

Acquired Immunodeficiency Syndrome and Black Americans: Special Psychosocial Issues

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Synopsis

Approximately 25 percent of persons diagnosed with acquired immunodeficiency syndrome (AIDS) have been black. This paper examines three areas of concern when focusing on AIDS in the black population: differences from whites in patterns of transmission of the infection, cultural factors that may affect health education efforts, and ethnically relevant issues in the provision of medical care to black persons with AIDS. Recognition of these differences is important in developing appropriate AIDS-related services for the black population.

First, the epidemiologic pattern of infection in the black population differs from whites. Although

they represent only 12 percent of the American population, blacks make up nearly one-quarter of reported AIDS cases. Currently, it is estimated that between 1 and 1.4 percent of the black population may be infected with the human T-lymphotropic virus/lymphadenopathy-associated virus (HTLV-III/LAV), a rate estimated to be three times that of whites. In addition, epidemiologic patterns of viral transmission in the black community suggest a greater incursion into the heterosexual population.

Second, educational interventions designed to slow the rate of infection need to be sensitive to cultural and behavioral differences between blacks and whites who are at increased risk for acquiring or transmitting an HTLV-III/LAV infection. These include possible differences in perceptions of being at risk and actual risk behaviors.

Third, in caring for black AIDS patients there are psychological, sociocultural, and medical care issues that are relevant. Research findings specific to health care for blacks are reviewed with particular reference to concerns that might arise in the treatment of black persons with AIDS.

Recommendations for research and health education efforts in the black community are presented.

AQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) is a disease that profoundly affects not only the physical health of the person afflicted but also, potentially, every facet of his or her psychosocial functioning (1). At present, there is no curative medical treatment available for AIDS (2,3), greatly increasing the importance of psychosocial factors for preventing infection and for coping and adaptation once infection occurs. To black Americans, the impact of AIDS presents several unique considerations. These include differences from whites in patterns of infection, effectiveness of preventive health education efforts, and psychosocial issues

affecting the health and mental health care of black AIDS patients.

Patterns of Infection

Despite the general perception that AIDS is nearly exclusively a "gay disease" (4), and a specific perception by some members of the black community that AIDS is a "gay white disease" (5), AIDS has disproportionately affected blacks (6-8). As of December 29, 1986, 28,593 cases of AIDS in adults have been reported in the United States (9). Of these, approximately 25 percent have

occurred among black persons, although blacks represent only 12 percent of the population. At this point, the Public Health Service (PHS) has estimated that approximately 1 to 1.5 million persons have been infected with the AIDS virus—HTLV-III/LAV (human T-cell lymphotropic virus type III/lymphadenopathy-associated virus. The International Committee on the Taxonomy of Viruses proposed the name “human immunodeficiency virus” for these viruses (10). If rates of infection parallel AIDS incidence ratios, then 1 to 1.4 percent of the black population is possibly infected with the virus (figures are based on the 1980 U.S. Census (11)). In contrast, 60.2 percent of diagnosed AIDS patients have been whites, suggesting that 0.3 to 0.5 percent of the white population may be infected. Clearly, AIDS has the potential to have a much more profound impact on the black community than among whites.

The Public Health Service estimates that by the year 1991 the cumulative number of cases of AIDS will reach 196,000 (155,000–220,000 range) (10). This estimate indicates an approximate tenfold increase in the cumulative number of cases at the start of 1986. Multiplying the number of cases among blacks at the start of 1986 by 10 yields approximately 49,000 cases by 1991 (table 1), if one follows the PHS model and uses the current relative incidence by ethnic group. Cumulative deaths would reach 31,500. Yet the Public Health Service speculates that the empirical model used to derive these overall estimates may *underestimate* by at least 20 percent the serious morbidity and mortality attributable to AIDS because of under-reporting or under-identification of cases (10, 12). Racial differences in the use of health care resources and risk behaviors may differentially affect the accuracy of the reporting of AIDS cases in black Americans.

