Optimizing the Care of Minority Patients with HIV/AIDS

Valerie E. Stone
Department of Medicine, Massachusetts General Hospital, Harvard Medical School, Boston, Massachusetts

Persons belonging to racial/ethnic minorities are disproportionately affected by human immunodeficiency virus (HIV) infection and/or acquired immunodeficiency syndrome (AIDS) in the United States, with higher numbers of infected individuals and higher HIV/AIDS-related death rates. Despite its substantial medical toll among minorities, HIV/AIDS has had a complex sociocultural legacy in many minority communities in the United States, especially in the African American community, which can present a challenge for patients and medical care providers. Many studies have found that minorities receiving care for HIV/AIDS are less likely to be satisfied with their HIV care and less likely to receive highly active antiretroviral therapy (HAART) than are other patients. The root causes of these disparities in care have not yet been well delineated. However, clinicians can optimize the care they provide for minority patients by using a cultural competence framework, enhancing patient-provider communication, diversifying their clinical staff, proactively enhancing receipt of HAART, and being attentive to issues related to adherence to HAART.

BACKGROUND AND EPIDEMIOLOGY

HIV/AIDS disproportionately affects minority communities in the United States. New AIDS cases have been increasingly concentrated among minority persons, especially black and Hispanic persons. In 2001, the proportion of reported AIDS cases in the United States that occurred in black persons was 50.2%, and 19% of cases occurred in Hispanic persons, although black and Hispanic persons constitute only 12% and 13% of the US population, respectively [1]. Improved outcomes of HIV/AIDS and decreased mortality associated with HAART in the United States have not benefited minorities to the same extent as white persons [1, 2]. A recent study found that HIV infection is among the largest contributors to the gap in life expectancy between black and white individuals in the United States, because there are disproportionate HIV infection rates and higher HIV infection–related death rates in the black community, which have persisted in the post-HAART era [2]. Furthermore, HIV/AIDS is one of the key clinical areas in which disparities were found and documented in the recently released Institute of Medicine report on health care disparities [3]. HIV/AIDS has had a disproportionate impact on minority communities, and studies have documented a pattern of disparities in care for minorities; these facts make the issue of treatment of minorities with HIV/AIDS a particularly timely and pressing one.

The HIV/AIDS epidemic among minorities in the United States has many components, affecting a diversity of minority communities. Important HIV/AIDS epidemiologic trends among minorities include an alarmingly high prevalence of HIV infection among minority men who have sex with men (MSM), reaching a level of >30% among African American MSM in several US cities [4]. HIV infection among African Americans in the South is spreading very rapidly and is predominantly due to heterosexual contact. HIV/AIDS among minorities in the Northeast is still more likely to be associated with injection drug use compared with those diagnosed in other regions of the United States [1].

The cultures and nationalities of minority individuals affected by HIV infection are quite diverse as well. Black communities include African Americans, as well as black persons from numerous African and Caribbean countries with diverse cultural and religious traditions. Hispanics affected by the HIV epidemic also contain a diversity of cultures, including Puerto Ricans, Dominicans, Mexicans, and others, all of whom may
have varying levels of acculturation and English language skills. Thus, although this article and other publications refer to “minority patients with HIV/AIDS” as a group, these individuals represent a diversity of cultures, nationalities, lifestyles, and cultural norms, as well as varying levels of education and socioeconomic status. Therefore, any effort to enhance the care and outcomes of minorities living with HIV/AIDS in the United States should be mindful of this diversity and should advance strategies that acknowledge and respect group and individual differences as a key part of the HIV/AIDS care process. It is important to note, however, that Centers for Disease Control and Prevention HIV surveillance data are reported by race and Hispanic ethnicity and not by country of origin or culture. Careful attention has been paid throughout this article to label racial and cultural data accurately with respect to how the data were collected—therefore “black” is used when the data refer to all black persons, and “African American” is only used when the data are known to refer specifically to American black persons.

The goal of this article is to review the areas in which minority patients with HIV infection or AIDS have special needs or expectations and those areas in which minority patients’ HIV/AIDS care has been documented to be less than optimal. Furthermore, in each of these areas, specific suggestions and strategies are provided that can be implemented at the individual and programmatic level to improve minority patients’ care and outcome. The areas that will be covered are optimization of overall HIV/AIDS care through cultural competency and enhanced patient-provider communication, diversification of the HIV program staff, optimization of treatment with HAART, adherence to HAART, and participation in clinical trials.

