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HIV prevention in the African-American community: Why isn't anybody talking about the elephant in the room?

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Introduction

Since 1986 I have given numerous lectures, talks, and even sermons to African-American audiences all over the United States about HIV/AIDS. I am an African-American professor at an Ivy League school of public health--which means I am something of a rarity--and I have never failed to get at least a polite response to my presentations.

The talks are rarely as interesting for me as the conversations afterward. Questions, observations, and reflections that rarely, if ever, find their way into a formal presentation inevitably become the real dialogue. Over the course of many years, the tone of this conversation has shifted very little. As I reflect on it, it is evident that I have been part of an ongoing, community-wide discourse about HIV that only occasionally finds its way into print.

This conversation has tremendously important implications for public health campaigns for HIV prevention. Before a comprehensive, effective plan for the prevention of the spread of HIV in African-American communities can be developed and implemented, there must be community-wide recognition of the severity of the HIV/AIDS epidemic and the threat it poses to community life. The key word here is "recognition," which is distinct from being "exposed to information." Exposure we have had, but one awaits a true, unambiguous, community-wide acknowledgement of the seriousness of the threat at the door.

When the HIV/AIDS epidemic began, one of the first strategies in national efforts to spread the word was to bombard communities at risk with posters, pamphlets, and televised public-service announcements about the epidemic. However, since 1993, the Centers for Disease Control and Prevention has reported that new HIV infections have reached a plateau of 40,000 cases per year in the United States (*1*), suggesting, among other interpretations, that we have reached the limit of our effectiveness in using health education as an HIV-prevention strategy. Significantly, although the number of new cases has

remained constant since 1993, the demographic characteristics of the epidemic have changed: The epidemic is now increasingly black and brown and less and less male and white (*1*).

One frequently offered critique of HIV-prevention programs in the United States is that we have not properly targeted prevention messages to reach those at greatest risk. In the African-American community, ostensibly heterosexual men who have sex with men, who do not identify themselves as gay and hide their bisexual behavior--"the brothers who are on the DL [down low]," as we call them--are an obvious example (*2*). These men do not pay attention to messages destined for gay men or, ostensibly, to the messages directed at black heterosexuals (*2*, *3*). I think we African Americans know about HIV/AIDS, but we are ambivalent about accepting the advice, the counsel, and the strongly worded recommendations that are directed at us about how to deal with the epidemic. Put another way, we understand the content and the import of the message. Many just don't trust the messenger.

I am one of the messengers. My wife (Mindy Thompson Fullilove) and I have been doing community-based public health research since 1986, and HIV/AIDS is one of our principal areas of investigation. Through surveys, ethnographies, and a variety of different qualitative research studies, we have probed the data, asked the hard questions, and have tried to listen carefully to what we perceive to be the rich variation in tones that comprise "the community voice" (*4*). Here is what we, and many of our colleagues, are hearing.

The community discourse

The black community--a term I use to group both African Americans and a broad spectrum of people from the African Diaspora who make the United States their home--has been engaged in a dialogue about HIV/AIDS that is a complex mixture of facts, urban myths and legends, and various bits of speculation about the origins of the epidemic and its true meaning for black folks (*5*). At the epicenter of the urban HIV/AIDS epidemic (that is to say, in New York City, and Jersey City and Newark, New Jersey), the epidemic has taken a heavy toll on family, friends, and neighbors. It is rare to find someone in these areas who has not suffered some sort of loss as a result of AIDS.

Although few, if any, dispute the existence of a problem, there is much speculation about what it all means. Discussions about HIV often include the following elements:

- "There are no coincidences. How can it be that both black Africa and black America are simultaneously threatened by the same virus?"
- "Epidemics of heroin and crack cocaine, two important factors in the black American HIV epidemic, didn't just happen, either." As one resident of Harlem once informed me: "The A train don't run to Colombia, so how did they get enough cocaine from there to here to wreck a whole community?"
- "The war on drugs put a lot of community members in jail, where, coincidentally, the highest prevalence of HIV infection in the United States is to be found."

- "Taking anti-HIV medications looks and feels a lot like bad, old-fashioned drug addiction. The drugs have to be taken every day, probably for the rest of one's life. If not taken, horrific consequences ensue. Taken improperly, the drugs can kill, either as a result of side effects or through the creation of a drug-resistant strain." I was once asked: "What's the difference between these medicines and cocaine? With both, your whole day is built around what you got to do to get them and take them, and with both, you be praying every day that they don't finally wind up killing you."

