ABSTRACT

Racial and ethnic minorities in the United States account for a disproportionate share of HIV/AIDS cases and have poorer treatment outcomes than white patients. Important contributors to these racial disparities include late testing for HIV infection, delays in accessing care and in initiating highly active antiretroviral therapy (HAART), and poor long-term continuity of care. Linkage and adherence to care are critical to obtaining positive outcomes in patients living with HIV. Adherence to care is closely linked to timely treatment with HAART. Several studies have noted that minority patients have a higher risk of suboptimal adherence to care. Barriers to adherence to HIV care for minority patients include financial or insurance obstacles, lack of familiarity with the healthcare system, language or cultural barriers, unstable housing situations, and ongoing substance abuse. Although few studies have examined strategies to improve retention in care for patients with HIV infection, it may be possible to adapt approaches that have been developed for other chronic diseases, such as cancer or diabetes. A variety of methods have been used to help patients remain engaged with care and to improve treatment adherence, including appointment reminders, smaller clinic settings, patient contracts, and the use of case managers. Providing a range of services (eg, general medical treatment, HIV care, substance use counseling, and mental health services) in a single clinic setting may help patients remain engaged in care, but is expensive and difficult to administer. Health system navigation, in which patients are linked to a peer or other individual who is able to help the patient overcome practical barriers to remaining in care, has been shown to improve clinic attendance and HIV clinical outcomes in racially diverse patient populations. Routine opt-out screening for HIV infection also has been proposed as a method to identify individuals with unrecognized HIV infection and link them directly into care, although there are potential practical barriers to the widespread use of this approach in routine care. More research is needed to identify approaches that will improve HIV outcomes for racial and ethnic minorities.

(Clear disparities exist in rates of HIV infection and clinical outcomes between different racial and ethnic groups in the United States. According to a 2007 report from the US Centers for Disease Control and Prevention (CDC), blacks account for approximately 51% of all HIV infections but only 14% of the US population; Hispanics account for approximately 18% of all HIV infections and 13% of the population; and whites account for 29% of HIV infections and 68% of the population. Although AIDS-related mortality has improved in all racial and ethnic groups since the introduction of highly active antiretroviral therapy (HAART) in the

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1990s, the incidence of AIDS-related mortality remains approximately 10-fold greater among blacks, and 4-fold greater among Hispanics, than among the US white population (Figure 1).\(^1\) A report from the US Institute of Medicine emphasized 3 key issues that are especially important in maintaining racial disparities in HIV outcome: late testing or failure to test for HIV infection, delays in initiating treatment, and poor long-term continuity of treatment.\(^2\)

**Racial and Ethnic Disparities in Testing for HIV Infection**

Several studies have demonstrated that minority patients in the United States are less likely to be tested for HIV infection. In an analysis of more than 4000 individuals with HIV/AIDS conducted by the CDC, 45% were first diagnosed within less than 1 year before an AIDS diagnosis. Compared with patients who were diagnosed earlier, these “late testers” were more likely to be younger, heterosexual, less educated, and black or Hispanic.\(^3\) Another study from the CDC that examined awareness of HIV status among men who have sex with men in 5 US cities (New York, Baltimore, Los Angeles, Miami, and San Francisco) found that although black men were much more likely than whites or Hispanics to have HIV infection (46% of black men vs 21% of white men and 17% of Hispanic men), HIV-positive black men were also much less likely to be aware of their HIV status.\(^4\) For the study population as a whole, 48% of HIV-positive men were unaware of their status, but approximately 70% of HIV-infected black men were unaware.

Many barriers to earlier HIV testing are common among minority populations. Access to testing services may be prevented by financial obstacles, but also by patient feelings of discomfort with or of limited accessibility to healthcare settings. Patient issues that contribute to poor HIV testing include HIV-related stigmatization and discrimination, lack of knowledge about HIV/AIDS, fear of an AIDS diagnosis, drug or alcohol use, and mental illness. HIV testing also may be reduced by several provider or health-system issues, including physician complacency about the risk of HIV infection, providers who feel incompetent or uncomfortable with discussions about high-risk behaviors, or missed opportunities to offer testing.\(^5\)

