The Elephant in the Room: AIDS Conspiracies in the Black Community
Robert Fullilove, EdD

There is an elephant in the room in the Black community: it is the widespread belief that the HIV epidemic represents a conspiracy to rid the world of Africans and African Americans. Yet, few studies have assessed how these beliefs might impact HIV programs. Further, HIV prevention strategies have failed to include this discourse in their efforts, and few health education programs have focused on the concerns that underlie this community discourse. This article discusses the manifestations of these conspiracy theories, their role in undermining HIV programs, and a way for these programs to evaluate and respond to these beliefs among their constituents.

In the summer of 2001, the online journal, AIDSScience, published my article, "HIV prevention in the African American community: Why isn’t anybody talking about the elephant in the room?," which built on the earlier writings of Harlan Dalton, Steven Thomas, and Patricia Turner. Since then, I have received responses from a significant number of HIV workers, community advocates, and activists, concurring with my observations and noting how the buzzy buzz regarding conspiracy has affected their work and credibility.

How Reality Supports Conspiracy Theories

The elephant, as the metaphor implies, is not hidden. HIV workers or researchers who make presentations or conduct workshops in the Black community frequently report that the loaded question is inevitably asked: “So . . . Where does this AIDS virus come from anyway?” The question is followed by a discussion of one or more of the conspiracy theories. The content of these theories is less important than the fact that they all suggest that AIDS is ultimately intended to eliminate “undesirables,” and that AIDS equals genocide.

Why are such theories more credible than those offered by AIDS researchers and scientists? One simple answer is that conspiracy scenarios represent an attempt to make sense of the complexities and anomalies that are associated with the epidemic. The facts that make these theories credible have their origin in the disproportionate burden that Blacks and other minorities bear in the epidemic. Many think: “We bear this burden because they are trying to get rid of us.”

How do policies and programs work to create this genocide scenario? The first part of the answer is that data on HIV...
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to conditions—the heroin and crack epidemics—and to the potentially effective solutions—assignment to drug treatment instead of incarceration—that might have prevented HIV from becoming embedded in the Black community. (In the more extreme rendering of this list of events, the drug epidemics are themselves part of the conspiracy because they created the ecological niche for the virus to thrive.)

Acknowledging Doubt

The unique experience of people of African descent in America has left a legacy of mistrust. For many people, that legacy lends credence to the conclusion, “They’re out to get us!” Even those who do not endorse such an explanation may have doubts about the intent of HIV prevention and treatment programs. These doubts may, in turn, be enough to influence the success of these programs.

The conspiracy theories all invoke “them” as the cause of the horror that Black communities confront. “Them” can be anyone or anything ranging from the federal government to other, hidden “powers-that-be,” whose existence is demonstrated by the fact that there is an epidemic raging out of control in the heart of the Black community.

Many readers may shake their heads in disgust at this description, which may invoke images of primitive peoples with primitive world views. Instead of seeing this phenomenon as a challenge to public health education, some may dismiss these observations because—and this is a direct quote from an audience member who heard a presentation on this topic—“Who has time for that kind of ignorance in 21st century America?”

Who indeed? We continue to believe that we are engaged in a battle between “real” facts, “true” facts, and ignorance. So public health policy makers continue to try to re-tool prevention messages that they believe will “break through the barrier of ignorance.” But it seems unlikely that the problem is that people are ignorant and in need of facts. To the contrary, people in these communities have serious, profound doubts based on real history and an all-too-accurate understanding of the effects of both the HIV and drug epidemics.

More importantly, people want their doubts addressed directly. The only way that the problem can be resolved is through an acknowledgement from experts in the HIV world that having doubts is not the same as having the wrong facts. These doubts will not be effectively countered by reasserting the facts and statistics that support a scientific worldview even if these facts and statistics are couched in ever more “culturally sensitive” presentations. HIV services need to acknowledge that facts and figures are subject to interpretation and that science is not the only lens people use to arrive at a personal interpretation of the meaning inherent in the same set of facts.

Enter the Elephant

The elephant in our living room is the failure of HIV policy makers, researchers, and providers to admit that we are not speaking directly to the doubts, beliefs, and fears of many, and that our failure to talk about those doubts only fuels the oft-expressed belief that “They don’t want us to talk about it because their domination and eventual extinction of us is possible only if we are ignorant.”

Significantly, there is empirical evidence that lends credence to these assertions. For example, an article published in the Journal of the National Medical Association—a journal published by the association that represents tens of thousands of African American physicians—presents supporting data from a survey of African Americans on AIDS conspiracy beliefs. Approximately 40 percent of survey respondents “strongly agreed” or “agreed somewhat” with the statement “AIDS is a form of genocide against African Americans.” Twenty-three percent “strongly agreed” or “agreed somewhat” with the statement: “AIDS was created by the government to control the African American people.”

