments. I would think there was something wrong with the needle.

HIV/AIDS genocide stories of this kind both reflect and perpetuate distrust, and that distrust has clear implications for the success of needle exchange programs. Free condom distribution programs don't fare much better. In a discussion among African American participants, the following exchange took place, in response to the prompt "how about free condoms?":

It goes back to the government \ldots . They hand out "NYC" condoms, and how many people believe in those, use those? None. (man #1)

[The condoms] could be faulty. (woman #1)

People might poke holes in them I was in high school and people were like, "You don't know if somebody poked holes in them." ... You hear stories about them, I know speaking to my male friends, that's something that would be their last resort. Plus they say that the condom is not as strong, it may pop easily, and just off basic instinct, people don't trust. (woman #3)

This level of distrust envisions a government that pokes holes in condoms distributed for "safe sex campaigns" and maybe puts HIV into syringes for a "clean needle exchange program." In response to the same prompt, members of a White focus group had a radically different response:

More people will use them if they get them for free. (woman #2)

People feel "a condom is a condom." (man #1)

This contrast reflects a massive difference in trust.

A related thread that appears in the rumors concerns differential treatments and cures. Following Fine's notion of the "Goliath Effect,"⁶⁵ many of the differential treatment rumors focus on the most prominent living African American who is HIV positive, the basketball star Earvin "Magic" Johnson. Here, however, these participants in an African American group interview focused on class rather than race:

I feel [Magic Johnson] has a whole team of people to keep him alive, and when it comes to your, like, average person, they go to the hospital.... This is not taken as seriously. (woman #5)

His private doctors are probably recommending different things from what we could do because we can't afford them. Why am I giving you \$200,000 pills when you can't afford \$200,000 pills? (man #3)

As the discussion of Magic Johnson continued, the notion of an existing cure became inseparable from a conspiracy rumor (albeit cynically profit-driven rather than racist):

I feel like they have the cure, and don't want to give it out. (woman #3)

I definitely do think they have the cure. (woman #2)

They're making so much money like. . . . (woman #1)

It's big business. . . . (woman #2)

[Does anyone get the cure? (moderator)]

Probably the ones that can afford it. (woman #2) [What do you think about Magic Johnson? (moderator)]

I want to say that he got the cure, but he says he has a low viral count... That's basically saying you got the cure, but you're saying it in a good way. (woman #1)

I feel that money talks . . . because he's still alive. (woman #2)

He beat the statistics. (woman #1)

[And that's because of the money? (moderator)] Yeah! (chorus—all participants)

White focus group participants also expressed some skepticism about health professionals and their cynical financial motivations, but they accorded AIDS researchers high status. The prompt "What motivates doctors?" produced the following brief exchange:

Money! (chorus-all participants)

I think some of them got into it for the right reasons.... I think [AIDS] doctors are more highly regarded.... That doctor in that situation would be something that you would ... want to help. (man #1)

Focus group interview conversations among self-identified Hispanic/Latino participants exhibited a more complicated set of stories, partly because some participants self-identified as Hispanic but explained in the course of the discussion that they were of Afro-Latino of Afro-Caribbean background, or African American. This appeared to correlate with exposure to some of the same stories that are common among African Americans. The context of comments, however, helps reveal the perspective from which participants were speaking. (For example, one woman in a Hispanic interview, who self-identified as Hispanic, at one point said, "as a Black woman") One participant in a Hispanic group interview did report the genocide rumor:

What I remember?... They're trying to get rid of African Americans, mainly starting in Africa, which is why they say it started in Africa but from what I heard it was apparently a manmade disease by the Whites, trying to get rid of the African race. (woman #2)

Interestingly, in the Hispanic groups, the main thrust of discussion was not about conspiracies, genocide, or trust, but about the central importance of education as an explanation of why HIV infection rates were high among racial and ethnic minorities; as the same participant said:

A lot of people that are minorities are not educated, and they should be educated. They don't take the time to teach people, in a lot of places—not in New York. We are, for the most part, educated in sex education. But in other parts of the United States, it's, they don't give them the same education. (woman #2)