In addition, the epidemiologic pattern for AIDS transmission among adult blacks differs from that of the white population, which suggests greater levels of risk to the heterosexual population (6–8) (table 2). Black homosexual and bisexual men account for 46.3 percent of all cases in blacks, and heterosexual IV drug users account for 35.4 percent. In contrast, among whites, 88.9 percent of cases are in homosexual or bisexual men, and 5.2 percent are heterosexual IV drug users. This difference in patterns of infection is most pronounced in New York City, which has the highest cumulative incidence of AIDS cases among intravenous drug users in the United States (13, 14). A second factor in the distribution among blacks is

Table 1. Projected cases of AIDS for black Americans ¹

Category	Total AIDS cases		Black Americans	
	1986	1991	1986	1991
Cumulative cases diagnosed at start of year.	19,000	196,000	4,750	49,000
Cumulative deaths at start of year.	9,000	125,000	2,250	31,250
Estimated number of persons infected with HIV virus.	1,000,000 to 1,500,000	...	250,000 to 375,000	...

¹ Total AIDS cases based on Coolfont planning conference, 1986 estimates. Estimates for black Americans assume that blacks will continue to constitute approximately 25 percent of all AIDS cases.

that the category of individuals with AIDS from foreign countries comprises primarily blacks from Haiti and Central Africa (15). Many of them are economically disadvantaged immigrants residing in New York or Miami who either lack private health insurance or financial resources or are ineligible for government-subsidized medical services due to their undocumented status (15,16). Early symptoms of AIDS may be ignored and, due to cultural differences in sexual norms among Haitians, rates of nonmonogamous sexual behavior may be high (15–17). AIDS testing of military recruits reveals a higher percentage of seropositive testing in black recruits, supporting concerns about the possibility of higher rates of heterosexual transmission in blacks (18). Researchers who studied rates of seropositivity among U.S. military recruit applicants tested for antibodies to the AIDS virus found a 0.9 per 1,000 seropositive rate among white recruits but a rate of 3.9 per 1,000 among blacks (18).

The importance of accurate predictions is critical. Often, these are used as the basis for allocating Federal, State, city, and county resources. As an example, it has been suggested that intravenous drug users with AIDS suffer a higher rate of acute opportunistic diseases than do gay and bisexual men, thus requiring more extensive medical care (14). Blacks who develop AIDS are more likely to be IV drug users but, for the most part, they have lower incomes and less education than whites who are similarly afflicted. In New York City, approximately 50 percent of IV drug users are on public assistance and depend on Medicaid for health insurance (14). The average cost of hospital care for an AIDS patient is \$147,000 (13, 19). However, more recent data

Table 2. Distribution of AIDS cases in adults, by race and risk factors, December 29, 1986¹

Risk factor	Total		White		Black	
	Cases	Percent	Cases	Percent	Cases	Percent
Homosexual or bisexual male	18,750	65.6	13,849	80.4	2,738	39.2
Homosexual or bisexual male and IV drug user ...	2,230	7.8	1,436	8.4	494	7.1
Heterosexual IV drug user	4,846	17.0	891	5.2	2,464	35.3
Immigrant from country where heterosexual transmission is thought to play a major role	584	2.1	3	0.0	578	8.3
Heterosexual contact with AIDS-infected or at-risk person	508	1.8	126	0.8	241	3.5
Transfusion	524	1.9	407	2.4	78	1.1
Hemophiliac	246	0.9	208	1.2	14	0.2
None of the above	905	3.2	321	1.9	383	5.5
Total cases	28,593	100.0	17,241	100.0	6,990	100.0

¹ AIDS surveillance data from the Centers for Disease Control.

indicate that hospital costs may vary widely according to geographic location (20). Nevertheless, hospitals in the black community are more likely to have to care for these patients and may suffer a severe drain of resources without adequate compensation.

Reducing Infection Rates

Slowing the transmission rate of the AIDS virus within the black community is critical. Several specific concerns are particularly relevant when focusing on blacks who are especially at risk for HTLV-III/LAV exposure. For all black Americans in potential risk groups, health educators need to be especially sensitive to differences in the vernacular used by blacks to describe sexual behaviors and methods of intravenous drug use.

Black homosexual and bisexual men. Public Health Service projections anticipate that information and interventions currently employed in the broader gay community will successfully lower the rate of transmission among homosexual men (10). However, assumptions that outreach efforts have reached and are effective with black gay and bisexual men are unproven. The black gay community continues to insist that the methods of educational outreach and intervention spearheaded by the white gay community have been ineffective in reaching black gay and bisexual men (21). Therefore, risk reduction behaviors within this population may actually be developing at a slower rate than among white gay men.

There is evidence that black gay and bisexual men may have somewhat different patterns of

sexual behaviors from white gay men (22). These include higher rates of both active and passive anal intercourse and bisexual involvement. Health education efforts critical to curtailing the spread of this infection may be hampered by a lack of sensitivity to ethnic and cultural differences.

