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Minorities and HIV Infection

Veneita Porter

This article discusses a preliminary comparison of responses to AIDS in ethnic communities and their basis in previously established support systems. The importance of public policy and its connection to racism and cultural insensitivities are discussed as they relate to communities of color at risk. Particular attention is paid to problems of communication and to the ethics involving confidentiality.

The AIDS crisis has emphasized the definite distinction between race and class in the United States. In order to see clearly the crisis as it is viewed in poor minority communities, primarily the Black and Latino/Hispanic communities, as well as its effects on them, it is necessary to look at how AIDS was originally connected with the gay male population when the epidemic first hit the United States in the early 1980s. The segments of the minority populations spoken of in this article are largely poor and working-class socioeconomic groups. Problems of poverty, coupled with poor medical maintenance and IV drug use, have existed in these communities for long periods of time; the occurrence of AIDS has simply compounded preexisting conditions among these populations.

Initially, discussions surrounding AIDS focused on the gay male population, mainly in large cities. AIDS was originally named GRID, gay related immune deficiency, because of the large number of those infected with the disease who were gay. Men in San Francisco were exhibiting clinical symptoms such as extreme weight loss, cancerous lesions normally found only in elderly men of Mediterranean descent, and unexplained pneumonias. Their deaths were swift and largely unexplainable. The disease baffled doctors, who were unable to diagnose it and who feared its potential spread.

AIDS also presented the media with a whole new range of possibilities. Here was a disease whose causes seemed closely related to the unexplored world of gay male sexuality. Here were indications of a world that middle America had known very little about. This world began to surface in the press, which initially defined the gay male community as made up of bars, restrooms, and public bath facilities, all of which became public domain for the media. Gay men who once had been thought of as leaders in the sexual

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revolution were now seen as lepers, as people became familiar with the theories surrounding the epidemic.

Yet for all this media attention, many stories were left untold. The typical profile of a person with AIDS was a white male usually residing in San Francisco or New York. Among the general public, many understood the concept of "high risk" and felt safe. Ethnic minority communities that had already dealt with the burden of a higher incidence of hypertension, infant mortality, and cancer than the white population breathed a sigh of ill-timed relief. Investigating the likely place of origin for AIDS, scientists identified the virus as first coming from Africa, mostly the central and eastern regions, and Haiti.

Indeed, the Centers for Disease Control (CDC) in Atlanta, Georgia, initially focused on Haitian immigrants as potentially identifiable carriers of the virus and placed them on its list of high-risk populations. When Haitians were first thought to be a risk group in the United States, the backlash against them was felt severely in the major cities. Haitian stores were put out of business, Haitian children were refused admittance to school, and Haitian domestics lost their jobs.¹ In an area clouded with apprehension and varying degrees of knowledge, the public response in the majority communities was based on fear, lack of information, and sometimes racism. Here was a disease that was closely linked with gay male sexuality and its environments and with African and Haitian immigrants, communities from which most of mainstream America felt separate. In the seven years following the first identification of AIDS in the United States, little was done to focus on the fact that AIDS is everyone's disease. It has only been during the past two years that this message has begun to be carried to the minority populations.

Minority health issues and health maintenance have become increasingly important in light of the AIDS crisis. The statistics are startling: while constituting 12 and 6 percent of the U.S. population, respectively, Blacks and Latinos/Hispanics account for 25 and 14 percent, respectively, of all diagnosed AIDS cases. As such, people of color represent 39 percent of the reported cases of AIDS but make up only 18 percent of the general population.²

In any population where poverty is a cofactor, poor health maintenance, high infant mortality, drug use, and a high incidence of sexually transmitted disease all play a large role in making poor communities, especially poor ethnic communities, a breeding ground for many types of disease. Surprisingly, it was not until recently, with the leadership of U.S. Surgeon General C. Everett Koop, that public health authorities clearly stated that people of color needed much more information about AIDS than they were receiving.

