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# BESAFE

**A Cultural Competency Model for African Americans**

National Minority AIDS Education and Training Center





# BE SAFE

## A Cultural Competency Model for African Americans



National Minority  
AIDS Education and Training Center

Howard University  
Washington, DC

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# Preface

**T**he National Minority AIDS Education and Training Center (NMAETC) is a collaborative network of health experts funded by the Health Resources and Services Administration (HRSA) to provide capacity building to agencies and providers that treat minority patients afflicted with the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). Capacity building focuses on strengthening organizational infrastructure and improving the delivery of HIV primary care services at clinics by using collaborative approaches, best care practices, and culturally appropriate clinical models. The ultimate goal of capacity building is to improve HIV/AIDS patient outcomes.

NMAETC is headquartered at Howard University in Washington, DC, with additional sites at The University of Texas Health Science Center at San Antonio, Charles R. Drew University of Medicine and Science, Tennessee State University, Xavier University, Navajo AIDS Network, Inc., and the University of Maryland. The mission of NMAETC is to improve HIV patient outcomes by increasing the core competencies of clinics and providers. To accomplish this mission, NMAETC works to increase: (1) the number and effectiveness of HIV/AIDS clinical and support services; (2) the number and frequency of HIV/AIDS patients treated; (3) the cultural competence of providers; and (4) the number of qualified HIV specialists. Included in this effort is a capacity building preceptorship program of HIV/AIDS specialists to train and educate health care providers who treat minority patients with HIV infection and AIDS. The preceptorship program includes hands-on education and training sessions in HIV/AIDS disease management. With the aim to develop and improve clinical provider skills under the guidance of an experienced faculty member the program results in a professional relationship that provides consultations, co-management, and other related support.

Recent statistics show that HIV disproportionately affects minority communities in the United States, particularly African Americans and Latinos. In response to these disparities, the NMAETC has developed an African American cultural competency model to be used by health care providers who treat African American patients with HIV/AIDS. The mnemonic, BE SAFE, is

a framework that uses culturally pluralistic content and perspectives based on the following six core elements: (1) Barriers to Care, (2) Ethics, (3) Sensitivity of the Provider, (4) Assessment, (5) Facts, and (6) Encounters. This BE SAFE book will discuss each of these six core elements in order to provide health care professionals with a culturally relevant framework that will assist them in providing primary health care services to African Americans infected with, or affected by, HIV/AIDS.

The BE SAFE African American model is intended to familiarize providers with a basic understanding of the African American patient, and his or her cultural background and beliefs. It is our hope that this book will pave the way for culturally responsive approaches to health care delivery.

# Acknowledgments

**W**e thank our colleagues for their contribution and support of this project.

NMAETC Staff

NMAETC Advisory Board

Pennsylvania Mid-Atlantic AETC

Pacific AETC

AIDS Education and Training Centers

Health Resources and Services Administration

Finally, we recognize health care providers who serve African-American patients and give tirelessly of their gifts and talents. It is for this reason that we seek to increase the resources available.



# Introduction

**A**s health care professionals discern the reasons for the existing disparities of care that increasingly affect people of color—especially African Americans—cultural competency becomes an important area for further investigation and development. Promoting cultural competency among health care professionals may help address barriers such as distrust of the medical community and cultural stereotyping of minority patients.

Culture is defined as a way of life developed and shared by a group of people and passed down through generations. It consists of complex elements, including tangibles such as tools, clothing, buildings, and works of art. Culture also may refer to integrated patterns of human behavior that include thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups.

Health is an important component of culture. Therefore, an HIV diagnosis will contribute to that component of an individual's culture. One reason is because of the negative stigma that society often associates with AIDS. However, AIDS' cultural impact is further influenced by its resulting emotional distress and societal discrimination, and the economic hardship it creates individually and in communities that are disproportionately affected by HIV/AIDS.

The National Minority AIDS Education and Training Center (NMAETC) wanted to develop a model for cultural competency that integrates its important features with issues unique to the lives and culture of HIV-infected individuals. To help develop this model, the NMAETC addressed the following questions:

- What is the available literature on cultural competency?
- What are comprehensive models of cultural competency?
- How does HIV affect the culture of an individual?
- Who should receive cultural competency training?

## METHODS

### *Overview of Model Development*

The NMAETC developed a unique model for African Americans infected with HIV by using the methods based on Dr. Josepha Campinha-Bacote's (1998) model, "The Process of Cultural Competence in the Delivery of Healthcare Services." A model development panel of 25 members was established and included physicians, advanced practice nurses, dentists, physician assistants, clinical pharmacists, and HIV/AIDS educators.

The panel also represented individuals from different African Diasporas, including those born in America, the Caribbean, Africa, and Latin countries. Panel members attended workshops conducted by Dr. Campinha-Bacote, where the constructs of several cultural competency models were presented—including her model, which includes cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire. Panel members selected, reviewed, and interpreted the data.

The BE SAFE model was finally developed through consensus and subsequently was presented at HIV/AIDS provider meetings and facilitated discussion groups for feedback. Responses were used to guide the reformatting of the draft into the final model recommendations. The model was used to develop this booklet on cultural competency for health care professionals who care for African-American patients infected with HIV.

### *Synthesis of the Model Constructs*

The synthesis of the model constructs began with an assessment of the available knowledge on cultural competency, followed by a workshop on the Campinha-Bacote model. The initial workshop consisted of several presentations that reviewed terminologies, standards, and guidelines on cultural competency, definitions of culture, and cultural competency levels, theories, and different models. Breakout groups were then convened to look at the strengths and weaknesses of the models and how they applied to a culture that included HIV/AIDS in an African-American community.

Day 2 of the initial workshop included developing a plan to create the model constructs. Assignments were given to all panel

members, which included literature review and further assessment of the strengths and weaknesses of the presentations and relevant data.

### ***NMAETC Consensus Process***

During a second workshop, panel members used the consensus process, through an interactive process of debate, to determine the final constructs of the cultural competency model and to devise a method of development and review. At this meeting, the panel reviewed the available data and draft recommendations from the prior workshop. Approval by each panel member was required before a final model was applied. The panel was divided into construct teams that were given specific writing assignments, as well as the resources of the literature reviews. The recommendations made at the workshop were included in the constructs of the decided model.

### ***Focus Group's Feedback***

Slide presentations of the model were given to groups of minority health care providers, followed by focus group discussions. Feedback and further barriers to the care of HIV-infected minority patients were elicited at these discussions. The feedback was integrated into the model.

## **RESULTS: THE BE SAFE MODEL**

BE SAFE is a framework that uses culturally pluralistic content and perspectives based on these six core elements: Barriers to Care, Ethics, Sensitivity of the Provider, Assessment, Facts, and Encounters. Following is a brief summary of these elements, and how they give health care professionals a culturally relevant framework as they provide primary health care services to minority individuals with HIV/AIDS.

### ***Barriers to Care***

Barriers to Care is defined as real or perceived gaps to providing quality care that are compounded by the relationship that HIV has to ethnicity. These barriers include African-American mistrust of the medical community, access to care issues, stigmas surrounding HIV, support systems, and bias in medical decision-making.

For example, the mistrust that African Americans have for the medical community is reflected in the disparities seen in HIV research between the participation of African-American and white patients. More widespread negative attitudes may explain why only half as many African-American as white patients attempt to obtain experimental HIV medications (Gillford 2002). Although specific examples are often given for African-American mistrust, there is evidence that it stems from centuries of medical mistreatment and abuse (Byrd and Clayton 2000).

Using access to care as another example, an October 2000 review of survey data by the Kaiser Family Foundation shows that African Americans' access to health care services is compromised by an uninsured rate that is 1.5 times that of whites. African Americans also get their HIV tests later than whites. For example, 43% of African Americans had 2 months or less between testing positive for HIV and an AIDS diagnosis, compared with 31% of whites. When African Americans do get access to care, it is often substandard. Data from the HIV Cost Services Utilization Study, a national probability sample of persons with HIV receiving medical care in early 1996, showed that African Americans were 1.5 times less likely to receive prophylaxis for *Pneumocystis carinii* pneumonia than whites.

## Ethics

Ethics is defined as a science of the human condition as it applies to the morality of beliefs, values, and behavior. The sources of ethics include reason, individual experiences, and societal experiences. Most of these experiences may include those factors that make up one's culture. Hence, having ethics as a component of a cultural competency model becomes very important.

It is the duty of health care professionals to do no harm and to do their best for their patients—which are the principles of beneficence and benevolence. Also, such acts can be looked upon as components of natural law—the ethical principle emphasizing the desire of all humans to do what is morally good. These principles support the valuing of different cultures.

Other important issues in the care of HIV-infected individuals include truth telling, confidentiality, HIV research, dealing with dying patients, and the responsibility of health care professionals. These issues often create dilemmas between the different

## BE SAFE MODEL

This framework comprises six core elements:

**Barriers to care**—real or perceived gaps to providing quality care that are compounded by the relationship of HIV/AIDS to ethnicity.

**Ethics**—science of the human condition as it applies to morality and belief systems.

**Sensitivity**—self-examination of one's biases and prejudices toward other cultures as well as one's own cultural background.

**Assessment**—ability of the health care professional to collect relevant patient health history data.

**Facts**—understanding of physiology, behavior, and patient's perception of his or her illness.

**Encounters**—necessary face-to-face interactions.



ethical layers, including the ethics of the individual, institution, and society.

In summary, the importance of ethics in determining the morally good practice of a health care professional in acknowledging and learning about the patient's culture is a construct of the cultural competency model.

### ***Sensitivity of the Provider***

The panel used Campinha-Bacote's construct of cultural awareness under the heading of cultural sensitivity. The sensitivity of the health care professional involves examining one's prejudices and biases toward other cultures, as well as an indepth exploration of one's own cultural background (Campinha-Bacote 1998). The importance of this construct was to prevent the health care professional from engaging in the phenomena of cultural imposition—the tendency to impose one's values on another culture (Leininger 1978).

Before one can begin to understand another's culture, it is important to identify one's biases and to determine where they are along a continuum that ranges from unconscious to conscious competence. Campinha-Bacote begins by describing unconscious incompetence as when a health care professional is not aware that cultural differences exist. Further along the continuum is conscious incompetence, where health care professionals still do not understand another's culture, but are aware of this lack of understanding and that differences do exist. Next is the consciously competent scenario, in which the health care professional becomes knowledgeable about cultural differences but is still in the process of learning about another culture.

Finally, the health care professional may become unconsciously competent when the knowledge of cultural differences now is appropriately incorporated in one's behavior and interaction with a patient of a different culture.

### ***Assessment***

Assessment is another construct incorporated from Campinha-Bacote. She defines this as the ability of the health care professional to collect relevant data regarding the patient's health history and present problems in the context of the patient's

cultural background (Campinha-Bacote 1998). The ethics section indicated that health care professionals are obligated to respect patients' rights. As stated by Leininger (1978), one such right is for patients to have specific cultural beliefs, values, and practices.

## **Facts**

The full assessment of a patient requires the understanding of physiology, behavior, and the patient's perception of his or her illness. In order to adequately design an appropriate treatment plan, the health care professional must individualize these characteristics to their patients. Therefore, an understanding from the perspective of the individual's culture, including biologic variations based on ethnicity, world views, and culturally specific behavioral patterns—is important.

For example, biological variations can be misleading when treating an African American infected with HIV based on experiences solely from a Caucasian model. Variations seen in clade HIV infectivity between different ethnic groups often show differences in the virologic and immunologic interpretations. There are different levels of risk associated with hypercholesterolemia, hyperglycemia, and other complications of highly active anti-retroviral therapy between different ethnic groups. It is important for health care professionals to become knowledgeable about these differences if they are to effectively treat African-American patients with HIV/AIDS.

