

13 HIV/AIDS in the African-American Community: Changing Concerns, Changing Behaviors

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For some time, the devastating impact of the HIV epidemic on the gay male community has been known. Yet it was not until almost 6 years into the epidemic that the research community first began disseminating statistics alerting the public to the havoc this disease would manifest among African Americans (Bakeman, McCray, Lumb, Jackson, & Whitley, 1987; Centers for Disease Control, 1987; Friedman et al., 1987; Mays & Cochran, 1987). Using the Centers for Disease Control surveillance data, at that time we estimated that there was three times the risk for AIDS in African Americans as compared to Whites (Mays & Cochran, 1987).

When AIDS first came to the attention of the medical community in 1981 (Gottlieb et al., 1981), it was thought of as a disease of gay men. However, we now know that perception was wrong. HIV was already present in the inner city of the Black community in 1981 when gay men were first being diagnosed. We know because African-American children who were born in 1977 in New York City, who never received blood transfusions, never injected drugs, and never had sex had developed AIDS. Already, in 1977 their mothers were HIV infected. This is our most direct evidence (MMWR, September 30, 1988). We also know that incidence rates of pneumonia-related deaths among Black addicts in New York City at the time showed increases paralleling the increasing deaths due to AIDS in the gay male community of Manhattan (MMWR, September 30, 1988). Some of these addicts were probably dying of AIDS, though we will never know for certain (Mays & Cochran, 1990).

Although the crisis for the African-American community may seem distant to those without direct ties to that community, the truth is that the HIV epidemic in

African Americans is something that we must all care about regardless of our ethnic/racial background, our sexual orientation, our drug use status, our age, or our moral beliefs. Because the problem of AIDS and HIV disease in Black Americans is one that will affect most everyone for many years to come.

We are quite serious when we say it will affect everyone, not just those infected by the disease and their loved ones, but even middle-class White Americans and African Americans alike. Because just as AIDS has impacted diverse segments of the African-American population, so too will it affect others who, although not personally a part of the Black community, are a part of a society that is influenced by the status African Americans occupy in the labor market, by their health care expenditures, by their illicit drug use, and by their availability or lack thereof as productive citizens.

AIDS in the Black community has and will affect each person in sometimes subtle and not so subtle ways. For example, each year when unions or employers renegotiate health care benefits what is, or rather what is not, available is frequently related to reported loss histories by the insurance companies and the cost of care. Lack of access to routine or preventive health care, use of emergency care for acute or routine primary care needs, and the cost of treatment for HIV disease and AIDS all impact the negotiations surrounding health care benefits. Monies budgeted for AIDS prevention are at times diverted from other health problems (Krieger, 1988). Money spent on AIDS may be money not targeted for other health concerns seemingly more relevant to those not directly affected by HIV disease.

In urban areas like New York, New Jersey, and Washington, DC, AIDS survivors are increasingly children left without parents (Michaels & Levine, 1992). These children face becoming a part of a foster care system that is already overburdened, underfunded, and not very successful at the placement of older children. Their contributions as productive citizens may be delayed or unfulfilled due to the effects of AIDS. Cases of AIDS in African-American infants and children may rob us of yet another Nobel recipient for peace or a great scientist, inventor, teacher, or even a good friend. Imagine if Magic Johnson, Max Robinson, or Arthur Ashe had never lived to reach adulthood. Imagine, too, their premature loss to the world.

Today, rates of newly reported cases of AIDS are higher for Blacks and Hispanics than other ethnic groups. And the future does not look good. For example, although incidence rates of syphilis and gonorrhea, diseases thought to be important co-factors for AIDS, have shown marked decrease in the population in general as gay men have altered their sexual practices to reduce their HIV risk, the Black and Hispanic communities have experienced increases in the last several years (MMWR, August 19, 1988). Even among gay men, Black gay men are not showing the deceleration of syphilis incidence noted among White gay men (Landrum, Beck-Sague, & Kraus, 1988).

AIDS IN DIFFERENT SUBPOPULATIONS

It has been said that AIDS represents a set of overlapping epidemics, each with its own particular characteristics. Generally, when the issue of AIDS in the Black population is addressed, this discussion stops with citing that more than one third of AIDS cases are in Blacks. However, this obscures some very important epidemiologic differences relevant to understanding both the level of concern and complexity of proposed HIV behavior changes.