The combination of misinformation and apathy in the culture of most poor communities has contributed to the disproportionate number of people with AIDS in these communities. According to Dr. Beny E. Primm, who runs the Urban Resources Program in Manhattan and Brooklyn, "People just feel 'I'm not an IV-drug user or a bisexual, it's not gonna get me.' But that's not the case. There are so many closet bisexuals and drug users, and former drug users who now are leading heterosexual lives, and infectious to others. It is totally alarming."³

Drug use, high infant mortality rates, high unemployment, low literacy rates, and other difficulties have stressed poor communities to the breaking point. Given inadequate social and medical services, and in some cases inadequate school systems, in addition to these problems, the fatigue that is experienced can only be compounded by the AIDS crisis.

On the other hand, the response of the vast majority of the gay male and lesbian population to this health crisis has been admirable. The swift and efficient mobilization of financial and emotional resources with which homosexuals have met the ever rising numbers of

people affected by AIDS both within and outside their own community has given an important reminder to public policymakers about how a disease should be handled from its onset. Washington's lack of response is a clear reminder of what can happen when any problem is ignored for too long. Yet it is well to examine the resources that the gay community has had at its disposal.

Organized and highly functional groups of gay men and lesbians often reside in highly concentrated areas of industrial and urban growth. These groups range from political to religious to social and sometimes ethnic. How visible and active these groups are may well depend on how liberal or flexible their surrounding environments are. Yet even in the most conservative of cities, there exist functioning gay networks from which individuals can derive support. Examples are the agencies in New York, San Francisco, and Boston which formed with the onset of the AIDS crisis. In these cities, the pressure to create a working system of individuals and institutions willing to combat the spread of AIDS was somewhat eased by the already existing networks within the gay communities.

These organizations should be kept in mind when one examines ethnic minorities and the AIDS crisis. In most poor communities, urban or rural, minority community centers have been losing ground since the early seventies. It has only been with the resurgence of interest in minority health during the past five years that any of the centers have remained open. When the AIDS health crisis was recognized in gay communities, there were already existing support systems; in minority communities, such systems were weak or nonexistent. Now the minority community is being asked to create information agencies and support systems to meet the needs of people ill with a disease denied by that very same community. Furthermore, the community-based organizations started at the onset of this health crisis began with a certain clientele in mind. Built primarily by and for white men to serve a defined client population, these organizations were ill prepared to serve an evolving client population — one that includes people of culturally, linguistically, and ethnically different backgrounds.

How is it possible to break through cultural bias and effectively inform minority communities about behavior and risk factors?

When AIDS was first talked about in the gay community, it was a given that one needed to discuss with candor and openness one's sexual experiences, one's sexual agenda, and one's sexual preference. Gay men who had been leaders in the sexual revolution talked honestly and openly about their sexual identities and what needed to change in terms of behavior in the AIDS crisis. But in minority communities, this discussion has been a long time in coming. Among Black women, who are thirteen times as likely to get AIDS as their white counterparts,⁴ the idea of sexual candor, or of sexual agendas, has been kept in the closet. There is a certain reluctance among individuals in ethnic communities to be openly gay or lesbian or for women to express sexuality in general. In Latino/Hispanic communities, the idea of women discussing sexuality may be perceived as unfeminine and perhaps immoral.

In speaking to people of color, the issues of homosexuality and bisexuality are usually best avoided. It is less threatening and more effective to concentrate on the issues of family, women, infants, and children when talking to communities where these populations are most at risk. "Minority agencies have sometimes been hesitant to fund and implement AIDS-related programs for fear [such programs are] being perceived as homosexual activities," says Norm Nickens, a representative of the San Francisco Human Rights Commission.⁵

In communities that have a strong religious tradition, the discussion of sexual behavior

by either sex is not welcomed. Minority bisexuals and homosexuals, it seems, must make a choice between their sexual and cultural identities.