In another example, individuals often have differing world views—sets of metaphorical explanations used by a group of people to explain life's events (Boyle and Andrews 1989)—that affect how they perceive the causes of their health, or illness.

## **Encounters**

Achieving effective encounters with patients from ethnically and culturally diverse backgrounds is a core component of cultural competence in the clinical setting. Encounters are necessary face-to-face interactions that allow health care professionals to effectively engage in cross-cultural interactions with culturally diverse populations (Campinha-Bacote 1998). Many encounters with specific ethnic groups are needed to effectively interact with those groups. Factors such as language, cultural norms, and concepts of personal space are important variable to consider when encountering African-American patients.

## CONCLUSION

Although a cure for HIV/AIDS has not been found, neither the accomplishment of the global response to date nor future challenges should be underestimated. Cultural competence in providing care for African-American patients with HIV/AIDS is a challenge that demands clear vision, renewed strength and will, and increased resources.

With the BE SAFE model, the NMAETC offers health care professionals caring for African Americans with HIV/AIDS a practice model that enhances their level of cultural competency. This model asserts that health care professionals begin their journey toward becoming culturally competent by:

1. Addressing overt and covert barriers to care;
2. Assessing their level of awareness and sensitivity toward African-American patients with HIV/AIDS;
3. Conducting a cultural assessment;
4. Obtaining knowledge about this cultural group; and
5. Maintaining effective clinical encounters.

We must remember that cultural competence is a journey—not a destination; a process—not an event; and a process of *becoming* competent, not being culturally competent.

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# I. Barriers to Care

Declines in overall AIDS mortality in the United States may be generating perceptions that it is under control. However, among African Americans of all age groups, HIV/AIDS rates are still a major public health concern; this is particularly the case among low-income, African-American women. Researchers estimate that 240,000–325,000 African-Americans—about 1 in 50 African-American men and 1 in 160 African-American women—are infected with HIV. Of that amount, it is estimated that almost 118,000 African Americans were living with AIDS at the end of 1998, according to data from the Centers for Disease Control and Prevention (CDC). In fact, the proportion of African Americans living with AIDS has grown and is now similar to that of whites (40%). Furthermore, although AIDS is no longer the leading cause of death among whites, it remains the fourth leading cause of death for African-Americans.

Providing appropriate interventions and therapeutic measures has been hobbled by numerous barriers to care, which are defined as real or perceived gaps to providing quality care. This is compounded by the relationship that HIV has to ethnicity. These barriers include African-American mistrust of the medical community, access to care issues, stigmas surrounding HIV, support systems, and bias in medical decision-making. While not discussed in detail here, researchers also have found an association between education literacy to HIV treatment adherence and barriers to care among African Americans living with HIV. Those subjects with lower education and/or literacy levels were more likely than participants with higher literacy levels to miss medication schedules because they were confused about dosage amounts.

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AIDS is the fourth leading cause of death for African-Americans.

## MISTRUST OF MEDICAL CARE SYSTEM

As noted by Crawley (2000), the concept of trust in race, ethnicity, and culture is complex. The U.S. Public Health Service study on “Untreated Syphilis in the Negro Male” (the infamous Tuskegee Study) is often cited as the prime example of why African Americans mistrust the medical community. However, other research suggests that this mistrust stems from a centuries-long history of medical mistreatment and abuse (Byrd and Clayton 2000).

Within the context of HIV/AIDS, such mistrust has generated conspiracy theories that government-sponsored HIV prevention programs are part of a governmental genocide plan against African Americans. Researchers contend that such views may unfairly depict African Americans as mistrustful, a stereotype that then may contribute to negative perceptions by health care professionals (Crawley 2000). Some evidence exists that this mistrust blunts the effectiveness of health education and other intervention programs in African-American communities (Thomas and Quinn 1991; Guinan 1993).

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Other research suggests that this mistrust stems from a centuries-long history of medical mistreatment and abuse.

## ACCESS TO CARE

Access to health care services long has been implicated as a contributing factor to the health disparities experienced by African Americans. Statistically, African Americans fare poorer than whites on several quality of care and access-to-care measures. An October 2000 survey by the Kaiser Family Foundation (KFF) found that more than half of African-American respondents (51%) believed racial differences exist in access to health care. For example, 67% of African Americans felt that they were less likely than whites to receive the latest HIV/AIDS treatment. In comparison, 67% of whites felt that African Americans received the same quality of routine medical care as they do, and 47% felt that African Americans were less likely than whites to receive the latest HIV/AIDS treatment.

In addition, 81% of African Americans believe access to HIV care and treatment in the United States is problematic, with income and race key factors affecting such access. Given that half of all African Americans live in families with incomes below

200% of poverty, significant rates of under- and non-insurance are at play. African Americans' access to health services is compromised by an uninsured rate that is 1.5 times that of whites, according to KFF survey data. Unfortunately, uninsured African Americans are at least three times more likely than those with private insurance or Medicaid to be without a usual source of care, and more than 3% of uninsured African Americans do not have a regular source of health care.

African Americans represent a greater proportion of Medicaid recipients with HIV/AIDS than whites (48% compared to 30%) and represent a smaller proportion of those with private insurance (15% compared to 70%), according to data from the HIV Cost and Services Utilization Study (HCSUS), a national probability sample of HIV-infected persons who received medical care in early 1996. Further analysis of HCSUS data showed that while access to care had improved for whites, it was less than optimal for African Americans. Baseline data that were adjusted for differences in CD4 counts and insurance coverage found that African Americans did poorer than whites on four of the six measures of health service and pharmaceutical use. Specifically, HCSUS indicators assessing the use of triple drug antiretroviral therapy—the recommended treatment regimen for delaying disability and prolonging the life of HIV infected persons—found that 56% of African Americans did not receive combination drug therapy, compared with nearly one-third of whites (32%). Additionally, African Americans were 1.5 times more likely not to receive preventive treatment for *Pneumocystis carinii* pneumonia—a common but preventable opportunistic infection in people with HIV—than whites.

56% of African Americans did not receive combination drug therapy, compared with nearly one-third of whites (32%).

Detecting disease early and implementing appropriate therapeutic regimens generally result in more favorable outcomes. However, African Americans are more likely to be tested later in the course of HIV infection than whites. According to KFF findings, 43% of African Americans had 2 months or less between testing positive for HIV and an AIDS diagnosis (compared to 31% of whites). Therefore, African Americans may be less likely to receive treatment early on in illness, which is recommended to delay disability and death.

## STIGMA

Significant continuing obstacles to successful HIV prevention programs are lack of awareness of HIV transmission modes; lack of knowledge of individual HIV risk factors; homophobia in the African-American community; and lack of a well organized, visible gay community of color with the resources to advocate for targeted program resources. Although agencies such as the Gay Men's Health Crisis have supported the issues confronting minority gay men, few programs are specifically targeted to gay African-American men, despite evidence that small-scale, community-level interventions directed to this population can be effective.

Accurate information about HIV transmission, as well as the reduction of stigmas associated with HIV infection, is a critical measure for prevention. Recent reports from the CDC (2000) and Institute of Medicine (2001) suggest a correlation between HIV knowledge and stigma, with those who have lower levels of HIV-related knowledge more likely to hold biased views regarding people living with HIV/AIDS. Other research has shown that people who fear HIV-related stigma and discrimination are less likely to seek information about prevention, may delay being tested for HIV and implementing treatment, and may be reluctant to discuss their HIV status and thereby preclude starting support networks (Herek 1998; Chesney and Smith 1999). Other data indicate 32% of African Americans would be very concerned that people would think less of them if they found out they had been tested for HIV. Concerns are even higher among those with less education and income than their counterparts: Those with less education and lower incomes (28% and 34%, respectively) are significantly more likely to be very concerned that people would think less of them, compared with those with higher education and incomes (15% and 20%, respectively) (KFF 2001).

Researchers believe that stigmas about homosexuality in minority communities inhibit some men from identifying themselves as gay or bisexual, despite their sexual activity with other men. For example, a multisite CDC survey of 8,780 HIV-positive men showed that out of men who have sex with men but identified themselves as heterosexual, 24% were African American, compared with only 6% of whites. By not identifying themselves as gay or bisexual, these men may not accept their own HIV risk, may not seek or receive HIV prevention or treatment services, and may unintentionally put their female partners and children at risk.



## SUPPORT SYSTEMS

In urban communities with significant populations of persons living with HIV/AIDS, the social networks and community norms that support neighborhood-based public health interventions have been destroyed. The increasing poverty of inner city residents and the corresponding increases in crime, violence, and drug abuse—and their associated risk behaviors—can only be countered by efforts to stabilize the community and prevent further destruction of its social networks. (Wallace, et al., 1995) state, “Because of the interrelated nature of the nexus of behavior leading to substance abuse and associated pathologies—including AIDS—general systemic social interventions will go far toward mitigating many of the urban ills of the United States, including a whole host of problems of public health and public order which now overwhelm the nation’s criminal justice and health care systems, problems for which substance abuse is a kind of universal matrix in which they are embedded and to which they contribute.”

## BIAS OF HEALTH CARE PROFESSIONALS

The attitude of health care professionals is one of the most significant barriers to the care of African-American patients with HIV/AIDS, and may prevent objectivity when considering medical treatment. Bias has affected the medical decision-making process and health care of African Americans for many years. Recent research has identified numerous examples of bias of health care professionals and the impact on treatment—from the much-publicized Schulman et al. study in the *New England Journal of Medicine* (1999) to data indicating less African-American accessibility to powerful HIV (triple cocktail) therapeutics.

Clinical encounters in which patients experience negative attitudes from health care professionals will greatly affect their decision to seek medical attention. African Americans have cited racial bias as a contributing factor to the quality of care received by minority patients. Twelve percent of African Americans, compared with 1% of whites, felt that health care professionals had treated them unfairly or disrespectfully because of their race/ethnicity (KFF 2001).

**TABLE 1. Interventions for Provider Bias**

- Know the patient's health literacy capability and provide medical information format and media that the patient can understand.
- Use community networks to provide patients access to social services.
- Develop trust with the patient through using effective communication tools.
- Implement cultural awareness and competency tools in clinical practice.

Clinical encounters in which patients experience negative attitudes from health care professionals will greatly affect their decision to seek medical attention.

African Americans felt they were victimized because of stereotypes from health care professionals such as the following:

- African Americans and other minorities are not able to pay for medical services.
- African Americans over utilize the emergency room for primary care.
- Young African-American mothers are unmarried.

Interventions that health care professionals can take to reduce bias are presented in Table 1.

Purnell and Paulanka (1998) assert that specific ethnic and cultural groups view health care professionals differently. A patient's perception of selected health care professionals is closely associated with previous contact and experiences with health care professionals and health care institutions. Generally, most African-American patients are suspicious and cautious of health care professionals they have not heard of or do not know. Many African Americans perceive health care professionals as outsiders, whom they resent for telling them what their problems are or how to solve them. Furthermore, research has shown patients treated by health care professionals who share their ethnic/racial and cultural heritage have better outcomes. However, African-American physicians, for example, account for only 3% of all physicians practicing medicine in the United States.

Most African-American patients are suspicious and cautious of health care professionals they have not heard of or do not know.

Of the 44% of African Americans who spoke to a health care professional about HIV/AIDS, one-half noted that HIV issues, particularly personal risk factors, were raised by them, not the provider. Interestingly, 22% of African Americans obtain HIV information from their church or religious community. This statistic and the other data mentioned above indicate that communication is a critical component to engendering trust between parties

when longstanding historical and sociopolitical frameworks exist for mistrust. Cultural awareness and understanding a patient's history of mistrust are critical not only to effective patient/health care professional interaction, but also to developing and disseminating culturally specific and targeted interventions.

