



Disparities in Care for HIV Patients

Results of the HCSUS Study

The HIV treatments introduced during the last five years of the 20th century are extending the lifespan of HIV-positive patients and increasing their quality of life. But the value of these treatments is limited if the people who need them most cannot or do not avail themselves of them. For example, most HIV-positive persons should receive highly active antiretroviral therapy (HAART)—the most up-to-date and effective treatment for HIV—as well as supportive services to assist with the other problems HIV can create and the same kinds of health care that everyone else needs.

Among the first questions HCSUS (see sidebar) sought to answer were whether some HIV-positive Americans were less likely than others to receive effective HIV treatment and other needed health care; what constituted the barriers to care, if any; and what can be done to remove those barriers and improve access to care.

Who Does—and Who Doesn't—Get HIV Treatment?

One of the key components of up-to-date care for HIV is a cocktail of powerful drugs referred to as HAART. HAART includes three classes of drugs: protease inhibitors, non-nucleoside reverse transcriptase inhibitors, and nucleoside reverse transcriptase inhibitors. Current care guidelines recommend that HIV-positive individuals with symptomatic disease as well as those whose immune function has declined (to the point that the number of white blood cells known as CD4 cells is less than 200 cells per millimeter cubed) should receive this treatment. The HCSUS researchers assumed that HAART was the appropriate treatment for more than 99 percent of HCSUS

Key findings:

- HIV-infected persons were less likely to receive highly active antiretroviral therapy (HAART) when it was initially introduced if they were African American or Hispanic; lacked health insurance or had public insurance; were exposed to HIV through IV-drug use; had less than a college education; had competing demands on their time, attention, or resources; or received their care from nonspecialists.
- African Americans and Hispanics were less likely to access experimental treatments (e.g., via participation in clinical trials) both because they lacked trust in their providers and because they lived long distances from providers with expertise in HIV care.
- Individuals who need other supportive services such as substance abuse treatment were also less likely to receive HAART.
- Some groups of HIV-positive patients were also less likely to receive other needed care, such as prophylactic antibiotics and routine preventive care.
- Although disparities in access to HAART among various groups are narrowing, increased use of case management to help HIV-positive patients coordinate their care would help eliminate those disparities.

participants; however, by the end of 1996, only 38 percent of eligible participants reported that they had received some form of HAART, even though all of them had received health care from a primary care provider during that time period.

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What Is HCSUS?

The HIV Costs and Services Utilization Study (HCSUS) is the first comprehensive U.S. survey of health care use among a nationally representative sample of HIV-positive persons who were in care for their HIV. The aims of HCSUS were to estimate the costs associated with HIV care; to identify barriers that affect access to HIV treatment as well as to other health care services; and to assess how HIV-positive status affects quality of life, productivity, and family life. Participants in HCSUS were interviewed several times over a 3-year period, making it possible to assess the effects of changes in HIV treatment.

Since it began in 1996, HCSUS has generated more than 70 original research publications on a wide variety of issues related to HIV infection. Highlights of the initial findings have been featured in several RAND Research Highlights (see Research Summarized). This Research Highlight reports findings from a series of questions posed during the initial interview regarding patients' access to and use of the latest treatments for HIV as well as other preventive care. The Highlight is one in a series summarizing HCSUS research. More information on HCSUS, including a list of publications, can be found at www.rand.org/health/hcsus.

Were those who did not receive HAART fairly evenly distributed throughout the population, or were there disparities in care between some groups of people and others? The good news was that the sickest patients—those with the lowest CD4 counts—were most likely to be receiving HAART. But race/ethnicity; insurance status; educational background (see Figure 1); competing demands on the patient's time, attention, or resources; and the means by which a person had become infected with the virus also affected his or her chance of receiving this most up-to-date treatment. Taking all other factors into account, African American and Hispanic persons were significantly less likely than whites to be receiving HAART. HAART is quite costly; therefore, it is not surprising that those without health insurance were less likely to be receiving HAART or to have ever received antiretroviral treatment than were those with private health insurance. However, those with Medicaid were also less likely to receive HAART, highlighting that this safety net health plan provides less generous coverage than other types of health plans. In addition, those with only a high school degree were less likely to be receiving HAART than those with at least a college education. And, without accounting for insurance coverage, those who were exposed to the HIV virus through IV-drug use, particularly women who were IV-drug users and women who had sexual contact with IV-drug users, were less

likely to be receiving HAART than those who had contracted the virus through other means.