Thus, there are two hidden problems in the ethnic communities: one, the unwillingness or inability to deal with open sexuality, and two, the church's or leading cultural institution's refusal to accept or even confirm homosexuality or bisexuality as part of its community make-up. So a cultural bias influencing health policy issues exists, and there is some difficulty in bridging the chasm between the gay community, which may engage in frank discussion of sexual practices and behaviors, and an ethnic community where such practices are not even acknowledged. Yolanda Serrano of ADAPT, a group of volunteers — many of them former addicts — who visit shooting galleries with prevention literature, says, "To overcome the barriers posed by cultural tradition, political suspicion, and personal anxiety is an immense, forbidding task. What we need is massive, constant education for this message to get across. It has to be constant, otherwise it's not going to work."⁶

This gulf must be crossed to allow the second step of discussion — what those behaviors and risk factors are.

AIDS presented an entirely different face when Black women who were partners of IV drug users or who were IV drug users themselves were also identified as persons with AIDS in the minority communities. Those communities were then confronted with new difficulties besides the reluctance to discuss the problem and the lack of information. Serrano states that she has seen the "pandemonium" in Black families when AIDS strikes: their isolation from neighbors and friends and the rigidly defined roles that make it difficult for women to negotiate safe sex. The disease itself may exhibit symptoms differently in people of color. There has been some initial medical evidence that people of color in larger cities have a much shorter period from time of diagnosis to death than their white counterparts.⁷ Existing problems, such as insufficient funding for medical research in minority communities, have already started to take a toll upon the ever growing numbers of people with AIDS. If there are insufficient funds to begin with in a community, a health crisis compounding this lack makes the stress more widely felt.

So what happens when a service agency built on one sort of model is asked to expand its services to deal with another sort of model?

The first step is to examine government response to the AIDS crisis. It is only during the last two to two and a half years that the Centers for Disease Control has put the issues of minorities and AIDS on its funding agenda. Racism, both institutionally and on a community basis, has been a problem within the health care community for some time. When coupled with the AIDS issue, racism can be an extremely powerful tool. Community agendas for medicine, research, and public health policy differ greatly from community to community and from general public policy concerns.

The gay male community has had a strong voice in making its AIDS agenda heard, ensuring that health officials and their government counterparts understand that human rights and gay civil liberties should go hand in hand in the AIDS crisis. Such political mobilization has not been matched in minority or ethnic communities. Minority communities must quickly and effectively learn to combine health coalitions and political coalitions in order to survive in this health crisis.

Government, community, and health officials must also address the problems of illiteracy and cultural influences in linguistic minorities if they are to deal effectively with the issue of health maintenance in poor communities.

"All Latinos are not the same," says Alex Compagnet, president of Salud, a new health

organization in the District of Columbia which is focusing on AIDS prevention. "We come from different countries and we have different customs and traditions and levels of education, and too many programs have failed to realize that. We need education that is culturally relevant, by Latinos for Latinos."⁸

Producing informative educational materials that are culturally sensitive and linguistically accurate is a time-consuming process for service agencies. Their success in this endeavor will be a measure of how effective they can be in the long term in dealing with a health crisis in poor or ethnically different minority communities. A Spanish translation of an English-language brochure discussing symptoms of AIDS is ineffective if it shows pictures of gay white men to an audience of Latino/Hispanic mothers. Messages must be presented to audiences in a culturally sensitive manner. Animation, drawings, and audio- and videotapes need to be used to reach ethnic minorities. Commercials, bus posters, resource manuals, and radio and television public service announcements are a few of the simple but effective ways that have been tried in some communities to reach these populations. Street outreach workers are a necessary aid in dealing with communities where social clubs or civic organizations do not play a major role.

It is important to be culturally aware of the community and to address the culture within its context. Often in poor communities, children are the only lifeline people have to the world. When legacies of money, educational endowment, and property are not available, children may provide the only positive community alternative. Thus, women of childbearing age who become ill with AIDS and die will leave certain irreversible legacies in terms of community loss. As more and more people of color are affected by drugs, and as their sexual partners are being affected by drugs and AIDS, the future of the minority group is in peril.