Gay/Bisexual Men

As illustrated by Table 13.1, 38% of reported AIDS cases in African Americans have occurred in gay and bisexual men. For many African Americans, the presence of gay men in the Black community was a surprise. Not until the AIDS epidemic has the community been challenged to understand this group and to respond compassionately to their needs. Consequently outside of most urban cities such as New York, San Francisco, Chicago, Los Angeles, Boston, and Washington, DC, there were very few infrastructures by which to reach these men.

Usually community groups that we have relied on in the past to respond to health epidemics, such as churches and community health agencies, have spent precious time in this epidemic struggling with their moral values, their homophobia, and their overall ignorance of these men who live within and contribute to the African-American community, even while leading somewhat separate lives. Unfortunately myths and ignorance have prevailed about them (Cochran & Mays, 1988).

As researchers, we know little about the HIV risk-related behaviors, lifestyle, or contextual issues of being both gay or bisexual and African American in order to offer any leadership to the biomedical researchers or the African-American community (Cochran & Mays, 1988). Sadly, we know less about the behavior of Black men who identify as bisexual than we know about Black gay men. We know even less about the bisexual behavior of those Black men who identify as heterosexual. Much of our approach to understanding bisexuality has been shaped by Kinsey's bipolar representation where heterosexuality is on one side and homosexuality on the other, with bisexuality seen as somewhere in the middle. This perspective does not include ethnicity, culture, class, or economic differences as interactive factors influencing the expression of sexual behavior or sexual orientation. For a man whose easiest means of generating income is through sex with other men or for whom long periods of same-sex incarceration such as in jail, prison, detention centers, or military service is a reality, same-sex sexual practices may not be perceived as gay sex (Mays & Cochran, 1990).

Although both Blacks and Whites may engage in similar sexual behaviors, it is not necessarily true that they perceive these sexual acts in the same way or

TABLE 13.1
AIDS Cases in African-Americans in the United States
Reported to the Centers for Disease Control as of 6/94

<i>HIV Exposure Risk Factor</i>	<i>Count</i>	<i>(%)</i>
Adults/Adolescents		
<i>Males</i>		
Sex with other men	40,500	(41%)
Injection drug use	36,426	(37%)
Sex with men/IVDU	7,434	(7%)
Sex with women	4,963	(5%)
Hemophilia/coagulation disorder	310	(0%)
Receipt of blood/blood products	732	(1%)
Risk not reported or identified	9,137	(9%)
Male subtotal	99,502	(100%)
<i>Females</i>		
Sex with men	9,014	(33%)
Injection drug use	14,160	(51%)
Hemophilia/coagulation disorder	20	(0%)
Receipt of blood/blood products	725	(3%)
Risk not reported or identified	3,762	(13%)
Female subtotal	23,810	(100%)
Pediatric (<13 years old)		
Hemophilia/coagulation disorder	31	(1%)
Mother with/at risk for HIV infection	3,038	(95%)
Receipt of blood/blood products	80	(3%)
Risk not reported or identified	50	(2%)
Pediatric subtotal	3,199	(100%)
Total cases	130,382	

Note: Data from the Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report 1994*; 6(No. 1), 9-13.

come to the same conclusion regarding their own sexual orientation (Cochran & Mays, 1988). Outreach activities or interventions geared toward a group who identifies as gay or bisexual may be less effective in raising concern and changing behaviors among African-American men who do not see themselves as gay. Given the differences in experiences between Black and White men, it would seem important that our intervention and research efforts use frameworks that incorporate the cultural, ethnic, and economic realities of our target groups. For men who have sex with other men for whom this activity is based on economic sustenance, insistence on behavior change must address the economic

issues. The African-American male facing a long incarceration in which heterosexual physical contact is denied challenges us to make our concern for HIV transmission his concern.

Intravenous Drug Users

In contrast to Whites, for African Americans the largest group affected by AIDS are injection drug users. At least 52% of reported AIDS cases among Blacks are related to intravenous drug use. This contrasts with 19% of reported cases in Whites. Unlike with gay men, the presence of drug users in our community has unfortunately a long history. Infrastructures such as state, county, and private substance abuse facilities have served as the primary vehicles for raising awareness and supporting risk-reduction activities. Yet like our experiences with gay men, public morality, negative attitudes, and ignorance have slowed the African-American as well as the non-African-American community's response to this group.