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## II. Ethics

**I**n providing culturally responsive services to African-American patients with HIV/AIDS, health care professionals must identify and address ethical issues inherent in the decision-making process of such patient care. For example, ethical issues such as confidentiality and truth are raised with questions such as:

- “Do I inform my patient’s sex partner that she is HIV positive when I know that such disclosure might cause her partner to harm her?”
- “Should my seriously mentally ill HIV-positive patient who has a history of discontinuing medication be allowed to leave the hospital?”
- “What do I say to my 13-year-old patient with AIDS who asks me what is wrong with him when his guardians have refused to let anyone disclose the nature of his illness?”

This chapter introduces the concepts of ethics and morality as they relate to HIV/AIDS patients and discusses ethical issues, such as truth telling, confidentiality, the duty of health care professionals to treat HIV-infected patients, the responsibility of health care professionals, insurance coverage for HIV infection, and clinical research on HIV infection. This chapter also will provide health care professionals with a clinical model of ethical decision-making, as well as self-examination questions to resolve ethical issues in clinical practice.

### ROLE OF MORALITY IN ETHICS

Ethics represents the impact that morality has on the beliefs, values, and practices of health care professionals. Ethics refers to how individuals or groups should or ought to behave (Leininger 1995). “But at its heart, ethics is the study of right and wrong, a study that concerns each person every day” (Boyle and Andrews 1989).

Furthermore, ethics is a branch of philosophy that uses reason to guide our judgment concerning the morality of human acts. In turn, morality is the application of ethics to our human behavior, and consists of three areas:

1. Personal morality, the values and duties the individual has adopted as relevant;
2. Societal morality, which is the shared beliefs about values and duties in a society, which are often based on culture, ethnicity, socioeconomic status, and geography and institutional morality; and
3. Institutional or group morality, which is shared beliefs about values and duties that are developed in a particular institution within a society.

There can be conflicts between these three areas; however, ethics can help one design a better path to work within these areas.

One conflict between the three aspects of morality is seen when institutional morality overrides personal morality. A health care professional may not want to care for an HIV-infected patient because of his sexual orientation. However, the morality of health care states that care must be provided to all who have illnesses requiring intervention. The group morality outweighs individual or personal morality.

## **ETHICAL CHALLENGES FOR HEALTH PROFESSIONALS**

Health care professionals are faced with an ethical challenge any time they must choose among several courses of actions, none of which is entirely satisfactory because each may result in harm to one or more persons. There are instances when an action that benefits one person may harm another. This raises the ethical issue of truth telling regarding the nature of a patient's illness. Family members may forbid a health care professional from telling their relative that he or she has HIV/AIDS. Yet it may be in the patient's interest to know the diagnosis and prognosis. Honoring the needs or requests of one party (in this case, the family members) may harm the interests of the other party (in this case, the patient). Yet, the health care professional may have a sense of loyalty to both parties. In addition, several ethical issues

exist regarding confidentiality when caring for African-American patients with HIV/AIDS.

## ***Truth Telling***

Truth telling presents an interesting ethical quandary when it falls to the health care professional to convey bad news to patients and families. Health care professionals have long believed that patients want to look to them for help in maintaining hope in the face of catastrophe. However, this belief has shifted, to where even in the face of catastrophe, hope is believed to enhance the patient's ability to take control of important life events, which is dependent on the patient knowing the truth about his or her clinical condition.

Patient autonomy in the health care professional-patient relationship honors not only the idea that the patient should have access to "the truth" but also the idea that all conditions required for remaining in control are met. The principle of autonomy applied to the patient's situation has evolved from being viewed as the patient's prerogative to refuse treatment to the right to refuse it, and finally to the right to play a central role in determining the course of treatment. In 1990, congressional passage of the Patient Self-Determination Act took patient autonomy further out of the realm of ethics and into the legal arena by giving patients legal recourse in expressing their wishes about specific treatments in critical situations.

## ***Confidentiality***

Confidentiality in the health care setting is a general ethical guideline. Confidentiality maintains trust between the health care professional and patients and also develops dignity in the relationship. However, how is this ethical guideline of confidentiality actually carried out by the health care professional? Confidentiality always has presumed the health care professional's willingness to keep a professional secret because he or she acknowledges that the patient may have to provide details that have the potential to be harmful, shameful, or embarrassing. The traditional way of understanding confidentiality is to focus on the health care professional's duty. However, only trustworthiness based on the professional's authentic commitment to respecting patients' rights and dignity assures the patient that he or she is in the hands of a benevolent professional.

The systems of record keeping and documentation add to ethical issues surrounding confidentiality, as evidenced by the following case:

A 25-year-old African-American man was diagnosed with HIV five years ago. He never sought treatment, but was eventually started on antiretrovirals when he developed a case of pneumonia. He was referred to the health department for case management services. During his application for these services, he brought in an application form for his health care professional to complete. This form requested detailed medical information about his health status. In keeping with the policy of the clinic, a signed informed consent was requested for the release of information. Several weeks later, the patient returned to the clinic, indignant, because his HIV status was disclosed in the form. After calming the patient down, it was discovered that he understood the informed consent to mean permission to say he had a medical condition, but not the details of his HIV status.

This case raises two points: (a) the unique issues related to the continued stigma surrounding HIV/AIDS, and (b) the confusion about the purpose regarding informed consent. (Whetten-Goldstein, et al., 2001) conducted a qualitative study of HIV positive patients and their perceived breaches of confidentiality in hospitals, clinics, and health departments by health care professionals. Those findings revealed that these patients perceived that breaches occurred by word of mouth, computers, facsimile, and written word. Patients indicated that sharing stigmatizing medical information among medical providers is a breach of confidence.

### ***Professional Responsibility to Medically Treat HIV Patients***

In addition to ethical issues related to truth telling and confidentiality, there is the ethical issue on the duty of health care professionals to treat HIV-infected patients. Although a clear ethical duty exists to treat all patients, there may be some hesitation and/or reluctance on the part of health care professionals when caring for patients with HIV/AIDS. Research shows that health care professionals are most likely to contract HIV infection if they injure themselves with a needle or other sharp instrument contaminated



with the blood of an HIV-infected patient (CDC 1988). Needle sticks are frequent and, fearing for their own safety, many health care professionals are reluctant to care for HIV-infected patients. The self-interest of health care professionals to avoid occupational HIV infection, however, may conflict with their professional duty and the need that such patients have for medical care.

### ***Occupational Hazards***

The risk of occupational HIV infection is small but not nonexistent (Lo and Steinbrook 1992). The risk of contracting HIV after a single needle-stick exposure to the blood of a seropositive patient is estimated to be 0.3%. The cumulative risk of occupational HIV infection depends on the health care professional's specialty. Surgeons and operating room staff are at highest risk for occupational HIV infection; they sustain skin injuries in 1.7% to 6.9% of operations (Gerberding, et al., 1990).

The magnitude of risk is only one component of a health professional's perception of risk. Some health care professionals may regard familiar and voluntary risks as more acceptable than unfamiliar, involuntary, and uncertain risks, even if the latter are far less likely statistically. The risk of occupational HIV infection seems especially ominous, since HIV infection may progress into full-blown AIDS and result in death; as well, the virus can be transmitted to loved ones. Health care professionals do not have complete control over the risk because percutaneous exposure can occur despite precautions.

### ***Provider-to-Patient Transmission***

There is also a risk of transmitting HIV to patients. CDC has estimated the risk that a patient will contract HIV from a seropositive surgeon during surgery as between 1 in 42,000 and 1 in 420,000 (Lo and Steinbrook 1992). The public perceives the risk of contracting HIV infection from a health care professional as much greater than the data would suggest, possibly because the patient has no control over the risk if he or she doesn't know that the health care professional is infected. In contrast, if patients are informed that a surgeon is seropositive, they can completely avoid that risk by switching care to a seronegative surgeon.

Strong arguments can be made for restricting the clinical activities of certain HIV-infected health care professionals (Lo and Steinbrook 1992). The ethical principle of nonmaleficence requires

that health care professionals avoid harming their patients. Health care professionals also have a duty to act in the best interest of their patients, even if they harm their own interests in the process.

## *Caring for Difficult Patients*

Caring for “the difficult patient” is another issue inherent in the ethical duty to treat all patients. Although several health care professional organizations—such as the American Medical Association, American Psychological Association, and American Nurses Association—have developed clear codes of ethics regarding the duty to treat all patients, many challenges and a sense of reluctance still remain when caring for patients with HIV/AIDS who also have a substance abuse problem (“the difficult patient”). How do health care professional resolve these feelings?

(Anderson and Barret 2000) offer health care professionals a model for ethical clinical decision-making. Health care professionals are required to reflect, to consider the possible implications of various actions from multiple perspectives, and to articulate the key considerations on which their actions are based. This model serves not only to improve clinical judgment but also to provide a clear intention to act in accordance with the highest standards. (Leininger 1995) suggests that health care professionals consider the following self-examination questions when attempting to address, reduce, or prevent ethical problems:

1. What are my ethical beliefs and practices and how can they influence the patient’s health and well-being?
2. How can health care professionals with strong ethnocentric values, biases, and actions prevent ethical dilemmas that lead to cultural imposition practices and conflict?
3. In what kinds of clinical contexts do health care professionals tend to impose their professional and personal ethical beliefs or values on patients, families, or groups?
4. In what ways can health care professionals prevent cultural imposition or best handle ethical or moral dilemmas?
5. What are the potential legal consequences associated with the health care professional who violates a patient’s ethical values?

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Health care professionals are required to reflect, to consider the possible implications of various actions from multiple perspectives, and to articulate the key considerations on which their actions are based.

If health care professionals begin with these questions and try to remain nonjudgmental toward patients, Leininger asserts that “many weighty ethical problems can be avoided or resolved.”

### ***Role of Responsibility in Medical Ethics***

The concept of responsibility also enjoys prominence because it can draw together a wide range of ethical ideas in a fashion pertinent to contemporary social existence. For some ethicists, it serves as a unifying principle of comprehensive ethical theory (Jonsen 1968). Responsibility virtually becomes the first principle of ethics, so that the admonition to “Be responsible!” conveys all that needs to be said about moral life (Jonsen 1968). The theoretical task is to unfold the dimensions of responsibility in their bearing on personal and social processes.

A health care professional’s responsibility does not end with patient care or with professional relationships wherein standards of quality care are maintained. It includes a public interest in the health care system as a whole, and in its ability to provide appropriate services for all people. It embraces the promotion of health in basic life patterns.

Responsibility embraces accountability for judgments and actions (Jonsen 1968). Because our actions affect the lives of fellow human beings, we have to answer to others for what we do. We must be able to give an account of our intentions, and their moral bases, that is credible within the relevant conversational context—whether it be familial, communal, professional, or public. Responsible health care professionals seek feedback from others because they are conscientious about quality performance. Structures of accountability may be formalized in well-defined review processes, including disciplinary hearings, and civil and criminal actions. Yet they also operate in everyday human interactions.

### ***Access to Care Issues***

Not receiving optimal medical care due to financial barriers is still another ethical issue when caring for African-American patients with HIV/AIDS. The lifetime cost of care for an HIV infected person is about \$155,000 (CDC 2001). Ultimately, employers’ and insurers’ reluctance to insure HIV-infected persons increases the public sector’s burden to provide care through

Medicaid and public hospitals. Medicaid finances over 50% of hospitalizations for persons with AIDS. Several factors explain the tendency for the public sector to fund treatment: (a) the AIDS diagnosis makes most persons presumptively eligible for Medicaid; (b) as the disease progresses, many previously employed persons cease working and lose their health insurance; and (c) because of low reimbursement levels, many health care professionals do not accept Medicaid patients—thus, patients who lose private insurance may also lose access to care. In addition, because of budget deficits, many states and counties are finding it increasingly difficult to pay for such indigent care.