"Sometimes in our culture," says Salud president Compagnet, "we speak of sex as something we have to hide, but SIDA [the Spanish acronym for AIDS] is a crisis that's affecting our community, and we have to take care of ourselves. Otherwise, many of our families will be affected and will disappear."

There is no denying that people of color are just beginning to wake up to the issue of AIDS in their communities. But how quickly will this awakening spread? Is there a way in which government officials and policymakers can speak directly and clearly to this population? If so, what long-lasting effect will this have on public policy?

Certain Black and other minority groups, such as the church and fraternal organizations, have yet to recognize AIDS as part of their civil rights agendas. Discrimination and AIDS go hand in hand largely because of the stigma attached to the behaviors associated with transmission of the virus. The Black and Latino/Hispanic middle classes, which may possess the technical and financial resources to launch educational campaigns, have resisted acknowledging that the spread of HIV infection has something to do with sexual behavior. To overcome the barriers posed by cultural tradition and political suspicion, it is important to understand that civil rights in the AIDS battle are intimately linked to the survival and nurturance of the minority community as we now know it. The fact that all communities will have to deal with AIDS in the next several years is becoming commonplace knowledge.

Considering the problems of massive education in communities that have yet to be reached, such as low literacy populations, prison populations, people who may not have English as their first language, and young people who may be making sexual decisions in the next few years, the job of AIDS education is enormous. Despite the possible encroachment on their civil rights and the threat of AIDS and ethnic and racial discrimina-

tion, the call to become more involved has yet to be sufficiently heard by communities of color. The fact that reproductive rights, prisoners' rights, and poor people's rights in general are integrally linked with AIDS and the rights of people with AIDS has not been recognized by the vast majority of the ethnic community. The bottom line regarding ethnic communities' civil rights — access to education, access to fair housing, and access to equal paying jobs — is affected by public policy and private-sector policies on AIDS and discrimination. If mothers and fathers can be turned away from public housing because of their HIV status, whether they are Black, white, or yellow is no longer a consideration. When the government in Washington says that AIDS-related discrimination is acceptable in some circumstances, whether the person being discriminated against is Black or white is moot. When HIV and antibody testing are routinely done without patients' consent in hospitals, the color of the patient is not important. When people can be denied access to housing, jobs, and medical help because of their HIV status, civil rights take on an entirely new and different meaning. People in the human health industry have known for a long time that the contents of medical records — possibly containing HIV test results — of prisoners, welfare recipients, and people on any kind of disability or insurance assistance can become common knowledge. Inappropriate access to medical records was a problem before AIDS, and this problem has increased now that HIV status is part of the picture.

Military recruits, welfare recipients, and prison inmates are examples of persons whose records are often given inappropriate access. If three times as many people of color as whites show up HIV-positive in military recruiting records, they are subject several times over to loss of employment potential in a population that is already heavily unemployed.¹⁰

With respect to the poor and the disabled, medical confidentiality is a myth. The individuals concerned must have access to the knowledge of their rights of confidentiality. If not, those rights will not be granted. An article published last year in the *American Journal of Public Health* warned that “the screening of selective populations involves the systematic collection of sensitive health care information. HIV infection is associated with sexual practice and drug use, universally regarded as confidential, and HIV-infected people are predominantly members of risk groups subject to persistent prejudice and discrimination.”¹¹

Related to the question of confidentiality of medical records is the possibility of mandatory HIV testing in the prison population. Prisoners are known to have very few rights, less medical assistance and less access to medical benefits than those not incarcerated, and very little voice in the community at large. How the issue of mandatory testing of the largely ethnic and closed prison population is decided is sure to affect the rights of the general community to which prisoners will eventually return.