**HIV INFECTION/AIDS CARE AND ITS CULTURAL AND SOCIAL CONTEXT**

Many African American patients and patients of other minorities approach the health care system and providers with distrust and suspicion. This distrust is often reported to have stemmed from research abuses that occurred during the Tuskegee Syphilis Trial. However, several authors have recently detailed centuries of medical abuses dating back to slavery that probably serve as the more complete basis of distrust in medicine and research among African Americans [5, 6]. Distrust may also be an issue for other minorities, especially Hispanics. These feelings of distrust among Hispanics often stem from a history of personal or family difficulties with the health care system and from a similar history of abuses in past research studies, such as those examining the efficacy of oral contraceptive pills [7]. HIV/AIDS and its complex baggage in minority communities magnifies these distrust issues because of beliefs regarding HIV/AIDS and its advent being a result of a “conspiracy” of some type, beliefs that are held by nearly one-half of African Americans [8, 9]. In addition to these broader societal contextual beliefs, some minority patients with HIV/AIDS may believe, because of culture, religion, or a personal belief system, that their HIV infection is some type of “punishment” [10, 11].

**STRATEGIES TO OPTIMIZE THE CARE OF MINORITIES WITH HIV INFECTION/AIDS**

*Provide culturally competent HIV/AIDS care.* In light of the many complex issues that minority patients bring to the clinical setting in addition to HIV/AIDS, it is critically important for the HIV/AIDS care provider to have a strategy to optimize the outcome of the patient-provider encounter. It is important for the clinician to be aware of the particular health-related cultural beliefs and practices within the predominant minority groups within his or her HIV/AIDS practice. In addition, one of the most important tools that HIV care providers can use to optimize the care of all their patients, despite differences in race/ethnicity, culture, or religion, is a cultural competence framework. Because of its ease of use in the clinical setting and applicability to a diversity of patients, a particularly useful framework is that of Carrillo et al. [11]. The particular strength of this framework is that it does not require the clinician to memorize the cultural beliefs and practices of numerous different groups. Instead, the framework relies on a structured dialogue between the provider and patient that elicits key issues of importance to the individual patient, whether these are due to culture, lifestyle, religion, or other factors. As a result, this framework avoids reliance on labels or assumptions, which can lead to stereotyping and can fuel misunderstandings between the patient and the provider.

The steps involved in applying this cultural competence framework are as follows: (1) Identify the patient’s core cultural issues. This can be accomplished by inquiring about values and preferences regarding his or her care, while being sensitive to and exploring any verbal or nonverbal “clues” to these preferences. (2) Explore the meaning of the illness to the patient—that is, explore his or her “explanatory model.” This can be accomplished by asking questions such as, what do you think has caused your problem? Why do you think it started when it did? How does it affect your life? (3) Explore the patient’s social context. Social context is explored through 4 main areas: (a) life control, which is largely determined by finances and other material resources; (b) change in environment, such as immigration; (c) literacy and language; and (d) support systems and stressors. (4) Negotiate across the patient-physician culture to develop a treatment plan that is agreeable to both sides. Using this framework, the key issues of importance to the patient are heard, valued, and incorporated into the chosen treatment plan. At the core of this cultural competence model is a mechanism for enhancing communication between patient and provider,
despite cultural differences. It is important to incorporate other mechanisms for enhancing communication in the care of minority patients with HIV infection, as detailed below.

