Curriculum:
Providing Culturally Competent Care for Transgender Native Americans who are HIV-Positive

Introduction

Welcome to the National Multicultural Center's curriculum on "Providing Culturally Competent Care for Transgender Native Americans who are HIV-Positive," one of a series of curricula covering a wide range of topics concerning the provision of culturally competent HIV-related healthcare services to individuals belonging to diverse ethnic, racial, and cultural groups.

Native Americans have the third highest rate of HIV/AIDS diagnoses, after African Americans and Latinos, although the total number of Native Americans diagnosed with HIV/AIDS is less than 1% of all diagnoses reported to the Centers for Disease Control and Prevention (CDC). The CDC does not compile surveillance data on the numbers of HIV/AIDS diagnoses among transgender persons. Several studies have concluded that the rates of HIV infection are likely high, due to a variety of behavioral and sociocultural factors, which will be discussed in the following modules. Clear epidemiologic data on HIV disease among transgender Native Americans specifically are absent. Because Native Americans and transgender persons have several serious HIV risk factors in common (e.g., financial difficulties, discrimination, high rates of substance use), the incidence of HIV disease among transgender Native Americans is likely to be high.

Not only are HIV surveillance data for the specific population of transgender Native Americans who are HIV-positive not available at this time, but the peer-reviewed literature provides very limited information on this category of patients. The data and discussions offered in this curriculum aim to provide an understanding of the unique set of sociocultural, financial, and health issues faced by this group of patients.

For the purposes of this curriculum, the following definitions will be used:

- Native Americans are members of the population that the US Census Bureau categorizes as American Indian/Alaska Native and include hundreds of officially recognized tribes. Other names sometimes used for this population include Native, American Indian, and Indian.
- "Transgender" refers to a range of gender-variant, gender-diverse, or gender-nonconforming individuals whose self-identification or self-expression differs from society's norms for male or female or whose gender identity differs from that with which they were identified at birth.

This curriculum will offer data and resources designed to increase understanding of the above issues and to support approaches that optimize patient outcomes among practitioners who manage the care of transgender Native Americans who are HIV-positive. This topic is characterized by complex issues regarding these individuals' risks for HIV transmission, access to care, and adherence to therapy. The resources listed in Module 4 and the references in each module provide additional information.

The 5 modules in this curriculum are:

1. HIV Epidemic Among Transgender Native Americans and Transgender Persons

2. HIV Transmission and Treatment Risk Factors
3. Cultural Competence Barriers and Challenges
4. Implementing Culturally Competent Care for Transgender Native Americans
5. Case Study and recommended activities

Learning Objectives of the Overall Curriculum

- Describe the impact of the HIV epidemic among Native American communities
- Describe the impact of the HIV epidemic among transgender individuals
- List the risk factors associated with the disproportionately high HIV infection rates among Native Americans
- List the risk factors associated with the incidence of HIV infection among transgender individuals
- Describe the challenges of providing HIV testing and access to care, and for supporting care retention for transgender Native Americans
- Identify key elements of culturally competent HIV treatment and prevention approaches for transgender Native Americans

Module 1—HIV Epidemic Among Transgender Native Americans

Learning Objectives

- Describe the impact of the HIV epidemic among Native American communities
- Describe the impact of the HIV epidemic among transgender individuals

Pre-training Assessment

1. Which of the following represents the percentage of all US HIV diagnoses that was reported among Native Americans during 2007 to 2010?

A. 45%

B. 1%

C.10%

D. 30%

E. None of the above

2. Which of the following represents the rate of new HIV diagnoses per 100,000 population among Native Americans in 2010?

A. 44

B. 116

C. 18

D. 14

E. None of the above

3. Is the following statement True or False?
The Centers for Disease Control and Prevention began to compile data on the number of transgender Native Americans in 2010.