Unfortunately, the survey is not without its flaws. It was conducted by telephone (thus is not representative of those community members who are too poor to afford one) and the sample for the study was small, only 71 respondents. The authors propose that their findings should serve, nonetheless, as the foundation for a
larger study that might explore in greater depth the degree to which such beliefs influence HIV prevention campaigns in the African American community. Time will tell whether or not other studies will, indeed, follow on the heels of this one and provide a direction for the creation of education campaigns that target conspiracy beliefs directly.

**Taming the Elephant on the Frontlines**

In the interim, quality control assessments for people being treated for HIV disease or using HIV prevention services might provide an opportunity to measure how much, and to what extent, such beliefs are present in specific client populations. Focus groups can be particularly helpful, because they are relatively easy to conduct, and in the hands of an experienced focus group leader—preferably one who is not a member of the clinic staff—participants are almost universally willing to share their opinions and beliefs. Many will go so far as to express gratitude that somebody eventually appears to care about these issues enough to raise and discuss them.

The questions that I have used are relatively simple:

- What’s the buzz on the street about HIV and AIDS and where they come from? What do you hear from your family members, your neighbors, or folks you hang with about the origins of the virus?
- Do you think that these explanations make sense? Do you have any opinions that are slightly different from the ones you have mentioned?
- How about the people on staff here at the clinic? Do you have any doubts about the advice we give? If so, what are they?

The trick, of course, is to avoid biasing participant responses by “leading the witnesses” so that they are tempted to endorse points of view that are ostensibly suggested by the focus group leader. To avoid this, it is useful to ask participants to talk about the beliefs of others and then segue into a series of questions about their own beliefs—and the impact these beliefs might have on their relationships with HIV program staff. This approach invariably results in: a list of the local conspiracy theories, a list of personally held theories about the origins of AIDS, expressions of doubt about whether or not they are true, and a variety of responses about the trustworthiness and credibility of clinic staff.

If conspiracy beliefs are prevalent and appear to influence the way in which individuals process what they are told by doctors, nurses, health educators, social workers, and case managers, the focus groups may also facilitate the development of appropriate responses to the service challenges that have been identified. Finally, if focus groups are done once or twice a year, clinic staff will be able to measure how much and to what degree remedial efforts—should they be warranted—are working.

**Conclusion**

The challenge that confronts us is not to “disprove” the existence of an AIDS conspiracy. Rather, it is to proactively confront the doubts that such beliefs may raise, and in so doing, to improve the effectiveness of HIV prevention and treatment interventions.

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**Clearinghouse: HIV and Black People**

**References**


Labels have power. They mean different things to different people and can lead to misunderstanding and misinformation. An HIV-infected Black man says "No" when asked if he is gay. But in response to the question, "Have you ever had sex with another man?" he answers, matter-of-factly, "Why, yes!"

Labels such as "gay," "bisexual," and "heterosexual" carry social implications that do not aid in discussions between people, whether the participants are in a client-provider relationship or are sex partners. Epidemiologists working in HIV data collection use the not-so-popular label "men who have sex with men," precisely because it describes the behavior and does not label the person.

In the Black and Hispanic communities in the United States, there is a significant proportion of men who have sex with both men and women but who do not tell their female partners about their bisexual behavior. Much has been written recently about this group of men, their HIV-related risks, and the failure of gay-focused prevention interventions to reach them. But little has been said about the risks their female partners face. This article reviews a recent U.S. study on this topic.

**More men of color are behaviorally bisexual than disclose this fact to female partners, but these men should not be vilified.**

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**Survey of HIV-Positive People**

Researchers from the Michigan Department of Community Health and the Centers for Disease Control and Prevention analyzed supplemental HIV/AIDS surveillance data collected between January 1, 1995 and June 30, 2000. Health department staff from 12 sites across the country—Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, New Jersey, New Mexico, South Carolina, Washington, and Los Angeles—interviewed HIV-positive people who were reported to the public health department.

Among the interview questions were: "Have you had sex with a man in the last five years?" and "Have you had sex with a woman in the last five years?" Answers given by the 5,156 male respondents were stratified by race and ethnicity and used to assign men to one of two mutually exclusive behavioral groups: men who have sex with men only or men who have sex with both men and women.

The study also examined self-reported sexual behavior among women who reported that they had sex with a man in the last five years. These women were asked "Have you had sex with a bisexual man in the last five years?" This information was stratified by race and ethnicity and measured the extent to which women were aware of bisexual identity or behavior in male partners. These women were not the matched sex partners of HIV-infected behaviorally bisexual men. Among 3,139 interviewed women, 240 reported having sex with a bisexual man.