Enhancing communication in clinical care. Several studies have found that minority patients are less satisfied with their HIV/AIDS care than are other patients [12]. Although many issues may contribute to this lower satisfaction, one issue that comes up repeatedly is patient-provider communication. Minority patients are more likely to experience communication difficulties, such as having trouble understanding their doctor and feeling like their doctor did not listen to them or did not ask the questions they had wanted or expected, and minority patients feel less involved in decisions regarding their health care than do others [13, 14]. Minority patients report that they needed more time to make HIV treatment decisions and more information about HIV treatment options [15]. Time spent with the medical provider has recently been found to be a key predictor of patients’ satisfaction with the health care that they receive [16]. Several strategies are suggested by these findings. We should endeavor to spend more time with our minority patients with HIV/AIDS, and we should spend more of that time listening to the patient. When we are doing the talking, we should enhance the patient’s comprehension of what we have said by asking the patient about their understanding in a way that is sensitive and not condescending. This can be done by asking, “Does that make sense to you?” or requesting that the patient repeat the agreed-upon treatment plan aloud. Providing follow-up written materials that are appropriate for the patient’s literacy level and language may also serve to enhance comprehension. Having nonphysician staff, such as nurses, physician assistants, case managers, or peer counselors, spend more time with the patient and answer patients’ questions may be particularly useful. The important role that these nonphysician staff play in enhancing patient satisfaction with HIV/AIDS care has data to support it—patients who have and can identify a primary nurse or case manager have been found to be more satisfied with their HIV care [12]. Medical interpreters should be an essential component for minority patients who are not fluent in English, because communication is markedly compromised if there is a language barrier between the patient and the provider.

Diversify the clinical staff. An analysis from the HIV Cost and Services Utilization Study recently found that racial concordance between the patient with HIV/AIDS and the provider essentially eliminates the disparity in time to receipt of HAART for African American patients [17]. This study provides compelling evidence of the potential benefit of diversifying our HIV/AIDS clinical staff. However, it is clear to all of us that very few HIV/AIDS physicians are racial/ethnic minorities; thus, any efforts to diversify the clinical staff may appear futile. Although it may be nearly impossible to recruit a clinical staff, especially a physician staff, that reflects the diversity of the patients we serve, small steps in this direction may make a substantial difference to minority patients. No matter how welcoming an HIV/AIDS care site is, minority patients will feel even more comfortable if at least a few clinical staff members are of their own racial/ethnic background. But if this is too challenging, we should at least endeavor to add medical assistants, front desk staff, and others who are more diverse and reflect the diversity of the community being served. Meanwhile, we should also remain optimistic that cultural competence training of our clinical staff may also make a difference in improving the care that minority patients receive from all of the staff.

Optimizing the receipt of care and HAART. Since early in the HIV epidemic, there has been evidence of disparities in the care provided to minority patients. Specifically, minority patients have reported more problems getting the HIV/AIDS care they needed and have been less likely to receive medications to treat HIV/AIDS [18–20]. Recently, several studies have documented that these disparities have persisted into the HAART era. Minorities have a longer average delay after diagnosis until receipt of HIV/AIDS care, and, once they begin receiving care for HIV/AIDS, they are still less likely to receive HAART than are nonminority patients [15, 21, 22].

The medical provider should be aware of the data regarding disparities in the receipt of HAART and use strategies in the clinical setting to optimize the likelihood that minority patients will be offered, prescribed, and actually take antiretroviral medications. Such strategies include working to build trust in the patient-provider relationship, ensuring that the patient participates in decisions about his or her own care, and providing enough time and information for the patient to make an informed decision [23, 24]. To this end, the physician should avoid letting clinical comorbidities, such as hepatitis C, and past side effects or other medication-related toxicities get in the way of providing the indicated antiretroviral therapy.

Enhance adherence to treatment. Once it became apparent how important adherence is to the success of treatment with HAART, HIV/AIDS care providers became understandably interested in whether adherence could be predicted and, furthermore, whether certain patients were more at risk for nonadherence than others. Unfortunately, there were early stereotypes circulated among HIV/AIDS care providers that minority patients were less likely to be adherent to HAART than were other patients, and even the lay press reported that HAART was, at times, withheld from minority patients because of these preconceptions regarding their ability to adhere to it [25, 26]. Surveys of HIV care providers have confirmed that these biases and stereotypes do affect providers’ treatment decisions and result in failure to treat some minority patients for whom HAART is indicated [27]. Research has shown that demographic characteristics generally are not predictive of adherence.
to HAART when studies control for the key predictors of non-adherence discussed below [25]. The HIV/AIDS treatment adherence literature presented and published over the past 5–6 years has documented that a very limited group of patient factors and behaviors are clearly and consistently associated with poorer adherence to HAART. These factors are depression, active alcohol abuse, active injection drug use, and low health literacy. Previous substance abusers appear to have adherence rates similar to patients with no history of substance abuse [28, 29].