**Delays in Initiating HIV Care and Treatment**

A large number of HAART-eligible patients with HIV infection are not in care and not receiving treatment. A 2005 analysis of HIV care patterns in the United States estimated that there are approximately 820 000 HIV-infected individuals between 15 and 49 years of age, and that approximately 480 000 of these individuals are eligible for HAART. However, only approximately 340 000 patients are actually in medical care for HIV (41% of individuals with HIV), and only approximately 268 000 are receiving HAART (55% of all HAART-eligible patients).\(^6\)

Minority patients are also at high risk of delayed entry into care. In one study that examined patterns of medical care among approximately 3500 individuals with HIV infection, black patients were 56% more likely to experience delays of more than 3 months before entering care than white patients, and Hispanic patients were 53% more likely to experience delayed treatment.\(^7\) Although this study did not examine specific barriers to

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**Figure 1. Age-Adjusted* Annual Rates of Death Due to HIV Disease by Race/Ethnicity, United States, 1990-2006**

Note: For comparison with data for 1999 and later years, data for 1990–1998 were modified to account for ICD-10 rules instead of ICD-9 rules.


ICD = International Classification of Diseases.

treatment in detail, the authors noted that having Medicaid coverage and having a usual source of care reduced the likelihood of treatment delays.

**OBSTACLES TO RETENTION IN CARE**

Retention in care is clearly essential in ensuring the best possible treatment outcomes for individuals with HIV infection, and patients who regularly attend primary care visits for HIV have better survival than patients who attend fewer physician visits. The results of a recent retrospective analysis of data from the University of Alabama at Birmingham illustrate that retention in care may be an important contributor to the racial and ethnic disparities in outcomes among individuals with HIV. These investigators reported that approximately 40% of patients missed at least 1 out of 4 clinic visits. Missed visits were significantly associated with nonreceipt or delayed receipt of HAART, and were the strongest predictor of virologic failure. Black patients had higher rates than white patients of missed visits, nonreceipt or delayed receipt of HAART, and viremic failure. In a recent retrospective study of more than 2600 patients from the Vanderbilt Clinic, black race, female sex, and illicit drug use were significant predictors of increased mortality risk. Differences in mortality between white and black patients were largely explained by lower levels of healthcare utilization by black patients, including a longer time to initiation of HAART and less time on HAART over long-term follow-up. Black patients were on HAART for an average of 46% of time in care, compared with 76% of time in care for whites ($P<.001$). The authors of this study noted that minority patients are less likely to engage in healthcare and attend clinic visits, more often wish to avoid starting treatment with HAART, and are more likely to have substance use problems or other factors that complicate treatment. Minority patients may be more likely to experience obstacles that contribute to poor adherence, including competing life priorities, chaotic lifestyle, unstable housing situations, difficulty navigating an often fragmented healthcare system, untreated mental health or substance use issues, barriers to patient-provider communication, and dissatisfaction with their experiences at the healthcare facility.

In addition to race or ethnicity, several other patient populations also may be at increased risk of poor access to care or treatment adherence. Younger patients or those newly diagnosed with HIV may be less aware of the seriousness of infection, and are also generally less experienced at navigating the healthcare system. Incarceration is associated with a high risk of interruptions of care. Even a relatively short jail sentence may interfere with treatment adherence or clinic visits, and the disruption of ongoing care is often far worse for those who have recently been released from prison. Finally, immigrant populations very often are uninsured, live in transient housing situations, and have language and other barriers that make it more difficult to navigate the healthcare system. Foreign-born individuals with HIV infection in the United States are also more likely to present for care when they are near the onset of AIDS. These observations suggest that greater attention is needed to ensure that vulnerable populations engage in HIV care earlier and remain in care over time.

**STRATEGIES TO IMPROVE ENGAGEMENT WITH CARE**

One of the challenges to successful HIV treatment is that relatively few studies have examined the effectiveness of strategies to help retain patients in long-term care. There are, however, important parallels between the obstacles to HIV therapy and treatment of other chronic conditions. For example, minority patients are especially likely to struggle with long-term adherence to diabetes treatment, and also are diagnosed with cancer relatively late in the course of the disease. It may therefore be possible to adapt approaches that have been developed to improve treatment adherence for other chronic, severe illnesses to HIV care. Appointment reminders are simple to use and may help some patients to remember their visits, although patients with HIV infection miss visits for many reasons other than forgetting. Another approach is “one-stop shopping,” which focuses on providing general medical care, substance abuse counseling, HIV treatment, mental healthcare, and other services at a single facility. Although this is potentially a very effective method for helping patients to remain engaged with care, it also can be relatively expensive. Provision of food, nutrition, transportation, and housing services also can help to stabilize patients’ lives and improve their ability to remain in treatment, but are also expensive and difficult to maintain. Other approaches that have improved patient engagement with care include the use of smaller clinics with fewer
providers, patient contracts, the use of exit quizzes to ensure that patients understand information that has been conveyed to them during their office visit, and the use of flexible scheduling. Case management is widely used in HIV clinics, and several studies have shown that this approach has the potential to significantly improve outcomes in patients with HIV. In one study, patients were randomized to either conventional passive referral or to a series of case management visits. Over a 12-month follow-up period, HIV clinic attendance was significantly higher for patients randomized to case management.