### ***Clinical Research***

Ethical issues in caring for African Americans with HIV/AIDS also include the topic of clinical research. Clinical trials data are used to develop treatment guidelines, new treatment modalities, and a host of other approaches to the therapeutic intervention for HIV-infected patients. Current data suggest African-American and Hispanic patients infected with HIV are less likely than whites to participate in clinical trials of new treatments. Therefore, data on African-American issues are often lacking in the guidelines used for making HIV-treatment decisions. Ethical considerations must be weighed when using these guidelines in making therapeutic decisions for African-American patients.

Critics contend that access to clinical trials is inequitable. Many persons are excluded from clinical trials because there are no study sites in their geographic region. Additionally, children, women, and people of color are underrepresented in clinical trials. Usually, children are restricted from clinical trials to protect them from the risks of unproven therapies. Also, women of child-bearing age who can become pregnant are generally excluded to protect their developing and future children from possible long-term side effects of unproven drugs. However, restricting women and children also harms them. In effect, they lack access to potentially beneficial therapies.

## CONCLUSION

Understanding ethical, moral, and legal values, norms, and practices among human cultures is a major challenge for health care professionals, who have to make appropriate health care decisions or actions (Leininger 1995). In addressing ethical issues, health care professionals must be aware of their—and their patient’s—ethical decision-making process. This awareness will prevent cultural imposition—the tendency of health care professionals to impose their values, beliefs, and practices on another culture because they believe that they are superior to or better than that culture (Leininger 1995). Leininger asserts that this imposition can result in patient dissatisfaction, nonadherence to treatment regimens, stress, and a host of problems, some of which can lead to legal problems for the health care professional. Therefore, it is prudent for health care professionals to examine their values, beliefs, practices, biases, and prejudices when caring for African-American patients with HIV/AIDS.

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## III. Sensitivity of the Provider

Health care professionals must be sensitive not just to others' personal cultural beliefs, practices, and values, but also to their own belief systems. This self-assessment is critical to successfully negotiating effective—and culturally competent—treatment plans for African-American patients.

Therefore, health care professionals must conduct an in-depth exploration of their own cultural background, and examine their own prejudices and biases towards other cultures (Campinha-Bacote 1998). These tasks are imperative, for there is a tendency to be ethnocentric regarding one's values, beliefs, and practices. Without being aware of the influences of their own cultural values, health care professionals risk engaging in cultural imposition—the tendency to impose their values on another culture (Leininger 1978). As discussed in the Barriers to Care chapter, provider bias affects the medical decision-making processes and is particularly problematic regarding HIV-infected individuals, because it could result in the undertreatment of such patients (i.e., less accessibility to triple-cocktail therapeutics or other effective treatment regimens). As mentioned in that chapter, negative attitudes from providers will greatly impact a patient's decision to seek medical attention.

A health care professional's understanding of cultural factors, their impact on a patient's life experiences, and the professional's personal response to cultural influences will result in greater capability to provide culturally sensitive health care. To fully understand where one is in the process of becoming culturally competent and sensitive to one's biases, it may be helpful to see cultural sensitivity along a continuum that ranges from unconscious incompetence to unconscious competence.

## STAGES OF CULTURAL COMPETENCE

(Campinha-Bacote 1998) and (Purnell and Paulanka 1998) identified four stages of cultural competence that directly relate to the health care professional's level of sensitivity or "consciousness" regarding interactions with patients from diverse cultural or ethnic groups.

1. *Unconscious incompetence*, in which the health care professional is not aware that cultural differences exist; essentially, he or she is "culturally blind." One example of cultural blindness is when a health care professional assumes that all African-American patients share similar values, beliefs, and practices — "They are all alike." This faulty assumption is based on the concept of intraethnic variation (cultures vary more within ethnic groups than across ethnic groups).
2. *Conscious incompetence* is being aware that one is lacking knowledge about another culture and realizing that cultural differences do exist.
3. *Conscious competence* is the conscious act of learning about a patient's culture, verifying generalizations, and providing culturally relevant interventions.
4. *Unconscious competence*. During this final stage, the health care professional clearly demonstrates the ability to automatically provide culturally congruent services to patients from a diverse cultural group.

### LEVELS OF CONSCIOUSNESS:

1. Unconscious incompetence
2. Conscious incompetence
3. Conscious competence
4. Unconscious competence

## FRAMEWORKS FOR CULTURAL SENSITIVITY DEVELOPMENT

A series of questions to facilitate self-awareness, a sense of self, awareness about others, and establishing a sense of "other" has been developed by cultural competency trainer and consultant Ira SenGupta of the Cross-Cultural Health Care Program in Seattle. Suggested questions for reflection include:

- What was your first experience with feeling different?
- What do you like about your ethnic identity?



- What are your earliest memories about people from cultural backgrounds, socioeconomic classes, and religions other than your own?

(Borkan and Neher's 1991) Developmental Model for Ethnosensitivity is another framework that can help health care professionals become more sensitive and appreciative of other cultures. This developmental model assesses the health care professional's ability to grasp cross-cultural issues and suggests strategies for improving cross-cultural communication and practice skills. The authors assert that ethnosensitivity can be viewed on a continuum from ethnocentrism to ethnorelativity. The model begins with the ethnocentric position of fear (distrust) and progresses through the phases of: (a) denial (culture blindness, over-generalization); (b) superiority (negative stereotyping of cultures); (c) minimizing (reductionism); (d) relativism (acceptance); (e) empathy (pluralism); and (f) finally, an ethnosensitive attitude of integration. The ultimate goals of Borkan and Neher's model are fostering ethnosensitivity—the ability to appreciate values and behaviors within the context of specific cultural norms—and ethnosensitive praxis, which is applying this ability to clinical practice.

## CRITICAL FACTORS

It is critical that health care professionals understand that health care is delivered to individuals and that characteristics other than race come into play, such as language, ethnicity, gender, sexual orientation, and life experiences. To effectively communicate with patients, health care professionals must understand how to talk about sensitive issues such as sexuality and drug use within a context understandable to the African-American patient. Equally important, the health care professional must provide this communication without reacting negatively when patient responses differ from his or her own values. Health care professionals also must be willing to explore a patient's life experiences to ascertain the underlying causes of the patient's behavior, which may not be apparent.

## CULTURAL SYNERGY

“Cultural synergy,” notes Campinha-Bacote, “involves more than respecting, understanding, and valuing another culture’s practices, beliefs, lifestyles, and problem-solving strategies.” The ability to speak a patient’s language is no guarantee that communication between the health care professional and patient will be effective. A key component to communication is shared understanding and shared context. The sensitivity of health care professionals is enhanced by understanding the convergence of multiple memberships in various cultural and subcultural groups that contribute to an individual’s personal identity and sense of culture. Understanding how these factors affect how a person seeks and uses medical care, as well as the historical relationship of that person’s culture to the medical establishment, is an integral component of culturally competent care.

## ESTABLISHING LEARNING ENVIRONMENTS

The sensitivity of health care professionals extends beyond minimally meeting cultural or language needs. They must create environments where learning can occur, which is instrumental to improving the health of both individuals and communities. Health care professionals must learn more about the cultural context, knowledge, beliefs, and attitudes of the communities they serve. Health care professionals who work with community groups and community members in identifying needs are ensured of having culturally relevant processes in place. Similarly, communities need to learn how their collaboration with health care professionals will improve access to and the quality of care.

## CONCLUSION

Health care professionals who will be effective in providing culturally sensitive care for African-American patients with HIV/AIDS will have these characteristics: (a) a good knowledge and understanding of their own world views, (b) an understanding of the particular groups they work with, (c) the knowledge of sociopolitical influences, and (d) the distinct skills (intervention techniques and strategies) needed in working with culturally diverse groups.

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**Providers can evaluate their own cultural sensitivity by assessing the following:**

- Personal values and attitudes—including those practices that promote mutual respect between health care professionals and patients (e.g., screening materials for offensive cultural ethnic or racial stereotypes, being aware and intervening, when appropriate, on behalf of patients when organizations display culturally insensitive behaviors).
  - Communication styles—including sensitivity to using alternatives to written communications (particularly for patients who may lack literacy skills).
  - Community participation—being aware of issues/concerns in the community of the patients being served and working with appropriate community institutions/ organizations to develop and implement programs.
  - Learning environments—for example, establishing culturally and linguistically responsive interior design, posters, pictures, and artwork, as well as magazines, videos, and films; ensuring that print information that delivers culturally targeted messages is literacy-sensitive.
  - Policies and procedures—including written policies, mission statement, goals, and objectives for cultural and language philosophies and practices.
  - Patient-sensitive clinical practice—developing a practice that avoids misusing scientific information and stereotyping group members while acknowledging the importance of culture.
  - Training and professional development—including requiring cultural competence training opportunities for the health care professional and staff, as well as making colleagues aware of cultural competency.
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## IV. Assessment

Assessment is the ability of health care professionals to collect relevant data regarding the patient's health history and present problem (Campinha-Bacote 1998). The basic premise of a cultural assessment is that patients have a right to their cultural beliefs, values, and practices, and these factors should be respected, understood, and considered when rendering culturally competent care (Leininger 1978). Understanding and negotiating with patients about the many social and cultural factors that influence their care can improve treatment outcomes and foster greater patient satisfaction.

### **CULTURALLY BASED ASSESSMENTS AND TREATMENT PLANS**

Culturally based assessments and treatment plans are especially appropriate in treating African Americans with HIV/AIDS. This is important because groups such as African Americans have been historically disempowered in and by the larger society. Effective health care professionals will be required to rethink and reconstruct basic principles that underlie their faltering health care system.

(Leininger 1978) defines a cultural assessment as a “systematic appraisal or examination of individuals, groups and communities as to their cultural beliefs, values, and practices to determine explicit needs and intervention practices within the cultural context of the people being evaluated.” Several user-friendly cultural assessment tools using a mnemonic format have been created to assist health care professionals in eliciting valuable data from patients (Berlin and Fowkes 1983; Stuart and Lieberman 1993; Like 1997). These mnemonic models are BATHE, ETHNIC, and LEARN.

## **BATHE**

**BATHE** stands for **Background, Affect, Trouble, Handling, and Empathy**. The **BATHE** model (Stuart and Lieberman 1993) can be used for eliciting information regarding the patient's psychosocial context.

The health care professional first inquires about the patient's **background** by asking questions such as, "What is going on in your life?" This question assists in eliciting the context of the patient's visit.

Assessing the **affect** of the patient is equally important. Asking the question, "How do you feel about what's going on?" can assist the health care professional to assess the patient's mood and allows the patient to report and label how he or she currently feels.

The health care professional also must assess the possible symbolic significance of the illness. A question such as, "What about the situation troubles you the most?" will elicit information in this area.

It is also important to assess the patient's functioning level. Asking the question, "How are you **handling** your illness?" will give the health care professional insight into the patient's level of functioning and provide direction for intervention.

Finally, the health care professional must be **empathetic** during the assessment phase of care. Commenting that, "It must be very difficult for you," legitimizes the patient's feelings and provides psychological support.

## **ETHNIC**

The **ETHNIC** model—**Explanation, Treatment, Healers, Negotiate, Intervention, and Collaboration**—is a user-friendly framework for culturally competent clinical practice. (Like 1997) states, "to become culturally competent is to be culturally humble... clinicians need to learn what questions to ask to elicit the patient's hidden cultural agenda—how patients explain their illness and what they expect, perhaps unconsciously, from a visit to a physician."

Like asserts that the health care professional must elicit the patient's **explanation** of his or her problem. He suggests asking questions to ascertain the patient's perception of his or her illness such as:

- “Why do you think you have these symptoms?”
- “What do friends, family, and others say about these symptoms?”
- “Do you know anyone else who has had or who has this kind of problem?”
- “What have you heard about/read/seen on TV/radio/newspaper concerning your illness?”