A. True

B. False

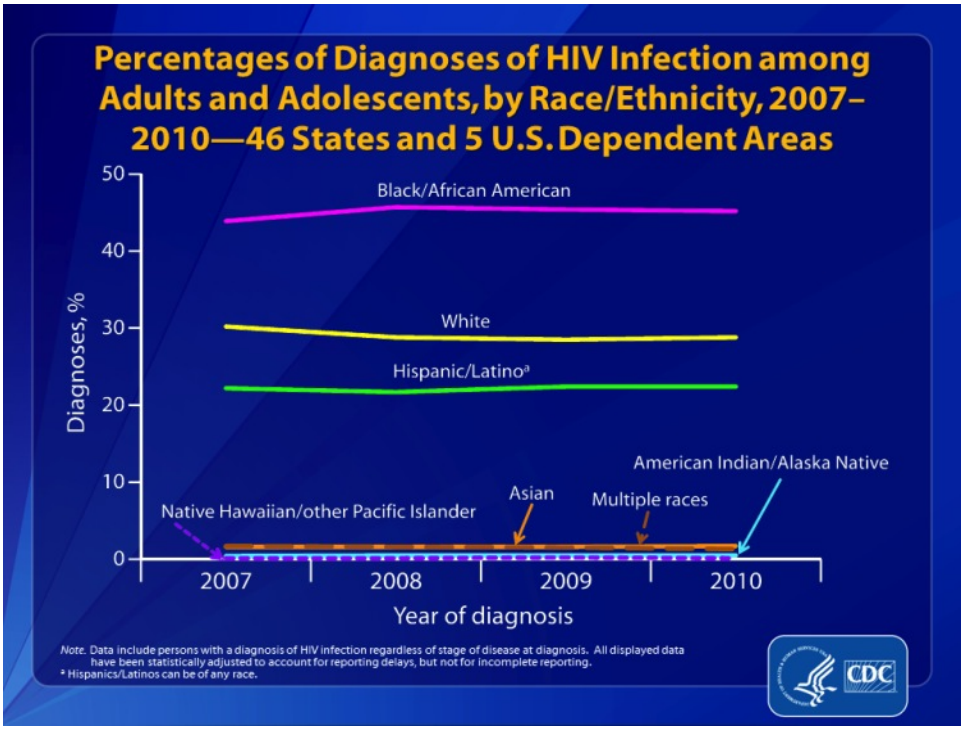
Overview of the HIV Epidemic Among Native Americans and Transgender Persons

The Centers for Disease Control and Prevention (CDC) has not developed HIV surveillance data for transgender Native Americans who are HIV-positive. For that reason, this module will focus on the epidemiologic data for Native Americans, whom the US Census Bureau classifies as American Indian/Alaska Native. The limited data on transgender individuals who are HIV-positive and on the proportion of Native Americans who identify as transgender or two-spirit also will be presented.

Except where indicated otherwise, the estimated numbers and rates of HIV diagnoses presented in this module are based on data from the 46 states and 5 US dependent areas that have had confidential name-based HIV reporting since at least January 2007; the estimated numbers and rates of AIDS diagnoses are based on data from all 50 states, the District of Columbia, and 6 US dependent areas. Population figures used to calculate those rates are based on the official post-Census estimates for 2009.[CDC Diagnoses 2009]