By asserting her faith in the ability of education to matter, this participant contextualizes her account of the conspiracy rumor: she trusts education, and the institutions that educate, to be working for the benefit of the people they serve. With this one equivocal exception, the genocide rumors were nonexistent in the White and Hispanic group interviews. HIV/AIDS rumors that were typical in the general population during the early 1990s (e.g., the rumor in which an anonymous malefactor places infected needles in gasoline pumps to prick the hands of unsuspecting motorists), and which reflect general fears of contracting the disease through everyday activities, also appeared only among the African American groups.⁶⁴

UNDERSTANDING THE DISTRUST AS HISTORY OR EXPERIENCED CULTURE

In different and sometimes overlapping ways, the rumors described here can be understood as (1) the result of historical experiences that have engendered distrust, (2) a result of continuing distrust, and (3) an indication of social anxieties associated with the HIV/AIDS epidemic, drug use (as a source of HIV and as an arm of the genocide attempt), and African Americans' place in American society. Establishing a genuinely trusting relationship between the public health professions and the African American community may be the only way to put rumors on the same road to extinction as rumors about mosquitos transmitting HIV.

Establishing trust poses real challenges, however; whether it is a consequence of collective memory or lived experience, African Americans are less likely than nearly any other ethnic or racial group in the United States to trust mainstream institutions.66-68 Specific distrust for health professions adds another multiplier. Fine and Turner cite the example of HIV-positive men who refused azidothymidine (AZT) treatments because they feared "sometimes it accelerates the rate at which full-blown AIDS develops in Black men."69(p63) In 2004. reports circulated that a local health clinic in upper Manhattan was engaged in experimentation on and torture of African American children as part of "hideous experiments by a cabal of plotters including the National Institutes of Health (NIH), the Catholic Archdiocese, GlaxoSmithKline, Columbia-Presbyterian Medical Center."40 Rumors of genocide reinforce and express the other factors that interfere with public health efforts.⁷⁰

The historical origins of African Americans' distrust of health institutions, from the Tuskegee syphilis experiment⁷¹ to myriad cases of egregious exploitation and mistreatment dating back to slavery, are not unimportant for trust.³² Turner argues that HIV/AIDS rumors and contemporary legends are not only based on history, but that they serve as tools of resistance against a genuine sense of threat to the group, including the actual bodies of its members.⁶ On the basis of the historical relationship alone, however, one would expect to find distrust throughout the African American publicwhich does not appear to be the case, as individuals usually trust their own doctors, something evident both in the literature on trust¹² and in the focus group interviews. Research has found no racial differences with respect to acceptance of an HIV vaccine,⁷² for example, and has found that African Americans were more supportive than the general population of volunteering for HIV vaccine trials.⁷³

The connection between conspiracy rumors and so-called "straightforward historical evidence" is problematic, however. A wide variety of scholarly attempts to understand this distrust cite the Tuskegee syphilis experiment as the archetype of racial exploitation in medical research and the basis for the distrust.^{25,50,74-77} Among African American focus group participants in this study, only one referred to the Tuskegee syphilis experiment or even recognized it when queried, and she conflated it with the Tuskegee Airmen. Historical events do not appear to be driving the distrust.

Treatment disparities may play a role in the persistence of distrust, and this was reflected in the focus group data on cures and treatments. Effective antiretroviral therapies are nominally available to everyone in the United States through a variety of federal and state programs, yet access to these drugs varies widely across geographic, political, and demographic boundaries in the United States.⁷⁸ Disproportionately lower spending on HIV/AIDS prevention in African American communities⁷⁹ also contributes to the trust gap. Even statements identifying at-risk groups can trigger anger, because of the implicit implication that there is fault associated with infection, as this excerpt from a focus group interview suggests:

[L]ook at everybody else who has AIDS, it's not mostly Black women who have AIDS, it's ridiculous. . . . So many people have it, but they're trying to say, "Oh, it's mostly Black women spreading it," it's really offensive to me. (African American woman, 2014)

Understanding such distrust as part of a reasonable response to underfunded and poorly designed programs is neither a complete nor a satisfying explanation, however: when funding is low, it makes sense to ask for more funding, not to reject efforts that are already funded. As with the legacy of historical abuses, underfunding may contribute to African Americans distrust of medical institutions,³² but until we understand the full range of causes and mechanisms for the distrust, health professionals will continue to confront difficulties irrespective of objective measures of validity. People who distrust can't be reassured by evidence they deem untrustworthy.