Health care professionals also must assess the types of **treatment** that patients have been taking for their illness. Questions such as, “What kinds of medicines, home remedies, or other treatments have you tried for this illness?” or “Is there anything you eat, drink, or do (or avoid) on a regular basis to stay healthy?” will assist health care professionals in collecting this data.

Some patients may be receiving care from alternative health care professionals and healers. Asking questions such as, “Have you sought any advice from alternative or folk healers, friends, or other people who are not doctors for help with your problems?” will clarify the use of nontraditional health care professionals.

**Negotiation** of a mutually acceptable treatment plan is of great importance for adherence to a prescribed regimen. The health care professional must try to find treatment options that will be mutually acceptable to patients and does not contradict, but rather, incorporates their beliefs. The health care professional must then determine an intervention with the patient, which may incorporate alternative treatments, spirituality, and healers, as well as other cultural practices (e.g., foods eaten or avoided in general and/or when sick). Finally, the health care professional collaborates with the patient, family members, other health care team members, healers, and community resources.

## LEARN

The **LEARN** guidelines—**Listen**, **Explain**, **Acknowledge**, **Recommend**, and **Negotiate**—were used by Berlin and Fowkes (1983) when conducting a cultural assessment.

- The first step is to listen to the patient’s perception of his or her presenting problem.
- Then **explain** your perception of the problem, whether it is physiological, psychological, spiritual, or cultural.
- The next step is to **acknowledge** the similarities and differences between the two perceptions. At times, it is easier for a health care professional to acknowledge and focus on cultural differences than to focus on similarities (Campinha-Bacote 1998).
- The third step is to focus on **recommendations** for treatment, which involve the patient’s input.
- Finally, the health care professional is to **negotiate** a treatment plan, considering that it is beneficial to incorporate selected aspects of the patient’s culture in order to render culturally competent care.

## *Explanatory Model (EM)*

(Kleinman 1980) offers health care professionals a cultural assessment tool that is based on the patient’s perception of the illness, which Kleinman refers to as the patient’s “explanatory model (EM).” In understanding the patient’s EM, Kleinman makes a clear distinction between two aspects of sickness: disease and illness.

Disease refers to malfunctioning of biological and/or psychological processes, while the term illness refers to the psychological experience and meaning of perceived disease... It is created by personal, social and cultural reactions to disease. That is, illness contains responses to disease which attempt to provide it with a meaningful form and explanation as well as control. Viewed from this perspective, illness is the shaping of disease into behavior and experience.



Explanatory models of patients can be elicited in all clinical settings if health care professionals are persistent and demonstrate a genuine, nonjudgmental interest in patients' beliefs. In addition, health care professionals must express the conviction to patients that knowledge of their explanatory model is important to planning an appropriate treatment (Kleinman 1980). (Kleinman, et al., 1978) suggest the following eight open-ended questions when assessing the patient's EM:

1. What do you think has caused your problem?
2. Why do you think it started when it did?
3. What do you think your sickness does to you?
4. How severe is your sickness?
5. What kind of treatment do you think you should receive?
6. What are the most important results you hope to achieve from this treatment?
7. What are the chief problems your sickness has caused?
8. What do you fear most about your sickness?

When conducting a cultural assessment among African-American patients with HIV/AIDS, responses to these questions will play a significant role in developing a culturally responsive treatment plan. This significance is demonstrated in the following case study.

### ***Case Study***

James Smith, a 32-year-old patient of African descent diagnosed with AIDS, presents to an outpatient clinic for management of his condition. Mr. Smith, who prefers to be called "Jimmy," was initially seen by a social worker. After engaging in an introductory conversation with the patient, the social worker obtained a social history assessment by integrating Kleinman's eight cultural questions. When asked what he thought caused his illness, Jimmy readily explained, "It's how I lived my life... sex, drugs, stealing, and all the other crazy things I did to get drugs."

When asked why Jimmy thought he got AIDS when he did, he responded, “I really don’t know. I didn’t know I was seropositive until some years into my illness. In fact, it was when I decided to straighten out my life and stop drug using that I found out about my diagnosis of AIDS.”

Jimmy was then asked what he thinks AIDS does to him. He stated that it has enhanced his relationship with God. He added, “It makes me want to live and accomplish my goal of going back to college, before He (referring to God) takes me.”

The social worker then asked how severe Jimmy thought his sickness was. He stated that, at times, he becomes angry and depressed because he doesn’t know what’s going to happen next. But he added, “I try to focus on my relationship with God to heal this area.”

The social worker then asked what kind of treatments did he think he should receive. Jimmy stated that he had a strong belief in herbs (herbal teas) and vitamins as well as a strong spiritual belief system.

When asked what are the most important results he hoped to achieve from these treatments, Jimmy stated that he hoped to maintain good health and hopefully not have to take any antiretroviral medications. He further explained his reluctance in taking any medication that the physician may give him because, “It affects other organs within your body.” Jimmy also reported the chief problem in having AIDS was increased stress. When the social worker asked Jimmy what he feared most about his illness, he responded, “Physical deformities, if I’d ever succumb to taking medications in the future. I’ve seen some people with HIV/AIDS who have physically deteriorated and that frightens me. I guess most people are afraid of dying. Death isn’t a fear for me; I’ve made preparation for it.”

This case study clearly demonstrates the valuable information that can be gained by conducting a cultural assessment using Kleinman’s eight questions. In formulating a culturally responsive treatment plan for Jimmy, it is important for the social worker to incorporate a mutually agreeable plan that includes:

1. Jimmy's belief in using herbal teas and vitamins;
2. Respect for and acceptance of his initial reluctance to take antiretroviral medication;
3. Increasing his knowledge base of antiretroviral medications;
4. Building on his spiritual belief in God;
5. Identifying strategies to manage his increased stress level;
6. Providing culturally specific approaches (i.e., spiritually) to cope with his anger and depression;
7. Discussing and exploring further his fear of possible physical deformity; and
8. Offering him hope in his quest to maintain a healthy life and return to college.

## INTEGRATION OF CULTURAL CONTENT

It is important for health care professionals to keep in mind that conducting a cultural assessment is more than merely selecting the “right tool” and asking the patient questions listed on the tool. The cultural assessment must be conducted in a culturally sensitive manner. One approach is for health care professionals to integrate cultural content into their existing assessment data. In contrast to having a separate cultural assessment tool/form, health care professionals may find it more helpful to revise their existing health history or assessment form to reflect culturally relevant questions (Campinha-Bacote 1995). If a cultural assessment is conducted in this manner, culture is not singled out; rather, it is appropriately incorporated into the patient's overall assessment.

(Buchwald, et al., 1994) suggests other techniques for eliciting cultural content from the patient in a culturally sensitive manner. First, health care professionals must listen with interest and remain nonjudgmental about what they hear. Some patients may openly share information about their lifestyle and behaviors that may sound shocking to the health care professional. To gain relevant information about the patient's lifestyle that may affect treatment,

the health care professional must continue to remain nonjudgmental and listen with genuine interest. Second, the health care professional may want to develop alternative styles of inquiry by adopting a less direct and more conversational approach to assessing the patient's background. Health care professionals may consider conversational remarks such as, "Tell me about yourself and your family." Another technique is to frame questions in the context of other patients or the patient's family. For example, "I know a patient who believes \_\_\_\_\_ about AIDS. Do you think that?" or "What does your mother think about AIDS?" Attributing explanations to another person can help patients disclose health beliefs and practices that they feel uncomfortable expressing directly (Buchwald, et al., 1994).

## CONCLUSION

Data obtained from a cultural assessment will assist health care professionals in formulating a mutually acceptable and culturally responsive treatment plan. Although it is critical to conduct cultural assessments on culturally and ethnically diverse patients such as African-American patients, cultural assessments should not be limited only to these patients. It is important to realize that "every patient needs a cultural assessment; not patients who look like they need a culturally based assessment" (Campinha-Bacote 1995). All patients have values, beliefs, and practices that must be considered and incorporated in the assessment, planning, and implementation of health care services. Conducting a cultural assessment on all patients will prevent "cultural blind spot syndrome," which is when health care professionals assume that there are no cultural differences or potential barriers to care because the patient looks and behaves much the same way they do (Buchwald, et al., 1994).

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## V. Facts

Providing culturally responsive health care to African-American patients with HIV/AIDS requires health care professionals to learn about this ethnic group's biological variations and their world view, which is a set of metaphorical explanations used by a group of individuals to explain life's events.

### **WORLD VIEW OF AFRICAN-AMERICAN PATIENTS**

One goal in obtaining cultural facts about African-American patients with HIV/AIDS is to understand the world view that forms the foundation for their actions and interpretations. World views can take several shapes, as noted below.

#### ***Spirituality***

Spirituality is one world view that affects a patient's actions and interpretations. For African-American patients, spirituality and religion play integral parts in their world view.

For many African Americans, their inner strength comes from trusting in God, and African-American churches have played a major role in African Americans' development and survival. Some African Americans believe that whatever happens is "God's will."

However common spirituality is in the human experience, the cumulative effect of AIDS and spiritual burdens can be devastating to the person living with AIDS. For many African Americans, confronting AIDS implies dealing with primary spiritual issues such as guilt, loss, and a search for meaning. Guilt that stems from a feeling of being punished by God may result in hopelessness and becoming resigned. However, some homosexual men who reconciled their sexuality and spirituality before their HIV diagnosis appear to deal quite effectively with their health issues. Health care professionals who are aware of the patient's

spiritual views must understand and respect their priority in the patient's life and health status. The health care professional may include the patient's spirituality in the dialogue to gain a better understanding of the patient's world view and culture.

## ***Stigmatization and Discrimination***

Despite the fact that the AIDS epidemic is at the end of its second decade, it remains a medical condition that is stigmatizing for those who are infected and still results in discrimination and rejection. Some families are rigid and unaccepting of HIV infected persons. In addition, most persons with AIDS describe being extremely fearful when they learn their diagnosis. They fear death and being alone, the worry and stress of physical and mental deterioration, and that the disease's stigma will be unbearable.

The fear of rejection may lead to deception and perpetuation of the disease. One account describes a 35-year-old mother whose husband had a history of drug use, which meant an increased risk for HIV/AIDS. She asked her husband to wear a condom to help protect her, just in case he was infected. Her efforts were directed at ensuring her safety, so that she would be able to provide care for their children. However, he refused, responding, "Why would you think I would need a condom? Do you think I have something?" About a year later, a friend found a sheet of paper with the husband's positive AIDS test results. The husband knew he was positive and was willfully engaging in unsafe sex with his wife. This scenario points to the fierce traditions of pride and machismo in the African-American male community that sometime preclude discussions of sex, adultery, and condom use. In this particular case, the mother was furious, suicidal, and burdened with emotion when she found out (Crute 1998).

## ***Support Systems***

As a cultural group, African Americans have a strong history of collective, group orientation. The importance of personal relationships and social support systems is manifest in the African proverb, "It takes a village to raise a child." From slavery times, it was imperative for slaves to work together. Considerable benefit was derived from sharing resources and information, and having supportive family and friends.



For serious health concerns, the world view of many African Americans reflects an “I can do” mentality. Family, friends, and other relatives play a significant role in the healing process within the African-American community. For example, a likely response when faced with an HIV diagnosis would be to contact the family elder or matriarch who has recommended effective herbal and other treatments in the past. Often, lifelong relationships with women in the community have more value than a clinician’s years of medical education and practice. Therefore, health care professionals should assess their patients’ social support network to identify advocates for treatment adherence and emotional support.