Both public health officials and minority community members must realize that simply because prisoners are behind walls does not mean that medical information and AIDS information should not reach them. Prisoners are woefully uneducated about safer sex techniques and about the role of drug-injection equipment in the spread of the AIDS virus. Prison officials' refusal or reluctance to discuss issues of homosexuality and drug use inside prison walls must be resolved. Limitations on the education of prisoners in the ways of safer sex and risk reduction put the families and communities who are on the outside waiting for them to return home at much greater peril than public officials realize. The very fact that the communities behind walls are mostly ethnic makes one wonder about the level of concern among public and prison officials with respect to the increasing needs of minority and ethnic populations.

In examining the possibilities for policy change, it is necessary to consider current national policies that will disproportionately affect people of color. All of the problems of poor minority communities make clear that in order to combat this disease and its further spread in the ethnic community, a joint effort will be required on the part of government policymakers and the members of minority communities.

What will encourage government officials and minority community members to join together to present a unified educational message and voice in the battle against AIDS?

Health policy agendas, public policy agendas, and community agendas will naturally differ. The benefit of every individual is important, but how those benefits are to be obtained will have to be resolved through lengthy discussions. Ethnic communities have every reason to be nervous, suspicious, and circumspect regarding the government's official intervention in their daily and intimate lives, and to view it as cause for both concern and education. The other issue that compounds the problem is that health centers currently operating under shrinking financial budgets are ill equipped to service the growing needs of HIV-infected clients. Minority communities, which have over and over again seen government and federal monies come into their communities only to be pulled out six or twelve years later, will naturally be suspicious when new monies are introduced to combat AIDS. Contracts involving long-standing obligations to these communities, as well as increased and supplemental fundings as AIDS case loads grow, must be part of public policy planning for ethnic minorities.

An important part of joining forces against the AIDS epidemic is experienced managerial assistance. Minority educational programs that have existed on sustenance funding should be encouraged to have financial and program planning, program administrators, and ongoing evaluation and assessment of the manner in which their agency and community needs are being met. Evaluation of management, along with productive, ongoing criticism, is a necessary component of any program-funding development. Simply because agencies are located in ethnic minority cultures does not mean that these managerial assistance packages should be neglected.

The question of women and AIDS demands the attention and concern of the minority population. Separate agencies and separate programs are needed for HIV-positive women, their children, and their families. AIDS in the ethnic community is a disease of families and cultures. People do not exist in a vacuum, and policymakers who have been working only with gay white men have recognized the limitations of this approach. In the past, the reproductive rights of women of color have, through mandatory sterilization programs, been violated. Such discriminatory practices are not a solution to the spread of AIDS in the minority family. The promotion of pre- and postnatal care for minority mothers and their babies must continue to be developed hand in hand with AIDS education and prevention.

Churches, community centers, and other existing social supports in an ethnic community must all be included in planning on public policy levels. No one should be left out in the battle against this disease. It is not just in medical but in all emotional and social environments that communities are hard hit by AIDS. Some positive steps are being taken in such states as Florida and Rhode Island, where the National Institutes of Health have made large minority grants available to local organizations. Ongoing epidemiological studies will be necessary in all minority communities.

Is AIDS a different disease in poor minority populations? Why is it that people of color with AIDS die so much sooner than their white counterparts? Is the rate of ongoing sexu-

ally transmitted diseases an issue? Is poverty a cofactor for AIDS? Is poor health maintenance from birth to death an ongoing factor? Why is it that women with AIDS die so much sooner than their male counterparts? Is there something that history or the history of medicine has not accurately looked into when considering sexually transmitted diseases and the minority community?