Forgotten is the notion that many drug users are sons and daughters, wives, mothers, and parents. As a war on drugs is waged whose key components are enforcement and incarceration, the contextual relationship of the drug economy in poor ethnic neighborhoods is overlooked. Lost, too, is a focus on the effects on Black Americans as the United States shifted from a manufacturing-based economy to one increasingly based on information-processing and high technology. These changes have not been accompanied by sufficient job placement, education, or training activities (Johnson & Oliver, 1991; Wilson, 1987). Increasing cost of housing, health care cutbacks, and crises in funding for education have results that translate into antisocial behaviors in the form of crime, drug abuse/use, and violence (Johnson & Oliver, 1991; Wilson, 1987). These crises coupled with a drug policy with little alternatives to enforcement and incarceration make it difficult for the United States to view injection drug use as a health problem whose outcome may be HIV disease.

Heterosexual Transmission

One of the fastest growing groups to be affected by AIDS are heterosexuals, particularly women. Seroprevalence data indicate increasing numbers of cases among women, particularly African-American women in the inner city. Infection rate among women has been calculated at 2½ times that of men (Rodin & Ickovics, 1990). In diagnosed cases of AIDS, African-American women have been particularly hard hit, accounting for 54% of all reported AIDS cases in women although they comprise only 15% of the adult female population. As of 1992, transmission of HIV infection as a function of heterosexual sex accounts for the greatest number of new infections in women.

An important implication of HIV infection in women is, of course, the in-

creasing occurrence of pediatric HIV cases. Currently 55% of all pediatric AIDS cases are in African Americans. And even here the ethnic differences in this epidemic are important. For example, 68% of White children with AIDS were infected as a result of risk from the mother, in contrast to 95% of Black children. The importance of this is what it means for the future. Pediatric AIDS will increasingly become a crisis in the health of African-American children, which is already experiencing one of the highest rates of infant mortality.

KNOWLEDGE AS A FACTOR IN THE EPIDEMIC

From this brief overview of the epidemiology of AIDS in African Americans, a picture emerges of the diversity of the epidemic when compared to Whites where 80% of cases have been concentrated among men who have sex with other men. But does the Black community really understand the epidemiology of AIDS in African Americans?

In 1981, when media attention began to focus on AIDS, that concern was centered on White gay men. So, like Whites, the Black community perceived AIDS to be a gay White disease. Even today when we conduct focus groups with African-American gay and bisexual men asking them how they avoid getting AIDS themselves, they sometimes feel that if they do not have sex with a White gay man, they will be less likely to become infected.

The next wave of media attention focused on IDUs who were African American or Hispanic as major carriers of the disease. So for many African Americans if they were not gay and or not an IDU, when the AIDS Public Service Announcements come on TV, the channel was changed.

Still many African-Americans who are in the age category where HIV infection is most prevalent, or who live near or in a high prevalence area have some knowledge about AIDS. They will usually tell you that you can get it from sharing needles or sex and that you can die from it. In surveys of AIDS knowledge, when compared to Whites, a small percentage of African Americans are more likely to believe that casual contact or unusual means such as transmission by toilet seats are possible (Seltzer & Smith, 1988). Hardy (1990) reported that African American and Hispanic-American adults, particularly those with less than an average education, were more likely to have misperceptions about transmission, somewhat less likely to rate condoms as effective prevention methods, and were less aware of the HIV antibody test. Although it is important to design campaigns that will effectively reach this small group, in general, most African Americans have a basic grasp of transmission routes for HIV disease. The question is whether this knowledge results in HIV risk reduction.

There is a big push to educate members of the Black community about the facts of HIV transmission. Many of the current HIV prevention and intervention efforts in the African-American community are based on public health models

that assume that the key to preventive behavior is knowledge. We often hear that this education effort is complicated by the literacy level in the community because brochures are frequently relied on to communicate knowledge, or it is complicated by the inability to use explicit pictures or language. These concerns, although certainly important, presume that if only there were accurate information about the facts of HIV infection, the epidemic would fade away as behavior change is enacted.

Psychology has often challenged this notion that knowledge alone is enough to lead to behavior change, especially when that behavior change may involve a change in one's lifestyle. Let us give you some examples of this from our research.

