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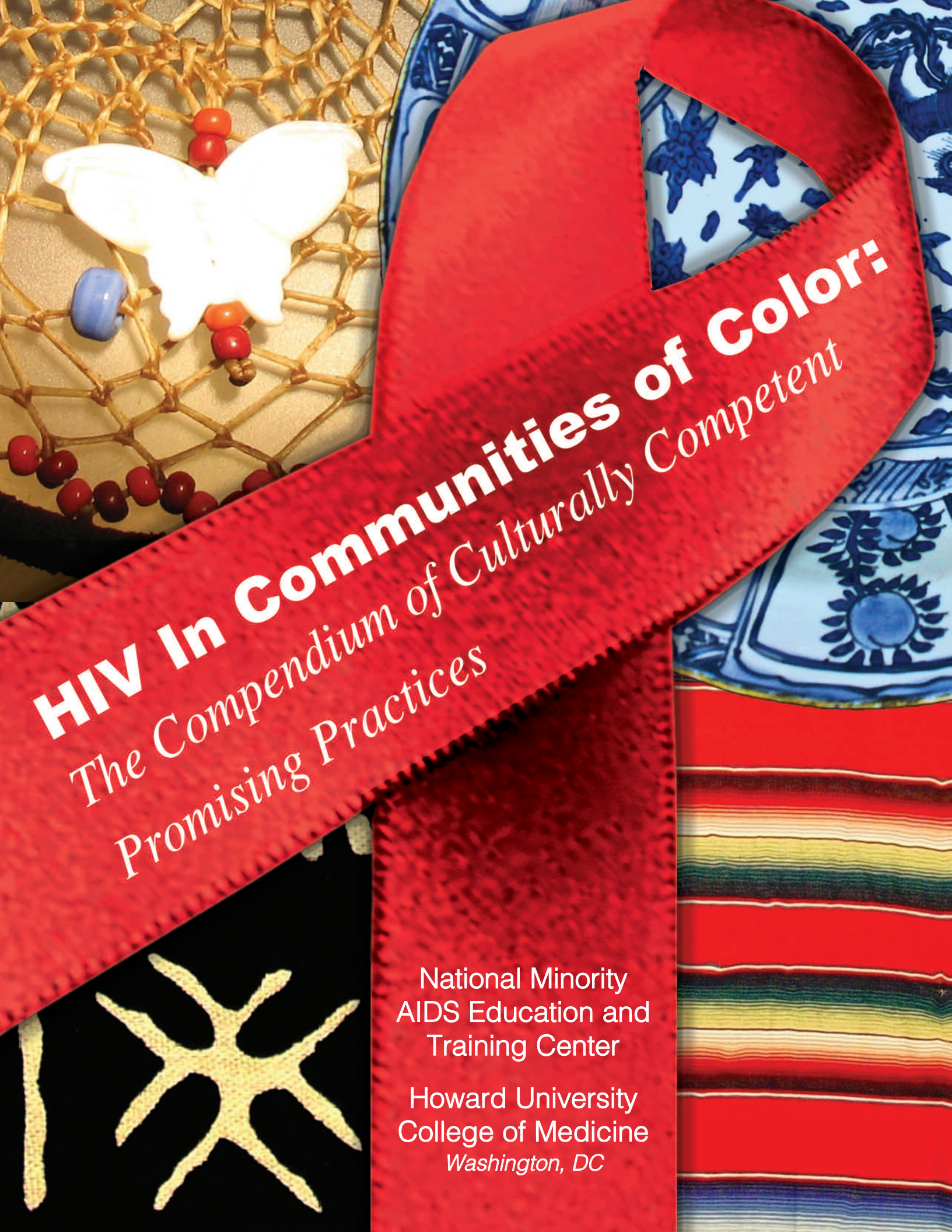
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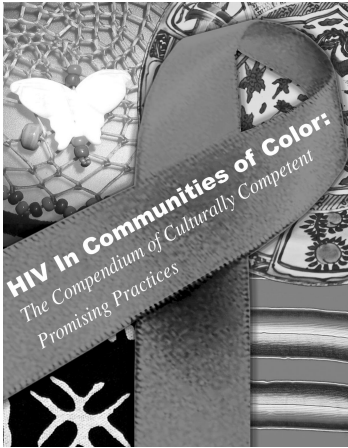
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HIV In Communities of Color:
*The Compendium of Culturally Competent
Promising Practices*

National Minority
AIDS Education and
Training Center

Howard University
College of Medicine
Washington, DC



HIV in Communities of Color: A Compendium of Culturally Competent Promising Practices

National Minority AIDS Education and
Training Center

Howard University College of Medicine
WASHINGTON, DC

GOULDA A. DOWNER, PHD, RD, LN, CNS
EDITOR

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CONTRIBUTORS

Donna Baird, PhD
University of Maryland University College
College Park, MD

Ricardo Caldera, MD
Howard University Hospital
Washington, DC

Jean Davis, PhD, DC, PA
Charles Drew University
Los Angeles, CA

Terence I. Doran MD, PhD
University of Texas Health Science Center at San Antonio
San Antonio, Texas

Goulda Downer, PhD, RD, LN, CNS
Howard University College of Medicine
Washington, DC

Ann Drobnik, MPH
Northern Plains Tribal Epidemiology Center
Rapid City, SD

Faria Farhat, MD
Howard University College of Medicine
Washington, DC

Mohamed Kanu, MA, MPH, PhD
Tennessee State University
Nashville, TN

Alawode Oladele, MD, MPH
Global Initiative for the Advancement of Nutritional Therapy
Atlanta, GA

Steven Tierney, Ed.D. CAS
Former Director San Francisco AIDS Foundation
San Francisco, CA

Laurine Thomas, PhD
Howard University College of Medicine
Washington, DC

Irene S Vernon, PhD and Pamela J. Thurman, PhD
Colorado State University
Fort Collins, CO

María Luisa Zúñiga, PhD and Estela Blanco, B.A.
University of California, San Diego School of Medicine
San Diego, CA

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We also wish to recognize the healthcare providers who serve Communities of Color and give tirelessly of their gifts and talents.

Introduction

The National Minority AIDS Education and Training Center (NMAETC) at Howard University College of Medicine is pleased to present this collection of materials as a valuable addition to the tools available to improve quality of care for minorities and help to prevent the spread of HIV in minority populations.

The NMAETC is involved in a number of cultural competency training, preceptorship, and capacity building activities to improve clinicians' knowledge and skills when working in cross-cultural environments. During its years of operation, the NMAETC has worked to improve HIV-related health outcomes for racial and ethnic minority communities disproportionately affected by HIV/AIDS. Our multi-pronged approach, which consists of Clinical Delivery, Cultural Competency and Infrastructure Management, has been deployed to focus our efforts on increasing the number of clinicians and community-based providers and on providing best HIV care practices using culturally appropriate clinical management models. Our clinical trainings are further used to expand the pool of HIV service providers who are willing and able to provide best care practices using culturally appropriate models.

Several national and local efforts continue to further the development of the field of cultural competence in the United States. The 2002 Institute of Medicine Report, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," included specific recommendations for the health-care system to pursue pertaining to the field of cultural competence as part of a multi-level strategy to reduce racial and ethnic disparities. Other national efforts, such as the U.S. Department of Health and Human Services Office of Minority Health's National Standards for Culturally and Linguistically Appropriate Services in Health Care, has provided a fundamental framework to assist and encourage health care providers to respond with sensitivity to the needs that culturally diverse patients bring to the health encounter.

In supporting the advancement of the field of cultural competence in HIV/AIDS care, the NMAETC launched, in March 2008, the first of a series of annual symposia to bring together renowned clinicians, cultural competency experts, policy makers and healthcare providers who work with minorities diagnosed with HIV/AIDS. The theme of the first symposium was, "HIV and Minorities: Cultural Competence and the Quality of Care." In recognition of the vital role cultural competency plays as a core component of quality health care, the NMAETC has chosen to publish this manual **HIV in Communities of Color: A Compendium of Culturally Competent Promising Practices**. This compilation is one of the outcomes of the 2008 symposium.

The collection encompasses a broad body of knowledge and expertise. It documents a group of initiatives undertaken nationwide to help providers optimize the services they render to minority patients. Case studies included in this compendium represents culturally appropriate service delivery practices that cover a variety of different issues, ranging from practices that promote preventive behavior to programs that maximize treatment outcomes for minorities disproportionately affected by HIV disease. Case studies were submitted by the symposium presenters using a template designed by the NMAETC to assist the authors in assembling and submitting their narratives.

For the purpose of this publication, the term “promising practice” is defined as, “a model, program or activity with at least preliminary evidence of effectiveness in small-scale interventions or for which there is potential for generating data that will be useful for making decisions about taking the practice to scale and generalizing the result to diverse populations and settings.” The term “promising practice” is in itself an acknowledgment that if it underwent a rigorous process of evaluation and validation, these practices could help us learn some lessons and perhaps show a potential for replication.

A panel of experts who reviewed and selected the case studies developed a set of five criteria for evaluating the proposed practices and determining whether or not they should be included in the compendium. Each proposed practice was required to meet a minimum of three of the following criteria in order to qualify as a promising practice:

1. Consistent and prolonged implementation
2. Suggested effectiveness in addressing the group identified
3. Successful use by at least one organization
4. Limited data to support the establishment of benchmarks
5. Potential for reliability

The purpose of this compendium is to help organizations and individuals expand their cultural competency skill set, particularly, with respect to, high risk and hard-to-reach minority populations. We trust that you will extract the lessons for yourselves and disseminate them, thus becoming an agent of change within your own community.



Irene S. Vernon, Ph.D. and
Pamela J. Thurman, Ph.D.

HIV/AIDS: Providing Care to American Indians/Alaska Natives (AI/AN) Women

“Whether an urban or reservation AI/AN woman, culturally common characteristics include a belief in traditional tribal ethics that consists of respect, appreciation and honoring of family and community and an understanding of the need for balance, reciprocity and obligation. These tribal ethics guide both individual and community reasoning and life.”

BACKGROUND

American Indians/Alaska Natives (AI/AN) women are a unique subgroup with unique histories and socio-economic conditions that place them at high risk for contracting HIV/AIDS. Historically, women held egalitarian positions in their communities. They had the right to choose marriage partners, divorce, own land, and property. In essence, they had the power to make their own decisions, choose their own destinies as well as guide the future of their tribal nations. Today, however, many are part of a silent and marginalized group, relegated to dependency on male partners. And although elements of traditional standing are found in the lives of many contemporary AI/AN women, like other women in the U.S., AI/AN women have less economic, social, and political power than men. This impacts every facet of their lives, particularly their health. They are especially vulnerable to HIV and related ailments due to high rates of sexually transmitted diseases and substance abuse. When this is combined with the multiple facets of poverty (i.e. poor quality care, unemployment and violence), stigma, and distrust of the medical systems, the risk for HIV infection is vastly increased.

DESCRIPTION OF BEST PRACTICE

To provide effective prevention programs for AI/AN women, it is important to have:

- comprehensive understanding of their historical roles within their respective societies as well as the evolution of current roles and responsibilities, and
- knowledge of their lack of trust in health care providers, and an in-depth awareness of the socio-economic conditions in which they live.

LEVEL OF INTERVENTION

Community-level, both urban and reservation.

PROSPECTIVE USERS OF THE PRACTICE

Any agency or individual working with AI/AN) women, including but not limited to Capacity Building Organizations (CBO's) staff, caregivers, trainers, state health departments, domestic violence shelters, social workers, doctors, women's centers, substance abuse programs, clinicians, etc.

PROBLEM ADDRESSED

There is a serious dearth of information on AI/AN women and HIV/AIDS. Consequently, this group is not receiving the care or services that address their specific health and social needs and concerns. There is also clear misunderstanding of the histories and cultural ways of these women, as well as current socio-economic conditions that place them at high risk of contracting HIV.

PURPOSE OF BEST PRACTICE

An improvement and increased development of new prevention, care and services for AI/AN women that will address their unique histories, cultures, and socio-economic circumstances in a comprehensive and culturally specific manner.

CONTEXT

The increase of HIV/AIDS among women is quite alarming. In some major cities AIDS is the number one cause of death for African-American women, ages 25-44.² This is a warning sign to those who work with AI/ANs, because the factors that place African-American women at risk are similar to those that place AI/AN women at risk. These include high rates of sexually transmitted diseases, substance abuse, and poverty – all of which promote the transmission of HIV/AIDS. Reports have shown that, between the years of 2001-2004, the number of cases for AI/AN women increased even though it decreased among White, Black, and Hispanic women.²

A major factor that places AI/AN women at risk for HIV is their high rates of sexually transmitted diseases. For example, after a syphilis outbreak in 2004 in a southwest community, the American Indian rate was 18.6 per 100,000 compared to the U.S. overall rate of 3.2.³

Poverty, another risk factor, has been shown to result in greater onset of disease and infection or vulnerability to it. Poverty for AI/AN women, in part, stems from the lack of employment, geographic isolation, low wages, gender inequality and low educational attainment. Substance abuse has been well established as a risk, and when combined with poverty, increases the vulnerability for women.³

Disturbingly, “AI/AN females and adolescents have shown high rates of substance use and AI/AN urban women report having engaged in more risky sexual behaviors than AI men.”⁴

Another major co-factor that places AI/AN women at risk is the high rate of violence that they regularly encounter. It has been found that women at high risk for domestic violence are demographically similar to women at risk for HIV infection and that AI women who have been sexually assaulted are known to engage in sexually risky behaviors such as having multiple partners, not using condoms, and engaging in substance abuse.⁵

The history of mistrust that AI/AN women have of the government and health providers often prohibits many of them from seeking diagnosis, assistance,

and medical attention. The distrust is due to a historical legacy of deliberate introduction of disease as well as sterilization abuses among AI/AN women. To reach AI/AN women effectively, it is vital that trust is built and that the health care providers must be provided with a cultural, historical, and socio-economic understanding of the community so that prevention models will respond to the multi-faceted needs of AI/AN women in a culturally and gender appropriate manner.