CONCLUSIONS

As the HIV/AIDS crisis begins its fourth decade, with ambiguities about origins, transmission, and treatments resolved in most sectors of society, there is some concern that the general population has become complacent about HIV/AIDS.⁸⁰ The persistence of genocide rumors within the African American public found in this research, however, demonstrates that for African Americans, social anxieties have not been addressed; high HIV infection rates don't appear to be the result of complacency. Changing behaviors will change infection rates, but behavior changes ultimately rely on trust. The nature of the rumors that developed in the African American public was never the same as those in the general population. One thing that is challenging about their existence and persistence is not their agreement or disagreement with views of historical events but their apparent independence of history.

Misunderstanding distrust can compound distrust. In terms of epidemiology, US health professionals typically respond to the HIV/ AIDS origin conspiracy stories both correctly and counterproductively. When health professionals see conspiracy rumors as evidence of ignorance that interferes with efforts to change behaviors, they risk reifying the trust gap, by labeling the person (the nonexpert) who has concerns as "ignorant." To dismiss or ignore genuine concerns about racial health disparities because they express themselves through distrust of logical, salient, and valid health professions initiatives confuses cause and effect. Thus, the conversation can become a struggle about who gets to control the tone and content of the discourse, and the side that suffers the depredations of the disease is also expected to surrender the discursive disputation about meaning-about the lived experience of a social group burdened with racism.

There are 3 important approaches to understanding the rumors about HIV/AIDS in the African American community. For folklorists and for a deeper understanding of the social and cognitive dynamics that underlie the rumors—understanding the origins, meanings, and methods of propagation is inherently important. Addressing the causes of rumors about the origins and transmission of HIV/AIDS

forms the basis of the research presented here, because their genealogy is inextricably linked to their meaning to the people who hear them, tell them, (sometimes) believe them, and engage in associated behaviors. Second, there is the information that rumors reveal about the anxieties and concerns of the communities where they persist. Clearly, the segments of the African American public (which may be among the most educated segments) that have sustained HIV/AIDS genocide rumors for decades continue to experience substantial social anxiety about extermination, particularly of the type identified in the United Nations resolution of 1949: threats to bodies, unique culture, and social identity.⁸¹ Finally, by understanding what rumors are and the legitimate anxieties they represent, it becomes possible to reframe "ignorance" as "counter-knowledge," and move beyond "education" toward the kind of cooperation (albeit contentious and at times combative) that raised the level of mutual trust between the US gay (White) community and research and public health institutions. Having suspicions of public institutions and an abiding distrust for official sources of knowledge about HIV/AIDS is not illegitimate. The question facing public health professionals is how to contend with the situation that the analysis of these rumors reveals.

Of course, there are no easy solutions. Distrust that is woven into the fabric of a society stratified by race cannot easily be undone. As stories, however, rumors are mutable and can fade-they are more symptom than cause. More effective public health interventions will require a reconceptualization of HIV/AIDS rumors and narratives not as "mistakes," or evidence of ignorance or errors of cognition. Rather, genocide conspiracy rumors and narratives within the African American public make more sense as what Waters called examples of "ethnosociology," with the understanding that "believers will be better acquainted with the social facts that are explained by conspiracy theories."82(p117) A measure as simple as ascertaining the prevalence of rumors in a particular community where an HIV/AIDS initiative will be undertaken-through focus groups with a crosssection of community members-can alert public health workers to the level of distrust (detecting rumors as a measure of distrust).

Even providing a forum where rumors can be openly spoken about may also help displace them. In this research, off-the-record comments by participants expressed relief and pleasure at having had a chance to participate in discussions where they could speak freely and without judgment about the stories they recounted.

No magic bullet can defeat rumors, but acknowledging the social facts about their origins and effects, and tracking changes in rumors, are necessary first steps to contending with them as part of the real social landscape in which public health education and other measures take place; rumors are neither static or epiphenomenal. Ultimately, only greater trust within the community can reduce the underlying function that rumors serve. Until that happens, awareness of the role, implications, and prevalence of rumors must inform and assist efforts by health professionals to contend with the preventable spread of HIV/AIDS.

About the Author

Jacob Heller is with the Sociology Department, SUNY College at Old Westbury, Old Westbury, NY.