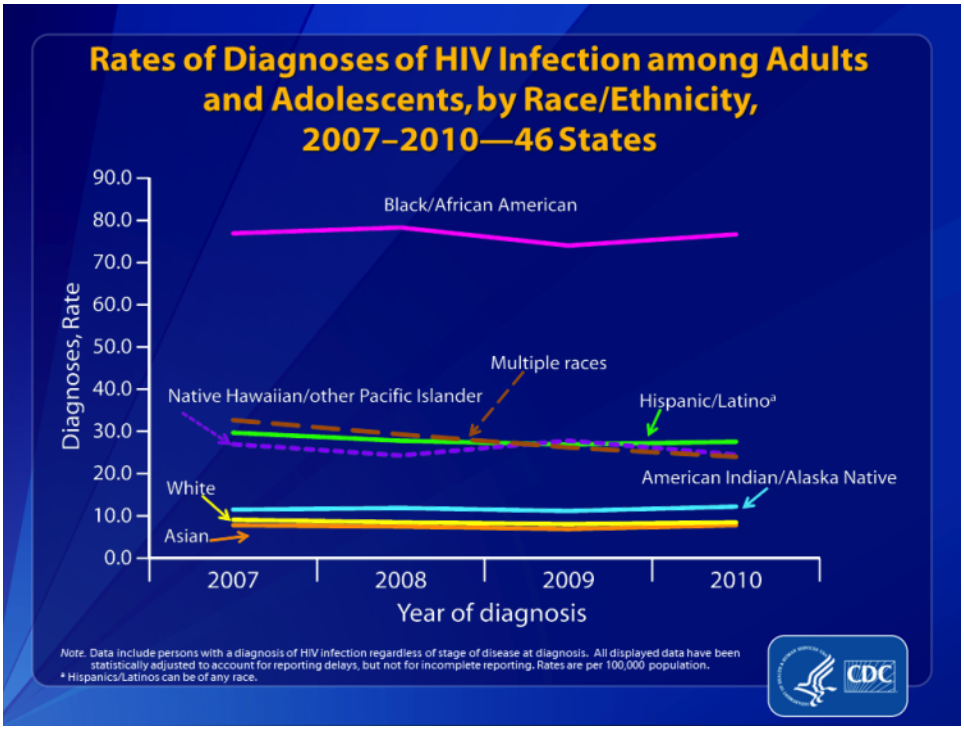
Figure 1.0 shows the percentage distribution of HIV diagnoses by race/ethnicity from 2007 through 2010 among adults and adolescents in the 46 states and 5 dependent areas with long-term HIV reporting. Throughout this time approximately 1% of diagnoses were among American Indians/Alaska Natives. Source: CDC 2011)

Figure 1.0



The following Figure 1.1 illustrates the rates of HIV diagnoses by race/ethnicity from 2007 through 2010.

Figure 1.1



Source: CDC 2011

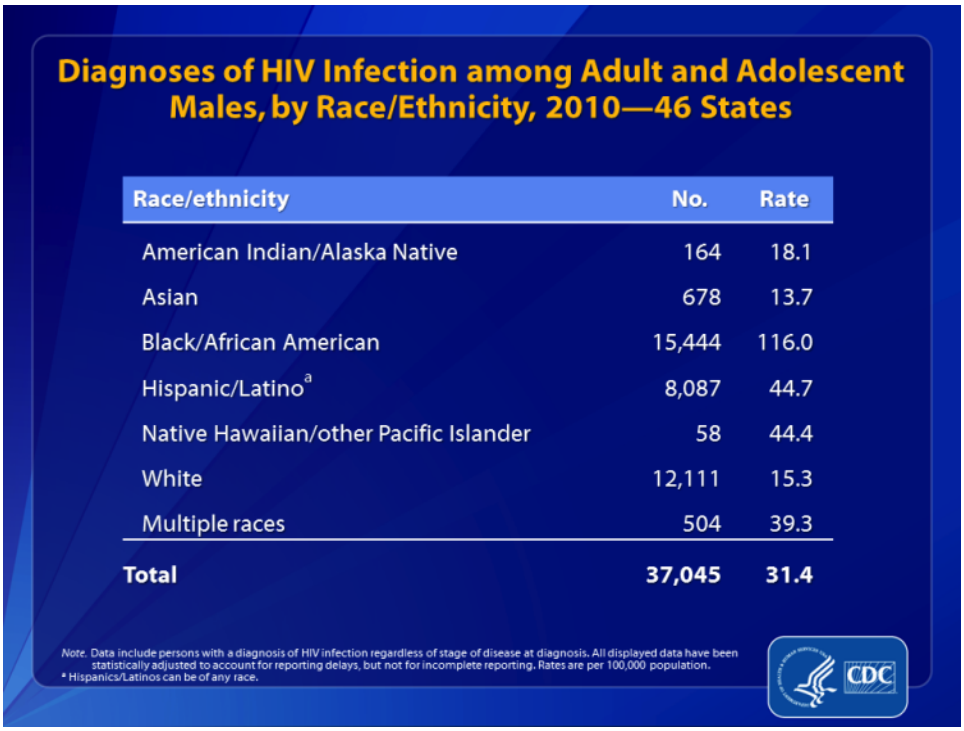
In the following Figure 1.2 the left pie chart illustrates the percentage distribution of HIV diagnoses in 2010 by race/ethnicity, and the right chart shows the 2010 percentage racial/ethnic distribution of the population of those states and territories. The percentage of HIV diagnoses among Native Americans approximately parallels their percentage of the total US population.