REQUIRED RESOURCES

The most important resource needed to address the needs of AI/AN women successfully is the active participation of the AI/AN people themselves. However, to utilize this resource, one must build a relationship based on trust, respect, and open communication. The relationship must, over time, include tribal members, health agencies and providers, women of all ages, tribal council members, and other leaders, both formal and informal. Since much of Indian country lacks resources, it is always important to collaborate with other health related groups, particularly since there are competing health priorities.

STEPS TO IMPLEMENT BEST PRACTICE

It is well established that knowledge is power, therefore the first logical step is to garner knowledge of the community where services, care, and prevention programming will be implemented. There are over 560 federally recognized tribes. Each has its own specific language, ceremonies, histories, health service systems, and socioeconomic conditions. It is of the utmost importance to understand the existing community dynamics. The next step is to build a relationship that is long-lasting and enduring. There may be a need to develop tribal resolutions or memoranda of understanding in order to work in Indian country. The relationships created will help in establishing these necessary documents.

BESAFE – Barriers to Care

- **Mistrust of the medical system**, due to the legacy of the introduction of diseases and the sterilization abuse of AI women.
- **Concern about the lack of confidentiality** which exists in many communities. Breaches of trust continue to be major barriers to requesting and obtaining educational materials and safe sex tools (e.g., condoms, dental dams, etc.), and to seeking care and treatment.
- **A high rate of poverty** is another barrier to quality of care, with data citing that 20 percent of AI women compared to 9 percent of white women are living in poverty.⁶
- **A high rate of violence is** one of the most significant barriers for AI/ANs to seeking care. Women are found to be twice as likely to experience a rape/sexual assault (5 per 1,000 ages 12 or older) compared to all races (2 per 1,000).⁷
- Lack of **specific programs** that are both culturally competent and responsive is a highly significant barrier to quality care.
- Language differences among the, 560 federally recognized tribes as well as those tribes that are not federally recognized.

BESAFE – Ethics

Whether an urban or reservation AI/AN woman, culturally common characteristics include a belief in traditional tribal ethics that consists of respect, appreciation and honoring of family and community and an understanding of the need for balance, reciprocity and obligation. These tribal ethics guide both individual and community reasoning and life.

BESAFE – Sensitivity of the Provider

Mainstream society often has romantic notions or stereotypes of the lives of AI/AN women. Providers need to know the reality about their cultures and be comfortable working in their communities in order to be effective. Further, there must be a level of acceptance of the providers' presence in the AI/AN circle. With the vast diversity of religion, language, and culture, it is important for providers to immerse themselves in the culture – they must study the history and the specific tribal culture in which they will be working; they must respectfully participate in cultural activities; develop relationships with tribal members; and finally, learn the tribally specific cultural protocols, rituals, ceremonies, customs and respectful attitudes. Cultural values of both provider and patient must be examined in order to successfully and sensitively engage in effective prevention programming.

BESAFE – Assessment

Providers must respectfully collect relevant data regarding patient health history and problems in the context of their cultural background. Each provider must assess his/her own cultural fluency if he/she hopes to work effectively with AI/AN women.

BESAFE – Facts

In Alaska, AN women over the age of 15 years, comprise 40% of the State's HIV/AIDS cases yet, these women represent only 16% of the State's population.¹

The main transmission of HIV for female adults and adolescents is high risk heterosexual contact (47%) followed by injection drug use (27%) and sex with injection drug users (14%).¹ When the percentage of injected drug use and sex with a drug user are combined, a disturbing 41% transmission rate results and, a dire correlation emerges between substance abuse and HIV/AIDS.

AI/AN women have lower earnings than White women. Nationally, annual income for full-time year round work for White women is \$30,900 compared to \$25,500 for AI women. The STD rates among AI women vary from area to area but overall, in 2004, they had the second highest rates of Chlamydia, gonorrhea and syphilis.

BESAFE – Encounters

It is always important to determine the level of comprehension in the English language and arrange for an interpreter, if needed. In addition, the level of health literacy is important. Often, providers forget or overlook asking the patient and family members how they would prefer to be addressed. Native people tend to build a sense of comfort and trust slowly so allowing the time for that is important. Time is always a factor for the provider, which often prompts them to, "get right to the topic." However, for Native people, this is a sure way to exhibit a lack of respect. Equally disrespectful would be talking

loudly, interrupting the speakers and attempting to over step the boundaries of a familiarity that has not yet been earned. Do not be afraid of silences. Respect is a key element, as is patience, and the ability to listen to what the patient is saying. In fact, important information may come in the form of a “story” about the family that may, initially, appear to be unrelated. However, the telling of stories is an important venue for many cultures and especially for the Native culture. Some Natives shy away from eye-to-eye contact. Further, some do not like firm, hard handshakes or invasion of personal space. Make an honest effort to learn the individual’s preferences as well as the norms of the community.

CHALLENGES

One challenge that may arise from attempts to implement a “best practices” could include lack of attendance at events, training, appointments, etc. This may not be entirely due to a lack of caring or interest, but to the “readiness” of either the individual or the community to address HIV/AIDS. Other barriers include lack of trust; concerns about confidentiality; turnovers in tribal government; tribal health board activities; transportation/gas; childcare; and lack of funding and personnel.

IMPACT

The development of community-based, participatory services can lead to a number of positive impacts, including the implementation of effective interventions; an increase in HIV/AIDS education/prevention efforts within the community as well as the providers who serve them; an increase of resource collaborations; a reduction in HIV/AIDS among women; and improved community health in general. A negative impact could be a complete refusal of communities to participate if they are not treated respectfully, ethically, in a manner that is not culturally responsive, and unprofessionally.

CRITICAL ISSUES AND LESSONS LEARNED

Many tribes have their own Internal Review Boards (IRB) or Research Committees (RC). Consequently, working within communities has become very difficult. There are strong historical reasons for the creation of these IRBs. It is a matter of record that most tribes have been exploited, taken advantage of and have had research conducted unethically, without their consent and without any sense of responsibility to the community.

Unfortunately, these occurrences are not all in the distant past. It is therefore vital that persons working within a tribal setting present themselves humbly and respectfully. Most tribes prefer that those who come to work within their communities are Native themselves. It is important that one never enters a community as an expert but as a partner.

Each community brings a wealth of ideas and information that outsiders would never know or understand, even after having been involved with a particular group for a while. As for Native women, specifically, it is important to recognize that when asking them to attend workshops, meetings, etc. that there is an expectation of the provision of food for an all day or half day event and perhaps even providing childcare and transportation reimbursement. Native women are the bearers of their culture and the concept of “family” is very important. Providers entering a Native community should recognize, as well,

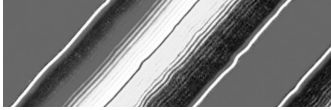
that they are entering a sovereign nation and as such, should enter as guests who are willing to listen and learn.

CONTACT INFORMATION

Colorado State University, Fort Collins, Colorado

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Ricardo Caldera, MD

HIV/AIDS: Providing Care to Latino Communities

“Cultural and linguistic competent providers that proactively engage with the Latino community seem to have a greater impact for reducing HIV-related disparities in this group.”

BACKGROUND

The Latino population in the United States is one of enormous diversity in terms of nationalities, cultural practices, educational levels and even in perceptions about the causes of health problems and treatment protocols. Linguistic and cultural barriers, low health literacy rates, poverty, lack of health insurance, and immigration issues account for only a few of the factors that make Latinos vulnerable to HIV infection^{1,2}. A vast majority of recent immigrants and first generation Latinos live in poverty and are more likely to be uninsured or underinsured, compared with White and Black Americans, thus preventing them from seeking proper and timely medical care³. Anti-immigration sentiment and an often non-inviting political climate have caused Latinos to distrust the U.S. government and their institutions. All these challenges paired with distinct patterns of healthcare seeking behaviors prevalent among Latinos, constitute an intertwined fabric of factors requiring close examination when addressing the needs of this group in regards to HIV/AIDS-related services. A growing body of research and practice on healthcare access and utilization indicates that community based organizations serving Latino communities may be well positioned to provide linguistic and culturally competent HIV/AIDS services.^{1,2}

DESCRIPTION OF BEST PRACTICE

The Latino population in the United States differs depending on the region where they settle, length of stay in the country, levels of acculturation, and English proficiency. It is imperative that HIV/AIDS best-practice strategies include recognition of the different cultural and ethnic backgrounds and incorporate them into their programs. Additionally, cultural and linguistic competent providers that proactively engage with the Latino community seem to have a greater impact for reducing HIV-related disparities in this group.

LEVEL OF INTERVENTION

- Community-based organizations (CBO)
- Clinics
- Hospitals
- Churches

PROSPECTIVE USERS OF THE PRACTICE

- CBO staff (administrators and care providers)
- Community clinic staff (administrators and care providers)
- Hospital staff (administrators and care providers)

PROBLEM ADDRESSED

Lack of culturally competent services for prevention, early diagnosis, and treatment of HIV infection among Latinos.

PURPOSE OF BEST PRACTICE

To promote a culturally and linguistically competent program that includes HIV testing, prevention, support, and health care with service delivery that reduce multiple barriers (i.e. financial ability, and medical insurance) often experienced by Latinos seeking assistance to address their health care needs.

CONTEXT

The lack of proper and timely healthcare constitutes one of the major challenges faced by Latinos, the largest and fastest growing minority group in the United States. Additionally, significant numbers lack English proficiency. This often prevents them from seeking medical care, and when they do, it is difficult to find providers who speak their language. Studies have shown that language barrier between provider and patient adversely impact healthcare outcomes ^{4,5,6,7}.

Furthermore, Latinos come from different cultural and educational levels, and many of them exhibit low levels of health literacy, hindering them from seeking preventive services and medical care. Many live in poverty and most are uninsured or underinsured. For undocumented immigrants who are infected with HIV/AIDS, the situation is more challenging because of the added fear of deportation.

REQUIRED RESOURCES

- Community lay health advisors who will help clients learn and navigate through the HIV healthcare system.
- Culturally and linguistically competent curricula to provide education, prevention, testing, and referral to care services.
- Strategies to increase awareness of the importance of creating Latino-friendly environments at participating CBOs.
- Provider training curriculum to promote the highest standards of culturally competent care at medical clinics serving Latinos.

STEPS TO IMPLEMENT BEST PRACTICE

Collaborate with existing medical clinics in developing a community-based HIV/AIDS education program will encourage Latinos to seek medical services. Reaching out to churches, radio stations and other media will help these programs grow and stay active. Persuade providers to make a commitment to learn about the Latino community will promote not only the programs but, most importantly, support Latino patients to access and remain in care.

**BESAFE –
Barriers to Care**

Language is probably the biggest barrier to accessing care services for Latinos. Anti-immigrant attitudes and fear of deportation can also prevent Latinos from receiving the adequate attention and services needed for HIV prevention. Lack of trust in providers decrease the chance of patients disclosing their status and adherence to medical treatment.

BESAFE – Ethics

Providers should provide their patients with accurate information necessary to make informed decisions. Healthcare workers should provide resources and literature including interpreters for non-English speaking patients, in the patients’ primary language thereby ensuring respect for a person’s right to make his or her own decisions. Latino patients should be treated equally regardless of race, sex, language, sexual orientation, religion, health status, and most importantly legal status. They should have the option to take an anonymous or confidential HIV test; and should be informed about the differences between the tests.

**BESAFE –
Sensitivity of the
Provider**

Healthcare providers should explore their own cultural beliefs. They will be more likely to provide culturally sensitive services if they are adequately trained with the skills and knowledge needed to work with Latinos. Becoming culturally sensitive is a conscious process. Avoiding assumptions regarding cultural beliefs and values is a suitable approach to understanding Latino patients’ needs. Finally, spending enough time with the patient to understand their cultural values has an enormous potential for improving patients’ trust.

BESAFE – Assessment

Providers should collect relevant information regarding patients’ medical history in a culturally sensitive way. Healthcare workers should use a systematic appraisal approach with every patient. Patients’ perception of their medical problems and treatments provided by traditional healers should be discussed in a non-judgmental way. Providers should respect patients’ spiritual beliefs and where possible, support those recommended treatments by the traditional healer that do not adversely affect the patients’ health. Providers must explain and negotiate with patients, the treatments recommended.

BESAFE – Facts

It is common among Latinos to believe that they have little control over diseases. This cultural construct is referred to as fatalismo, which consists of examples such as considering HIV to be Gods’ punishment. In addition, family participation has shown to increase adherence to medical visits and treatment. Providers should welcome the participation of family members and their willingness to assist the patient. Latinos expect humility from healthcare providers; arrogant providers will not gain their trust.

Prayers and the use of folk medicine and traditional healers such as (curanderos, sobadores, etc.) are viewed by Latinos as complementary to medical care. Providers should become familiar with these practices and discourage use of remedies that are proven to be harmful. Latino males are traditionally characterized by their “strength and bravery” or machismo, which may pre-

vent them from seeking medical care until they are very sick, thus increasing their chances for late diagnosis and treatment for HIV infection. On the other hand, women's role as primary care givers in the society makes them more likely to seek medical care.

BESAFE - Encounters

During the first encounter, the healthcare provider should make every effort to determine the patient's level of acculturation, often times correlated with English proficiency and length of stay in the country.

Making eye contact with Latino patients is important since it conveys a sense of respect, and a friendly smile will help to make the patient feel welcome and accepted. Shaking hands when the medical encounter begins and at the end of the interview will also contribute to the process of building trust. Latinos feel that the provider shows respect when they address the patients as Mr., Ms., or Mrs. followed by the last name.

Questions to a recent immigrant regarding immigration status should not be asked since this may break client trust.

Family members or friends should not be used as interpreters; rather trained interpreters should be the only option for providers who are not proficient in the patient's native language.

It is also important for the provider to find out if the patient has close extended family since family is often a very important source of support – although in some instances it may be a source of stress.

CHALLENGES

Latinos face unique challenges for HIV testing, prevention, care, and treatment. Among the most salient are language barriers, cultural beliefs, levels of acculturation, medical insurance, and financial situation. The significant diversity within the population in the U.S. is an important challenge when it comes to understanding the intertwined nature of these differences.