Intravenous drug users. For intravenous drug users, most of whom identify themselves as heterosexual, less educational outreach has been organized. Substance abuse programs are in a precarious position. It is difficult to discuss how to sterilize drug works or paraphernalia without appearing to advocate drug use rather than abstinence. Interventions that highlight the deadly effects of AIDS or advocate abstinence to avoid infection are not likely to be effective. Drug users already face the threat of death with each injection. In contrast to the homosexual-bisexual population, many addicts tolerate poor health along with their addiction and therefore may resist AIDS messages with this focus.

Incarcerated persons. Another potential risk group are prisoners (23). Currently, blacks make up a higher proportion of the prison population than is warranted by their numbers in the general population. During periods of incarceration, prisoners may engage in homosexual behaviors but not view themselves as either homosexual or bisexual. While drug use is illegal, it does occur in prison. Drug paraphernalia, such as needles, are scarce in prisons and consequently are likely to be reused. Interventions that advocate the use of condoms or cleaning of drug works are often unacceptable to prison authorities since these facilitate illegal activities.

Issues in the Care of Black AIDS Patients

Little information published to date has addressed the specific psychosocial needs of black AIDS patients. The vast majority of articles on the psychosocial impact of AIDS address the emotional and behavioral responses of white gay men with AIDS (24). Nevertheless, it could be expected that one would find a common human element in reactions to a life-threatening illness. Thus, we would expect that AIDS patients, regardless of ethnicity, experience profound psychosocial disruptions including affective distress, loss of or severe strain on existing social support systems, and financial distress (25-27). Black Americans differ in respect to the resources available and the cultural norms at work in coping with their illness. These differences may be manifested in such areas as help-seeking behavior (28), perceptions of the severity of medical or psychological problems (references 29,30 and unpublished manuscript by V. M. Mays and C. S. Howard: "Symptom and Service Utilization Problems in a National Sample of Black Women: Implications for Psychotherapy Research"), perceived barriers to the use of health care facilities (31,32), or the use of informal help systems (28,33).

In thinking about adaptation to any life-threatening illness, there are three major areas of focus: psychological resources (personality, coping resources, support); sociocultural factors (social stigma, external resources); and aspects of medical care (symptoms, patient-physician relationships, treatment decisions) (34,35). For AIDS, the adaptation is a particularly complex process, regardless of the patient's ethnicity (26,27, 36). Some special issues are important in thinking about the black AIDS patient.

Psychological issues. Psychological factors are extremely important in enduring the stress of AIDS (26). AIDS patients who demonstrate a "fighting spirit" may have a longer survival period and do better psychologically (36). This fighting stance in the face of adversity is consistent with the Southern tradition of "I can do" instilled in many American blacks (37,38), and it may serve black AIDS patients well in coping with their disease. On the other hand, this sense of independence may also make it difficult to accept and develop appropriately dependent relationships with caretakers when those persons are outside family or community networks. This attitude is especially true for the black male for whom a sense of

independence is strongly associated with maleness (37).

The role of informal social networks and family systems as alternatives or supplements to professional help has been well documented (28,39-41). Structural characteristics of social networks may also determine use of professional help (42). For many ethnic minorities with limited access to health care information, the family and friendship networks are the dominant influence on health behavior and a trusted source of health information (43,44). Although blacks may consider physicians as the most credible source of information, they may refrain from asking questions because they do not wish to appear ignorant, or they perceive that physicians are too busy to talk to them (44,45).

The implications of this behavior are threefold. First, inclusion of family and friends, with permission of the patient, when information is being dispensed may enhance medical compliance by raising the level of knowledge of the informal advice network. Second, creation of an atmosphere that encourages questioning by the patient can assist in overcoming problems of reticence. Again, this may help ultimately to improve medical compliance. Third, AIDS educational interventions may be most effective if basic information is targeted to the general black population.

Sociocultural issues. Several sociocultural factors may complicate the adaptation of black AIDS patients. First, an AIDS diagnosis may result in identification of socially stigmatized behaviors that were previously hidden, such as drug abuse, sexual preference, or nonmonogamous sexual relations. As a community black Americans, for the most part, exhibit particularly negative attitudes toward homosexuality, perhaps due in part to strong religious beliefs (unpublished manuscript by V. M. Mays: "Perceived Discrimination and Black Women's Relationships").