Certain cultural norms also impact the interaction between the patient and health care professional. For example, when some African Americans communicate with a health care professional, eye contact, touch, facial expression, and language become relevant. Many African-American patients are sensitive to hasty treatment by non-African Americans. This again relates to the communal nature of the African-American culture. To really understand a patient’s particular issues, sufficient time must be allowed in patient care and assessment. The selection of an appropriate treatment strategy could be significantly influenced by the amount of time given to engaging in dialogue or invested in interactions. Additionally, the African-American culture represents a rich oral tradition. Thus, handing someone a piece of paper with treatment instructions and walking away may not be as effective as asking detailed questions and discussing the patient’s fears and feelings.

In short, a critical way of addressing AIDS-related emotional issues is finding models that respect the patient’s culture, worldview, and concerns. Health care professionals should assume that the patient’s concerns are valid. They should be mindful that their attitude and ability to create a safe environment will affect a patient’s willingness to participate in the treatment process.

## BIOLOGICAL VARIATIONS

Obtaining facts about biological variations also is critical to the culturally sensitive treatment of African-American patients with HIV/AIDS, for whom culturally relevant care and diagnoses are of paramount importance. (Purnell 1998) identifies biological variations in disease, health conditions, and drug metabolism. This field of study is called “biocultural ecology.”

The following case study emphasizes the importance of understanding biological variations among African-American patients.

### *Case Study*

Leo L., a 37-year-old African-American gay man, came to the AIDS clinic in September 1996, presenting with fever, mouth ulcers, and a dermatomal vesicular rash. Mr. L. tested positive for HIV. He indicated that he had twice before tested HIV negative, in 1990 and in 1993. In February 1997, prior to any antiretroviral therapy, his CD4 count was 157 cells/mm<sup>3</sup> and HIV-1 viral load (Roche RT-PCR) was 886 copies/ml. He felt entirely well. He then commenced treatment with indinavir + AZT + 3TC, after which his viral load was consistently undetectable by Roche RT-PCR, (<400 copies/ml) through December 1998. Despite his prompt and complete virologic response, his CD4 cell count never rose. His adherence to therapy was judged to be quite good, and he remained well, clinically (Jenny-Avital 1999).

Patients who are treated with highly active antiretroviral therapy (HAART) and have undetectable viral loads are expected to have an appropriate corresponding rise in the CD4 counts (El-Sadr, et al., 2000; Ledergerber, et al., 2001). Leo’s viral load was undetectable by the Roche assay after treatment, but his CD4 remained low. Most commercially available HIV-1 RNA plasma viral load assays have been optimized with clade B viruses and may yield misleadingly low RNA levels for non-B clade viruses (Clarke, et al., 2000). This case demonstrates the use of an older assay for viral load, which gave results that were artificially low. Further investigation showed that his viral load was artificially low because the test (Roche RT-PCR version 1.0) is more sensitive for the subtype of HIV found in the West, namely, subtype clade B. This patient’s infection represented the local transmission of subtype A. He had never traveled out of the United States but, along with some of his sexual partners, he lived in an area of New York City largely inhabited by immigrants.

## **HIV Subtypes**

In situations where HIV exposure may be transcultural or transgeographic, one must consider other possibilities, such as different types of HIV, which has two major types: HIV-1 and HIV-2. HIV-1 is the major cause of AIDS worldwide, whereas HIV-2 is endemic in West Africa and rare outside that region.

HIV-2 has interesting pathological differences from HIV-1. It has been shown that HIV-1 has a set point (initial viral load) that's up to 28 times higher than HIV-2. Patients with HIV-1 typically have a viral load set point of 78,000 copies, vs. 2500 for HIV-2 (Andersson, et al., 2000). Rates of infection and progression in HIV-2 are also lower than in HIV-1 (Hu, et al., 1996; Andersson, et al., 2000).

HIV-1 and HIV-2 can be further categorized into genetic subtypes or clades. The system currently used to classify HIV-1 and HIV-2 into subtypes is based primarily on genetic sequences coding the envelope (Env) and structural (Gag) proteins, and methods to infer the phylogenetic relationships between them (Hu, et al., 1999). HIV-1 has at least 10 subtypes that are designated A through J in the order that they were identified (Simon, et al., 1998). HIV-2 has 5 genetic subtypes designated A through E (Brodine, et al., 1997).

HIV-1 viruses have been organized into 3 major groups: group M (major group), includes subtypes A through J; group O (outlier); and group N (Sullivan, et al., 2000).

*Group M* is responsible for most of the infections worldwide. The greatest number of different group M subtypes has been identified in Africa. Recombination has been found to occur between specific subtypes, for example, E and G. No conclusive evidence has been found for differential rates of transmission or progression associated with various group M HIV-1 genetic subtypes (Jones, et al., 1999).

*Group O (outlier)* is rare and has at least eight subtypes. Most group O HIV-1 infections have been identified in Africa; much smaller numbers of infections have been identified in Europe. Group O currently is found in the Central African countries of Cameroon and Gabon, and in France (Fauci and Land 2000). The highest prevalence of HIV-1 group O infections is in Cameroon,

which is also the country of origin for the first reported case of group N HIV (Sullivan, et al., 2000). Group O was first isolated in Cameroon and Gabon in 1990 and noted to be highly divergent from other HIV-1 clades. Subsequently, a cluster of 9 HIV-1 infected individuals was found in France, 8 of whom emigrated from Cameroon and 1 who was a French native diagnosed with HIV-1 group O. More recently, a case of group O was found in the United States (Brodine, et al., 1997). The occurrence of infections with group O HIV-1 viruses is of considerable interest, because HIV EIA kits do not consistently detect serologic responses to infections with group O viruses (Sullivan, et al., 2000).

*Group N* was identified by Simon et al. from 1995 blood samples from a 40-year-old Cameroonian woman with AIDS (Simon, et al., 1998).

It is important to recognize that most subtypes, although originating in Africa, are not necessarily confined to that continent. Global travel and migration patterns may introduce subtypes not typical for a particular region. For example, health care professionals should be aware that persons with epidemiologic contacts with Central and West Africa may be infected with a non-B HIV-1 subtype and should order and interpret RNA concentration determinations in these patients in light of this possibility. As (Sullivan, et al., 2000) indicated:

Physicians caring for persons with clinical evidence of AIDS, especially those with behavioral risk for HIV infection or epidemiologic links to Africa, but for whom EIA results are negative, should consider the possibility of infections with group O or group N and contact their state or local health department for assistance with the diagnosis of group O or group N infection.

The global distribution of HIV-1 subtypes is summarized as follows, and in Table 1.

- Subtype B predominates in the United States, Central and South America, the Caribbean, Europe, and Eastern Europe.
- Africa includes all of the subtypes, including B; however, subtype A is predominant. In South Africa, subtype C is the most common, followed by subtype B. Subtypes A, C, and D have dominated in viral isolates from sub-Saharan Africa (Zuger and Sax 1996).

- Thailand, Vietnam, and Indonesia predominantly have subtype E, but Indonesia also has B. China and India predominate with subtype C.

A study by (Sullivan, et al., 2000) used a population-based surveillance registry to identify HIV-infected persons in the United States at increased risk for group O and group N infections (those born in or near African countries where group O infections had been reported). He found no cases of group N and that group O was uncommon. However, out of 37 samples, 32 had group M; 16 had subtype A; 5 had subtype B; and subtypes D, F2, G, and recombinant A/J had one each. There were 2 with group O. Sullivan suggested that African-born persons may have HIV strains typical of their birth country and that ongoing subtype surveillance may allow early identification of novel or emerging HIV strains.

**Table 1. Global Distribution of HIV-Subtypes (modified from Brodine et al. 1997)**

Region	Highest Subtype Prevalence	Moderate Subtype Prevalence	Low Subtype Prevalence
North America	B		A,C,D,E,O
Central America	B		
Caribbean	B		
South America	B	F	
Western Europe	B	A,C,D,E,F,G,J	C
Eastern Europe	B	A,C,D,F,G	O
West Africa	A		C,D
Central Africa	A	C,D,E,F,G,H,O	B
East Africa	A	D	
Horn of Africa	C	A	
South Africa	C	B	D
Thailand	E	B	C
Vietnam	E	B	A,E
China	C		
India	C		

A study by (Zaidi, et al., 1999) pointed out that as the epidemic progresses, the introduction and transmission of different subtypes become more likely. Persons in this surveillance study who had subtypes A and G had moved to the United States from Sierra Leone in 1997 and Gabon in 1998, respectively. The authors further imply that this may have ramifications for using vaccines, which are subtype B based.

It is extremely important to realize that commonly used screening tests may not detect group O infections (Loussert-Ajaka, et al., 1994; Schable, et al., 1994) and patients who are HIV-1 negative but who fit the clinical disease may harbor group O (Loussert-Ajaka, et al., 1994). Health care professionals should be aware that genetic subtypes of HIV influence laboratory characterization of HIV infection. Infections with HIV-1 group O may not be detected by some HIV enzyme immunoassay tests. The RNA amplification tests also may underestimate viral copy number for HIV-1 subtypes A, E, F, and G. If patients who may have been HIV infected outside the United States have symptoms suggestive of immunosuppressive disease and are repeatedly HIV enzyme immunoassay test negative, further diagnostic tests to rule out infection with non-B subtypes of HIV-1 or HIV-2 may be needed. State health department laboratories may provide further information on the availability of such tests (Sullivan, et al., 1997).

Non-B subtypes of HIV-1 have been proposed to be significant in the transmission, clinical course, disease monitoring by HIV-RNA concentration, clinical care, detection by HIV EIA, and vaccine development. However, many of these issues are not fully resolved (Sullivan, et al., 2000). In Africa, Thailand, and India, HIV is predominantly a heterosexual disease and non-B subtypes predominate. Some studies suggest that subtype E may have enhanced heterosexual transmission that may be due to increased replication in Langerhans cells, which are located in the vaginal mucosa and may be the cell types that first become infected during heterosexual transmission (Brodine, et al., 1997; Soto-Ramirez, et al., 1996; Zuger and Sax 1996). Subsequent studies have failed to show subtype-specific differences in the ability of isolates to infect Langerhans cells, and infectiousness for Langerhans cells may be a function of strain differences independent of subtype (Hu, et al., 1999). Subtype B may be less efficiently transmitted heterosexually than the other subtypes, particularly E (Brodine, et al., 1997).

Evidence against differential transmission of HIV subtypes includes (a) the presence of non-B subtypes in Europe without rapid spread; (b) similar rates of perinatal transmission without intervention in different parts of the world; and (c) similar estimates of per-sex-act transmission among couples in Europe, North America, and northern Thailand (Jones, et al., 1999). A significant study by Quinn et al. involving 415 couples followed for 18 months in which one partner was HIV-1 positive and one initially negative found that the viral load is the chief predictor of the

risk of heterosexual HIV-1 transmission, and that transmission is rare among persons with levels of less than 1500 copies of HIV-1 RNA per milliliter (Quinn, et al., 2000).

In monitoring and diagnosing infections using the viral load (HIV RNA), it is important to realize that first-generation assays do not accurately quantify HIV-1 RNA levels in many individuals infected with non-B serotypes (Alaeus, et al., 1999). A problem with the commercial assays for RNA quantification is that most, if not all, validation has been carried out on samples from individuals infected with the B subtype of HIV-1 (Alaeus, et al., 1997). In Africans and individuals of African descent who seem to clinically fit criteria for infection or who appear to be worse clinically than their viral loads indicate, one should consider non-B clades and make sure that the laboratory is using the most modern or second generation tests that have a better chance of quantifying non-B clades (Nkengasong, et al., 1998; Alaeus, et al., 1999).