IMPACT

Incorporating the common elements of Latino culture and establishing the necessary differences when designing and implementing an HIV program for specific groups may improve the cultural competency of HIV programs. Cultural competency among healthcare providers has tremendous potential for increasing timely access to services, thus reducing the rate of late diagnosis, the onset of co-morbidities, and ultimately reducing the number of deaths in this population.

CRITICAL ISSUES AND LESSONS LEARNED

As a provider, not having any preconceived notions of the patient is of paramount importance. Learning about the patient, while at the same time implementing what was learned in the program, will create a solid relationship between the provider and the patient. Educating patients to become knowledgeable about the disease process and to make informed decisions regarding their health will create a strong long-lasting bond between patient and provider.

CONTACT INFORMATION

Howard University Hospital, Washington, DC

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Terence I. Doran MD, Ph.D.

HIV/AIDS: Providing Care to Adolescents

“Comprehensive, culturally sensitive training in the unique issues associated with adolescents who are HIV positive or at risk, including cognitive, developmental, physical and mental health issues, will assure that the special needs of this population are addressed. All of the issues related to testing, diagnosis and treatment of HIV and STDs are different in adolescents, and the training should reflect this.”

BACKGROUND

Approximately 50% of new HIV cases in the United States occur in individuals below 25 years of age.¹ Adolescence is distinct from “teen” in that it is a time when young people are experiencing physical, cognitive, developmental and social changes which impact decision making. This may start before they are teens, and extend into their 20s. Adolescents often have the same risk factors for HIV as adults, including unprotected sexual intercourse and use of illicit drugs which may put them at increased risk. They engage in such “adult behaviors”, often without the emotional or cognitive skills to recognize or avoid the associated dangers. Adolescents typically have characteristics of language, dress, music, behaviors, and thinking which separate them from adults or children. Hence, they can be viewed as a culture or subculture within the larger cultures in which they exist. Thus they may be a subculture within American culture as a whole, as well as ethnic, urban-rural, migrant, same sex, etc. A positive HIV status further separates people in this age group from peers and the major culture(s) from which they come. Clinicians should approach adolescents as members of a culture in which they are somewhat familiar, but in which they are not part, and, at best, can attempt to gain some competence in understanding and being respectful of aspects of culture with which they might not understand or agree.

DESCRIPTION OF BEST PRACTICE

Adolescents belong to a subculture within other dominant cultures.¹ It is necessary for clinicians, case managers, social workers, pharmacists and other professionals dealing with this age group to become familiar with this unique population and to approach them as they would any other distinct group.

LEVEL OF INTERVENTION

Community Based Organizations (CBOs) or clinics serving adolescents and young adults with sexually transmitted infections, onset of mental health issues, alcohol use, substance use, and/or pregnancy in which HIV testing is applicable. Part of the training is also to recognize that practices which are applicable to adults and younger children may not be applicable to adolescents.

**PROSPECTIVE
USERS OF THE
PRACTICE**

Physicians, dentists, nurses, nurse practitioners, physician assistants, pharmacists, social workers and case managers of local CBOs and clinics providing adolescent health care.

**PROBLEM
ADDRESSED**

Failure to recognize and appropriately address the unique cultural needs of adolescents.

**PURPOSE OF
BEST PRACTICE**

Comprehensive, culturally sensitive training in the unique issues associated with adolescents who are HIV positive or at risk for the disease, including cognitive, developmental, physical and mental health issues, will assure that the special needs of this population are addressed. All of the issues related to testing, diagnosis and treatment of HIV and STDs are different in adolescents, and the training should reflect this.

CONTEXT

Approximately half of all new HIV cases are acquired in the adolescent years. Language, dress, music and other aspects of their culture differ from the broader societies from which they come. In addition, adolescents often have not completed their education, acquired abstract reasoning skills, and may have nebulous concepts of the link between behaviors and consequences. They are often not forthcoming with information, use terms that are unique to their age group, and feel alienated from adults and peers after acquiring HIV. Self esteem may be poor and mental health issues such as depression, behavioral disorders and psychotic illnesses often begins to appear in this age group.²

**REQUIRED
RESOURCES**

Community based organizations, juvenile detention centers and clinics working with high-risk or HIV-infected adolescents should be approached about training in the unique culture and issues of adolescents. Clinics need clinicians, case managers and staff who are trained in the unique needs of adolescents with chronic diseases.

**STEPS TO IMPLEMENT
BEST PRACTICE**

An initial training on adolescent cognitive development, physical changes of puberty, the impact of substance use and abuse, and sexual development and mental health issues, should be followed up with presentations and workshops on:

- Populations of teens with HIV,
- Impact of cognitive development,
- Impact of substance use and abuse on HIV acquisition and treatment,
- Problems in adherence among adolescents with chronic illnesses, and
- Related issues such as pregnancy, STDs, adolescent education and employment, support systems and other issues which relate to success in care.

BESAFE – Barriers to Care

Cognitive development and education are major barriers to adolescent understanding of their disease and to long term successful care. Distrust of authority figures and feelings that there is no “home” for their care are important issues. Transportation and health insurance are often real issues, more so when adolescents have not disclosed their status to family or friends. Scarcity of clinicians willing and competent in the care of adolescents, especially those with HIV, is a barrier in systems designed to deal with adults and children, but not the gray zone in-between. Finally, sexual orientation and sexual identity issues can be overwhelming in individuals who are just recognizing their own sexuality. As well, the overlay of ethnicity, rural-urban issues, legal issues, developing mental health and substance abuse problems, and sometimes language and isolation can have major impacts.

BESAFE – Ethics

The adolescent population presents unique issues in medical and legal ethics particularly as it is linked to consent. Legal age for consent varies by state. Similarly, in some states, teens below the age of 18 may legally be tested and treated for HIV, STDs, pregnancy and/or substance abuse issues, but not for other medical problems. It then becomes the responsibility of the provider to become aware of these statutes and adhere to them.

Lack of parental or family support systems becomes problematic in young people who may be legally allowed to consent, but lack the emotional and cognitive ability to make some of the necessary decisions regarding their healthcare without the guidance of a responsible adult.³

BESAFE – Sensitivity of the Provider

Respect and tolerance for the adolescent patients' viewpoints is critical. This includes patients who differ from the providers by a generation or more, as well as, by language, education and perhaps ethnicity. Providers have to be willing to accept adolescents where they are and be sensitive to their viewpoints and special needs. Assumptions about adolescent knowledge of issues may mislead a provider into overly simplistic or overly complex explanations. Adolescent feedback may be minimal which may give a false impression of what is understood.

BESAFE – Assessment

A structured, complete record of medical, social, and psychological assessments should be assembled on each patient at the initial encounter. Issues such as disclosure to family members and/or friends should be assessed. Adolescents may be willing or unwilling to be treated. As difficult as it is to keep some adults on treatment regimens, adolescents may be at the extreme end of the spectrum in terms of adherence. Documentation of treatments, efforts to assure adherence and counseling aimed to improve adherence should be documented.

BESAFE – Facts

- Adolescents are in a transitional stage from concrete to abstract thinking. Some may never achieve complete abstract reasoning. Some may revert to concrete thinking during stressful periods.
- Physical and hormonal changes of puberty are important in decision making about medication doses; with those in the early stages of pubertal development needing pediatric medication doses; with those in the late (adult form) of development needing adult doses, and some which are less clear.⁴
- Mental health changes (onset of depression, bipolar disorder and schizophrenia) often occur in the teens and twenties.²
- Adolescent experimentation with “adult behaviors” including sexual activities, and alcohol/drug use and abuse may not be accompanied by good decision making such as condom use, or the avoidance of sex after heavy alcohol and drug use.
- There are legal and ethical issues that are unique to providing medical care for adolescents who are infected with STDs, who are substance abusers and who are pregnant.
- These individuals may not have disclosed their sexuality or HIV status to their families or friends, which may further isolate them during a difficult time of life.

BESAFE – Encounters

Initial encounters should allow adolescents to express fears, ask questions and explain their unique situation in a safe and welcoming environment. Talking down to them as if they are children, or talking to them with medical jargon and terminology that is beyond their level of education and cognition may cause them to avoid follow-up care. Risk factors and behaviors should be explored, often recognizing that in their own mind they may not clearly have accepted that they are homosexuals or bisexuals, transgendered, and have not yet accepted that their HIV is real. They may have erroneous knowledge of diseases, body parts and functions. These should be explored non-judgmentally. At follow-up encounters explore new issues and often re-explore previously discussed issues. Information about sexuality, numbers of partners, substance use, and related issues will frequently change as the comfort level and feeling of acceptance improve. Respect, acceptance and a non-judgmental attitude will allow the patient to gain trust in the provider and the system. Without this, the chance of success in future treatment is unlikely. Patients should be allowed to bring parents, guardians or partners to become educated and for support. Knowing when to allow such support persons to be present will depend on patient preference, and age.⁴⁻⁶

CHALLENGES

Early identification of HIV in adolescents is a significant problem. Many do not have insurance or transportation, do not recognize risk factors for disease, and do not have a medical home. When patients are identified as having HIV, getting them to a clinical program in which staff has the willingness and knowledge to work with this group is a major challenge.

IMPACT

Adolescents are members of a unique but transient culture in which they are in the midst of constant physical, emotional, cognitive and social change. Recognition of this time of life as a unique subculture will facilitate keeping patients in care and on track to a healthier adulthood.

CRITICAL ISSUES AND LESSONS LEARNED

Adolescents are not children. They are not adults. They are unique in almost every aspect of their development. They do not think like adults. They do not act like adults, even when they believe they do. Mistakes that are made at this age by the patients and providers will have long term impact on their future care. Clinicians and other care providers will only succeed when they respect the adolescents, work to understand their culture and their constantly changing knowledge and needs⁶.

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University of Texas Health Science Center at San Antonio, San Antonio, Texas

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Donna Baird, Ph.D., ACS, LCPC

HIV/AIDS: Providing Care to Adults 50 Years of Age and Older

“Older adults with HIV are more likely to be diagnosed late in the disease process, experience disease progression more quickly, and survive for a shorter period than their younger counterparts.”

BACKGROUND

In recent years the number of older persons living with HIV/AIDS has increased¹. However, details about HIV/AIDS in elderly populations are still sparse. What is known is that there is a tendency for people over 50 to not think of themselves as at risk of getting infected^{1,2}. Yet, in 2005, persons over 50 accounted for 15% of new HIV/AIDS diagnoses, 24% of persons living with HIV/AIDS, 19% of all AIDS diagnosis, 29% of persons living with AIDS and 35% of all deaths of persons with AIDS¹. Additionally, with aging come physiological changes, which increase risk for infections including HIV. Older adults with HIV are more likely to be diagnosed late in the disease process, experience disease progression more quickly, and survive for a shorter period than their younger counterparts³. For example, 37% of persons 80 years and older have been reported to die within a month of diagnosis^{3,4}. Further, studies^{5,6} have shown that physicians and other health providers have neglected to discuss sexual health with older patients. Moreover, limited empirical research has been done with this population.

DESCRIPTION OF BEST PRACTICE

This promising practice promotes HIV/AIDS testing, care and education for older adult populations. Infection among older adults has remained constant since the beginning of the epidemic. Older adults are less likely to get tested, tend to be diagnosed at a later disease stage, and appear to have a lower sense of risk than their younger counterparts. It is imperative that comprehensive prevention programs are developed and treatment services are implemented that target the needs of the older population to provide education and care that is timely and sustainable.

LEVEL OF INTERVENTION

These promising practice strategies are most feasible at the individual and community based organization level.

PROSPECTIVE USERS OF THE PRACTICE

Health professionals, care providers and senior centers.

PROBLEM ADDRESSED

- Increasing rates of HIV/AIDS infections among older adults
- Increased vulnerability of older women

PURPOSE OF BEST PRACTICE

- Lack of targeted prevention programs and treatment resource for adults 50 years of age and older
- Lack of age relevant information materials

- Improved treatment and services targeting adults 50 years and older
- Improved knowledge and awareness that result in reduction of risk behaviors
- Voluntary counseling and testing programs and partner notification for older adults

CONTEXT

It is important for agencies providing care and treatment to older adults have information about HIV/AIDS and its impact on that population. Understanding sexuality amongst older persons is critical to successful implementation of discussion groups, prevention and treatment efforts. Consideration of other health factors affecting this group and the potential for health concerns to be compounded by a diagnosis of HIV/AIDS are paramount considerations when working with adults older than 50.

REQUIRED RESOURCES

- Development of informational materials targeted for older adults.
- Focus group discussions at senior living areas.
- Highly visible and targeted distribution of educational materials at health offices, government offices on aging and organizations such as, American Association of Retired Persons, and other groups that target older adults.

STEPS TO IMPLEMENT BEST PRACTICE

Knowing a population and the nuances that impact that group is a major step to developing programs. It is important to include members of the target population when trying to develop messages and age-relevant materials. Collaborating with organizations that target older adults can make this process more efficient and cost effective. Programs should be sustainable.

BESAFE – Barriers to Care

Stigma and fear are fundamental barriers to older adults accessing treatment and care. Additionally, a lack of risk perception, basic knowledge about HIV/AIDS, and traditional values that prohibit open discussion about sexuality also serve as barriers.

BESAFE – Ethics

Transparency is vital. Clients should be included as active participants and they should be made to feel that their contributions are critical to the process. Demonstrating mutual respect and sensitivity will help to create a successful and meaningful experience.

BESAFE – Sensitivity of the Provider

The provider should be prepared to address the fears and feelings of hopelessness that are often experienced by this population. Also, understanding stigma and the myriad of issues that affect disclosure is an integral part of treatment. Showing empathy in a manner that is client-centered can communicate to the client that he/ she and the issues they face are important, and as a provider you are there to provide objective support. Maintaining confidentiality and privacy may be of utmost importance to help build trust and facilitate disclosure.

BESAFE – Assessment

During the assessment, it is vital to understand (as much as possible) about the client as a whole. Solicit information that will help to inform diagnosis and treatment. Usage of standardized questionnaires might be helpful in this process. Use of motivational interviewing skills is also a good technique to determine client perspective and to ascertain treatment goals. Be mindful that the client should be approached in a manner that puts him/her at ease, and which promotes the therapeutic process.

