
DISPARITIES AND GAPS IN HIV RESEARCH AND CARE

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The HIV/AIDS epidemic has impacted people of African descent worldwide. Of the estimated 40 million (range 34–46 million) adults and children currently living with HIV/AIDS,¹ more than half (25.0–28.2 million) live in sub-Saharan Africa. Further, approximately 1.3–1.9 million reside in Latin America, 350,000–590,000 live in the Caribbean, and 790,000–1.2 million reside in North America. It is well documented that African Americans are significantly over-represented among individuals with HIV/AIDS in the United States.² What is less well known, however, is that African Americans are dramatically under-represented in HIV/AIDS research studies. A recent Medline search revealed that of more than 48,000 articles published on HIV/AIDS between January 1996 and January 2003, only 1.4% of articles refer to African Americans and/or blacks (K.Y.S., unpublished data, 2003). This under-representation is striking considering that African Americans accounted for 38.4% of the 816,149 cases of AIDS reported to the Centers for Disease Control and Prevention from 1985 through 2001 and for 50.2% of the 35,575 newly diagnosed cases of HIV reported in 2001 alone (Figure 1).²

Given the impact of HIV/AIDS in our com-

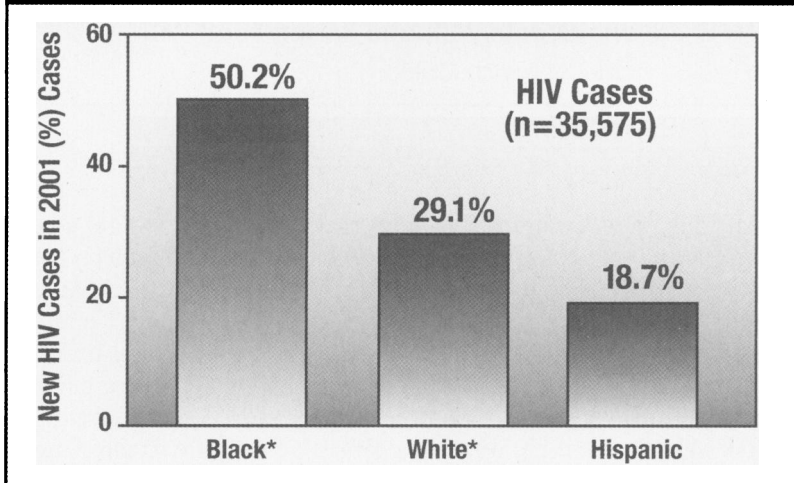
munities, it is critical that efforts to find a cure and optimize treatment strategies focus on these populations. Historically, however, African Americans have been less likely to participate in clinical trials than whites. One recent study revealed that 14% of adults receiving HIV care participated in clinical trials, and 24% received experimental medications.³ However, African Americans were 50% less likely than whites to be clinical trial participants or to receive experimental medications. Among those who sought experimental medications, whites received them more often than African Americans—77% and 69%, respectively ($P=0.03$).

As a result, African Americans have less access to investigational state-of-the-art drugs and treatment strategies than whites, a situation that appears to be leading to higher rates of viral transmission and, ultimately, to the ever-increasing incidence of HIV infection in our communities. Further, this lack of participation in clinical trials denies African-American and Latino patients the benefits of treatment—including lower rates of morbidity and mortality—that are derived by patients receiving state-of-the-art care. Several studies have shown that African-American and Latino patients infected with HIV receive suboptimal care compared with whites.^{4,5} Increasing the numbers of patients who participate in clinical trials can help overcome this disparity.

A separate but equally disturbing issue is that studies in which African Americans are not adequately represented may have limited clinical relevance because of the under-recognized differences between African Americans and other groups and because of the issues that disproportionately impact people of color. For example, the HIV Outpatient Study (HOPS) reported that whites were significantly more likely to develop lipatrophy than nonwhites, and blacks were sig-