In 1986, while in the field collecting data from young heterosexual African Americans as part of a larger study on the intimate relationships of Black Americans, we added some questions about AIDS knowledge. At that time we gathered data from 92 sexually active, young African American female college students in Southern California. In 1988, we went back again and sampled 51 sexually active African-American women college students and in 1990 another 57 sexually active women. The question here is are these young African-American college women knowledgeable about HIV transmission, is the knowledge increasing as a function of time, and does having accurate knowledge about the facts of HIV lead to changes in at-risk HIV behavior?

The first issue concerns level of knowledge about AIDS and whether or not this is increasing over time. Table 13.2 shows the differences in our three sam-

TABLE 13.2
Changes over Time among Sexually Experienced African-American College Women

	Year Sampled		
	1986 (n = 92)	1988 (n = 51)	1990 (n = 57)
Percent correct on AIDS knowledge test	72.6% _a	78.6% _a	86.8% _b
Mean worry about getting AIDS	2.70 (1.81) _a	3.82 (1.77) _b	4.18 (1.90) _b
Percent knowing that condoms provide HIV protection	95.2%	98.0%	100%
Percent who have changed their sexual behavior to reduce AIDS risk	49.5% _a	68.6% _b	76.0% _b
Percent using condoms 50% or more of the time	35.4% _{ab}	23.5% _a	50.0% _b
Percent who always use condoms	9.8%	5.9%	12.5

Note: Differences evaluated by ANOVA or chi-square test. Letter subscripts indicate groups that differ significantly when evaluated by either Newman-Keuls or chi-square post hoc tests.

ples of African-American women. From 1986 to 1990, correct answers to an AIDS knowledge test (27 items) rose significantly from 73% to 87%, $F(2, 189) = 15.71, p < .001$. Also, by 1990, every woman we surveyed knew that condoms could be used to prevent HIV infection. Other changes, too, occurred including increasing worry about contracting HIV, $F(2, 196) = 13.32, p < .001$, reporting behavior changes to reduce HIV risk, from 50% of our sample in 1986 to 76% in 1990, $\chi^2(2) = 43.57, p < .001$, and more frequent use of condoms, with 50% of women 1990 reporting that they used condoms at least half of the time, $\chi^2(2) = 8.15, p < .05$. However, the percentage of women who reported always using condoms with every partner did not change significantly during that time period. Clearly, something more than knowledge of HIV and its prevention will be needed to generate further change.

A second issue is whether or not accurate knowledge about HIV transmission leads to appropriate behavior change. When we compare those women who reported that they have changed their behavior to reduce their risk with those who have not over the three time points in their levels of AIDS knowledge, there is little evidence that knowledge is the determining variable. As can be seen in Table 13.3, scores on the AIDS knowledge have improved significantly over time, $F(2, 182) = 14.26, p < .001$, but there is no significant effect associated with behavior change. Also, women did not differ in their ratings of risk from donating blood, an activity that carries no risk of HIV infection at all.

Instead, worry about getting AIDS, which increased significantly over time, $F(1, 189) = 7.59, p < .001$, also was significantly greater in those women who reported that they had changed their sexual behavior, $F(1, 189) = 22.80, p < .001$. In addition, those women in 1988 and 1990 who had changed their behavior rated their vulnerability to getting AIDS as significantly more likely than those women who had not changed, $F(1, 93) = 7.41, p < .01$. This finding is similar to another of our studies of young heterosexual adults, where we found that worry about contracting AIDS was a proximal correlate of HIV risk-reduction behavior (Cochran, Keidan, & Kalechstein, 1990).

What can we conclude from these results? Perhaps, most importantly, knowledge appears to be a distal factor in risk reduction. That is, the function of accurate knowledge may not be behavior change but rather to set the stage for people to know the right thing to do. What makes them enact these changes may be an increase in perceived risk for AIDS. It is interesting to also note that in the 1988 sample of African-American women, those who rarely if ever had sex with White men viewed themselves as being at less risk for AIDS than those women whose partners were more likely to be White (Spearman $\rho = .36, p < .05$). This suggests that beliefs in the African-American community that AIDS is not particularly a problem for Blacks may yet linger. Indeed, at one point we asked our subjects to rate the risk for contracting AIDS on 10-point scales for several groups of people. As shown in Fig. 13.1, in 1986, women erroneously believed that AIDS was more likely to occur in Whites than African Americans.