BESAFE – Facts

- The rate of HIV/AIDS infection among older adults is increasing.
- Many older adults do not typically exhibit sexual health seeking behaviors.
- Stigma and fear often impede disclosure and timely treatment.
- Many older adults are often in denial about their exposure to HIV/AIDS risk.
- The physiological impact of aging makes the older adult more predisposed to infections including HIV.
- Older adults tend to be diagnosed in later stages of the disease and there is increased chance of death shortly after diagnosis.
- Ethnic minorities and women are at increased risk.
- Many health professionals have neglected to provide screening, diagnosis and treatment for this population.

BESAFE – Encounters

Providers should be mindful to provide the clients with information that is simple and clear. Older adults can become easily overwhelmed with too much information. When possible, and with the permission of the client, it might be advisable to include a family member in discussions, particularly as it relates to care and management of the disease. Non-verbal body language that is open and relaxed sends the message that the provider is listening and that the concerns of the client are important.

CHALLENGES

The impact of stigma among older adults can be more severe than with the younger population, thereby deterring access to testing and care. Many older persons do not perceive themselves to be at risk for HIV/AIDS, therefore, addressing risk perception is vital. Additionally, effort is needed to restructure the thinking of health care professionals to understand, and not underestimate the HIV risk of older persons. There is a continued need to educate clinicians about HIV/AIDS and the unique medical needs of older adults. It is also important that providers be aware that some older adults engage in same sex activities and some use drugs. These pose an increased risk for exposure to HIV.

IMPACT

Providing clinics, agencies and community-based organizations with culturally relevant information to educate providers, as well as older persons may reduce risk of exposure, and promote earlier testing and treatment. Furthermore, an educated community may reduce the impact of stigma among this targeted group thus improving health outcomes related to HIV/AIDS.

CRITICAL ISSUES AND LESSONS LEARNED

Simultaneous multi-level approaches to educating and informing this population is important. Special attention to older women is important because of the sensitive body changes that increase the vulnerability of women as they age. Incorporating the total health needs of older persons can send a strong message that the well-being of the individual is important. This may contribute to building trust in a therapeutic relationship.

CONTACT

University of Maryland University College, Maryland

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Mohamed Kanu, MA, MPH, Ph.D.
and Faria Farhat, MD

HIV/AIDS: Providing Care to Muslims Immigrant Communities

“Some studies have suggested that certain beliefs and practices constitute protective factors from HIV infection for Muslims. These include monogamous relations, abstinence from sex outside of marriage, ritual washing after intercourse and abstinence from alcohol consumption, which often leads to reckless sexual acts. For these reasons, many Muslims tend to think that HIV/AIDS is not a threat to their communities.”

BACKGROUND

The Muslim religion has its roots in the Middle East, but through migration it has spread to many parts of the Western world. Census estimates the population in the United States as varying from 2.8 million¹ to 7 million². Although not traditionally viewed as such, Muslims are an ethnic minority, with many sub cultures. As with other such groups, they are a diverse heterogeneous community, representing many histories of migration, acculturation, racial identity, language, assimilation and country of origin. As their numbers increase in the United States, the cultural norms associated with this group should be understood and addressed to improve patient-provider interactions and the care that serves individuals within this faith. This is particularly so when it comes to providing HIV-related care since one approach will not fit every member.

Some studies^{3,4,5} have suggested that certain beliefs and practices constitute protective factors from HIV infection for Muslims. These include monogamous relations, abstinence from sex outside of marriage³, ritual washing after intercourse⁴ and abstinence from alcohol consumption⁵, which often leads to reckless sexual acts. For these reasons, many Muslims tend to think that HIV/AIDS is not a threat to their communities.

Although some of the extant literature affirms that Muslim religious practices can act as protectors against HIV infection, there is also available research evidence suggesting that some rituals carry the risk of infection. Examples of these include the head-shaving of male pilgrims during the annual pilgrimage to Mecca (known as Hajj), and the use of a teeth-cleaning stick (Miswak). Without proper caution, these practices constitute some risk for transmission of infection⁶. It has been reported that, during one Hajj, 25% of male pilgrims exposed themselves to blood borne infections by sharing razor blades. Even though head-shaving is not generally practiced here in the United States, Muslim residents in the country can benefit from a pre-pilgrimage seminar focusing on this topic.

These practices constitute important considerations for HIV/AIDS prevention. They underscore the need for education programs focusing on health promotion and disease prevention. Ideally, these should be channeled through mosques or other settings where Muslims regularly congregate. Further, it should not be presumed that all Muslims strictly adhere to religious practices of monogamous

relations and abstinence from sex outside of marriage³. This is especially important for teenagers who could indulge in unsafe sex practices because of peer pressure. Furthermore, data to monitor HIV/AIDS in this population in the United States are scarce. This is because most of the studies focusing on HIV/AIDS and Islam, or Muslims, have been conducted outside of the United States.

DESCRIPTION OF BEST PRACTICE

Muslims in America are a mixture of immigrants as well as indigenous individuals. While they share a common identity in the practice of their faith, there is also great variation in their cultural practices. Some of these differences are based on ethnic backgrounds or places of origin. Given this diversity, developing effective HIV/AIDS prevention programs for this population requires strategies that are rooted in sensitive cultural and religious practices. These programs must first seek to win the trust of the “leadership” of the community and try to forge collaborative networks with local mosques and other shared facilities.

LEVEL OF INTERVENTION

- Mosque
- Community-based organizations
- Clinics
- Hospitals

PROSPECTIVE USERS OF THE PRACTICE

- Universities
- Health Professionals, Care Providers
- Community based organizations
- State health departments

PROBLEM ADDRESSED

Several factors account for this, feeling among some Muslims that they are secure from the disease because their religion preaches high moral standards relating to sexual activity⁷.

Abstinence from premarital and extramarital sex are strong teachings of the Muslim faith. Some associate HIV infection with those non-religious acts. The fear of being stigmatized continues to prevent individuals from taking full advantage of clinical and prevention programs. It also makes it difficult for this community to share accurate history about risk factors and trust “others” who work with them, even if they are health professionals. There is a need to educate the American Muslim community of their vulnerability to HIV infection. Clinicians may not have enough knowledge about their patients’ culture, religious practices. The best way to obtain information from these patients is to educate them about HIV risk factors and preventive strategies.

PURPOSE OF BEST PRACTICE

Workable HIV prevention programs among Muslims will require collaboration with key partners such as family members, faith-based community organizations, religious leaders, and health professionals sensitive to their religious and

cultural practices. Testing, counseling, and referral activities will be better coordinated when significant cultural practices are adequately addressed.

CONTEXT

The Muslim community in the United States is not homogenous. It comprises foreign-born as well as indigenous Muslims. The latter group is largely composed of African Americans, while the former is an amalgamation of people from different regions of the world – Asia, Africa, and the Middle East. Andrea Elliot, writing for The New York Times in 2007 paraphrased comments from John Zogby that, the population residing in the United States is comprised of 25% African American, 34% South Asian and 26% Arab⁷. Because of this diversity, it is important to stress that recommendations for dealing with HIV/AIDS issues must take into consideration religious characteristics as well as cultural variations.

This best practice guide is focused mainly on immigrant Muslims residing in the United States. This is because some of the practices that have been highlighted are prevalent in their countries of origin. The use of the Miswak, for example, is unlikely to be found among indigenous Muslims.

The availability of health insurance or the lack of it is critical for improved health outcomes. This compounds existing problems of language barriers, among others, such as limited economic resources.

REQUIRED RESOURCES

- The most important resource in working with this community is trust. Establishing trust in this community requires time and serious commitment to understand Muslim perceptions and values.
- Since many members of the community are often recent immigrants, they may not fully understand how to work within the system to access health related resources. Therefore, HIV/AIDS prevention experts need to understand this limitation and exercise patience and caution in providing services that are not considered demeaning to clients.
- The “leadership” is typically highly regarded and their involvement is critical to mobilizing the community to address HIV-related concerns.

STEPS TO IMPLEMENT BEST PRACTICE

Gaining entry into this community through linkages made with trusted and vested leaders is the first step. The mosque, which is the hub of the Muslim community, may provide a trusted platform for patients to obtain information about HIV prevention and management. Muslim health professionals and members of the health committees within the mosque is a viable approach to gaining entry into the Muslim community. Many mosques have community outreach programs for youngsters as well as adult Muslims and non-Muslims alike. These mosque-based programs, as well as other community outreach events, can be leveraged to reach the Muslim community.

**BESAFE –
Barriers to Care**

Findings of a recent survey, indicated that Muslims show much empathy to colleagues with HIV/AIDS⁸. While a majority is empathetic, some perceive the infected person to be noncompliant to the observance of strict religious sexual and health practices. They argue that remaining chaste until one is married, non-involvement in extramarital sex and not using illicit drugs are enough antidotes to HIV infection. This and other considerations might impede others to seek testing for the disease.

Some Muslim practices could also be an impediment to prevention and/or care. For example, those who observe fasting, especially during the holy month of Ramadan are less likely to allow blood extraction for HIV testing. The test can be offered in accessible labs or clinics after sun set hours in the month of Ramadan.

BESAFE – Ethics

Providers should try to obtain information about Muslim culture and beliefs so that appropriate interventions can be offered. As with many other religions and cultures, there may be differences in practices depending on patient's personal beliefs. Patients should be encouraged to discuss their practices and beliefs so that providers can give appropriate advice about health issues.

**BESAFE – Sensitivity
of the Provider**

Issues of cultural insensitivity to Muslim practices must be carefully addressed by providers.

While the population of Muslims has grown in the United States due to immigration, most health care providers to this population are non-Muslims. Further, religious and cultural differences are often compounded by language barriers. A key solution to addressing this problem is involving family, community members, and religious leaders as major stakeholders in HIV/AIDS prevention campaigns. These stakeholders can serve as a buffer between health care providers and campaign beneficiaries.

**BESAFE –
Assessment**

Each patient is unique. Generalized perceptions about one's religion, cultural background, and sexual preferences or health behaviors cannot be applied to every scenario. Providers need to conduct in depth assessments patiently and carefully, to obtain sound information from the patient.

BESAFE – Facts

With the general perception among many Muslims is that HIV is an insignificant threat to them. Consequently, more data need to be collected for a more careful review of this perception. Providers should talk to patients and obtain appropriate health histories, keeping in mind all the risk factors that can lead to HIV transmission. This conversation should be done in a culturally sensitive manner.

BESAFE – Encounters

Muslims in America come from many different countries, and some may have difficulty communicating in English. Due to stigma attached with the diagnosis of HIV itself, and that fact some risk factors may be taken as immoral and un-Islamic, the providers should avoid using family members as interpreters if the patient cannot communicate in English. Providers should also consider intro-

ducing themselves to their patients in a culturally appropriate manner, for example, many Muslim women do not feel comfortable shaking hands with male health care providers.

CHALLENGES

Few studies have been conducted on American Muslim patients with respect to HIV management issues and prevention. More data needs to be collected. Providers should take the initiative to discuss the risk factors in a culturally sensitive way.

IMPACT

It is important to collect data regarding HIV in American Muslims so that the burden of the disease can be evaluated and lessons learned from good or bad practices. If providers continue to learn about the culture of their patients and obtain information in an appropriate manner, patients will develop trust and share health histories. This will help providers make correct diagnosis and devise management strategies.

CRITICAL ISSUES AND LESSONS LEARNED

As the number of American Muslims grows, it is important to educate this group regarding important health issues, such as HIV. The opportunity to learn about patients' culture will help providers convey their recommendations more effectively, and may help with prevention and treatment recommendations. Community based organizations and religious leaders can play an important role in improving their understanding of the disease and help break stigma associated challenges.

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Tennessee State University, Nashville TN and
Howard University College of Medicine, Washington, DC

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Laurine Thomas, Ph.D., and
Goulda Downer, Ph.D., RD, LN,

HIV/AIDS: Providing Care to Caribbean Immigrant Communities

“All staff should provide clients with repeated assurances of confidentiality, starting with outreach, proceeding to intake and continuing throughout the course of treatment and management. It is sometimes helpful to explain to clients that the facility and its staff are mandated by law to maintain confidentiality and that staff can and will be disciplined for any breaches. This will go a long way in building trust and keeping the patient in care.”

BACKGROUND

Caribbean countries are affected by a wide array of social, economic and development issues. Many are exacerbated by the spread of HIV and AIDS. Second only to Sub-Saharan Africa, the Caribbean basin, with over 1.6% of the adult population infected with HIV, has a higher prevalence than any other area of the world.¹ The situation reflects startling contrasts. At one extreme, Haiti has the highest prevalence in the entire western hemisphere at 3.8%. At the other, Cuba has one of the lowest at 0.1%. The Bahamas at 3.3%, Trinidad and Tobago at 2.6% and Guyana at 2.4% are all heavily affected.² Factors, such as AIDS mortality rates and transmission patterns, vary across countries and areas.³

These variations may be attributed to the diversity of the region evidenced by languages, religion, race, cultural practices, culinary preferences, socio-economic status, geographic location and even politics. Nevertheless, there are a few grim constants throughout the region, such as the stigma attached to HIV infected individuals. In addition, traditional, religious and cultural norms prevent people from talking openly about HIV and AIDS in most countries. As a result, misinformation and prejudice about the disease continue to thrive.⁴

Reflecting global patterns, heterosexual sex is the most prevalent mode of transmission throughout the region. Women and young people are particularly vulnerable⁵. Injected drug use, although a prominent factor in the spread of the disease worldwide, plays a minimal role in the epidemics documented throughout most of the Caribbean. The exceptions are Bermuda and Puerto Rico⁶. Estimates show that men who have sex with men account for 12% of the infections. However, homophobia and cultural taboos about sex between men are major barriers to access and utilization of testing and treatment services. As a result of the presumed under-reporting of HIV among men who have sex with men, some estimate that the actual prevalence rate among this sub-population may be higher.⁷ Indeed, stigma surrounding HIV because of general cultural taboos about sex, and particularly the unfounded perception that HIV is a disease that primarily affects men who have sex with men, makes preventing the spread and treatment of the disease very challenging in the Caribbean and for Caribbean nationals residing in the United States.