**Partner Knowledge of Male Bisexual Behavior**

The study found that the proportion of HIV-positive men who have sex with men who also reported having sex with women in the previous five years varied by race and ethnicity: 34 percent among Black respon-
dents, 26 percent among Hispanic respondents, and 13 percent among White respondents. These racial and ethnic differences, which were statistically significant, are consistent with previous studies measuring the prevalence of bisexual behavior among HIV-positive men who have sex with men.

The proportion of women who contracted HIV through heterosexual sex and who knew that one or more of their male sex partners were behaviorally bisexual also varied by race and ethnicity. Black and Hispanic women were statistically significantly less likely (6 percent each) than White women (14 percent) to be aware that their partners were bisexual. Again, the published literature is consistent with these findings. The study did not measure the proportion of HIV transmission that occurs between bisexually active HIV-positive men and their female sex partners, but the study’s data suggest that it may be greater than the small proportion reported in the Centers for Disease Control and Prevention’s HIV/AIDS surveillance statistics. This suggests that more men, particularly men of color, are behaviorally bisexual than disclose this fact to their female partners, leaving female partners with incomplete information on which to base their risk reduction decisions.

**Microbicides: Protection Against Nondisclosure**

These findings underscore the urgent need to develop female-controlled methods of HIV prevention, methods that do not require women to acknowledge the use of HIV protection to their sexual partners. A number of societal norms come into play to prevent open and honest communication on this topic. Societal scorn about homosexuality and bisexuality on the part of both men and women make it a difficult topic to discuss. Many women may still hold to the myths that a “manly man” could not possibly be having sex with other men, or that a woman would somehow know if her man also desired other men. Even in the best of circumstances, issues of trust, betrayal, responsibility, and gender roles make this a difficult topic for couples to discuss, especially within the context of a long-term relationship.

While waiting for society to become more accepting of same sex relationships, prevention providers need to give heterosexual actively women tools to protect themselves. Topical microbicides are often cited as a solution. Microbicides, several of which are in development, can be applied in the vagina or the rectum and may not be apparent to sexual partners. Some microbicides have anti-microbial activity that does not kill sperm, making them appropriate for the broadest population of women, including those who may want to get pregnant while preventing HIV transmission. In these ways, microbicides have distinct advantages over both the male and female condoms. They have the potential to decrease both male-to-female and male-to-male HIV transmission.

Although several microbicides are in various stages of development, many barriers impede their widespread use. Experience with nonoxynol-9 underscores the need for thorough testing. Although nonoxynol-9 demonstrated in-vitro anti-HIV activity, clinical trials showed that prolonged use was associated with lesions and epithelial disruption, actually increasing the risk of HIV transmission. There has been minimal financial support, either through the government or pharmaceutical companies, to advance microbicide research. Additionally, clinical trials that are deemed ethical, safe, and which have measurable outcomes are a challenge to structure.

**Conclusion**

While the data from this study suggest that the lack of disclosure about homosexual behavior may increase the risk of HIV transmission to heterosexual partners, it is crucial that behaviorally bisexual men, particularly those in the Black and Hispanic communities, not be vilified for their secrecy. Until society accepts the full range of human sexuality as normal, many people will not disclose this behavior. Where do we start to change the cultural norm that views same-sex behavior as deviant? Everywhere and anywhere. In conversations with our children and the attitudes we pass on to them. In conversations with friends. In our houses of worship, where so many turn for support. We must all make efforts to promote more open discussions of sexuality and sexual orientation in all of our communities.

**Comments and Submissions**

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
Recent Reports

African American Media Perceptions of HIV

A content analysis of HIV-related coverage in African American newspapers revealed a pattern of distrust toward both the government and the “AIDS establishment” with regard to the origins of the disease and the level of commitment to eradicate the pandemic.

Researchers defined African American newspapers as those that “serve, speak, and fight for the black minority.” Researchers selected five newspapers representing five metropolitan areas: New York, Chicago, Washington, D.C., Atlanta, and Oakland, Calif. They identified 201 HIV-related articles published from 1991 to 1996, a period during which there were rapid increases in HIV among minority populations.

Researchers analyzed the content of each HIV-related article in terms of four categorical “frames”: some articles were classified into more than one frame category. The moral frame focused on individual behavior. The health frame emphasized HIV prevention and treatments. The political frame examined social, political, or economic forces. Finally, the assets frame addressed solutions for resolving the pandemic.

Though early mass media coverage relied heavily on moral framing, only four articles in this sample used the moral frame, exploring the implications of premarital, extramarital, and unprotected sex. None discussed injection drug use.

Health represented the primary frame for nearly half of the articles. Of these, one-third focused on the need for basic research, one-third explored prevention (though only two articles addressed drug-related prevention strategies), and one-quarter focused on treatment, incorporating issues such as underrep-resenta-tion of African Americans in research trials.