TABLE 13.3
Comparisons of African-American Women Who Have and Have Not Changed HIV Sexual Risk Behaviors

	Year Sampled				Significant Effects ¹		
	1986		1988			1990	
	Has Changed (n = 45)	Has not Changed (n = 45)	Has Changed (n = 35)	Has not Changed (n = 16)	Has Changed (n = 41)	Has not Changed (n = 13)	
Percent correct on AIDS Knowledge Test	70.4%	74.6%	75.0%	76.2%	84.6%	80.4%	T
Mean ratings for AIDS risk from donating blood ²	—	—	3.1	3.3	3.5	3.1	
Mean worry about getting AIDS	3.2	2.2	4.2	2.9	4.6	2.8	T,C
Perceived vulnerability to getting AIDS ³	—	—	2.0	1.7	2.1	1.6	C

¹Evaluated by 2 x 2 ANOVAs, T = significant main effect over time, C = significant main effect of changing behavior, T x C = significant time by behavior change interaction.

²Rated on a 1 to 10 scale, with 1 = no risk at all; data not collected in 1986.

³Rated on a 1 to 4 scale, with 2 = "not too likely"; data not collected in 1986.

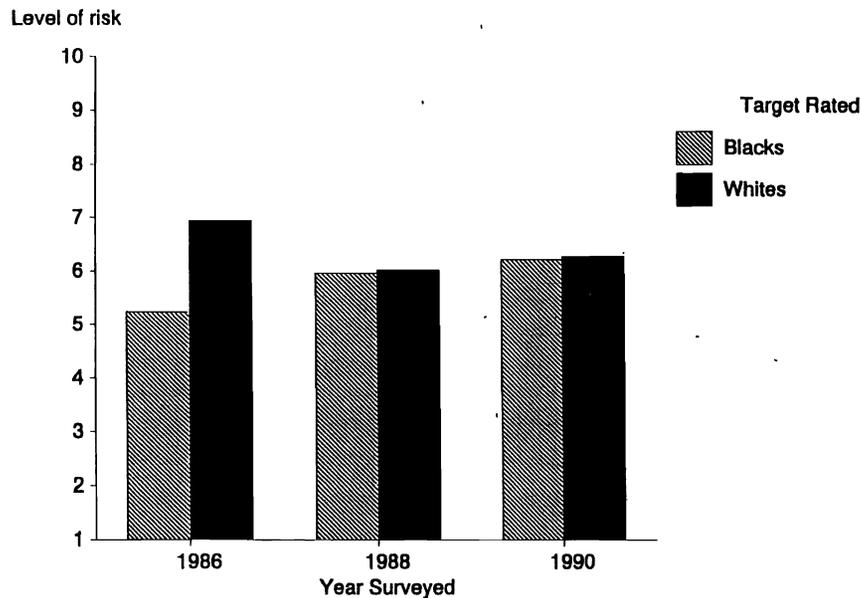


FIG. 13.1. Perceptions of black versus white AIDS risk among black women college students.

By 1988, that false belief appeared to be fading. But even in 1990, women still did not really know the relative risk for AIDS between African Americans and Whites, continuing to perceive themselves as not being at any greater risk than White Americans. This time-by-target-rated interaction, $F(2, 185) = 16.59, p < .001$, is a sad commentary on how a little bit of knowledge (such as that condoms should be used) does not mean that people fully understand the nature of the risk that confronts them.

WHAT WILL AIDS MEAN FOR THE BLACK COMMUNITY?

How do we change the level of concern that presently exists about AIDS among African Americans? As psychologists, it is strange for us to ponder how to make people worry. One way of accomplishing this is through focusing efforts on what AIDS means both in the short and long run for the African-American community. In the short run, AIDS means many things, one of which is intimate behavior change. We do not know to what extent people actually know how to accomplish this. Much of the information that we do have is derived from the Knowledge, Attitudes, and Behaviors (KAB) studies funded through the Centers for Disease

Control or the National Health Interview Survey seeking to determine the accuracy of an individual's knowledge relative to a set of facts. For example, the question may be whether using a latex condom during vaginal intercourse will decrease your risk for AIDS. This requires a simple yes/no answer. The more pertinent questions of what do people know about how to use a condom, what kind of condom to use, when to put the condom on, and how to take it off safely are generally not asked.