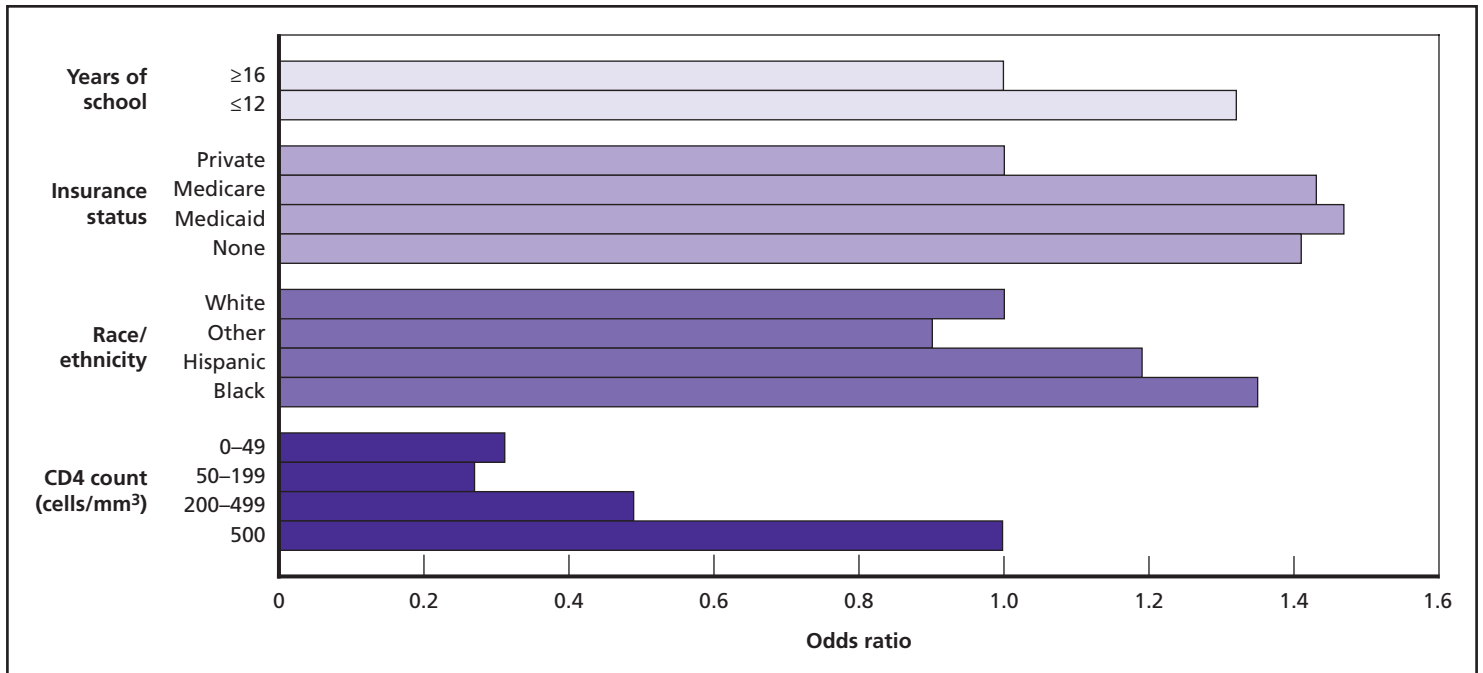
What Might Explain These Disparities in HIV Treatment?

The research suggested a number of factors that might account for why some people with HIV are receiving the most effective treatment while others are not.