Correspondence should be sent to Jacob Heller, Rm 2031, Sociology Department, SUNY College at Old Westbury, Old Westbury, NY 11568-0120 (e-mail: hellerj@ oldwestbury.edu). Reprints can be ordered at http://www. ajph.org by clicking the "Reprints" link.

This article was accepted August 6, 2014.

Acknowledgments

Earlier versions of this research were presented at the annual meeting of the American Sociological Association; August 14–17, 2010; Atlanta, GA; and the 2012 annual meeting of the Eastern Sociological Society; February 23–26; New York, NY.

Thanks to the anonymous reviewers' helpful and constructive comments, and to Amanda Frisken for her detailed and diligent reading and feedback of numerous versions of this article.

Human Participant Protection

This research activity was approved by the Old Westbury College institutional review board.

References

1. Centers for Disease Control and Prevention. HIV Prevalence Estimates–United States 2006. *MMWR Morb Mortal Wkly Rep.* 2008;57(39):1073–1076.

2. Allport GW, Postman L. *The Psychology of Rumor*. New York, NY: Henry Holt & Co; 1947.

 Shibutani T. Improvised News: A Sociological Study of Rumor. Indianapolis, IN: Bobbs-Merrill Educational Publishing; 1966.

4. Kimmel AJ, Keefer R. Psychological correlates of the transmission and acceptance of rumors about AIDS. *J Appl Soc Psychol.* 1991;21(19):1608–1628.

5. Fumento M. *The Myth of Heterosexual AIDS*. New York, NY: Basic Books; 1990.

 Turner P. I Heard It Through the Grapevine: Rumor in African American Culture. Berkeley, CA: University of California Press; 1993.

7. Duesberg P. *Inventing the AIDS Virus*. Washington, DC: Regnery; 1996.

8. Shilts R. *And the Band Played On*. New York, NY: St Martin's Press; 1987.

 Osmond DH. Epidemiology of HIV/AIDS in the United States. HIV In site knowledge base chapter. 2003. Available at: http://hivinsite.ucsf.edu/InSite?page=kb-01-03. Accessed February 2, 2010.

10. Knight P. Introduction: a nation of conspiracy theorists. In: Knight P, ed. *Conspiracy Nation*. New York, NY: New York University Press; 2002:1–20.

11. Foucault M. Language, Counter-Memory, Practice: Selected Essays and Interviews. Ithaca, NY: Cornell University Press; 1977.

12. Halbwachs M. *On Collective Memory.* Chicago, IL: University of Chicago Press; 1992.

13. Zelizer B. Reading the past against the grain: the shape of memory studies. *Crit Stud Mass Commun.* 1995;12(2):214–239.

14. Chicago Dept of Public Health. *STI/HIV Surveillance Report, 2011.* Chicago, IL: City of Chicago; 2011.

15. Wolseley RE. *The Black Press*. Ames: Iowa State University Press; 1990.

 Pride A, Wilson CC II. A History of the Black Press. Washington, DC: Howard University Press; 1997.

17. Washburn PS. *The African American Newspaper: Voice of Freedom*. Evanston, IL: Northwestern University Press; 2006.

 Gandy OH. Audience construction: race, ethnicity and segmentation in popular media. Paper presented at: 50th Annual Conference of the International Communication Association; June 7, 2000; Acapulco, Mexico.

19. Gibbons RA, Ulloth D. The role of the Amsterdam News in New York City's media environment. Journal Mass Commun Q. 1982;59:451-455.

20. Centers for Disease Control and Prevention. 2009. HIV and AIDS among gay and bisexual men. CDC fact sheet. December 2013. Available at: http://www.cdc. gov/nchhstp/newsroom/docs/CDC-MSM-508.pdf. Accessed February 2014.

21. Holtgrave DR, Crosby RA. Social capital, poverty, and income inequality as predictors of gonorrhea, syphilis, chlamydia and AIDS case rates in the United States. *Sex Transm Infect.* 2003;79(1):62–64.

22. Gebbie KM. Policy watch. Vaccines don't work without people, where do you go for information? *AIDS Read.* 2007;17(9):465–466.

23. Airhihenbuwa CO, Webster JD, Titilayo OO, Shine R, Smith-Bankhead N. HIV/AIDS and the African-American community: disparities of policy and identity. *Phylon.* 2002;50:23–46.