As is the case with many immigrant groups, Caribbean nationals face challenges accessing health care. These are often compounded for HIV infected individuals. The stigma attached to the disease constitutes a barrier to early testing, timely care and treatment. For instance, for some patients, keeping the first clinical appointment is psychologically very challenging. Others decline even to be educated about HIV for fear that they might be perceived to be HIV positive.

DESCRIPTION OF BEST PRACTICE

This promising practice for HIV care and management of Caribbean immigrants residing in the United States utilizes to strategies designed to mitigate stigma. This includes acts to prevent social isolation and harassment thus increasing willingness to purchase condoms, alters behaviors, promote prevention, testing counseling, treatment, and support services. These are common strategies to promote timely and regular use of screening and treatment for Caribbean nationals.

LEVEL OF INTERVENTION

The proposed strategies are most feasible in outpatient clinics, hospitals or Community-Based Organizations (CBOs).

PROSPECTIVE USERS OF THE PRACTICE

The suggested recommendations are relevant to individual clinicians, social service providers and administrators.

PROBLEM ADDRESSED

Failure to recognize and adequately address the cultural differences, attitudes and beliefs of Caribbean nationals with HIV/AIDS as well as the impact this has on their accessing screening and treatment services in a timely manner.

PURPOSE OF BEST PRACTICE

Promoting comprehensive cultural sensitivity training for clinicians and associated staff to reduce stigma and improve clinical outcomes.

CONTEXT

Country variations in language, including terms used to refer to HIV and certain risk behaviors, may potentially impede effective patient/provider communication. Clinicians should take the time to discuss the specific culture of individual patients and to consider variations in age, education, gender, and socioeconomic status.

REQUIRED RESOURCES

Organizational commitment to periodic program review aimed at identifying socio-demographic patient variables and contextual factors that influence how services are delivered.

STEPS TO IMPLEMENT BEST PRACTICE

Step 1: Acknowledge stigma as an issue not only for patients but also clinicians

Engage clinicians, administrators and other staff involved in the treatment and management of patients in a series of dialogues to identify personal biases

and feelings toward them, how these are manifested during service delivery, and what steps could be taken to address problem areas.

Step 2: Build patient-provider trust

Building trust takes time and consistency. Where possible, patients should see the same provider or group of providers throughout the course of treatment so that there is an opportunity to build relationships and trust. In addition, every effort should be made to structure appointments, particularly initial appointments, to allow time for patients to express themselves, ask questions about their health and the management of the disease, learn of community resources, and generally establish rapport with their providers. For some patients, receiving care from a provider of their own culture or who speaks the same language helps to build trust. Others prefer providers from the dominant culture, particularly if they believe that someone from their culture might disclose their status to others in the community. Thus, there is no hard and fast rule on the necessity of cultural concordance between providers and patients. Each case must be evaluated separately on its own merits.

Step 3: Provide assurances of confidentiality

All staff should provide clients with repeated assurances of confidentiality, starting with outreach, proceeding to intake and continuing throughout the course of treatment and management. It is sometimes helpful to explain to clients that the facility and its staff are mandated by law to maintain confidentiality and that staff can and will be disciplined for any breaches. This will go a long way in building trust and keeping the patient in care. It is also beneficial to post notices or make information available in layman's terms, and where patients are likely to view them, about the institutional commitment to confidentiality.

Step 4: Create safe physical spaces

- Anonymous testing centers mitigate some of the concerns around fear and stigma that patients may feel.
- Integrating HIV services into care for other health conditions, may decrease the likelihood of a patient's status being inappropriately disclosed. Only the treatment provider and the billing department would know the reason for a particular visit.

BESAFE – Barriers to Care

a. Stigma - Stereotyping/ racism/ homophobia

There are several sources of stigma that constitute barriers to appropriate and timely use of HIV/AIDS services in the Caribbean immigrant community. These include, but are not limited to, the stigma of transmission, the stigma associated with male homosexuality, stigma about a specific nationality and stigma around social status.

Stigma of transmission –Infected persons in the Caribbean are often characterized as immoral, ignorant, and deserving of their condition. Many infected persons cannot disclose to their family members or even their partners for fear of rejection, violence and even expulsion from their home. Thus, they may hesitate to access care, be sporadic, and/or lack the social supports that would facilitate effective use of treatment and care.

Stigma around homosexuality – Caribbean nationals residing in the US may believe that the laws against homosexuality that are so common in the Caribbean also apply in the US. Some immigrants may believe that people with HIV are gay and that someone who is HIV positive looks “a certain way.” Thus, they may be unwilling to disclose a diagnosis for fear that it will infer that he/she is a homosexual.

Stigma of nationality - At times, HIV-related stigma is associated with a particular nationality. Dating back to the eighties, Haitians have been stigmatized as the source of the epidemic. As a result, many Haitians are particularly reluctant to be screened or treated while in the U.S. An additional concern for all Caribbean immigrants are U.S. immigration rules that can exclude or make entry into the U.S. and citizenship difficult, if not impossible, for individuals who are HIV positive.

Stigma around social status - Caribbean societies are very class conscious and such distinctions are maintained by most Caribbean communities in the U.S. Since HIV has traditionally been viewed as a disease of the lower classes, some persons of higher social standing have resisted being screened or treated because they feel separate, different, and/or perhaps better than those they consider likely to be infected. Some providers laboring under the same misconceptions do not offer screening or treatment to higher class persons under the assumption that they could not possibly be HIV positive.

b. Mistrust of the medical system due to confidentiality concerns

Providers need to be aware that Caribbean patients come from countries that purport to value privacy and confidentiality, but whose health care systems do not typically operate according to these values. Consequently, patients often present for screening or treatment with heightened concerns about whether their privacy will be safeguarded. These concerns are particularly heightened when the service delivery site is located in a Caribbean neighborhood. Sometimes patients feel panic and shame on spotting clinic staff that they know from within their community. In addition, given the small populations of many of the islands, social networks tend to be tight. Potential patients may fear that even the staff, or others they do not personally know, may know someone related to them and their positive status may be divulged.

c. Language/ immigration status

Once in the United States, interacting with and navigating the health system may be difficult for persons who are not comfortable conversing in English. Although English is the first language of most Caribbean countries, Spanish and French are also prominent. In addition, in some countries particularly among residents with lower levels of education, it is common to use the local dialect for most verbal communication. One key example would be Haitian Kreyol, one of Haiti’s official languages.

Concerns that an HIV diagnosis could lead to deportation or denial of citizenship often prevent Caribbean immigrants from seeking care. Undocumented, uninsured or underinsured persons are often reluctant to access public services for fear that contact with government authorities may pose problems for them.

BESAFE – Ethics**d. Competing life issues**

The majority of Caribbean immigrants in the United States who are HIV positive belong to the lower socioeconomic strata. Thus, they face not only HIV, but issues such as undocumented status, poverty, homelessness, and job insecurity. Life stresses may lead to substance abuse, mental health problems, and other co-morbidities such as heart disease, hypertension, and diabetes. In addition, some may come from countries where tuberculosis is rampant. Circular patterns of migration, seen not only among migrant workers but also in other groups, may prevent Caribbean patients from accessing care on a regular basis. Thus, for many, seeking treatment for HIV/AIDS is not a top priority. Their seeming lack of concern may be disconcerting to providers whose primary focus is on appropriate and prompt management of their disease. Nevertheless, providers need to understand that HIV/AIDS is but one of what is often a myriad of problems that their Caribbean patients face. Delivering holistic services or creating one-stop service delivery locations can often provide patients with the assistance they need to resolve various issues and accord their health the attention it needs.

a. Morality/Spirituality

Religion plays a key role in Caribbean societies. Church attendance is a regular part of daily life. Church leaders are key opinion shapers. Their views on HIV/AIDS and their condemnation of many of the behaviors that lead to transmission have been adopted by many segments of the society. These views are related to the stigma attached to the disease and those who contract it. Religious and spiritual beliefs may also promote fatalism and a belief that HIV infection is the result of fate, thus minimizing the importance of prevention and the efficacy of treatment.

b. Belief systems

The most common mode of HIV transmission in the Caribbean is through sexual contact. Discussions about sex are highly taboo in many sectors of Caribbean society. As a result, many adults are not educated about their own bodies or about safe sex methods, and are embarrassed and reluctant to discuss these topics.

Persons who are at high risk for HIV may believe certain myths about the origin of the disease, attributing it to voodoo or a conspiracy against certain groups in the population. In addition, infected individuals may also have very little knowledge about the disease. As a result, when they are asymptomatic or not experiencing incapacitating symptoms, they are often not that concerned about managing the disease, and therefore resistant to treatment.

In many Caribbean societies, people believe in the efficacy of alternative therapies in the form of traditional medicine and voodoo healing. In the United States, once infected, such persons may avoid seeking Western medical treatment or pursue both simultaneously. Providers need to be sensitive to this possibility and be prepared to accommodate patients' use of alternative systems of health care.

BESAFE – Sensitivity of the Provider

c. Confidentiality

Given the heightened concerns around confidentiality noted earlier, an ethical approach to HIV/AIDS screening and treatment require providers to be sensitive to patients' concerns and to be prepared to make all reasonable efforts to be responsive to them.

a. Recognizing and redressing personal bias

Like patients, providers often hold biases or stereotypes regarding HIV and/or certain racial ethnic groups. At any stage, respect for the patients' opinions and viewpoints is vital. Providers who attend cultural sensitivity and competency trainings are more likely to be equipped to identify and eliminate attitudes and beliefs that might compromise the care they deliver. In addition, such training equips providers with skills to communicate in ways that are respectful of patients and easy for them to understand.

b. Honoring the patient's perspective and autonomy

Providers must take into consideration the likelihood that Caribbean patients who are HIV-positive, might have cultural taboos limiting or forbidding discussion of sex; believe in myths about transmission and treatment; hold moral and spiritual views that condemn infected persons; and prefer to rely on alternative treatments for their condition. Providers should not be condescending but should demonstrate a willingness to understand and respect the patient's perspective and modify, where possible, approaches to managing the disease.

BESAFE – Assessment

Culturally competent and responsive care for an HIV positive Caribbean patient begins with collecting relevant information about his/her culture and beliefs relative to the disease. In order to have a systematic but individualized approach to patient care, it would be useful for providers to prepare a few questions ahead of time that they could pose to patients to elicit useful and necessary information. Illustrative questions might be:

- You have a diagnosis of HIV. How do you feel about that?
- How is that viewed in your community?
- What do you know about HIV/AIDS?
- Do you feel that telling people you have HIV is a mistake?
- How do you feel about your status?
- Do you have any family or other social support?
- What can we do at this facility to ensure that you receive the best possible care?
- What questions do you have about your condition?

Due to the stigma and confusion that many patients might feel surrounding a diagnosis of HIV/AIDS, providers should expect that they may need to pose these questions individually and repeatedly in order to arrive at honest responses. As mentioned earlier, a crucial step in delivering culturally competent care involves building patient-provider trust.

BESAFE – Facts

- As a result of the stigma attached to the disease, Caribbean nationals may not disclose their HIV status to their families or friends. Consequently, social isolation, depression and related mental health challenges may surface.
- The HIV disease and behaviors leading to its transmission are highly stigmatized in the Caribbean.
- Discussion of sex and other behaviors leading to HIV transmission is often taboo.
- Myths about the transmission of HIV and the efficacy of treatment abound.
- Confidentiality concerns are paramount for many HIV-positive Caribbean patients.
- Concerns about deportation or negative impacts on immigration status may hinder access to and utilization of treatment.
- HIV/AIDS may be one of many serious life issues facing a Caribbean patient who is HIV-positive.
- Alternative and complementary therapies for HIV are widely accepted and often preferred.

BESAFE – Encounters

Initial encounters characterized by respect and a non-judgmental attitude may establish trust between the client, the provider, and the system. Greet each patient using the title, “Ms., Mrs. or Mr.,” and never by the first name. Invite the patient to sit wherever comfortable for him or her. Patients may be embarrassed to discuss or fully disclose their health conditions especially on the first few visits. To help them open up, use case scenarios such as, “I know a patient who has so and so, how do you feel about that?” Being respectful and patient can significantly increase the chance of success in future treatment.

CHALLENGES

a. Culturally incompetent providers and staff

Although effective care relies on a partnership between the provider and the patient, the onus is on the Provider's front line staff to set the stage for the quality of care that will be rendered. Incompetent providers and staff who show little or no consideration for the patients' culture undermine the potential effectiveness of any care that may be delivered. Illustrative indicators of cultural incompetence in the care setting include:

- Excessive waiting times.
- Repeatedly interrupting patients while they are speaking.
- Dismissing patients' accounts of their condition or their treatment preferences.
- Refusing to answer patients' questions about their condition.
- Rushing patients through visits, exams, or other interactions.
- Addressing patients in overly familiar or condescending terms that offend cultural norms.
- Not maintaining patient confidentiality.
- Using language or terminology that patients cannot understand.

b. Lack of resources to provide cultural competency training to providers and staff

In today's climate of dwindling resources and competing priorities for health care delivery, providing culturally competent care must be a priority for organizations. If not, sufficient resources will not be allocated to ensure that this happens. The lack of resources for cultural competency training and ongoing review of the quality of care afforded are a challenge to delivering quality services to patients of all backgrounds.

c. Institutional procedures that prevent or limit the delivery of culturally competent care

Some institutions continue to use outdated approaches instead of holistic services or clinic facilities that indicate that users have STDs. These institutional practices can impede the best efforts to provide culturally competent care.

d. Insufficient time for Provider/Patient interface

Providers face increasing pressure to treat more clients in less time. This means that they often lack the time necessary to establish relationships with each patient and to build trust. This reality poses a challenge for providing quality care.

IMPACT

- Fewer new infections among Caribbean Nationals
- Early treatment leading to better clinical outcomes
- Informed patients who remain in care
- Improved quality of life
- Quality service rendered by proficient providers

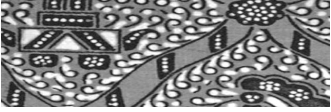
CRITICAL ISSUES AND LESSONS LEARNED

The cultural/ethnic diversity of the Caribbean region requires tailored HIV prevention, care and treatment efforts. Providers should work with the Caribbean patient to first gain trust, then identify needs and together develop a sustainable plan of care.