Delays in Entering Care. Factors related to delayed entry into treatment, which can profoundly affect AIDS mortality, are one source of disparities in HIV treatment. The HCSUS researchers found that nearly one-third of HCSUS participants delayed treatment three to six months or more after their initial diagnosis. All else being equal, individuals who delayed initiating treatment more than three months were more likely to have been diagnosed before 1992, to be African American or Hispanic, to be sick at the time of diagnosis, and to have no usual source of health care. Of great concern is that the actual proportion of HIV-positive individuals in the general population who delay care is likely to be much greater than the HCSUS findings suggest, because the HCSUS participants, by definition, had seen a care provider at least once in the preceding six months and because the study excluded individuals who died shortly after diagnosis.

Receipt of Investigational Therapy. One way patients gain access to the most up-to-date treatments is through participation in clinical trials—the large-scale studies that test the effectiveness of the newest treatments on a large, diverse population. Disparities were found in the extent to which subgroups of participants enrolled in these clinical trials and in access to experimental medications by other means. Those who were privately insured but received their health care through health maintenance organizations were less likely to participate in clinical trials than those with traditional fee-for-service coverage. Those who received their regular care more than a mile from the nearest clinical trial center were less likely to participate in clinical trials than those receiving care close to a center. African Americans and Hispanics were less likely than whites to participate in clinical trials or to receive experimental drugs by other means, even after taking into account their insurance status, education, disease severity, and means of infection. Although minorities had less success in obtaining experimental treatments than did whites, most of the disparity in receipt of experimental treatments was due to minorities *seeking* such treatments less often. Such findings suggest that the failure of African Americans to participate in clinical trials or to try to obtain experimental medications might be the result of both mistrust of health care providers and the health care system and difficulties in getting to the sites where the studies are being conducted.

Figure 1
Odds of Not Currently Receiving HAART at Second Follow-Up (1997–1998)



Geographical Barriers. Residents of rural areas were less likely than urban dwellers to be receiving HAART. And about two-thirds of those who did receive it traveled to an urban area for their care.

Physician Factors. The type of physician providing participants’ HIV care also affected their access to the most up-to-date care. Physicians who care for people who are HIV-positive fall into one of three categories: infectious disease specialists, who tend to treat a high volume of HIV-infected patients; high-HIV-volume generalists (family practitioners or general internists); and low-HIV-volume generalists. A survey of physicians whose patients were enrolled in the study revealed that the high-HIV-volume generalists had knowledge about the disease that was nearly equivalent to that of the specialists; the researchers termed these physicians “expert generalists.” In contrast, the low-HIV-volume physicians tended to be less knowledgeable about the disease and its treatment; the researchers termed these physicians “non-expert generalists.” Participants who received their HIV care from infectious disease specialists or expert generalists were significantly more likely to be receiving HAART than were patients of non-expert generalists.

The physician’s impression of the likelihood that a patient would comply with the treatment regimen may also have played a role. HIV treatment guidelines actually recommend delaying HAART for noncompliant patients—that is, those who have a history of failing to follow a doctor’s orders, particularly with regard to adhering to treatments.

The guideline is based on evidence that inadequate adherence promotes drug resistance, which can erode the treatability of HIV and might increase its spread. According to the physicians’ survey, 89 percent agreed with the guideline. The researchers termed these physicians “selective” and the other 11 percent “nonselective.” Patients of selective providers received HAART later than patients of nonselective providers. Hispanics, women, and those with annual family incomes less than \$25,000 who were patients of selective providers experienced delays in receiving HAART compared with other ethnic groups, men, and those with higher incomes, respectively. Among patients of nonselective providers, no such disparities in treatment initiation were found. However, no evidence was found that the patients whose treatment was delayed were nonadherent or that the groups singled out were more likely to be nonadherent than others. This finding—that the majority of physicians who treat HIV patients are making treatment decisions based on bias and unfounded beliefs—should be cause for concern.