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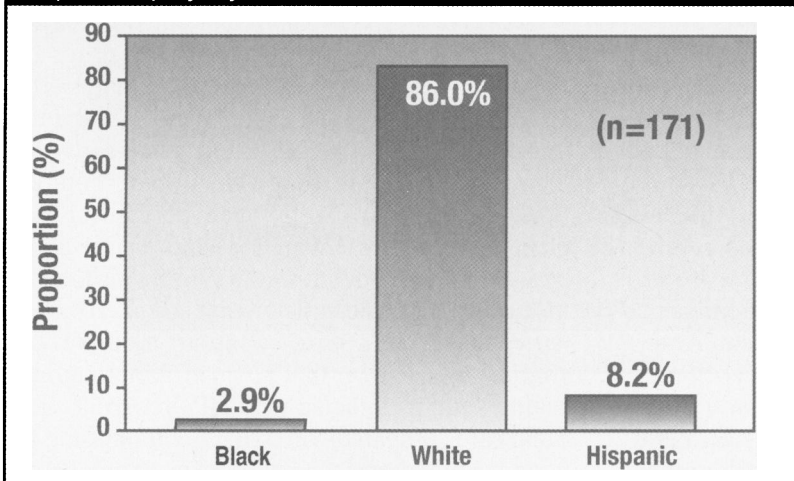
Figure 1. Demographics of New HIV Cases Diagnosed in 2001



*Not Hispanic.

Adapted from CDC: Surveillance Report. 2002.²

Figure 2. Proportion of Moderate to Severe Lipoatrophy by Race



Adapted from Lichtenstein KA, et al. *AIDS*. 2001;15:1389-1398.⁶

nificantly less likely to do so than nonblacks, even after adjusting for age, HIV disease status, duration of antiretroviral therapy, and use of particular antiretroviral agents.⁶ Of the 1,077 subjects in this study, 72% were white, 9% were black, and 13% were Hispanic. Moderate or severe lipoatrophy was reported in 171 patients of whom 5% were black and 18.9% were white. The proportion is

densely populated by these groups and when a safe and secure clinical trials environment is provided for patients to participate in clinical research.

A dearth of African-American and Latino physicians is another important factor contributing to inadequate representation. While 12.3% of the U.S. population is black, only 2.5% of

shown in Figure 2. This finding differs from the anecdotal experiences of clinicians who treat large numbers of black patients with HIV, which suggest that lipoatrophy is a common problem. Are blacks truly less likely to experience lipoatrophy than whites as the HOPS findings suggest, or are the results due to under-representation of blacks in the trial? Accurate answers will only come when African Americans are adequately represented in these studies.

One group addressing this concern is the Women's Interagency HIV Study (WIHS) Collaborative, which has enrolled 2,628 adult women (2,059 HIV-seropositive, 569 HIV-seronegative).⁷ Of the women enrolled, 57% were African American, 22% were Hispanic/Latina, and 18% were white—proportions that more closely mirror the current demographic profile of women infected with HIV. The efforts of the WIHS investigators clearly demonstrate that it is possible to recruit sufficient numbers of African Americans and Hispanics/Latinos to obtain information relevant to these populations. Recruitment of persons of color is improved when clinical trial centers are located in cities

physicians are black and an even smaller number of that group is involved in treating patients with HIV/AIDS.^{8,9} The situation is only slightly better for Hispanics, who comprise 12.5% of the U.S. population but only 3.4% of physicians. One encouraging note is that the percentage of blacks and Hispanics graduating from medical school is increasing. In 2001–2002, 7.2% of graduates were black and 6.1% were Hispanic compared with 5.3% and 5.5%, respectively, in 1992.^{8,9} Enrollment in medical school has increased for both groups as well during the same period. Nevertheless, greater efforts must be made to both increase the number of African-American and Latino physicians and, in particular, to increase the number involved in HIV/AIDS clinical research and care. Greater diversity among investigators could shift the focus of HIV/AIDS research toward the populations who have been disproportionately affected by the current epidemic and substantially improve the quantity, quality, and variety of studies involving these patients. A larger pool of clinicians of color could also help mitigate lingering issues of mistrust of the medical community among African Americans. One recent study in the *Archives of Internal Medicine* found that 727 of 909 (80%) blacks surveyed nationally feared they would be used as guinea pigs for medical research.¹⁰ In addition, clinicians of other cultures who treat blacks and Latinos must learn to deliver culturally competent care in an environment that is safe and comfortable.

Last, but not least, greater efforts must be devoted to providing education on prevention methods that have been shown to reduce transmission among other high-risk populations, such as gay white men and commercial sex workers, including regular use of condoms and repeated HIV testing.

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