24. Millett G, Malebranche D, Mason B, Spikes P. Focusing "down low": bisexual black men, HIV risk and heterosexual transmission. *J Natl Med Assoc*. 2005;97(7 suppl):52S–59S.

25. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *Am J Public Health*. 1997;87 (11):1773–1778.

26. Sengupta S, Strauss RP, DeVellis R, Quinn SC, DeVellis B, Ware WB. Factors affecting African-American participation in AIDS research. *J Acquir Immune Defic Syndr*. 2000;24(3):275–284.

27. Pickle K, Quinn SC, Brown JD. HIV/AIDS coverage in black newspapers, 1991–1996: implications for health communication and health education. *J Health Commun.* 2002;7(5):427–444.

 Corbie-Smith G. The continuing legacy of the Tuskegee syphilis study. *Am J Med Sci.* 1999;317(1): 5–8.

29. Jacobs EA, Rolle I, Ferrans CE, Whitaker EE, Warnecke RB. Understanding African Americans' views of the trustworthiness of physicians. *J Gen Intern Med.* 2006;21(6):642–647.

30. Mokwunye NO. African Americans, trust, and the medical research community. *Online J Health Ethics*. 2006:3(1). Available at: http://aquila.usm.edu/ojhe/vol3/iss1/3. Accessed September 21, 2014.

 Chambre SM. Fighting for Our Lives: New York's AIDS Community and the Politics of Disease. New Brunswick, NJ: Rutgers University Press; 2006.

32. Washington HA. Medical Apartheid: The Dark History of Medical Experimentation on Black Americans From Colonial Times to the Present. New York, NY: Doubleday; 2006.

33. Petersen LA. Racial differences in trust: what have we sown? *Med Care*. 2002;40(2):81–84.

34. Bogart LM, Thorburn S. Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? *J Acquir Immune Defic Syndr*. 2005;38 (2):213–218.

35. Thomas SB, Quinn SC. The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the black community. *Am J Public Health.* 1991;81(11):1498–1505.

36. Herek GM, Capitano JP. Conspiracies, contagion, and compassion: trust and public reactions to AIDS. *AIDS Educ Prev.* 1994;6(4):365–375.

37. Hofstadter R. The Paranoid Style in American Politics and Other Essays. New York, NY: Vintage Books; 1964.

38. Mason F. A poor person's cognitive mapping. In: Knight P, ed. *Conspiracy Nation*. New York, NY: New York University Press; 2002:40–56.

39. Fenster M. *Conspiracy Theories*. Minneapolis, MN: University of Minnesota Press; 1999.

40. Drugs, disease, denial. June 29, 2005. Available at: http://nypress.com/drugs-disease-denial. Accessed September 21, 2014.

41. Farmer P. *AIDS and Accusation: Haiti and the Geography of Blame.* Berkeley, CA: University of California Press; 1992.

42. Lee S. Benetton advertisement. *Rolling Stone*. 1992;12:2.

43. Kolata G. The genesis of an epidemic: humans, chimps and a virus. *New York Times.* September 4, 2001:F1.

44. Chappelle D. AIDS monkey. Available at: http:// www.youtube.com/watch?v=A-IEzYZMo1k. Accessed September 21, 2014.

45. Pilot (first aired episode) of *30 Rock*, NBC television, October 10, 2006.

46. Fiske J. *Media Matters*. Minneapolis, MN: University of Minnesota Press; 1996.

47. Editorial. Bill Cosby's AIDS conspiracy. *New York Post*. December 4, 1991:26.

48. Zeman N. Will Smith rides high. Vanity Fair. July 1999:88.

49. Dobbs M. Wright's wild charges. *Washington Post.* May 5, 2008. Available at: http://voices.washingtonpost. com/fact-checker/2008/05/wrights_wild_charges.html. Accessed September 21, 2014.

50. Bates KG. Is it genocide? *Essence*. September 1990:76–78, 116, 118.

51. Brandon DT, Isaac LA, LaVeist TA. The legacy of Tuskegee and trust in medical care: is Tuskegee responsible for race differences in mistrust in medical care? *J Natl Med Assoc.* 2005;97(7):951–956.