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Alawode Oladele, MD, MPH

HIV/AIDS: Providing Care to African Immigrant Communities

“African immigrants may be particularly vulnerable to HIV infection because of the economic instability and social isolation that can accompany migration and because they often migrate without their partners”

BACKGROUND

The 2000 census, reported that there were approximately 28.4 million foreign-born individuals living in the United States, accounting for 10.4% of the total population.¹ Census and community data also estimate that well over one million immigrants, representing approximately 6% from Africa, currently reside in the United States.¹ About 57% of that number immigrated between 1990 and 2000. African immigrants may be particularly vulnerable to HIV infection because of the economic instability and social isolation that can accompany migration, and because they often migrate without their partners.¹ Within the communities in the United States, knowledge of HIV testing and prevention is almost non-existent due to the cultural taboos and prevalent stigma attached to the disease at every level.¹

While data on HIV rates in foreign-born populations are not always readily available, advocates and providers working with these populations, report a paucity of culturally appropriate and culturally sensitive resources and services. Networks of Community Health Workers (CHW), representative of different African immigrant communities in which HIV is most prevalent have been established in the Atlanta Metro area. The CHWs act as cultural brokers and intermediaries between the community members and the healthcare/social service system.

Health care workers have two main types of interaction with community members. The first involves home visits. During the home visits, CHWs provide one-on-one or family counseling and education. It is in this environment that intense education and Rapid HIV testing is done in order to ensure confidentiality; and minimize apprehension and fear. The second forum is group centered and involves community meetings, focus groups, social groups, and education sessions. During these meetings, community members, sometimes separated by gender, discuss health and social issues that are deemed to be of a less 'private and sensitive nature. In these settings CHWs assist during open discussions about HIV.

DESCRIPTION OF BEST PRACTICE

Numerous studies have shown the efficacy of utilizing the CHW concept in programmatic areas where culture and language barriers to patient education and access to care are of concern. While the model is often associated with primary health care campaigns in the developing world, community health

workers are also deemed important domestically when working with immigrants.

The CHWs initiative is a comprehensive, community based program, specifically designed to provide resources and access to needed HIV services in a culturally appropriate and logistically straightforward and manageable way. This initiative uses workers in the delivery of services, education, and counseling to provide an “insiders” advantage within the target communities. These workers are members of the target communities and therefore have an understanding of norms, behaviors, and differences that are unique to every culture. They are able to address the specific health needs of the community using their working knowledge. Typically, this knowledge can never truly be attained by an “outsider.”

LEVEL OF INTERVENTION

The Community

PROSPECTIVE USERS OF THE PRACTICE

Community based organizations, other non-governmental organizations (NGOs), public health agencies.

PROBLEM ADDRESSED

Training and resource needs of health care providers working with diverse immigrant populations

PURPOSE OF BEST PRACTICE

- Bridge cultural mediation between immigrant communities and the mainstream health care system.
- Provide culturally appropriate and accessible health education and information, often by using popular education methods.
- Promote efforts focused on African immigrants receiving proper and timely HIV-related services.
- Provide informal counseling and social support.
- Advocate for individuals and communities within the health and social services systems.
- Provide direct services and administer HIV screening.
- Build individual- and community-level capacity focused on HIV prevention and treatment.

CONTEXT

The four ideas that construct the basis for the CHW ideology in program planning and implementation, as outlined by John van Willigen, are: local knowledge, participation, empowerment, and sustainable development.¹

The concept of local knowledge refers to the knowledge and practices that are embedded in a local community. Since the 1960's, researchers have realized that local knowledge systems are very much like those of experts. They are structured; rooted in time-tested beliefs, and, unlike the knowl-

edge of experts, provide a unique insight to the inner workings of a community. It comes out of the unique experiences shared by people within that community.

Participation, in this context, refers to the involvement and representation of the community members (African Immigrants) as complete, unmitigated, and recognized as vital to the success of the program.

Empowerment refers to “a theoretical framework in virtue of which knowledge and praxis are socially constituted, historically contextualized, value-based, and multi-dimensional”⁵. Under this framework, goal attainment is less important than the opportunity to experience the empowering processes that lead people to believe in their own efficacy.”⁶ Thus, people participate in actions that govern their health. Clients, instead of feeling alienated, will become empowered through gaining new knowledge and understanding of themselves and their community, by taking responsibility for their own health and well being, and by learning and utilizing development skills available to them.

Lastly, there is a crucial component of sustainability which can be defined as the ability of a program to continue with the efforts of the stakeholders, without the need for further future funding. This is achieved by utilizing local knowledge, participation, and empowerment as both goals and guidelines during program implementation. The program will be more likely to become sustainable because of the recognition of such ideas. As van Willigen also points out, using a local knowledge base in program design will create a greater probability that it will be a sustainable success.⁵

REQUIRED RESOURCES

- Development of a community health workers (CHW) program.
- Implement rapid HIV testing in the field.
- Conduct a needs assessment of target immigrant/communities where knowledge is lacking.
- Hire a case manager to help manage the social needs of patients with multiple high risk factors.

STEPS TO IMPLEMENT BEST PRACTICE

- Start-up: hire staff, prepare space
- Form/maintain community partnerships
- Hold community meetings/forums
- CHW retention examination period
- Develop CHW progress reports
- Develop monitoring and evaluation reports for quality and effectiveness control
- Present evaluation findings to stakeholders
- Present program impact to stakeholders
- Disseminate information to broader community through media, publications, and local venues/events

**BESAFE –
Barriers to Care**

- Social stigma
- Religious beliefs
- Traditional health beliefs and practices
- Social structure, family, and gender roles
- Low health literacy
- Trust among clients that CHW staff will maintain their confidentiality in the community

BESAFE – Ethics

The CHWs are members of the target communities, so they are more readily accepted by the immigrants they work with. However, it is very important to educate the CHWs on issues of ethics and confidentiality as they attempt to gain the full trust of the community. If the CHWs are not trusted, the intimate nature of the HIV related work that they do will continue to be a barrier to accessing the community, even for insiders.

**BESAFE – Sensitivity
of the Provider**

Although there are increasing concerns about addressing the HIV needs of ethnic minority groups in the United States, there are still significant gaps in knowledge, especially within underserved African Immigrant populations. In order to move toward cultural proficient, health care providers must understand the needs of the African Immigrant populations they serve.

BESAFE – Assessment

Key steps to assessment of the CHW Model include the development of the following:

- A dissemination plan for the programs' activities, findings, and data in order to promote information sharing and replication
- An evaluation plan to assess effectiveness in attaining the program-and client-specific goals and objectives
- A sustainability plan outlining the strategy to support operations when current funding has ended
- A management plan that will outline job descriptions and responsibility and the key personnel associated with the implementation of the program
- A timeline of the program's specific goals, objectives and activities
- Various monitoring and evaluation reports

BESAFE – Facts

Many immigrants are at-risk for HIV and there is a lack of culturally appropriate related services targeting them. While data on HIV rates in foreign-born populations like African immigrants are not always readily available, numerous states are reporting increased rates. Providers who work with these populations are also reporting increased numbers in recent years.

BESAFE – Encounters

Community health workers can serve as cultural brokers and intermediaries during encounters between the African-immigrant patients and the health-care/social service system.

CHALLENGES

Africans Immigrants have multiple layers of identity—national origin, region, ethnicity, language, gender, socio-economic status, social structure, values, education, traditional beliefs and practices, to name a few. The major challenge in addressing some of these cross-cultural issues is the avoidance of stereotypes while attempting to come up with meaningful guidelines and suggestions for healthcare providers in the United States.

IMPACT

Through education and skill-building activities, African-immigrants will become empowered to take responsibility for their own health and well being, and to master development skills that can be used in all areas of their community.

CRITICAL ISSUES AND LESSONS LEARNED

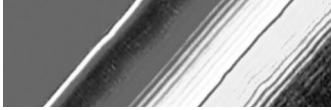
African immigrants are a very diverse population, representing numerous ethnic groups, speaking many languages, and depicting a wide array of cultural backgrounds. Their immigration experiences are different and so are their historical, political, and religious beliefs and practices. As a result of this diversity, HIV prevention, care and treatment efforts must be tailored to their diverse needs.

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María Luisa Zúñiga, Ph.D.
and Estela Blanco, B.A.

HIV/AIDS: Providing Linguistically-Effective Care to Latinos who are English-Language Learners and Live in Communities along the United States-Mexico Border

“Promoting provider critical self reflection about cross-cultural and linguistic differences that may exist between them and their patients may promote increased awareness about challenges faced by their English-language learner patients”

BACKGROUND

In the United States (U.S.) health care delivery system, effective cross-cultural communication between patients living with HIV and their providers is critical particularly when patients are English-language learners who often experience language-mediated challenges when navigating the U.S. health care system. Our work with patients of Mexican origin who are HIV-positive living in the U.S.-Mexico border region has improved our understanding about delivering linguistically and culturally effective care. We have learned, for example, about the importance of provider sensitivity to the patient’s ability to express herself/himself using an interpreter; the role that HIV-related stigma may play in patient care utilization; and provider attentiveness to the context of the patient’s daily life.^{2, 3, 4} Importantly, the best practice recommendations provided below can be applied to other ethnic groups who are also English language learners. The author’s original research,^{2,3,4} as well as review of existing literature, provides evidence that strategies to address patient/clinician language differences and clinicians’ willingness to integrate such strategies can improve health services encounters for patients.

DESCRIPTION OF BEST PRACTICE

The application of community-based participatory research (CBPR) addresses language-related barriers to HIV care for Latinos living in communities along the Mexican border region. A discussion of the application of CBPR to improve delivery of culturally-effective care is found in Zúñiga, ML.¹

LEVEL OF INTERVENTION

- Community-based organization (CBO)
- Clinics

PROSPECTIVE USERS OF THE PRACTICE

- CBO staff (administrators and care providers)
- Community clinic staff (administrators and care providers)
- Hospital staff (administrators and care providers)

PROBLEM ADDRESSED

- Language as a barrier to access and utilization of HIV-related care.
- Adolescents

PURPOSE OF BEST PRACTICE

- Understand how language differences can influence health care access.
- Improve understanding of how language barriers are related to other barriers to healthcare access.
- Describe examples of language-related barriers and how they can be identified and addressed.
- Improve provider ability to deliver linguistically-effective care.

CONTEXT

Improving the capacity of U.S. health service providers to deliver linguistically and culturally-effective HIV care to the growing U.S. Latino population is of significant public health relevance because:

- US Latinos comprise 15% of the U.S. population; however 17% of all new HIV infections in 2006 were among Latinos.⁵
- HIV is a growing problem in the U.S.-Mexico border region.⁶
- 78% of U.S. Latinos age five and older speak Spanish at home.⁷

Stone and colleagues⁸ found that 60% of providers felt confident in their ability to explain clinical trials procedures during recruitment to potential participants who speak Spanish;⁹ and, recruitment of Latinos into HIV clinical trials remains a health disparities problem in the U.S.⁹

REQUIRED RESOURCES

- Providers' commitment to the delivery of linguistically- and culturally-appropriate care is important to minimize barriers to health care access for patients who are English-language learners.²

STEPS TO IMPLEMENT BEST PRACTICE

- Assess patient's ability to communicate effectively with care provider. For example, conduct focus groups to understand community perspectives related to language and accessing care.
- Identify opportunities and strategies to recognize and address language-related barriers and include patients in this process. For example, when feasible, ask patients if they prefer an interpreter in person or by phone.

BESAFE – Barriers to Care

Barriers to health care access and the provision of quality care related to language considerations are well documented in the research literature.^{2,3,4}

Examples of linguistically-and culturally-mediated barriers to care may include: prescription labels and instructions written in English instead of Spanish.

- This reduces adherence or promote inappropriate self-administration of medication.
- HIV-related stigma among Latinos as a barrier to care has been mentioned in the context of trusting providers (e.g. patient concern over who will have access to their information).²
- Trust is compromised when Latino patients feel stereotyped by providers.²
- HIV clinical trial eligibility criteria that includes ability to speak/read/write English.¹⁰

BESAFE – Ethics

Ethical considerations related to the delivery of linguistically effective care include:

- Differential delivery of care resulting from provider perceptions of patients' English-language comprehension or assumptions may lead to sub-optimal clinical encounters or access to care.⁹
- Providing informed consent of medical research only in English only instead of Spanish as well may decrease participation in research among those who are just learning the language.¹⁰

BESAFE – Sensitivity of the Provider

Promoting provider critical self reflection about cross-cultural and linguistic differences that may exist between them and their patients may promote increased awareness about challenges faced by their English-language learner patients. This may be done by:

- Dissemination of research findings from studies with Latino patients living with HIV may serve to stimulate provider critical reflection.
- Providers are also encouraged to seek out information from their patients regarding perceived language-related barriers to health care.

BESAFE – Assessment

Community-based participatory research methods may be useful to improve understanding of challenges faced by communities with large English-language learner populations.¹

BESAFE – Facts

- Disparities in HIV care access related to language barriers are well documented in the literature.^{8,9}
- Health care access has been linked to patient/provider language considerations, particularly in the context of participation in research.^{2,8,9}

BESAFE – Encounters

- Clinical encounters that provide English-language learner patients with options to choose between an in-person and phone interpreter may foster improved patient-provider trust and communication.

CHALLENGES

- **Translation Cost:** Expenses associated with professional translation of materials may limit opportunities to provide all

IMPACT

materials in a given language. Prioritizing what to translate may be accomplished with feedback from a community advisory board. A less desirable alternative is asking staff to translate. However the resource may not be valid if the material cannot be reviewed by a person who is linguistically competent in the field of HIV care.

- **Time:** Providers may face challenges to obtaining interpreters for clinical encounters in a timely manner.
- Conducting focus groups with Spanish-language dominant Latinos living with HIV provides a voice and an opportunity to discuss a variety of barriers to health care access and participation in HIV clinical trials for Mexican Latinos.^{2,10} This information can be then used to help inform solutions.
- Meaningful engagement of community members can help providers to better understand and improve their ability to communicate with health care recipients who are English-language learners.