Many persons living with HIV infection have concurrent depression, are substance abusers, are alcohol abusers, or have ≥2 of these issues [30]. Although we do not have evidence that depression is more prevalent among HIV-infected minority patients, it may be more difficult to diagnose in them than in other patients [30]. Thus, routinely screening all patients with HIV/AIDS, especially minority patients, for depression before initiating HAART is essential. Similarly, it is most appropriate to screen all patients for substance abuse issues, not just those who acquired HIV infection through injection drug use. Many experts advocate attempting to treat or at least having a management plan in place for these issues before initiating HAART, because of the likelihood of poor adherence to HAART if these issues go unaddressed. The HIV/AIDS care provider and the mental health or drug treatment professional should aim to collaborate on behalf of the patient to optimize HIV treatment as well as mental health outcomes.

In addition to these factors, it is important to assess the patient’s beliefs about HAART before beginning treatment, because minority patients may have a wide variety of misconceptions about medications used to treat HIV infection [8, 9]. It is important to be aware that, although race and ethnicity have generally not been found to be predictive of adherence, there are, in fact, several psychologically based factors that may disproportionately impact minority patients’ willingness and ability to adhere to these regimens. These include distrust and concerns about potential harms associated with taking medications that some regard as “poison” or experimental, as well as less of a belief in the effectiveness of these medications [6, 8, 9, 23, 29, 31]. Strategies for assisting the patient develop more positive attitudes and beliefs about HAART include the use of support groups, peer educators, and a treatment buddy. Building a high-quality and trusting therapeutic relationship before beginning HAART will also serve to enhance adherence. Three key studies that examined adherence showed that the quality of the patient-provider relationship may be one of the most important predictors of adherence, particularly among minority patients and women with HIV/AIDS [23, 24, 28]. In addition, of course, logistical supports are also instrumental in enhancing patients’ adherence to HAART and have been reviewed extensively elsewhere [25, 32].

**Minority patients with HIV/AIDS and clinical trials.** No discussion of minorities and HIV/AIDS care is complete without a discussion of HIV clinical trials. Minority patients have historically been underrepresented in HIV-related clinical trials, despite their overrepresentation among those living with HIV infection and despite a number of initiatives that have been undertaken to address this problem, including development of the Community Programs for Clinical Research on AIDS. A recent examination of this issue revealed that minority patients with HIV/AIDS were only one-half as likely to participate in a clinical trial, compared with white patients [33]. It is widely believed that many of the concerns mentioned earlier, including the legacy of abuses in past research studies, distrust of the health care system broadly, and beliefs regarding conspiracies having started and fueled the HIV/AIDS epidemic in minority communities, all contribute to the lower rates of participation in clinical trials among minorities. Understandably, HIV/AIDS care providers believe that minority patients are less interested in HIV clinical trials, and the care providers are therefore less likely to invite minority patients to participate [34]. The complexities of these issues suggest that there is probably no easy answer for enhancing the enrollment of minorities in clinical trials. However, despite this, a simple intervention at an academic medical center in which all new HIV-infected patients received the same information about HIV clinical trials in their preferred language, regardless of race or ethnicity, served to equalize the rates of participation in clinical trials [35]. Therefore, it is probably most appropriate for HIV care programs to avoid assumptions about minority patients’ interest in clinical research and, instead, to proactively approach all patients about participation in clinical trials and matter-of-factly answer their questions and address any concerns they may have.

**SUMMARY**

Minority patients are disproportionately affected by the HIV/AIDS epidemic. In addition, however, disparities in care that have negatively affected minorities with HIV/AIDS have been repeatedly documented. An approach to care that uses a cultural competence framework, enhances communication between minority patients and their providers, endeavors to use a more diverse array of staff members, proactively enhances the likelihood of receipt of HAART, and uses an evidence-based approach to thinking about adherence will improve the likelihood that minority patients will engage in care, be satisfied with care, and have positive HIV/AIDS-related outcomes.

**References**

2. Wong MD, Shapiro MF, Boscardin WJ, Ettinger SL. Contribution of