Finally, the physician’s race may play a role in African Americans’ delays in receiving HAART. Among the HCSUS participants, African American patients with white physicians began HAART significantly later than did African American patients with African American physicians and white patients with white physicians, suggesting that racial/ethnic differences between HIV patients and their physicians may influence the timing of HAART initiation. (The researchers focused their racial/ethnic comparisons on Afri-

can Americans and whites because there were too few cases for comparison among the other racial/ethnic groups.)

Competing Needs. Yet another barrier may explain the apparent inability of many HIV-positive individuals, particularly women, to receive needed care. Individuals with competing demands on their time, attention, or resources—such as parents caring for young children or an aging parent or individuals having difficulty paying for food, clothing, and housing—were less likely to avail themselves of antiretroviral treatment than those without such demands. Women were more likely than men to report putting off seeking care because of responsibilities for the care of others. African Americans and Hispanics were more likely than whites to report being hampered by competing economic demands.

Co-Occurring Disorders. Participants who reported having recently abused illicit drugs, being addicted to drugs, or having contracted HIV through IV-drug use were less likely to be on HAART. However, those who reported mental health problems or alcohol abuse were no less likely to be given HAART than participants with no history of mental health problems or alcohol abuse.

Unmet Needs for Supportive Services. Being HIV positive often goes hand in hand with the need for mental health or substance abuse treatment, loss of employment and health coverage, and a need for housing assistance and other services. Participants who reported unmet needs for supportive services that address these ancillary problems were less likely to access HAART treatment than those who were better able to manage their needs. Those with case managers—professionals who help their clients receive a variety of needed services—had fewer current problems and were more likely to receive needed care. However, only 57 percent of participants reported having had contact with a case manager in the previous six months. Based on these findings, some of the HCSUS researchers are now testing the effect of increasing case management on underserved HIV patients' access to care.

Do Some Groups Suffer Worse Outcomes Than Others?

The apparent disparities in access to the most up-to-date care might be expected to result in differences in death rate, illness severity, or health-related quality of life, but is that the case? The answer is complicated.

In spite of the disparities in access to HAART between African Americans and other ethnic groups, a new HCSUS analysis finds that the risk of an individual dying was *not* greater for African Americans than for other ethnic groups when a myriad of other factors were taken into account. However, higher mortality rates *were* associated with lower

income, lower educational attainment, and less wealth. This finding suggests that African Americans do tend to die earlier from AIDS, but not because of their race. Health-related quality of life (HRQOL) is a concept that refers to a person's perception of his or her physical or emotional health over time and the effect of those perceptions on the person's satisfaction with life.

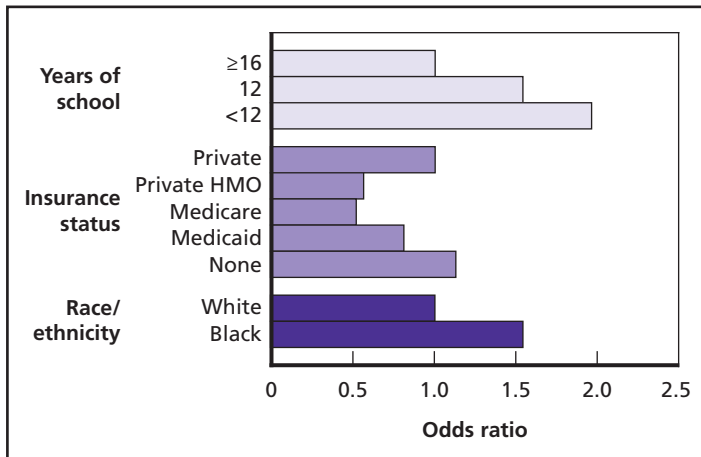
Among the HCSUS participants, HRQOL was affected primarily by disease progression. An increased perception of physical limitations was associated with greater symptom intensity, pain, and fatigue (which worsen with disease progression). Particular symptoms—white patches in the mouth, nausea or loss of appetite, persistent cough, difficulty breathing, and weight loss—rather than characteristics such as ethnicity, income, or access to care—were associated with poorer HRQOL. Still, access to care may be indirectly related to HRQOL because reduced access to care leads to faster disease progression in terms of symptoms and complications as well as CD4 count.