And so on.

Many facets of this community-wide discourse have had destructive, divisive consequences. Community discussions do not stop at speculating about the source of all of this death and destruction. The fear of HIV/AIDS as a gay, white disease has also exacerbated the homophobia that has always been present in black communities (*5*-*7*). In many neighborhoods, it has generated a paralyzing stigma around being HIV infected that has driven many HIV-positive black community residents to hide their status and, in hiding their status, remain out of the clinical centers where the disease might be effectively managed.

But more curiously still, there is a tenacious, collective belief that HIV infection happens to someone else, to "them," the folks who are not at all like me. The stigma, in other words, not only causes great psychological harm to those who are its targets but also creates a barrier that prevents public health messages about risk and HIV prevention from getting through to those who are steeped in this collective denial. Secure in the knowledge that it is those "others" who are affected, many refuse to acknowledge that they might be at risk. I have become convinced after years of working in HIV-epicenter neighborhoods, such as Harlem, that this kind of denial--*HIV infection happens to folks who are not at all like me*--is at the root of many of the new HIV infections among women of color who have no known risk factors.

The way to prevent new HIV infections in these communities is not through better, more tightly focused health-education campaigns, although these efforts will succeed with *many* people who make risky choices about sex and drug use. Not all new infections (or all old ones, for that matter) result from uninformed risk taking. Structural factors--racism, poverty, and inadequate access to health care--also figure prominently among the causes of new and old HIV infections in black communities in the United States. When risk behaviors are largely shaped by social, cultural, and economic forces that are not under an individual's control or will power, simple education campaigns--those directed at changing how people make choices--cannot significantly or substantially reduce risk behaviors.

This is not news. Within the public health discourse about HIV/AIDS, these structural limits on the effectiveness of our behavioral interventions are accepted as a given. Significantly, AIDS policy-makers and researchers are increasingly interested in examining structural interventions for HIV prevention (*8*). There is, however, one institution that is the very exemplar of poverty and racism in the United States, whose role in HIV transmission and prevention cannot be ignored, and that is, in principle, within the scope of our local and national efforts at structural reforms, namely, the prisons. In New York (the state

with 20% of all the AIDS cases nationally), the prisons house a population that is 85% black and Latino (9). These institutions have historically been places where persons at risk for contracting the virus have been housed with persons infected with HIV. Between widely prevalent drug use and both consensual and nonconsensual sex, prisons play a key role in the dynamics of maintaining the infection within poor communities of color (10).

Significant efforts have been made in recent years to reduce the risk of HIV infection in these institutions. Inmates are screened for HIV, those who are either newly tested as positive or are already known to be infected are given rapid access to treatment, and a variety of efforts are made to help infected inmates make the transition between the prison and their communities before they are released (1). However, during the early years of the epidemic, this threat went unrecognized. We may never learn how many new infections were created during the height of the war on drugs as a result of the cycling of inmates from their home communities, to the prisons, and then back into the community where, in all too many instances, the cycle began again.

Many black women cite this cycling in and out of prison as the source of the DL. In its simplest form, it can be understood as one of the sequelae of life in prison. During their tenure as inmates, some black men will have sex with other men in prison, then resume heterosexual behavior when they return to the community. If this hypothesis is correct, then the impact of incarceration on the epidemic deserves much greater focus and study than has been the case to date.

Bisexual behavior in African Americans is, however, not restricted to men who have spent time in prison. Sexuality in the black community in the United States is extraordinarily complex and embraces variations of homo-, bi-, and heterosexual expression that defy easy classification. However, the significant increase in HIV infection among men who have sex with men (1-3)--a label that attempts to group together any male-to-male sexual activity--suggests that, however it might be defined, the number of men having sex with men has become significant and a factor difficult to ignore in the "blackening" of the HIV/AIDS epidemic.

The elephant in the room

As a teacher, I am firmly rooted in the traditions of modern philosophy. I am obsessed with a desire to demonstrate to my students that almost nothing in life is self-evident. We derive meaning from facts by spinning them in ways that fit our notions about how the world operates. When black people--be they from Africa, the Caribbean, or the United States--examine the facts about AIDS, they cannot avoid the sense that HIV just might be a 21st century version of the old-fashioned lynch mob.