Almost three-quarters of the articles employed a political frame. More than one-third of these articles focused on the need for federal funding for HIV services and research and the cost and accessibility of drugs. Some articles alleged that treatments and information about HIV were either suppressed or manipulated by those in power for personal economic gain. Almost one-third of politically framed articles identify racial bias as a significant factor in the spread of the virus. Five percent of politically framed articles presented the epidemic as a governmental plot toward genocide, while an additional 27 percent assigned indirect responsibility to the government due to budget cuts and political inaction. Five articles addressed the problems of widespread denial and homophobia in the African American community. Finally, 14 percent of the selected articles used an assets frame to highlight the achievements of African American individuals and organizations.

Predicting Risk among African American Men

African American gay men, bisexual men, men of low socioeconomic status, and men experiencing significant psychological distress had higher rates of behaviors that might lead to HIV transmission than other African American men, according to a Los Angeles study of psychosocial predictors of risk in this population.

Between 1993 to 1997, community sources recruited 502 18- to 50-year-old, U.S.-born, African American men differing in sexual orientation, HIV status, and substance use history. Fifty percent of the sample identified as heterosexual, 34 percent as gay, and 16 percent as bisexual. The sample included 308 HIV-negative men and 185 HIV-positive men. Respondents participated in interviews and filled out questionnaires regarding psychosocial factors and sexual risk.

African American men who have sex with both men and women had a higher “mean risk index” than either African American heterosexual men and men who have sex with men. This finding is particularly significant because bisexual behavior represents an important and understudied channel of transmission to the heterosexual community. Furthermore, many bisexual
men in this study reported that their female partners and heterosexual friends were unaware of their bisexuality. High psychological distress—regardless of serostatus—was associated with greater levels of “risky” behavior.

### Comprehension of HIV-Related Information


Heterosexual African American and Latino men and women identified a variety of misunderstandings about HIV and associated risk behaviors during focus groups in the Houston area. Chief among these perceptions was that HIV was created to harm marginalized populations.

Researchers conducted 21 focus groups with 133 subjects in the Houston area. Focus group participants responded to advertisements in places such as gyms, university campuses, and crack houses. Participants ranged in age from 13 to 59 years. Each focus group was homogenous in terms of both race and gender, and was conducted by a facilitator with matching characteristics.

Almost all of the focus groups included expressions of theories of governmental involvement in the origin of HIV. Respondents often claimed that HIV was created as a tool of genocide. Other respondents expressed beliefs that HIV resulted from laboratory experiments that got out of control. Still others insisted that a cure to HIV exists but is being withheld by the government as a further attack on minority populations.

Another widespread theme was the contention that HIV is visible in a person’s appearance. Respondents often cited physical appearance, odor, and personal hygiene as indicators of an individual’s HIV status. Finally, respondents commonly expressed views of HIV as a disease affecting others.

### Gay Men of Color Have Higher HIV Rates


A Los Angeles study found that African American gay men were four times more likely to become HIV-infected than their White counterparts, despite similar or lower levels of HIV-related risk behaviors. Researchers selected 438 23- to 29-year-old gay male Los Angeles County residents during 1999 and 2000. The sample was 53 percent White, 23 percent Latino, 13 percent Asian/Pacific Islander, and 12 percent African American. Participants filled out a standardized questionnaire regarding items such as sexual and drug-use behavior, and HIV testing practices. Interviewers also tested participants for HIV, syphilis, and hepatitis B.

African American men reported lower numbers of recent male partners, lower prevalence of recent unprotected receptive anal sex, and less lifetime injection drug use compared with White men. Of the 51 participants who tested HIV positive, however, a much lower proportion of African Americans (15 percent) were aware of their status compared with the other racial groups:
- Asian/Pacific Islanders (33 percent), Latinos (47 percent), and Whites (59 percent).

In addition, compared with White men, African American men had older partners and more African American partners. After controlling for the effects of these two factors, there was a 20 percent reduction in the relative odds of infection for African American men compared to White men, suggesting that partner type may account for some of the disparity in HIV rates between these two groups. African American men also tended more than other races to have partners of the same race as themselves (“assortative mating”) and to have partners with either much greater risk or much lower risk than themselves (“dissortative mixing”).

**Next Month**

At a time when diminished government spending threatens HIV services, support group approaches—central to HIV care since the beginning of the epidemic—deserve attention as a cost-effective strategy. In the March issue of *FOCUS*, **Marc Wallis, LCSW**, a clinical social worker at the UCSF AIDS Health Project (AHP) and a substance abuse specialist at the University of San Francisco Counseling Center, summarizes the history of support groups and discusses keys to ensuring their success.

Also in the March issue, **John Tighe, LCSW**, the Groups Coordinator of AHP’s primary prevention programs, recounts the design of the program’s Sex and Sobriety Group and the group’s evolution over the course of two years.
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