Second, black Americans tend to maintain fairly frequent contacts with kin, receiving much support in return (46). Black AIDS patients, like other groups, have experienced rejection by family members. Yet, the impact of rejection for blacks may be more severe, given existing cultural norms emphasizing the kinship network as the provider of both tangible and emotional social support. Elsewhere, it has been noted that persons with AIDS are in particular need of emotional and illness-related support (36). Many AIDS programs offering support services, such as buddy programs,

housecleaning, and others, are found in predominantly white gay organizations, groups which generally lie outside the neighborhoods and support networks of many black gay men. There are very few full-service minority AIDS programs providing culturally specific services to black AIDS patients.

Third, past difficulties with the health care system, including long waiting periods in low cost clinics, cultural barriers in communication, and lack of financial resources, complicate the willingness of blacks from the lower socioeconomic segment to seek medical care at the first signs of AIDS-related symptoms or to seek treatment for nonemergency AIDS-related health problems, even after they are diagnosed. Time of survival after diagnosis is shorter for blacks, as they tend to seek treatment long after the appearance of early symptoms (47). This observation includes cases in black children.

Issues in medical care. The medical care of black AIDS patients raises additional issues precipitated by possible sociocultural differences between patients and health care providers.

Symptoms and diagnosis. Three areas of disease and diagnosis are of special concern in the care of black AIDS patients. First, blacks are less likely to present with Kaposi's sarcoma, a clinical manifestation of AIDS that has a better short-term prognosis than acute opportunistic infections (48). Thus, blacks may enter treatment more severely ill and in need of greater levels of medical and psychosocial care.

Second, ethnic differences previously demonstrated in non-AIDS-related psychiatric diagnosis and in the expression of psychological distress may have implications for the treatment of black AIDS patients. Thus far, the primary psychiatric diagnoses of AIDS patients have been atypical affective disorders. In general, studies have indicated that the mental health profession tends to underdiagnose affective disorders and overdiagnose schizophrenia in blacks, particularly black males (49). Mental health professionals tend to believe that blacks rarely suffer from bipolar disorders, perhaps because they view hyperactive behavior as normal black male aggressive behavior (49). Also, as Jones and Grey (49) pointed out, blacks with affective disorders exhibit delusions and hallucinations more frequently than whites and hence are at risk for misdiagnosis of thought disorder.

The major problem seems to be cultural differences in the presentation of symptoms. For exam-

ple, the tendency for black males to be somewhat remote, withdrawn, and formal in the presence of white professionals may be misinterpreted as the patient's attempt to cope with an underlying thought disorder or schizophrenic psychotic process rather than a culturally relevant stance when dealing with a nearly foreign white world. The patient may, in fact, be quite depressed but deem it culturally inappropriate to reveal this emotional distress. It is equally possible that unwillingness to talk to white physicians may be viewed as depression rather than resistance (49). Language, mannerisms, and style of behavior that are culturally determined may, if not understood, result in misdiagnosis.

Third, in the evaluation of neurological impairments seen in a significant percentage of AIDS patients (35,50), diagnosis of impairment may be complicated in persons whose educational background and interest in current and past political affairs differ from those of the examiners. The following incident may illuminate possible pitfalls in such situations.

One of the authors, Dr. Cochran, witnessed an examination of the mental status of a hospital inpatient, an uneducated elderly black man with advanced heart disease, by several young white health professionals. Cognitive impairment was a distinct possibility. Questions assessing knowledge (for example, names of presidents and politicians) revealed a marked deficit. Yet when she asked the patient about the current baseball pennant race, the patient proved remarkably lucid, brightened considerably, and lost his withdrawn demeanor. One can only imagine the patient's thoughts during the early stages of the examination. However, when questions relevant to him were used to evaluate his cognitive abilities, no significant deficits were observed. This example underscores the importance of translating frequently used assessment procedures into the "language" of the patient.

Patient-physician communication. To the extent that cultural, ethnic, or racial barriers create communication difficulties for AIDS patients and their physicians, the effectiveness of the patient-physician relationship will be undermined (51). In the treatment of AIDS, the patient-physician relationship is critical to the quality of care received. A myriad of physical ailments can occur, necessitating accurate and prompt treatment. Collaborative patient-physician relationships can facilitate this response. AIDS patients need adequate medi-

cal information about their disease in order to know what symptoms to monitor and report to their physicians, when to call their physician for unexpected assistance, and how to comply with the treatment process. If the patient and physician cannot effectively communicate, survivability of the patient is potentially compromised.