Figure 1.2

Source: CDC 2011

Figure 1.3 shows the estimated numbers and rates (per 100,000 population) of HIV diagnoses among adult and adolescent males, indicates a rate of 18.1 for American Indian/Alaska Native males—a higher number than among whites but lower than most other nonwhite groups.

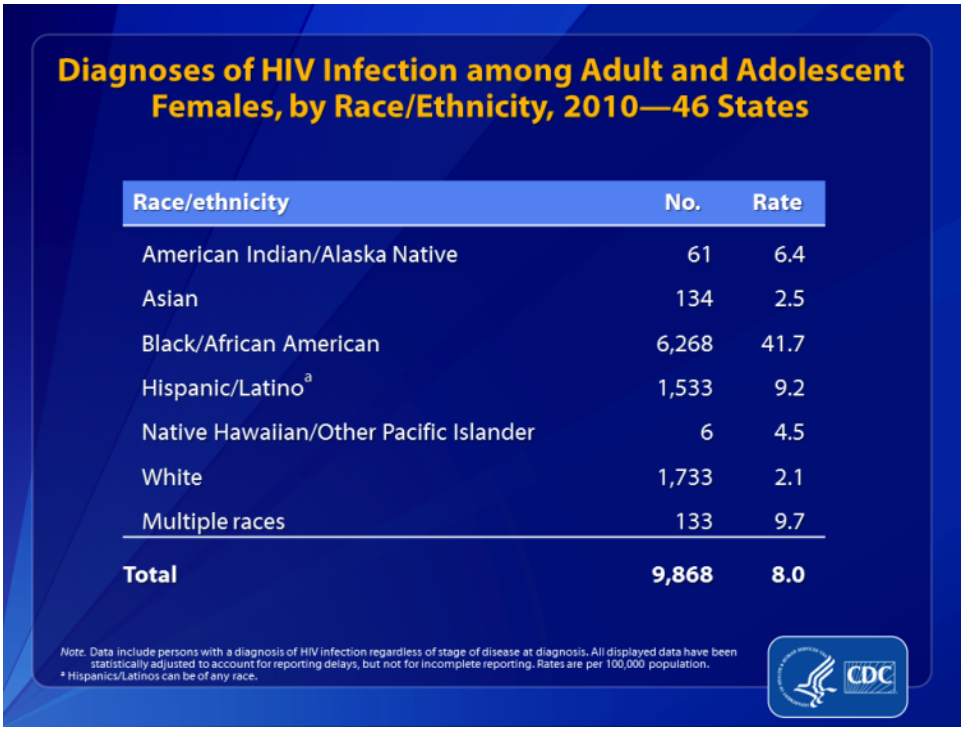
Figure 1.3



Source: CDC 2011

The estimated numbers and rates (per 100,000 population) of diagnoses of HIV infection among adults and adolescent females in the 46 states with long-term HIV reporting, indicates a rate of 6.4 for American Indian/Alaska Native females (Figure 1.4).