CRITICAL ISSUES AND LESSONS LEARNED

The following critical issues and lessons learned are based on findings related to barriers to care among Spanish-language dominant Latinos living with HIV in the US-Mexico border region²:

- There is a genuine concern on the part of many providers to accommodate the patient's language needs.
- Providers are aware of the barriers that limited English proficiency places on a patient's ability to participate in clinical trials and have been forthcoming in providing recommendations on how to improve this.
- Patient resourcefulness to bring their own interpreter, however, was not necessarily a bridge for this barrier when clinical trial materials were available in English only.
- Patients in our study were aware that culturally-effective clinical communication is enhanced when receiving care from clinicians who are of Mexican-origin and familiar with Latino culture. However, they also expressed appreciation to providers in general and were particularly appreciative of efforts made by their non-Latino providers to learn Spanish.
- In addition to bolstering clinician training in delivery of culturally and linguistically-effective care, exploring the potential role of phone interpretation services or interactive, computer-mediated interpretation during clinical encounters, may also be worthy of study.

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University of California, San Diego School of Medicine
Division of Global Public Health, San Diego, CA

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Steven Tierney, Ed.D. CAS

HIV/AIDS: Providing Care through the San Francisco AIDS Foundation’s Black Brothers Esteem Project

“This program not only targets these populations, but also recognizes and respects the importance of spiritual health in addition to physical, mental and emotional health.”

BACKGROUND

African-American men who have sex with men (MSM) in the United States are disproportionately affected by the HIV/AIDS epidemic. Socio-economic and cultural factors including poverty, lack of access to health and wellness programs, substance abuse, and social disenfranchisement have been documented as major contributors to this disparate impact. Not surprisingly, African-American MSM living in two boroughs in the city of San Francisco – Tenderloin and South Market – exhibit high rates of HIV as a result of extreme poverty, social isolation and crime embedded in a vibrant street economy based on drugs and sexual trades.

The San Francisco AIDS Foundation (SFAF) – the oldest and largest provider of HIV services in Northern California – delivers culturally appropriate services in the Tenderloin and South Market areas to improve the health status of African-American MSM. Black Brother Esteem (BBE) is a project implemented by the San Francisco AIDS Foundation that promotes inclusion and spiritual growth among African-American MSM. Consistent implementation and dissemination efforts of the BBE project for the past 17 years suggest that this practice has the potential for replication in another setting and or with a different target population.

DESCRIPTION OF BEST PRACTICE

BBE identifies, trains, and supports a group of peer health educators (PHEs). The PHEs promote community-based participation, empowerment and sustainable development projects. All members of the BBE are involved in interventions which impact the individual, the group and, most importantly, the community in which these men live.

LEVEL OF INTERVENTION

Community-level interventions.

PROSPECTIVE USERS OF THE PRACTICE

Any agencies, e.g., Community Based Organizations (CBO), State Health Departments, Universities, or individuals working with urban African-American MSM.

**PROBLEM
ADDRESSED**

Currently, very few culturally-specific HIV interventions exist for African-American MSM. The BBE program not only targets these populations, but also recognizes and respects the importance of spiritual health in addition to physical, mental and emotional health. Creativity and the arts are tools also used to empower the members in this project.

**PURPOSE OF BEST
PRACTICE**

The purpose of the practice is to enhance the health and wellness of members of the BBE group and the community in which they live. The program believes that individuals are not solely responsible for their health challenges but they are, and can be, supported to be responsible for the solutions.

CONTEXT

In this era of evidence-based programming, BBE stands out for several reasons. First, the members and staff believe very strongly in collecting data to identify and monitor the success of their program and its components. In addition, membership training and development efforts have created a very savvy population. These men believe that if they invest their time in BBE, there will be an improvement in health status. They expect nothing less and eagerly participate in the development of health outcome measures and data collection and analysis.

Second, while many programs limit the scope of their services to more easily measure impact, BBE understands and respects the complexity and richness of urban life. The program components, while primarily focused on primary prevention and prevention for positives, incorporates multiple aspects of the men's reality: the need for stable housing, the need for employment skills and options, the need for access to health care that is culturally appropriate for African-American gay men, the inclusion of and promotion of spirituality for these men, as well as nutrition.

**REQUIRED
RESOURCES**

The most powerful resource for the BBE program is the PHEs and its members. For example, each year the men take on a specific topic. In 2006, the topic was access to appropriate medical care. The members produced a brochure entitled, "My American Dream: To Be Strong and Healthy" which required the PHEs to engage in research (i.e., medical provider surveys and data analysis), writing, editing, graphic design and printing. They surveyed clinics and medical providers to determine where the most effective and appropriate care could be accessed. Throughout the community, this brochure is valued because the voices are authentic and trustworthy.

**STEPS TO
IMPLEMENT
BEST PRACTICE**

Build a safe and welcoming community for members by:

- Choosing the right staff
- Recruiting and supporting the appropriate peer health educators
- Providing "space and time" for the membership to come together
- Offering staff training

**BESAFE –
Barriers to Care**

- Providing a climate for open communication and exchange of new ideas²
- Insuring advancement opportunities (e.g., volunteers to PHE status to internships to paid positions)

The population of San Francisco has changed during the past decade. In 1995 the population was 12% African American.¹ In 2005, it was less than seven percent. It is estimated that amongst the gay community, 4% are African American.² Health statistics reveal that African Americans make up 12% of all new HIV infections and are over represented in substance use and mental health treatment data.³ Identifying health outcomes is complex and challenging in this environment. Therefore, identifying sources of appropriate health care is a significant barrier.

BESAFE – Ethics

Involving the community and impacted populations is crucial to developing culturally appropriate services and prevention programs. Similarly realizing, respecting and incorporating the realities of life: spirituality, economic stability, housing, safety, and community connection are crucial to program success.

**BESAFE – Sensitivity
of the Provider**

To reach the African-American MSM community, it is critical that staff come from that community and are culturally proficient in working with the community. It is crucial that project staff embrace self-determination as a core principle and operate the program from a sustainable resource place in true partnership with key agency leaders.

BESAFE – Assessment

BBE is engaged in a full range of monitoring, evaluation and research activities. A central organizing principle of the BBE is respect for members who participate in research or evaluation activities engaged by the program. Membership confidentiality is protected with great care. The program respects and values research and evaluation and, in doing so, safeguards members' time and privacy in all research activities. As well, it is important to guarantee members the right to participate in desired services without being burdened by the demands of evaluation or research.

BESAFE – Facts

The impact of HIV amongst men of color and specifically MSM has been well documented. The May 2008 Kaiser Family Fund "Fact Sheet: Black Americans and HIV/AIDS (http://www.kff.org/hiv/aids/upload/6089_05.pdf) confirms data reported in 2004 by the National Prevention Information Network. HIV Prevention Fact Sheets (CAPS.web@ucsf.edu. © July 2004, University of California) support the need for services which more effectively partner with the community in the design and delivery of services.

**BESAFE –
Encounters**

Providers need to establish a sense of respect and trust during all encounters with the client. A non-judgmental attitude, one of genuine concern which convinces the client that information will be handled confidentially is necessary. For example, providers should, (1) be honest and not condescending, (2) Ask for clarifications and explanations of words or terminology that are unfamiliar, and (3) be prepared to hear about housing, food, and spirituality needs. Having a list of resources to help address these needs can help foster patient-provider relationships. This may also help strengthen adherence to treatment plans.

CHALLENGES

Motivation and connectivity are the primary challenges for membership. The multiple challenges of life in urban centers for these men are demanding and de-motivating. Poverty, lack of economic opportunity, homelessness, and loss of family and community connection make it a constant struggle to find the strength and motivation to attend meetings and participate in volunteer activities and community education events. Staff and PHEs do a tremendous job keeping members connected and focused on successful outcomes.

On an agency level, in these tough economic times, it is critical that the program maintains the resources to be sustainable and that clients and community are aware of this. Programs that lack resources develop what is known in business as a “poverty mentality”, worrying about infrastructure and thus being less able to operate in true partnership between management and membership. Members should be safeguarded from these concerns.

IMPACT

The brochures “My American Dream” is an excellent example of the impact of this program. http://www.sfaf.org/files/site1/asset/bbe_strong_healthy.pdf Programs in which the participants are full partners in the planning, delivery, evaluation and evolution of the services are great successes. The programs developed skills, self-determination and power. These are indicators for enhanced ability to define health and wellness for the individual and the community and to build services to achieve and maintain health.

Too often, programs targeting the African-American community fail to deliver on the key components of reliability and sustainability. In sharp contrast, BBE is in its 17th year of being a member supported project. Participants can and do embrace it with confidence.

CRITICAL ISSUES AND LESSONS LEARNED

The BBE program is deeply committed to the physical, mental and spiritual health of its members and community. The identification of, support, education and empowerment of a new cadre of community leaders will be the long term community impact. Reduced HIV infection rates among the members are a direct impact. Engagement in care, prevention of re-infection, and reduction of viral load are the goal, for HIV+ members.

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Former Director San Francisco AIDS Foundation, current member of the San Francisco Health Commission, San Francisco, California

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Ann Drobnik, MPH

HIV/AIDS: Providing Care to American Indian and Alaska Native Communities

“Culturally-specific interventions, developed in partnership with Native communities, have a great potential for success. The HIV/AIDS interventions that address culture and identity nuances are promising practices for AI/AN. Especially since culture and identity are protective factors against high risk behaviors.”

BACKGROUND

An understanding of the underlying historical, cultural and structural factors that impact Native populations' communities is necessary in order to implement effective HIV community-level interventions. American Indian and Alaskan Native (AI/AN) tribes and villages are sovereign nations and, as such, have a right to determine HIV programming in their communities.¹ The tribes also have a trust relationship with the U.S. government, established through the U.S. Constitution and numerous treaties, that gives them access to direct services or direct funding for health care from the U.S. government. Despite this, Native people have the lowest per capita spending of any group that receives health care from the U.S. government, including members of the military, veterans and prisoners.² Native Americans living in urban areas face distinct challenges. They come from tribes across the U.S., and unlike other minority groups, do not necessarily reside among other Native people. In fact, some may not have any connection to other Native people. They can be invisible in large cities, often mistaken for another race. While some AI/ANs may return to their reservation communities, others remain disconnected from their culture and traditions. Further, the populations living in reservations tend to be geographically isolated, with minimal access to health services, particularly specialty care for HIV/AIDS. They often travel long distances for care, either because services are not available or accessible where they live, or due to concerns about confidentiality. Native people experience historical trauma and intergenerational grief as a result of forced displacement, break up of communities, and the loss of language and culture that have occurred throughout U.S. history. These myriad factors contribute to increased risk for disease, including HIV, among this population.³ Connection to culture, community and identity has been found to be protective factors against HIV risk behaviors, particularly among AI/AN youth.^{4, 5, 6}

DESCRIPTION OF BEST PRACTICE

American Indian and Alaska Native tribes and communities have a unique culture and history and a unique relationship with the United States government. To develop HIV/AIDS prevention programs and clinical services, understanding the context of history and culture and taking the time required to develop solid relationships with tribal leaders and community members, is vital. Best practices in HIV treatment provided to AI/AN populations must include factors that acknowledge sensitivity to clients' potential mistrust of federal health initiatives delivered to their community.

<p>LEVEL OF INTERVENTION</p>	<p>Community</p>
<p>PROSPECTIVE USERS OF THE PRACTICE</p>	<p>Any agency or individual working with Native communities – Community based organizations, state health departments, universities.</p>
<p>PROBLEM ADDRESSED</p>	<p>Currently, very few culturally-specific, HIV interventions exist for this population. There are several reasons for this, including the lack of accurate data on HIV among AI/ANs, the flow of prevention and treatment dollars, a lack of culturally specific evidence based models, and a lack of understanding of Native culture and history among public health professionals.</p>
<p>PURPOSE OF BEST PRACTICE</p>	<p>To foster community partnerships that will address planning, development, implementation, and evaluation of culturally competent and responsive HIV counseling, testing, referral and prevention programs with Native communities.</p>
<p>CONTEXT</p>	<p>Native communities often face serious challenges to meet the needs of their people in regards to HIV/AIDS services. These include a lack of financial and human resources, including frequent turnover of clinicians many of whom do not have the linguistic experience with clients who have HIV/AIDS; understaffing issues; and lack of capacity to implement and evaluate population-specific interventions. Further, there are very few culturally appropriate prevention interventions available for AI/AN groups. Adapting and implementing existing evidence-based interventions is resource intensive and most tribal health programs do not have the capacity to create or modify existing curricula. HIV/AIDS disease is not the only health concern for AI/ANs. Many Native communities still struggle with disparate rates of co-morbidities such as STDs,^{7,8} substance abuse⁹, violence,^{10, 11} and rampant stigma still surrounds sexually transmitted diseases. Yet, data to support the need for prevention programs and services in Native communities are scarce.</p> <p>Surveillance data does not accurately reflect the problem of HIV/AIDS in Native communities, as some tribal facilities do not screen routinely for risk, offer testing, or report cases. Racial misclassification is also a factor in the lack of data. Native people often are mistaken and reported as people of other racial and ethnic backgrounds.^{12, 13} In developing HIV programming and services in reservation communities, it is crucial that collaboration occurs with the tribal leaders. Due to the long history of broken promises to the tribes, building relationships with leaders like chairmen and council members, tribal health directors and other community stakeholders and a long-term commitment to the community is required.</p>

REQUIRED RESOURCES

The most important resource is the community itself, and its leaders. An investment of time to build relationships with the community and its leaders, and a commitment to sustaining and strengthening those relationships throughout the course of the work is a critical resource. Tribal governing structures can block or lend support to initiatives, ultimately determining whether or not programs or services are implemented. Native communities also are in need of both human and financial resources to develop and carry out HIV programs and services. Health infrastructure is lacking, high staff turnover, and staff who lack training in HIV are common challenges. Native-specific, evidence-based prevention models are greatly needed.