For example, in dispensing medical advice, white physicians may be unaware of differences in dietary practices, of lack of priorities given to future orientation or long-range planning, and of the influential role of kin, particularly for black women, in health behaviors. Quite often intravenous drug users function within a present-time orientation that mitigates against taking medical advice that involves planning for the future. It is best to work with, rather than against, this orientation in giving medical advice to the person with AIDS.

Neurological complications increase the risk that there will be impaired mental competence that prevents full participation in medical treatment decisions. In such instances, the standard protocol in the medical community is to turn to the family of origin for shared medical decisions. However, some black families may also be unfamiliar with medical procedures or have difficulty understanding or communicating with the physician. Hospital personnel use interpreters when there is an obvious language barrier, and it may be useful to use "interpreters," such as knowledgeable friends of the patient or culturally sensitive hospital personnel, who can assist the physician in communicating with the family.

Ethical issues. Ethical dilemmas can readily occur in the medical care of AIDS patients (52). After repeated hospitalizations for acute opportunistic infections, AIDS patients and physicians eventually confront questions of supportive care versus life-sustaining treatments. Current ethical and legal guidelines recommend that these decisions be shared by the physician and informed, competent patients (52). Such decisions, particularly by the patient, often require some understanding of technical information. However, lower levels of education and lack of familiarity with hospital procedures in some segments of the black population may make this educational process more difficult.

Other issues may arise in the care of the black AIDS patient. For example, in deciding when heroic medical treatment is futile, physicians must be sensitive to possible biases in their own

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decision-making if resources available to the patient for continued inpatient or outpatient treatment appear scarce, or if the patient is likely to return to intravenous drug usage.

And, finally, cultural and religious influences in the black community may complicate decision-making about continuing treatment. Many of the major black churches, including fundamentalist Christian denominations and some Baptist traditions, view homosexuality as especially sinful (53). A recent poll found that almost 40 percent of fundamentalist Christians believed that AIDS is a punishment from God for the way homosexuals live (54). Persons who hold these beliefs may view resuscitation efforts as interfering with God's plans. In coping with these situations, health professionals can be helpful if they dispense culturally relevant advice. For example, black Americans, particularly women, frequently cope with psychological difficulties through prayer (33). Often this prayer is for God's will to be done or for a miracle. In assisting the black family confronted with difficult decisions, it may help to encourage the family to pray for guidance and support in their decisions as a way of making a miracle happen, rather than to adopt a passive or antagonistic stance.

Summary and Recommendations

In this review, we have sought to highlight psychosocial issues that are of particular concern when the impact of AIDS in the black community is considered. As we have noted, differences in sociocultural influences between blacks and whites necessitate a sensitivity to possible differences in patterns of infection, the impact of preventive health education efforts, and the coping process of

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black AIDS patients. These differences have broad implications for education, prevention, and allocation of resources within the black population. In thinking about the AIDS crisis in the black community, we recommend the following measures as a means of ameliorating the impact of AIDS on the entire black population and to help reduce the incidence of HTLV-III/LAV infection in the black community.

1. Research. Recommendations for needed research can be categorized in three broad areas:

- an examination of the role that the black family structure, community supports, cultural values, patterns of help-seeking, and perceptions of severity of medical and psychological problems play in the inhibition or facilitation of the transmission and incidence of the HTLV-III/LAV virus.
- epidemiologic studies that include large numbers of black gay and bisexual men, intravenous drug abusers (including recreational intravenous drug abusers), and heterosexuals at high risk.
- an exploration of the most effective methods for the delivery of clinical services, intervention, and prevention efforts that are consistent with the cultural, class, geographic region, and the sexual preference diversity that exists among high-risk groups of black Americans.

2. Information and education. Research for needed information and education can be categorized into three broad areas with four recommendations:

- establishment of a national clearinghouse on AIDS in the black population to provide health care professionals, community organizations, and self-help groups with accurate up-to-date informa-

tion on the medical, psychological, and political aspects of AIDS.

- development of prevention strategies and materials that are culturally sensitive and meaningful, as well as gender-, lifestyle-, and age-appropriate in order to inform effectively and reduce the transmission and incidence of the HTLV-III/LAV virus within the diverse population of black Americans.
- information reported by Federal agencies that includes breakdowns by both gender and ethnic group.
- collection of data by Federal agencies in a manner that allows for differences in the patterns of ethnic groups to be clearly documented to provide accurate information for health care planning and public policy use.

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