It is like our style of teaching college undergraduates. Generally, we test them for knowing isolated facts—not how these facts are related or what their implications are. At UCLA in our sections on abnormal psychology rather than asking simple multiple choice questions about the symptoms of an anxiety disorder, we now present vignettes that require the students to have an understanding of the facts rather than merely memorization or recall skills. Health psychologists have long known that how people understand the ins and outs of needed self-care behaviors is as, if not more, important than merely knowing the nature of the illness itself. Patients may know they should take antibiotics four times a day, but if they do not understand how to space the dose out or the foods that may lower the effectiveness of the antibiotic or what to do when they forget a dose, then they may not be effective practitioners of their own health-related behaviors. This same thinking is applicable to HIV risk reduction.

We need to mount better research efforts. Studies have to focus less on standard knowledge assessment and instead get at how much understanding of the facts there is and the context in which the behavior is practiced (Mays & Cochran, 1993). As part of our national research project on African-American men who have sex with other men, we initially conducted focus groups with Black gay and bisexual men throughout the United States (Bellinger, Mays & Cochran, 1989; Mays et al., 1992). What clearly emerged were differences in the conceptualization of sex behaviors. Current messages used in the generally White gay community did not have the same levels of association to sexual practices for some African-American gay and bisexual men. For these men, sex is thought about and talked about with a different set of symbols and meanings. This should not come as a surprise to us because language and metaphors about sexual behaviors differ in degrees between heterosexuals and gays (Chesboro, 1981; Goodwin, 1989). They differ between men and women (Tannen, 1990). They also differ among ethnic groups (Adams, 1982; Smitherman, 1977).

Important also to behavior change is the perception of risk and the resulting differences in motivations for behavior change. In an earlier article, we made the point that HIV risk-reduction activities, for example, by poor ethnic minority women, must be viewed within the total context of their lives (Mays & Cochran, 1988). First, in targeting risk behaviors for change, it is important that we attempt to understand the origins of those behaviors from both an individual and sociocultural perspective. What is the role of community norms (Cochran & Mays, 1991)? How will behavior change affect economic or emotional support

within interpersonal relationships or family units (Peplau, Cochran, Mays, in press)?

Second, we need to design approaches that focus comprehensively not only on the individual but also the individual as a responsible member of a social or familial network. For African Americans, ethnically based values of cooperation and unity may be more powerful motivators of behavior change than strict appeals to individualistic action, such as "protect yourself" (Mays, 1989; Mays & Cochran, 1988). For example, one model of AIDS education that appears effective in changing attitudes and behaviors in some segments of the Black community is an appeal for change based on responsibility to others in the community. Men are asked to practice safer sex in order to survive as a needed father or support for their parents (Cross, 1990; Mays, 1989). Women are asked to be more assertive regarding condom usage in order to stay alive to take care of their parents or children. They are asked to promote condom usage as an act of rebellion, as a collective force to be a united unit with her partner to fight racism and genocidal efforts (Gasch, Poulson, Fullilove, & Fullilove, 1991; Mays, 1989; Mays & Cochran, 1988). African-American men and women could be encouraged to practice risk reduction in order to ensure the existence of the Black race and to build a future for others. For example, Gasch et al. (1991) proposed helping African-American women to view condom usage not as a barrier method within a genocidal framework that distances the woman from her partner but rather as an Afrocentric approach in which the condom is a protective barrier against the outside diseases proliferated against Black people to weaken their health. The act of using a condom becomes an Afrocentric proactive behavior that ensures long health for the woman and her partner as well as builds a bond that strengthens the unity with her partner. This approach is based on a model of social responsibility rather than individualistic preservation.

In the long run, AIDS/HIV will have a pervasive impact on the life expectancy and rates of morbidity and mortality in the African-American community. Solving the problem of HIV transmission in the Black community means solving some of the other problems that have confronted us for quite some time: ineffective contraceptive behaviors and injection drug use. It also means solving the distal determinants of these problems such as poverty, under- and unemployment, inferior education, and racism (Duster, 1988; Johnson & Oliver, 1991; Cochran & Mays, 1994). To accomplish this, we need, each of us, to join together in the fight against AIDS. For those of us who are scientists, this frequently means crossing disciplinary boundaries. For example, melding the perspectives of psychology and public health or psychiatry and immunology. It also means listening to what AIDS/HIV affected and infected communities have to tell us about their experiences and concerns in their own cultural languages. And finally, tackling HIV infection in the African-American community means trying once again to conquer social problems that in the past have left us discouraged. We are left with no other choice.

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