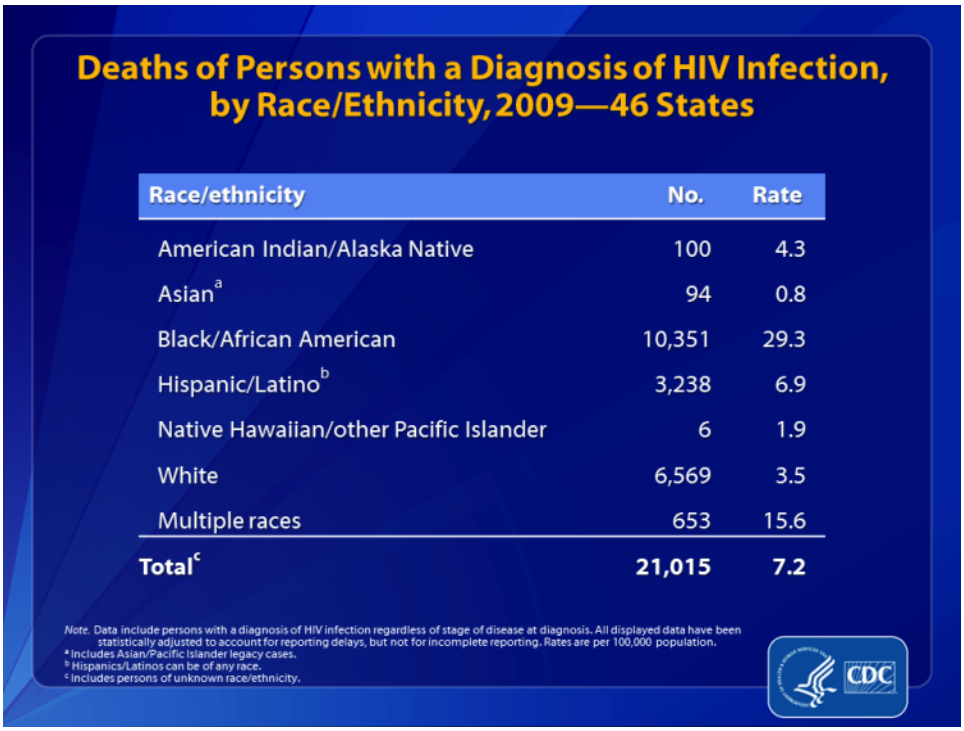
Figure 1.4



Source: CDC 2011

The next figure 1.5 shows the estimated numbers and rates of deaths in 2009 by race/ethnicity of HIV-positive individuals. Relatively few deaths occurred among American Indians/Alaska Natives, although the rates (4.3 per 100,000 population) were the third-highest, following African Americans and Latinos.

Figure 1.5



Deaths of Persons with a Diagnosis of HIV Infection, by Race/Ethnicity, 2009—46 States

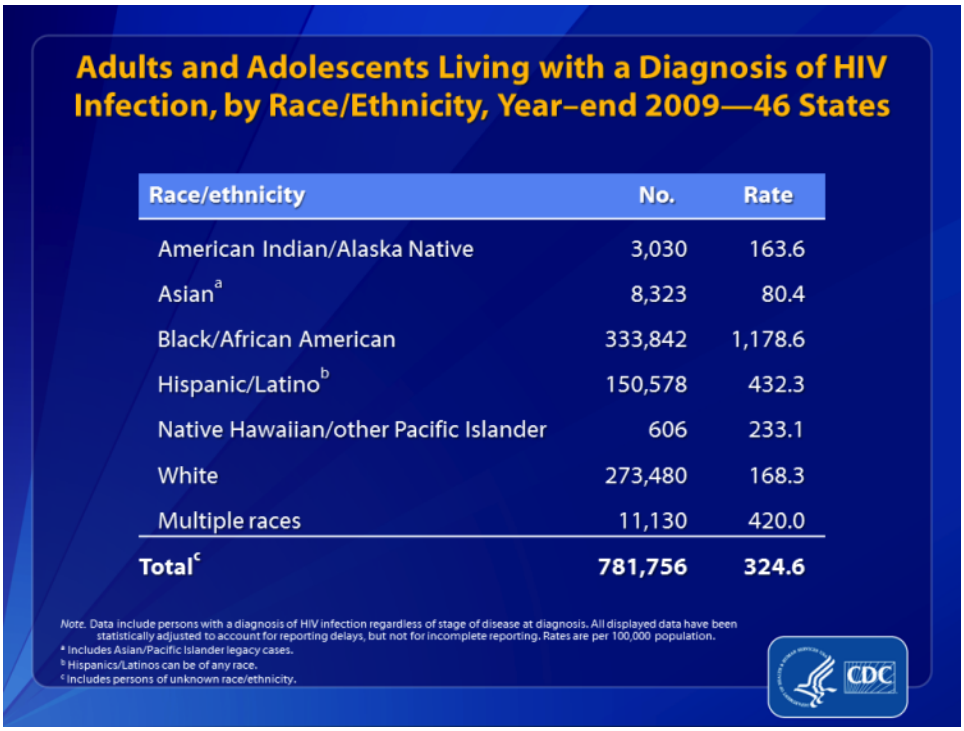
Race/ethnicity	No.	Rate
American Indian/Alaska Native	100	4.3
Asian[a]	94	0.8
Black/African American	10,351	29.3
Hispanic/Latino[b]	3,238	6.9
Native Hawaiian/other Pacific Islander	6	1.9
White	6,569	3.5
Multiple races	653	15.6
Total[c]	**21,015**	**7.2**