I am by no means the first or the only African-American researcher to raise this point. In 1989, in "AIDS in Blackface" (7), one of the most prophetic essays ever written on HIV/AIDS, Harlon Dalton noted, "The black community's impulse to distance itself from the epidemic is less a response to AIDS, the medical phenomenon, than a reaction to the myriad social issues that surround the disease and give it its meaning" (p. 205).

In this spirit I think it would be a useful exercise to list the "myriad social issues" to which Dalton refers and then develop a set of hypotheses about the way in which these facts are likely to be used to form beliefs, attitudes, opinions, and actions related to HIV prevention in the communities that are most affected by the epidemic. Here is a reasonably unbiased, slightly expanded version of the beliefs I listed earlier.

- The epidemic started in black Africa and currently rages there out of control.
- Two waves of drug epidemics in the United States involving heroin and then crack followed closely on the heels of the collapse of the economic fabric of many urban African-American communities.
- These epidemics spawned the creation of the drug dealer as the employer of last resort in the most impoverished areas of the community. Just as all of these developments became dominant features of community life, an infectious disease epidemic appeared that--in black America--preys primarily on drug users.
- A war on drugs was declared by municipal, state, and federal governments, resulting in the incarceration of significant numbers of drug users, the group most at risk of HIV infection.
- Prison life increases the risk of exposure to HIV exponentially and is followed by the release of huge numbers of ex-inmates back into the community.
- Back in the community, many ex-inmates become vectors through which the virus reaches women and the children that many of them will bear to these men.
- The most visible government response is a public health, anti-HIV campaign whose major emphasis is on the use of condoms.

At a community forum in San Francisco a number of years ago, a member of the audience summed this all up when he asked, "If you guys are 100% effective, and everybody be using condoms, what happens to the birth rate? Don't it go down? If we disappear because we're too afraid to make babies, how's that any different than being wiped out by this AIDS thing?"

Members of affected black American communities are bringing various versions of this point of view to every HIV-prevention campaign we in the public health community mount. Whatever is being said is perceived as irrelevant by many listeners because what is being heard is, "Damned if you do, damned if you don't."

So what is the point? It is simple: Nowhere in our national HIV-prevention agenda for the African-American community do we ever confront "the elephant in the room." This proverbial elephant refers to a significant, critical element of a problem or conflict confronting a particular group that is so huge it

cannot possibly be ignored but is, in fact, never acknowledged by group members. Because it is never acknowledged, no effective solution is ever developed. Nowhere do we seriously acknowledge how much the facts of the epidemic pass through a filter in black America that leaves each pamphlet reader, each listener of a public service announcement, each viewer of a televised special on HIV/AIDS to wonder how much of this is real and how much of this is just another element in a genocidal plot to rid the world of "undesirables." As one participant in a Harlem community meeting on HIV/AIDS observed to me, "White folks think AIDS is about a virus; black folks think AIDS is about genocide." The name of the elephant, in other words, is genocide.

In "AIDS in Blackface" (*7*), Dalton wrote at length about the barrier that fears of genocide create for HIV-prevention programs. He wrote, "I have no particular investment in the term genocide; I simply want to jumpstart the conversation that usually dies out whenever the word is deployed" (p. 223).

That was written in 1989. Has the conversation died out? Significantly, the prediction that Dalton made for the future--that "AIDS is rapidly changing from mostly white to predominantly black and brown" (p. 223)--is the reality of the year 2001. What may have appeared as paranoia in 1989 now has the suspicious air of a prophesy come true; or worse, a prophesy that came true precisely because it was ignored.

Elephant-in-the-room jokes are funny because of the absurdity of not talking about something that is too big to ignore. If there is to be an effective partnership between the public health community and the African-American community to prevent HIV infection, we must be able to have an open, undoubtedly painful, discussion about AIDS and genocide. Dalton’s belief that "we African-Americans have been reluctant to ‘own’ the AIDS epidemic, to acknowledge the devastating toll it is taking on our communities, and to take responsibility for altering its course" requires that we begin to have that conversation. It has been 12 years since he wrote those words, but never have they held greater import for our nation’s future.

References and Notes

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