STEPS TO IMPLEMENT BEST PRACTICE

- **Step One:** Become familiar with the structures and leaders of Native communities. Identify those members who have decision-making authority and who are responsible for health services.
- **Step Two:** Get involved in community events and listen to local tribal radio stations to become familiar with community culture. Speak to members about their unmet needs.
- **Step Three:** Recognize and honor the importance of culture and tradition in health interventions; involve the community in planning and implementing the program or service.
- **Step Four:** Be ready to deliver. In other words, show up and be reliable. Native communities have become accustomed to outsiders coming in for a short period of time and then leaving without gaining any benefit from the program.
- **Step Five:** Establishing long-lasting relationships and making a strong commitment to the community will contribute to successful services.

BESAFE – Barriers to Care

Community members may not seek HIV/AIDS related services due to concerns about confidentiality. In rural reservation communities, members know each other and may even be from the same families. For a stigmatizing illness such as HIV/AIDS, individuals may not feel comfortable seeking testing or care in their own community where they are likely to know the clinic staff. In urban areas, medical providers are rarely part of the community which they serve, which can also create a lack of trust and an additional barrier to care.

BESAFE – Ethics

Involving community leaders and impacted populations is crucial to developing culturally appropriate services and prevention programs. Interventions that are designed without substantial community input are not likely to succeed. Stigma is still an issue in Native communities. Therefore, identifying leaders who are supportive of HIV services can be helpful in overcoming resistance that may exist.

BESAFE – Sensitivity of the Provider

Providers should recognize that Native people in the US come from over 500 tribes and are very diverse in terms of culture and tradition, and level of connectedness to their communities. In addition, many Americans view AI/AN in an almost exclusively historical context and hold a romantic view of their

culture, with little understanding of contemporary circumstances. Avoiding assumptions about culture, such as assuming that a patient observes traditional spiritual practices or holds certain beliefs about health, is encouraged as the experiences of individuals are determined by many factors and vary greatly by tribe and geographic region.

BESAFE – Assessment

Modesty is a common value in Native cultures and as such, sensitive questions such as those about sexual or drug using behaviors should not be asked up front. Instead, time should be taken to build rapport and trust with the patient. For example, the provider may start with introductions and begin the assessment with less-sensitive questions. Interactions between a patient and provider of the opposite sex may be uncomfortable for the patient, particularly among older, more traditional individuals. Also, since racial misclassification is an important barrier to collecting accurate data on AI/ANs, patients should be given the opportunity to self-identify their race/ethnicity.

BESAFE – Facts

As a group, AI/ANs, after African-Americans, have the shortest time between diagnosis with HIV/AIDS and death indicating that they are being detected at a later stage of the disease and are not having access to timely treatment, despite recommendations.¹⁴ As with other minority groups, women are a growing proportion of new cases, and injection drug use plays a large role in transmission.¹⁴ Native peoples face disparities in nearly every area of health, due to discrimination, poverty and lack of access to services. Intergenerational grief and trauma are the lasting impacts of this history. However, Native communities are also incredibly resilient because of it.¹⁵

BESAFE – Encounters

Effective patient-provider communication requires the establishment of trust and confidentiality, particularly when providing HIV services. Native people tend to view health issues holistically, and are quieter and more emotionally reserved. Silence is not necessarily uncomfortable for them, and avoiding eye contact is common. Some AI/ANs may not be comfortable answering direct questions about sensitive topics like sexual behavior or drug use, and may be uncomfortable being touched without explicit permission. In small rural communities, providers should be prepared to provide referrals to testing and treatment services outside of the community, where concerns about inadequate services and confidentiality can be minimized.

CHALLENGES

Native communities face many challenges in implementing HIV prevention and care services. Challenges include lack of funding, lack of personnel, concerns about confidentiality and geographic distance from services. Providers who work with these communities often face challenges in developing relationships and trust with tribal and community leaders. A significant investment of time is mandatory. However, funding requirements often include an expectation for project implementation to occur and results to be produced in a short timeframe.

IMPACT

Culturally-specific interventions, developed in partnership with Native communities, have a great potential for success. The HIV/AIDS interventions that address culture and identity nuances are promising practices for AI/AN, especially since culture and identity are protective factors against high risk behaviors. Community involvement and cultural relevancy in programming allow for greater ownership and buy-in, and ultimately, sustainability. Potential negative impacts arise from lack of follow-through, commitment, and lack of communication with leaders which can erode trust.

CRITICAL ISSUES AND LESSONS LEARNED

When an outsider approaches a Native community, it is important to present his or herself as a resource available to assist in addressing their self-identified needs. Having preconceived ideas or plans makes it more difficult to gain trust and work in a true partnership. This also applies to patient-provider interactions. A provider working with the patient to identify needs and potential solutions will be more effective than a provider directing a patient in what they should do.

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Northern Plains Tribal Epidemiology Center, Rapid City, SD

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I. Jean Davis, Ph.D., D.C. P.A.
 Goulida A. Downer, Ph.D.,
 R.D., L.N., C.N.S.

HIV/AIDS: Providing Care to Black Women in Urban Communities

“Poverty, racism, issues of self-esteem, a history of sexual, physical and other abuse, lack of health insurance, lack of transportation, lack of child care, homelessness, inconvenient hours at service delivery sites, stigma around HIV, provider insensitivity, and lack of information on risk factors and treatment options prevent some African-American women from seeking care in a timely and appropriate manner”

BACKGROUND

Women of color have been disproportionately affected by the AIDS epidemic since its beginning. That impact is growing¹. It is estimated that women of color account for more than eight in ten new HIV infections occurring among women in the United States, a much greater proportion than their representation in the population overall^(2,3). Higher mortality rates among this population are associated, in part, with poverty, low levels of health literacy, barriers to health care access and utilization, and inadequacies of the provider-patient relationship⁽⁴⁻⁶⁾. Inadequate provider-patient relationships may lead to a low utilization of preventive and screening services, increased risk for HIV/AIDS co-morbidities including mental health problems and poor adherence to Highly Activated Antiretroviral Therapy (HAART), thus reducing health outcomes and survival⁽⁷⁻⁸⁾. Poor health among persons in poverty may also limit treatment options and decrease the chances of surviving the disease.

While African-American women represent 13% of the U.S. female population, they account for 64% of female AIDS cases. Furthermore, HIV/AIDS is the third leading cause of death for black women in the U.S. and the leading cause of death for black women aged 24-34. In 2006, the rate of new infections in black women was nearly 15 times that in White women at 55.7 infections versus 3.8 infections per 100,000 women, respectively (MMWR, September 12, 2008). In addition, among females, Blacks are the most likely to have an initial diagnosis of AIDS, thereby more likely to die due to AIDS related complications.

DESCRIPTION OF BEST PRACTICE

- HIV Prevention
- Early Intervention
- Connection to Care Directly after Diagnosis
- Continuity of Total Care
- Retention in Care.

LEVEL OF INTERVENTION

The proposed strategies are most feasible at the clinic, hospital or Community Based Organizations (CBO) levels.

**PROSPECTIVE USERS
OF THE PRACTICE**

Health care providers serving African American women (OB/GYN, family medicine and internal medicine providers, early intervention programs AIDS service organizations, community-based organizations, and minority health physician programs such as the National Medical Association and National Black Nurses Association)

**PROBLEM
ADDRESSED**

- Lack of and/or inadequate HIV health promotion
- Lack of HIV screening
- Lack of direct connection between screening and medical intervention

**PURPOSE OF
BEST PRACTICE**

To improve health promotion and disease prevention through increased screening based on the Center for Disease Control and prevention HIV testing recommendations.

CONTEXT

African-American women have the highest rate of HIV/AIDS among women residents in the U.S. This population has lower rates of direct medical interventions at time of diagnosis and lower rates of retention in care.

**REQUIRED
RESOURCES**

Multi-pronged community-based efforts aimed at educating African-American women about HIV risks and treatment options, motivating them to get tested, linking those who test positive to care and provide on-going support and follow-up to ensure that women remain in care. This type of effort requires collaboration among providers, grassroots social service organizations, the faith community, and other women serving agencies within the community.

**STEPS TO IMPLEMENT
BEST PRACTICE**

At the community level:

Formative assessment (e.g., focus groups) of community needs, involving consultation and advisement from key stakeholders to identify gaps in women's knowledge. Available services to inform curriculum development and community education messages that target women and stress the importance of HIV testing, early diagnosis and treatment.

At the service delivery setting:

Step One: Providers need to receive cultural competency training in order to identify personal and institutional biases that may affect care offered to African-American women.

Step Two: Individualized health education and support for care seeking behaviors including medication-adherence and linkages to ancillary support to address life issues.

BESAFE – Barriers to Care

- Poverty, racism, issues of self-esteem, a history of sexual, physical and other abuse, lack of health insurance, lack of transportation, lack of child care, homelessness, inconvenient hours at service delivery sites, stigma around HIV, provider insensitivity, and lack of information on risk factors and treatment options prevent some African-American women from seeking care timely and in an appropriate manner⁹. Provider views on HIV/AIDS and their condemnation of many of the behaviors that lead to transmission have been adopted by some women and form a barrier to care¹⁰.
- Resource constraints that limit providers' exposure to cultural competency training focused on specific concerns of disadvantaged population groups.
- The notion that HIV was created as part of a conspiracy to harm African Americans remains popular among certain sectors of the community¹¹. Women who hold this view are likely to be reluctant to seek care at institutions that they perceive to be in league with the "conspiracy."

BESAFE – Ethics

Ethics refer to issues of morality and its impact on one's beliefs, values and behaviors. Religion plays a key role in African-American societies. African-American women typically hold deeply rooted spiritual beliefs, may attend religious services regularly and shape key opinions based on the views of church leaders.

In addition, due to the taboos around frank discussion of sex and body parts and functions, many African-American women have little knowledge of HIV or other STDs and are not likely to seek or continue care when they are asymptomatic or not experiencing incapacitating symptoms. Therefore, providers need to be proactive in offering prevention and treatment services to those who otherwise may not request them. Also, initial patient encounters should serve as opportunities to build trust and offer patients education not only about HIV disease but also basic facts on reproductive biology and women's health. At the same time, providers need to respect patient autonomy and engage women as partners in their care with the locus of control over treatment decisions residing with the patient and not the provider.

Given the heightened concerns around confidentiality an ethical approach to HIV/AIDS screening and treatment require providers to be sensitive to patients' concerns and make all reasonable efforts to be responsive to them.

BESAFE – Sensitivity of the Provider

African-American women have long been the subject of stereotypes that have affected the way they are viewed by certain providers. For example, the image of African-American women as being promiscuous and sexually precocious is widely propagated. Consciously or not, providers may allow stereotypical thinking to affect the treatment options they offer to female patients from this ethnic group. For example, they may make assumptions of risk status and subsequent treatment decisions based on the patient's physical appearance. Cultural competency training can assist providers to recognize and eliminate biases that could negatively impact the quality of care that they deliver.

BESAFE – Assessment

Culturally competent and responsive care for an African-American female patient who is HIV positive begins with collecting relevant information about her lifestyle and beliefs relative to HIV. Relevant information is any aspect of a patient’s life that could impact the efficacy of care that the provider proposes to deliver. For example, does the patient face competing life issues such as homelessness, domestic violence or substance abuse that would make it difficult for her to access and remain in care. In order to have a systematic but individualized approach to patient care, it would be useful for providers to prepare a few questions ahead of time that they could pose to patients to elicit the necessary information.

BESAFE – Facts

Heterosexual women’s reproductive biology places them at a greater risk of contracting HIV than heterosexual men. This risk increases among women with STDs. African Americans have high rates of gonorrhea, syphilis, and Chlamydia, which in turn places this group of women at higher risk for HIV. African-American women are less likely than women of other ethnicities to get married and because of the imbalance in the ratio of women to men, these women are more likely to be in concurrent/non-monogamous relationships. The nature of these relationships may support power dynamics and be more likely to engage in risk behaviors such as not using a condom. This may also encourage younger women to enter into relationships with older men.

BESAFE – Encounters

- Promote cultural competency among providers
- Conduct a cultural assessment of the patient (lifestyle, beliefs about HIV, attitudes and behaviors relative to sexuality) during the initial encounter and update over the course of the patient-provider relationships
- Work with the patient to address actual and potential barriers to care proactively

CHALLENGES

Providers and staff with poorly developed cultural competencies who exhibit “unconscious incompetence” regarding the cultural difference that exist between and within ethnic groups and/or lack knowledge about another culture.

Illustrative indicators of cultural incompetence in the care setting include:

- excessive waiting times
- interrupting patients while they are speaking
- dismissing patients’ accounts of their condition or treatment preferences
- refusing to answer patients’ questions about their condition
- rushing patients through visits, exams, or other interactions
- addressing patients in over familiar or condescending terms that offend cultural norms
- failing to maintain patient confidentiality
- use of language or terminology that patients do not understand
- lack of resources to provide cultural competency training to providers and staff
- Institutional procedures (Barriers) that prevent or limit the delivery of culturally competent care.

Need For Comprehensive Services:

- The paucity of effective, one-stop shopping services in urban areas as well as factors such as inconvenient hours, locations that are not readily accessible by public transportation, and services that do not offer childcare can be a challenge to the delivery of culturally competent care to African-American women.
- Insufficient time for providers to provide culturally competent care.
- Providers face increasing pressure to treat more clients in less time. This means that they often lack the time necessary to find out about each patient as an individual and build trust. This reality poses a challenge to providing quality care.

IMPACT

Expected Outcomes:

- Fewer new infections among African-American women
- Increased access to early HIV/AIDS diagnosis and treatment for infected African-American women
- Enhanced cultural competency among HIV providers serving African-American women at risk of or infected with HIV
- African-American, female patients infected with HIV reporting greater satisfaction with the quality of care they receive

CRITICAL ISSUES AND LESSONS LEARNED

Providers that access training in cultural competency will be able to identify with their patients/clients and assist with strengthening possible health care seeking behaviors. Patients/clients may seek services more regularly and remain in care.

CONTACT INFORMATION

Charles Drew University, Los Angeles, CA

National Minority AIDS Education and Training Center,
Howard University College of Medicine, Washington, DC

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Howard University
College of Medicine

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