52. Rosin H. The homecoming: paranoia and plague in black America. *New Republic.* June 5, 1995:21–31.

53. Baldwin J. *The Evidence of Things Not Seen*. New York, NY: Holt, Reinhart & Winston; 1985.

54. Whitfield SJ. An anatomy of black anti-Semitism. *Judaism.* 1994;43(4):341–359.

55. DeParle J. Talk of government being out to get blacks falls on more attentive ears. *New York Times*. October 29, 1990:A12.

56. Curtis T. The origin of AIDS: a startling new theory attempts to answer the question "was it an act of God or an act of man?" *Rolling Stone*. March 19, 1992:54–59, 61, 106.

57. Cohen J. Debate on AIDS origin: *Rolling Stone* weighs in. *Science*. 1992;255(5150):1505.

58. Holden C. *Rolling Stone* rolls over for Koprowski. *Science*. 1993;262(5138):1369.

59. Marriott M. Needle exchange angers many minorities. *New York Times*. November 7, 1988:B8.

60. A strong endorsement for clean needles [editorial]. *New York Times.* September 25, 1995:A14.

61. Schwartzman P. Clergy fears needle exchange plan; proposal to limit HIV spread could encourage drug abuse, pastors say. *Washington Post.* March 1, 2000:M3.

 Klonoff EA, Landrine H. 1997 Distrust of whites, acculturation, and AIDS knowledge among African Americans. *J Black Psychol.* 1997;23(1):50–57.

 Sasson T. African American conspiracy theories and the social construction of crime. *Sociol Ing.* 1995; 65(3–4):265–285.

64. Gas trick upset. Available at: http://www.snopes. com/horrors/mayhem/gaspump.asp. Accessed September 21, 2014.

 Fine GA. The Goliath effect: corporate dominance and mercantile legends. J Am Folklore. 1985;98 (387):63–84.

66. Demaris A, Yang R. Race relations and interpersonal mistrust. *Sociol Spectr.* 1994;14(4):327–349.

67. Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. *Public Health Rep.* 2003;118(14):358–365.

68. Simpson B, McGrimmon T, Irwin J. Are blacks really less trusting than whites? Revisiting the race and trust question. *Soc Forces.* 2007;86(2): 525–552.

69. Fine GA, Turner PA. *Whispers on the Color Line: Rumor and Race in America*. Berkeley, CA: University of California Press; 2001.

70. Quinn SC. Belief in AIDS as a form of genocide: implications for HIV prevention programs for African Americans. *J Health Educ.* 1997;28(suppl 1):S6–S12.

71. Jones JH. *Bad Blood*. New York, NY: Free Press; 1993.

 Zimet GD, Liau A, Fortenberry VD. Health beliefs and intention to get immunized for HIV. J Adolesc Health. 1997;20(5):354–359.

73. Allen MA, Liang TS, La Salvia T, et al. Assessing the attitudes, knowledge and awareness of HIV vaccine research among adults in the Unites States. *J Acquir Immune Defic Syndr.* 2005;40(5):617–624.

74. Reverby S. *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study.* Chapel Hill, CA: University of North Carolina Press; 2000.

75. Maddox AH. The anthrax scare: the Tuskegee Study revisited. *Amsterdam News*. November 1, 2001:13.

76. Zanoni C. The deadly disease: African American men battle HIV/AIDS epidemic. *Amsterdam News*. November 11, 2004;1:31.

77. Zook KB. Special report: the New York City AIDS experiment. *Essence*. February 2007:196–201.

 Pund B, Lefert A. National ADAP Monitoring Project Annual Report. Washington, DC: National Alliance of State & Territorial AIDS Directors; May 2011.

 Kaiser Family Foundation. AIDS drug assistance programs. February 2014. Available at: http://kff.org/ hivaids/fact-sheet/aids-drug-assistance-programs. Accessed February 27, 2014.

 Balán IC, Carballo-Diéguez A, Ventuneac A, Remien HR, Dolezal C, Ford J. Are HIV-negative men who have sex with men and who bareback concerned about HIV infection? Implications for HIV risk reduction interventions. *Arch Sex Behav.* 2013;42(2):279–289.

81. Civil Rights Congress. We Charge Genocide: The Historic Petition to the United Nations for Relief From a Crime of the United States Government Against the Negro People. New York, NY: Emergency Conference Committee; 1951.

82. Waters AM. Conspiracy theories as enthosociologies: explanation and intention in African American political culture. *J Black Stud.* 1997;28(1):112–125.