One public official stated that he had no idea how many people of color were currently involved in the testing of drugs to combat AIDS. Such ignorance must be stopped. Some national agendas and some baseline numbers need to be set in the involvement of minorities in AIDS protocols. Drug addiction and drug complications have long been used as an excuse to keep minorities out of medical protocols, perpetuating the stereotype that many people with AIDS have gotten the disease through involvement with drugs. CDC statistics clearly show that this is not true. The history of IV drug use and its interactions with AIDS and AIDS complications is an important epidemiological study, but other facts must also be examined. It has taken a long time to realize that AIDS is a medically complicated disease, and it has taken just as long to realize that it is also a socially and ethnically complicated disease. Added to this are complications of political agendas as they affect public policy.

Involving minority communities and giving them self-empowerment is the only way to effectively fight AIDS. Public health will continue to be an evolving population issue as communities begin to discover solutions to their immediately apparent problems, and to identify seemingly hidden ones. For example, Arturo Olivas, director of Cara a Cara (Face to Face), a Los Angeles-based AIDS prevention organization, found that in the Latino/Hispanic community, "programs that focus on women to try and get men to use condoms won't work. We're trying to make it the macho thing to do. The theme of a new poster campaign aimed at Latin men features a male face that is half human and half skeleton. The message: 'AIDS Attacks Even the Most Macho.'"

Similarly, it is an ex-IV drug user who, understanding the intricacies of that community, can best talk about what it's like to be part of that culture. And people with AIDS, through their willingness to share their experience of the disease, may be the best advocates of prevention. It is hoped, however, that it will be the survivors in a healthy minority community who will provide examples of the effectiveness of safer sex, safer needle use, abstinence, and condom use programs.

In ethnic communities, sound public policies and politics must be used to heal the wounds that have been suffered in relations between some of the community-based organizations, AIDS agencies, and government policymakers. Eight years into the epidemic, answers are still coming too slowly. In order to know the facts and act on them effectively, minority populations must hear the message and learn to empower themselves so that they can face an existing problem and become part of an evolving solution. 🖐

Special thanks to Robin Bradford and Tom Menard.

Notes

1. Leonard A. Eisner, *Fair Employment Report* (December 1983): 206.
2. Centers for Disease Control, "AIDS Among Blacks and Hispanics in the U.S.," *Morbidity and Mortality Weekly Report* 35, no. 42 (October 24, 1986): 655-666.

3. Dr. Beny E. Primm, in Richard Goldstein, "AIDS and Race, A Hidden Epidemic," *Village Voice*, March 10, 1987, p. 25.
4. Mary Guinen, "Epidemiology of AIDS in Women in the U.S. (1981-1986)," *Journal of the American Medical Association* 257, no. 15 (1987): 2039-2049.
5. *Exchange* 4 (May 1987): 2.
6. Yolanda Serrano, in Goldstein, "AIDS and Race," p. 27.
7. Dr. Wayne Greaves, "People of Color: The Discriminatory Impact," *The Report from the New York City Commission on Human Rights* (September 1986): 3.
8. Alex Compagnet, in Sandra G. Boodman, "Everyone Talks about AIDS — but Hispanics," *Washington Post Weekly Report*, January 4-10, 1988, p. 31.
9. Ibid.
10. Randall Stone Burner, "Risk Factors in Military Recruits in HIV-Positive Antibody," *New England Journal of Medicine* 315, no. 21 (1987): 1355.
11. Larry Gostin and William Curran, "AIDS Screening Confidentiality and the Duty to Warn," *American Journal of Public Health* 77 (March 1987): 364.

"Here we are at an international AIDS conference. Yesterday a woman came up to me and said, 'May I have two minutes of your time?' She said, 'I'm asking doctors how they feel about treating AIDS patients.' And I said, 'Well, actually I'm not a doctor. I'm an AIDS patient,' and as she was shaking hands, her hand whipped away, she took two steps backward, and the look of horror on her face was absolutely diabolical. Now for that to happen at an international AIDS conference where you're going to meet people with AIDS is, well, I really don't know, but let me say this to all people who are PWAs, Don't be sad, don't go out there and cry all the time and mope around and be sad, be happy, live the rest of your life that you've got left, spend it to the fullest. **"**