Health-system navigation—also referred to as patient navigation—is another approach that has received considerable recent attention. Although originally designed to improve linkage to care for patients with cancer, navigation systems are now being adapted to improve adherence to care for patients with HIV. Patient navigators help to identify, anticipate, and overcome barriers to remaining in HIV care. Different navigation programs have taken a variety of approaches to the selection and training of patient navigators. The use of peer navigators who are similar to patients in demographic characteristics, culture, or language may help patients to remain engaged in care, and participating as patient navigators also may help peers to remain adherent to their own care. However, the peer navigator model also presents challenges related to the navigator’s level of education or literacy. In addition, if the peer and the patient are both from a relatively small cultural or demographic community, this approach may pose real or perceived risks to patient confidentiality. The patient navigator cannot be expected to take on the roles of a social worker or case manager, but they may receive training in strength-based perspectives (ie, building upon the patient’s capacity for change), motivational interviewing (overcoming resistance to change), and employing the transtheoretical model (assessing the patient’s stages of change and readiness to adopt health-promoting behavior). The effectiveness of the health system navigation approach was evaluated in a study of 437 patients (44% black and 23% Hispanic) who were enrolled at 4 urban HIV treatment programs in the United States. Patient navigators in this study were college-educated individuals who were trained to provide appointment and services coordination, accompany patients to appointments, perform healthcare referrals, and to develop and maintain relationships with other service organizations. At 6-month and 12-month evaluations, patient navigation significantly reduced several different barriers to care, including problems making appointments or knowing where to go for care, with insurance, or with transportation. The proportion of patients with at least 2 clinic visits during a 6-month period increased from 64% at baseline to 79% at 12 months, and the proportion of patients with an undetectable HIV viral load increased by 50% between baseline and 12-month evaluations.

Routine opt-out HIV screening, in which patients must give consent to forego testing, has recently been advocated by the CDC to help identify undiagnosed HIV-positive individuals. A recent large study compared routine opt-out rapid HIV testing with a standard diagnostic approach of physician-directed HIV testing for high-risk or symptomatic patients seen in a large urban emergency department (ED). Over a 2-year period, the 2 strategies were used during alternating 3-month periods, for a total of 1 year with each strategy in the same ED. A total of 6933 HIV tests were conducted in the ED during the routine opt-out phase versus 243 during the standard diagnostic phase. Routine opt-out testing identified more HIV-infected patients in the ED than the conventional diagnostic approach, although the number of additional new
HIV infections identified was small (15 vs 4 patients over a 1-year period). In addition, although routine opt-out testing has been proposed as a method to improve early diagnosis, most of those identified in this study already had advanced disease. The mean CD4+ cell count at diagnosis was 69 cells/µL in the opt-out phase versus 19 cells/µL in the standard diagnostic phase.

Finally, many international HIV experts have advocated a test-and-treat approach to HIV care, in which all at-risk individuals in the population are annually tested for HIV infection, and those testing positive are immediately linked to HAART initiation irrespective of CD4+ cell count. A recent mathematical modeling study based on the South African population found that this strategy could reduce the prevalence of HIV to less than 1% in South Africa within 50 years.22 Pilot studies are currently examining similar approaches in Washington, DC, and New York, NY.

CONCLUSIONS

Significant racial and ethnic disparities in HIV incidence, outcomes, and treatment have persisted since the disease was first identified. Delays in accessing healthcare and obstacles to remaining in treatment are important causes of these disparities. Improving patient engagement in care is an essential first step to begin closing these gaps. However, there is still an important unmet need for novel approaches that can be rigorously tested, as well as more funding to evaluate and implement these approaches.

REFERENCES