It is also important to recognize that dual and recombinant infections do occur. This has been documented in Brazil, where dual and recombinant infections are emerging as an integral part of the HIV/AIDS epidemic (Ramos, et al., 1999). A study in Thailand also documented dual infection with both subtypes B and E (Artenstein, et al., 1995). Dual infection may involve coinfection with both HIV-1 and HIV-2. In these patients, plasma HIV-1 RNA levels may be lower than if they were infected with only one virus (Andersson, et al., 2000). Dual infection is of lesser import in the United States, where subtype B overwhelmingly predominates and HIV-2 is rare. Nevertheless, dependent on background and immigration patterns, patients theoretically can be dually infected with HIV-1 clade B and non-B and with HIV-1 and HIV-2. In Thailand, intravenous drug users (IVDUs) were initially infected primarily with subtype B, while the heterosexual patients were infected with subtype E (Brodine, et al., 1997). In time, the subtype distribution in Thai IVDUs has become increasingly subtype E, documenting additional factors of sexual risk (Wasi, et al., 1995). The demonstration of dual infection in humans raises several potentially important issues regarding the pathogenesis, global epidemiology, and control of HIV-1. The biological effects on the host through the interaction of two distinct viral subtypes may be additive, synergistic, or inhibitory (Artenstein, et al., 1995).

It is important to consider the ethnic origins of patients and their contacts. This may be particularly important for African-American patients who may present with atypical presentations. Atypical presentations include patients who (a) test negative but

are suspected of having HIV, (b) have a low or undetectable viral load in the presence of CD4 cells that do not rise appropriately with HAART, and (c) appear clinically worse than their immunologic status would predict. Older viral load tests are optimized for subtype B and may not measure other subtypes of HIV-1 or may give incorrect low values for viral load. The most important factor in HIV transmission may be the viral load. Ethnic and cultural background, geographic migrations, and intercultural contacts may have profound implications in the diagnosis, management, and treatment of HIV infection.

### ***Other Biological Variations***

The appropriate use of cultural facts in HIV management of African-American patients also allows the health care professional to appreciate differences in skin color and other biological variations. For example, birthmarks occur in 20% of African Americans as compared to 1% to 3% of other ethnic groups.

#### ***Pigmentation***

The skin hyperpigmentation of African-American patients changes the presentation of many common skin manifestations.

Jaundice, pallor, petechiae, inflammation, and localized hyperpigmented lesions often must be interpreted differently in dark-skinned individuals. The lack of the red hue in dark skinned patients makes the differentiation of pallor confusing. This has to be interpreted as a gray color. Jaundice can be missed in the observation of the skin only; therefore, the examination of the sclera, palms, and soles of the feet becomes critical. Petechiae also must be observed on the oral mucosa and conjunctiva. Inflammation is often missed until the flare becomes severe. Palpation must be used in localizing warmth, induration, and tightness of the skin in early cases. Lesions of Kaposi's sarcoma and bacillary angiolomatosis can be overlooked and confused with other lesions in the dark-skinned patient. A well-lighted examination with palpation of all suspected lesions is important in these patients.

#### ***Hyperglycemia, Diabetes, and Related Diseases***

An awareness of at-risk populations for specific endemic diseases allows the health professional to provide culturally appropriate screening and education for the prevention of complications associated with HIV and its treatment. Conversely, an awareness of the antiretroviral complications as they specifically



relate to the predisposing diseases in African-American patients will eliminate further risks associated with these drugs. Hyperglycemia, new onset diabetes mellitus, and an exacerbation of diabetes in predisposed patients have been seen in patients receiving protease inhibitors. African-American patients have been noted to have an increased genetic susceptibility to diabetes mellitus, with an increased incidence of 1.6 times that seen in patients of European descent. Furthermore, it is anticipated that high frequencies of the G protein beta 3 subunit 825T allele in Africans may contribute to obesity, type 2 diabetes, and hypertension when westernization of lifestyles occurs (Siffert, et al., 1999). The so-called “thrifty genotype” hypothesizes that African populations may have genes that determine increased fat storage, which in times of famine represent a survival advantage, but in a western environment result in obesity and type 2 diabetes. The association of lipodystrophy and hyperlipidemia needs to be taken in the context of these predisposing conditions, and the choices of antiretroviral combinations must also be done within the context of the patient’s risks for disease complications.

### *Variations in Drug Interactions*

The variations in drug interactions in HIV-infected African-American patients must be considered, particularly because most HIV clinical trials have been conducted on European-American men. More recently, an increased effort has been made to include African-American patients in clinical trials, but the knowledge of pharmacokinetics in such patients is in its infancy. An example of the variations seen with African Americans has been described by (Campinha-Bacote 1998) in psychiatric clients who experienced higher incidences of extrapyramidal effects with haloperidol decanoate than European-American patients. In addition, African Americans show higher levels of tricyclic antidepressants and faster therapeutic responses than their European American counterparts for similar dosages of these drugs.

In addition to ethnic differences leading to variations in drug metabolisms, the cultural biases of health care professionals may also contribute to drug usage in African-American patients. African Americans are at a higher risk of misdiagnosis for psychiatric disorders and therefore being given inappropriate drugs. According to (Adebimpe 1981), statistics reveal higher frequencies of psychosis and lower frequencies of mood disorders in African-American patients. Such patients also receive higher doses of neuroleptics more frequently and are given high-potency depot neuroleptics more often than European Americans.

## CONCLUSION

The goal of attaining cultural facts about African-American patients is to provide the health care professional with an overview of the patient's world view as well as the needed knowledge on this ethnic group's biological variations. This knowledge will assist health care professionals in rendering culturally appropriate care. Because cultures are constantly evolving, no health care professional can become completely familiar with the health beliefs and biological variations of all their patients. Furthermore, patients cannot expect such encyclopedic awareness from their health care professionals. Finally, health care professionals cannot rely solely on textbooks for culturally specific knowledge and facts; they must develop the necessary skill to obtain cultural facts directly from the patient (Campinha-Bacote 1998). Skill in conducting a cultural assessment will prevent possible stereotyping of African-American patients.

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## VI. Encounters

**A**chieving effective encounters with patients from ethnically and culturally diverse backgrounds is a core component of cultural competence in the clinical setting. Encounters are necessary face-to-face interactions that allow health care professionals to effectively engage in cross-cultural interactions with culturally diverse populations (Campinha-Bacote 1998).

Campinha-Bacote further contends there are occasions where previous interactions with three or four patients from a particular cultural or ethnic group provide a knowledge base about that particular group. However, these three or four patients' values, beliefs, and practices may or may not represent that of all individuals from that cultural group. Therefore, many encounters with specific ethnic groups are needed to effectively interact with that group. Factors such as language, cultural norms, and concepts of personal space are important variables to consider when encountering African-American patients.

### COMMUNICATION

Accurate and effective communication between patients and health care professionals is the most essential component of the health care encounter (Office of Minority Health 2001). Language is one of many factors that can influence effective encounters. Language is more than communication; it is the essence of culture (Carter 1995). It offers security and provides a sense of pride. Although the dominant language spoken among patients of African descent is English, they may also speak another language or dialect.

Many people refer to the informal language spoken by some African Americans as “Black English” (or Ebonics). This term is incorrect because Black English is not a language, but a dialect in which the pronunciations of words may be different (Campinha-Bacote 1998). For example, some African Americans may pronounce “the” as “de.” Therefore, “these” may be pronounced as

“dese.” Another dialect spoken by some African Americans is Gullah, which is a dialect derived from several West African languages and has the elements of a Creole language. It is most often spoken by African Americans originating from Hilton Head Island in South Carolina or the Sea Islands of Georgia. After the Civil War, islands, such as Sapelo Island and Hilton Head, were left to the freed slaves, who developed their own culture. Today, the descendants of the freed slaves speak Gullah. Health care professionals may perceive the patient who speaks Black English or Gullah as uneducated or illiterate. However, health care professionals must refrain from assuming an African-American patient is poorly educated or lacks intelligence if he or she uses these dialects.

African Americans speak English with numerous phrases/expressions or idioms, which are sometimes referred to as slang or street talk. Examples of these expressions include: “my bad,” for a mistake or error; “sugar,” for diabetes; “the monkey,” for HIV/AIDS; or “coat,” for condom. Also, there are subtle differences in the usage of words, not just differences in language. For example, African-American patients may use the terms “high blood” and “low blood” to refer to two unrelated conditions—hypertension and anemia. Health care professionals must refrain from assuming an African-American patient is poorly educated or lacks intelligence if he or she uses dialects.

When conducting a health interview with an African-American patient who may be linguistically challenging, remember to:

- Speak clearly in short simple sentences or phrases.
- Look at and speak directly to the patient.
- Watch for nonverbal cues.
- Listen carefully to your patient.
- Speak slowly and use visual aids to assist you if needed.
- Refrain from using professional jargon, technical terminology, or slang words.
- Anticipate a longer session. Effective communication takes time.
- Request that the patient repeat the instructions or general content of the discussion to check comprehension.

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Health care professionals must refrain from assuming an African-American patient is poorly educated or lacks intelligence if he or she uses dialects.

- Avoid labeling of patients. Some African Americans tend to speak loudly, especially when anxious, when excited, or when trying to get a point across. This may be misinterpreted as anger or aggression by the health care professional, when in fact the loudness is a manner of expression or the dynamics of speech.

English may not be the native tongue of some patients of African descent, and a medical interpreter may be required. However, it is important not to assume that patients will prefer their native language if they are able to speak English. In working with medical interpreters, (Like 2000) suggests that health care professionals use the clinical interviewing mnemonic, “TRANSLATE.” The health care professional must address such issues as trust, roles of the interpreter, advocacy for the patient, nonjudgmental attitude, setting, language, accuracy, time, and ethical conflicts. Like recommends the following questions to address these issues:

- *Trust*—How will trust be developed in the patient-interpreter triad relationship? And how will trust be developed in relationships with the patient’s family and other health care professionals?
- *Roles*—What roles will the interpreter play in the clinical care process (language, interpreter, culture broker/informant, culture broker/interpreter of biomedical culture, advocate)?
- *Advocacy*—How will advocacy and support for patient and family-centered care occur?
- *Nonjudgmental attitude*—How can a nonjudgmental attitude be maintained during health care encounters? How will personal beliefs, values, opinions, biases and stereotypes be dealt with?
- *Setting*—Where and how will medical interpretation occur during health care encounters (e.g., use of salaried interpreters, contract interpreters, volunteers)?
- *Language*—What methods of communication will be used? How will linguistic appropriateness and competence be assessed?

- *Accuracy*—How will knowledge and information be exchanged in an accurate, thorough, and complete manner during health care encounters?
- *Time*—How will time be appropriately managed during health care encounters?
- *Ethical issues*—How will potential ethical conflicts be handled during health care encounters? How will confidentiality of clinical information be maintained?

If health care professionals do not speak the same language as the patient, they may want to learn a few key phrases that will demonstrate their interest. A health care professional's interest and caring will be evident despite the language barrier. In addition, health care professionals should not feel that silence must be filled in with small talk. Give your patients a chance to formulate their thoughts, especially if they are still trying to speak a language that is not native to them. Observe your patients to get a feel for how they use silence or "pause time."

## CULTURAL NORMS

The health care professional's lack of knowledge of cultural norms among African-American patients with HIV/AIDS can be another source of conflict during a cross-cultural encounter. Many cultures have specific taboos: things that would be frowned on and therefore never done by anyone within that cultural group. These taboos can be potential land mines in a cross-cultural encounter. Issues of sexual orientation, homosexuality, and attitudes about death must be considered in encounters with African-American patients with HIV/AIDS.

Additionally, issues and concepts of respect are critical—in particular, addressing an older African American by his or her first name without using the title of Ms., Mrs., Dr., Pastor, Minister, or Mr. can be considered disrespectful. Use of titles is especially important when one is suffering from a chronic disease since it says to the patient, "In spite of this disease, I validate you, and you are worthy of respect."