What About Other Kinds of Needed HIV-Related Health Care?

Because of HIV's debilitating effect on the immune system, a person in the advanced stages of HIV is susceptible to other types of infections, which may ultimately be responsible for much of the morbidity and some of the mortality associated with AIDS. Treatment guidelines recommend administering appropriate antibiotics prophylactically—that is, to prevent the infections from occurring in the first place. The HCSUS researchers considered whether some participants had greater access to these medications than others. Participants were asked whether they were receiving medication to prevent *Pneumocystis carinii* (now known as *Pneumocystis jiroveci*), a potentially fatal type of pneumonia. Fully 30 percent were not receiving this medication (a figure that improved to 26 percent some two years later). African Americans were one-and-a-half times less likely than whites to receive this medication. Education was also a factor: Those with no more than a high school education were less likely to have received the medication than those with at least a college education. Insurance source had an impact as well: Those enrolled in private HMOs and those on Medicare were more likely to have received this medication than those on private fee-for-service plans or those on Medicaid (see Figure 2).

Unlike the HCSUS participants, who reported receiving regular medical care, only 40 to 60 percent of the general HIV-positive population is estimated to receive such care. Nevertheless, a number of HCSUS participants reported going without routine preventive care. Women in the study reported few difficulties in obtaining annual gynecological

Figure 2
Odds of Not Receiving Antibiotic Prophylaxis



exams; however, the likelihood of receiving appropriate gynecological care was greater for women whose usual source of gynecological care was in the same location as the source of their HIV care than for women whose gynecologist was not affiliated with an HIV clinic. Gynecologists were more likely to provide appropriate care for vaginal symptoms than were other providers, a major concern given the potential consequences of inadequate gynecological care for women who are HIV positive. Finally, as described in the first research highlight in this series (RB-9067, 2005, http://www.rand.org/pubs/research_briefs/RB9067/), many participants described unmet needs for dental care, which is critical to the health and quality of life for persons who are HIV positive.

On the Horizon: Where Are Things Headed?

By the end of the HCSUS study, racial/ethnic disparities in access to HAART had narrowed. Nevertheless, the

evidence from some recent analyses of HCSUS follow-up surveys confirms that timely access to appropriate HIV treatment remains a critical issue for some groups, in some cases those at highest risk for becoming infected. However, as a result of HCSUS, those groups and, in many cases, the barriers that prevent their getting needed care, have been identified.

Greater coordination of health care services and other needed social services as well as expanded access to case management will address some of the gaps, such as the inaccessibility of care for those who are caregivers to children or elders or those in need of substance abuse treatment. One intervention that resulted from release of the initial HCSUS findings—an initiative to increase case management—may be able to play a role in equalizing access to care, according to recent research by some of the original HCSUS researchers. Widespread education is also needed to address some of the gaps—both for those entering and working in the health care professions and for those in high-risk groups. For example, the findings of a recent study of the quality of care received by HCSUS participants who were IV-drug users suggest that improving physician education might improve the care received by this group, which constitutes some 34 percent of the HIV-infected population.

As time passes, the face of HIV will be changed—both by continuing treatment progress and by the failure of prevention efforts among some groups. These changes will necessitate some reassessment of the needs of HIV-infected patients. However, at least for now, we can pinpoint those groups that need more attention and focus efforts on designing interventions to address their needs. ■

This Highlight summarizes RAND Health research reported in the following publications:

Andersen R, Bozzette S, Shapiro M, St Clair P, Morton S, Crystal S, Goldman D, Wenger N, Gifford A, Leibowitz A, Asch S, Berry S, Nakazono T, Heslin K, Cunningham W. Access of Vulnerable Groups to Antiretroviral Therapy Among Persons in Care for HIV Disease in the United States. HCSUS Consortium. HIV Cost and Services Utilization Study, *Health Services Research*, Vol. 32, No. 2, 2000, pp. 389–416.

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