Personal and interpersonal space can influence cross-cultural encounters. Personal space refers to one's behavior and attitude toward the area around the person. The amount of personal space

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The health care professional must address such issues as trust, roles of the interpreter, advocacy for the patient, nonjudgmental attitude, setting, language, accuracy, time, and ethical conflicts.



that people need as a comfort zone varies from individual to individual and from culture to culture. Territoriality is the term used to describe the attitude and behavior exhibited by an individual when claiming, defending, or reacting emotionally to personal space, especially when personal space has been invaded by others. When you first sit down to speak with patients, ask them to sit where they feel most comfortable. This will allow people to choose the distance that feels right to them. For example, African Americans tend to feel comfortable at a closer distance than do American Indians or Asian Americans.

When interacting with the African-American patient, take time to establish common ground through sharing experiences and exchange of information. Demonstrate a caring approach by being considerate and polite and giving the appearance of being unhurried. A caring approach will be recognized even when there is difficulty with words. To be effective, some pleasantries may be essential before obtaining the patient background information and medical history. The health care professional may want to start with less sensitive areas of discussion, then proceed to the health interview. Health care professionals should not be afraid to ask about something that they are unfamiliar with or not sure about. Open-ended, honest questions show an interest in the patient, respect for his or her culture, and a willingness to learn. This type of questioning also allows the patient to more fully express feelings, opinions, and ideas. Avoid asking embarrassing personal questions in front of a patient's visitor. Know also that in some cultures, questions regarding male or female reproduction are embarrassing in the presence of someone of the opposite sex, even if he or she is married.

Although face-to-face interaction with African-American patients is the most effective way to obtain the skills needed for effective cultural encounters, health care professionals may want to consider using case scenarios. Group discussion among health care professionals that uses case scenarios can provide viable options on how to respond to potentially difficult encounters with African-American patients. The Appendix to this chapter includes four case scenarios depicting challenging encounters with patients of African descent and a history of HIV/AIDS.

## CONCLUSION

There are several effective strategies for ensuring effective encounters with African-American patients. (Campinha-Bacote 1996) identifies the following key points for effective cross-cultural encounters:

- Recognize differences, but build on similarities.
- Remember that communication is inevitable. Culturally sensitive communication requires cultural knowledge and skill, an awareness of the role that one's own cultural values play in communicating, and engaging in many cross-cultural encounters.
- Develop a cultural habit—the desire to want to effectively build relationships with patients from culturally different backgrounds.
- Recognize that intra-ethnic variations exist among all cultural and ethnic groups. Specifically, there are more differences within cultural groups than across cultural groups. This will avoid stereotyping and labeling.
- Remember that cultural competence is a journey, not a destination; a state of becoming, not being.
- Become sensitive to nonverbal clues and communication. Be aware that some of your usual nonverbal communication may be insulting to specific cultural groups.
- Remember that when conflicts exist between the health care professional and patient, health care professionals should look within themselves as a possible source of error.
- Engage in many direct, face-to-face cultural encounters.

Face-to-face interaction with African-American patients is the most effective way to obtain the skills needed for effective cultural encounters.

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# Appendix: Case Scenarios

## CASE SCENARIO 1

Kenny, a medical student, was filling out the medical record form for Mrs. Jones, a woman who appeared to be of African descent but who had an unfamiliar accent. Mrs. Jones will find out that she is HIV-positive when she meets with the physician in another 10 minutes. One question on the form was “Ethnic origin?” Kenny asked, “What is your ethnic origin?” Mrs. Jones said, “Oh dear, we’ve always been Americans.” Kenny marked, “None” on the medical record form. Another question on the form was about cultural practices. “Do you have any special cultural practices?” Kenny asked. “Of course not,” Mrs. Jones replied. “We are just like everyone else around here.” Kenny again recorded “None” on the medical record form for the cultural practice question.

### *Discussion Questions*

1. What would you have asked to obtain Mrs. Jones’ ethnic origin?
2. If Mrs. Jones did not know her specific ethnic origin, what could be recorded?
3. How would you ask questions to find out about Mrs. Jones’ cultural practices?

## CASE SCENARIO 2

A 44-year-old woman of African descent came in alone to the clinic for her monthly visit. She had a T-cell count of 34 and a viral load of 110,000. She was given information about anti-retroviral therapy and was asked to begin treatment with lamivudine/zidovudine (Combivir) and efavirenz (Sustiva).

When asked if she understood the dosage and side effects, she nodded her head in agreement that she understood. When asked if she had a support system among family members or friends, she said, “They do not know.” When questioned by the health care professional when, or if, she would disclose this information to her family, she responded, “I am okay.” During the second visit, it was discovered that she was not adhering to the regimen. Her viral load was increasing and her T-cell count was declining.

### ***Discussion Questions***

1. How could the health care professional be more culturally sensitive?
2. What intervention, if any, would you implement regarding support for this client?

## **CASE SCENARIO 3**

Carol, a 35-year-old woman of African descent, comes to the clinic for a follow-up visit after having an HIV test. Upon receiving her results through the post-counseling interview, it is discovered that Carol is really Carl, a 35-year-old man who has recently been released from prison. Further discussion reveals that Carl participated in receptive anal sex while he was incarcerated. Upon asking him his sexual orientation, he insists he is heterosexual and goes on to explain that now that he is HIV positive he can never return to his native country in the Caribbean because of the stigma attached to HIV/AIDS. He gives a series of expressions in Patois that would be used to describe a person like him and what would be done to such a person. Clearly, Carl is dealing with a series of issues that may pose a challenge to the health care professional.

### ***Discussion Questions***

1. As a health care professional, what can you do to increase your understanding of this patient’s culture so that you can get this patient into treatment?
2. How can you find out the meaning of the Patois expressions to better understand this patient’s issues and provide appropriate medical care?

## CASE SCENARIO 4

Mr. J, a 43-year-old man of Caribbean descent, has been HIV-positive for the past five years. He has kept his diagnosis a secret from his family, including his wife and two sons, and his friends and co-workers. During his last visit, his physician explained that his viral load has continued to increase and his CD4 count has dropped from 550 to 300 during the past three months, despite treatment with antiretroviral medications. He is disappointed. The patient asked whether he should be taking more of the medicine he brought back from a visit to his native home. This is the first time anyone has become aware that he is taking other “medicines” in addition to those prescribed. He is convinced that this medicine, called “Strong Back,” has kept him as healthy as he has been for the past five years. He is unable to give the scientific name of the medicine and has no idea what the liquid concoction contains. He is convinced that he will die without his two tablespoons of “Strong Back” every morning and every evening.

### *Discussion Questions*

1. What is Mr. J’s most immediate need?
2. How can you help support his cultural beliefs while safeguarding his health?
3. What steps can you take to encourage Mr. J to get the support he greatly needs?
4. How do you find out the ingredients in “Strong Back”?





## VII. Conclusion

**A**lthough a cure for HIV/AIDS has not been found, neither the accomplishment of the global response to date nor future challenges should be underestimated. Cultural competence in providing care for African-American patients with HIV/AIDS is a challenge that demands clear vision, renewed strength and will, and increased resources.

In this booklet, we have offered health care professionals caring for African Americans with HIV/AIDS a model of practice—BE SAFE—to enhance their level of cultural competency. This model asserts that health care professionals begin their journey toward becoming culturally competent by:

1. Addressing overt and covert barriers to care;
2. Assessing their level of awareness and sensitivity toward African-American patients with HIV/AIDS;
3. Conducting a cultural assessment;
4. Obtaining knowledge about this cultural group; and
5. Maintaining effective clinical encounters.

We must remember that cultural competence is a journey—not a destination; a process—not an event; and a process of becoming competent, not being culturally competent.



# Glossary

**AIDS:** acquired immunodeficiency syndrome. This disorder is caused by human immunodeficiency virus (HIV) type-1 or type-2 (Jones, et al., 1999).

**African (n):** a native or inhabitant of Africa; an individual of immediate or remote African ancestry, especially indigenous peoples of black ancestry (adapted from Webster's Ninth New Collegiate Dictionary, 1999).

**African American (n):** 1. Refers to black individuals living in the United States with African ancestry. 2. Refers to individuals of African heritage living in the United States having similar experiences, cultural heritage, and ancestry of former slaves (University of Maryland, 2000). Current U.S. census data show there are approximately 36 million African Americans living in the United States, accounting for 13 percent of the nation's population. The term "African American" may also be used to designate South and Central Americans of black African descent (Encyclopedia Britannica Online, 2001).

**African-American Regions of South America:** These regions include the coastal areas of the Guianas, Venezuela, Colombia, Ecuador, Peru, most of eastern Brazil, and Northwestern Argentina. Most of these areas are not considered "black" today but are identified in regional terms. Thus, coastal Ecuadorians in general are called montuvios, coastal Peruvians criollos, and northwestern Argentines criollos or gauchos. Many African American Colombians who were designated as mulattos on colonial censuses were called mestizos on later censuses. Changes in African cultural identity were facilitated by the rapid adoption of European religion and language in slave populations (Encyclopedia Britannica Online, 2001).

**Afro-American:** an American of African and especially of black African descent (adapted from Webster's Ninth New Collegiate Dictionary, 1999).

**Biocultural ecology:** scientific field that identifies biological variations in disease, health conditions, and drug metabolism.

**Cultural competence:** “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations” (Cross, et al., 1991).

**Culture:** the shared traditions, customs, beliefs, history, values, norms, and behaviors that provide a group with a framework for:

- Defining themselves individually and collectively
- Interpreting their reality and events
- Setting a psychological orientation towards life

Determining how one responds to, influences, and is influenced by people, events, circumstances, and conditions in one’s environment.

**Diaspora (n):** a historical dispersion of a group of people deriving from similar origins, i.e., the African Diaspora includes African Americans, Africans, Caribbeans, Afro-Russians, Black Brazilians, Afro Latinos, etc. (University of Maryland, 2000).

**Diversity (n):** tends to recognize the distinctiveness of the pattern of beliefs, traits, dispositions, and behaviors that are traditionally or generally considered to characterize an identifiable group.

**Ethnic (adj):** of or relating to races or large groups of people classed according to common traits and customs; a member of an ethnic group; especially a member of a minority group who retains the customs, language, or social views of his or her groups (Webster’s Ninth New Collegiate Dictionary, 1999).

**Ethnicity:** refers to a population’s or group’s common cultural heritage, as distinguished by such characteristics as norms and customs, language patterns, and values and beliefs.

**Linguistic competence:** Providing readily available, culturally appropriate oral and written language services to limited English proficiency (LEP) speakers through such means as bilingual/bicultural staff, trained medical interpreters, and qualified translators.

**People of color (n):** a term used to describe all non-white racial or ethnic groups (University of Maryland, 2000).

**Pluralism:** refers to the broad differences, similarities, and inequalities of experience, beliefs, values, and practices among various groupings within the broader society.

**Race:** 1. a local geographic or global population usually distinguished by genetically transmitted physical characteristics (adapted from *The American Heritage Dictionary of the English Language*. Fourth Edition, 2000). 2. A group of people united or classified together on the basis of common history, nationality, or geographic distribution: the German race.

**Subculture (n):** an ethnic, regional, economic, or social group exhibiting characteristic patterns of behavior sufficient to distinguish it from others within an embracing culture or society (Webster's Ninth New Collegiate Dictionary, 1999).

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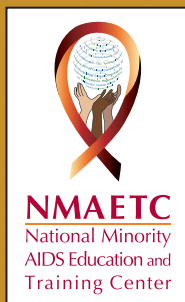
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National Minority  
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Supported by a grant from HRSA HIV/AIDS Bureau,  
Health Resources and Services Administration  
HRSA Grant No. 6U 69 HA 00039 03

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