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting. Rates are per 100,000 population.
[a] Includes Asian/Pacific Islander legacy cases.
[b] Hispanics/Latinos can be of any race.
[c] Includes persons of unknown race/ethnicity.

Source: CDC 2011

At the end of 2009, 781,756 adults and adolescents were estimated to be living with a diagnosis of HIV disease in the 46 states with long-term HIV reporting, yielding an overall rate of 324.6 per 100,000 population (Figure 1.6). However, among American Indians/Alaska Natives the rate was 163.6 per 100,000 population.

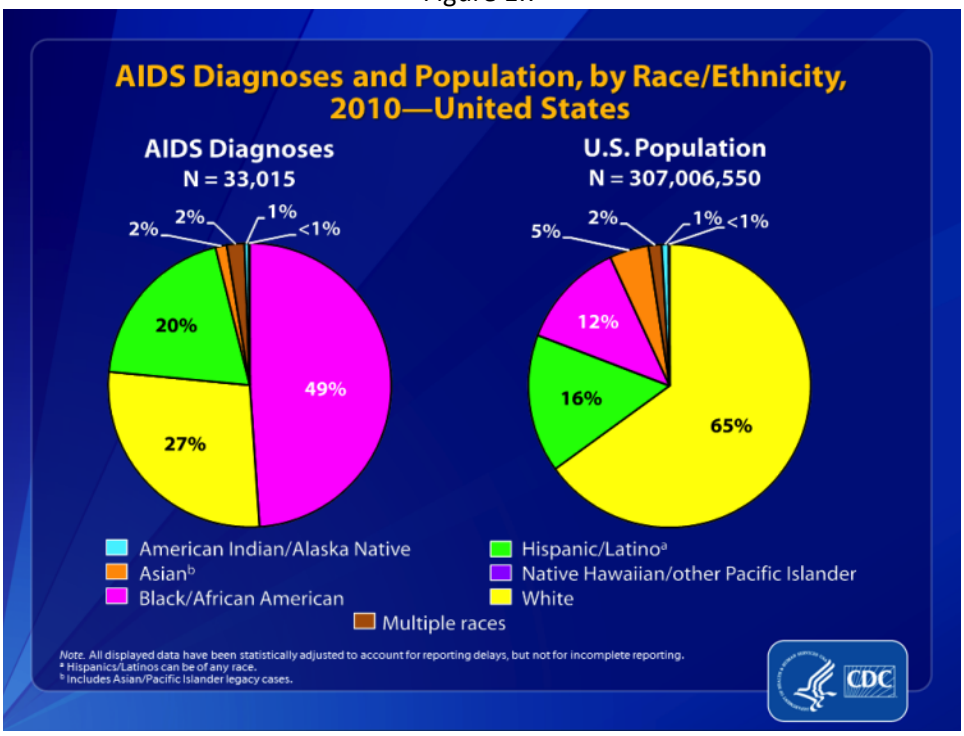
Figure 1.6



Source: CDC 2011

In Figure 1.7 , the left pie chart shows the percentage distribution of AIDS diagnoses by race/ethnicity in 2010, while the right-hand chart shows the racial/ethnic percentage distribution of the US population in 2010. Native Americans comprised approximately 1% of the total US population in 2010 and of AIDS diagnoses that year.

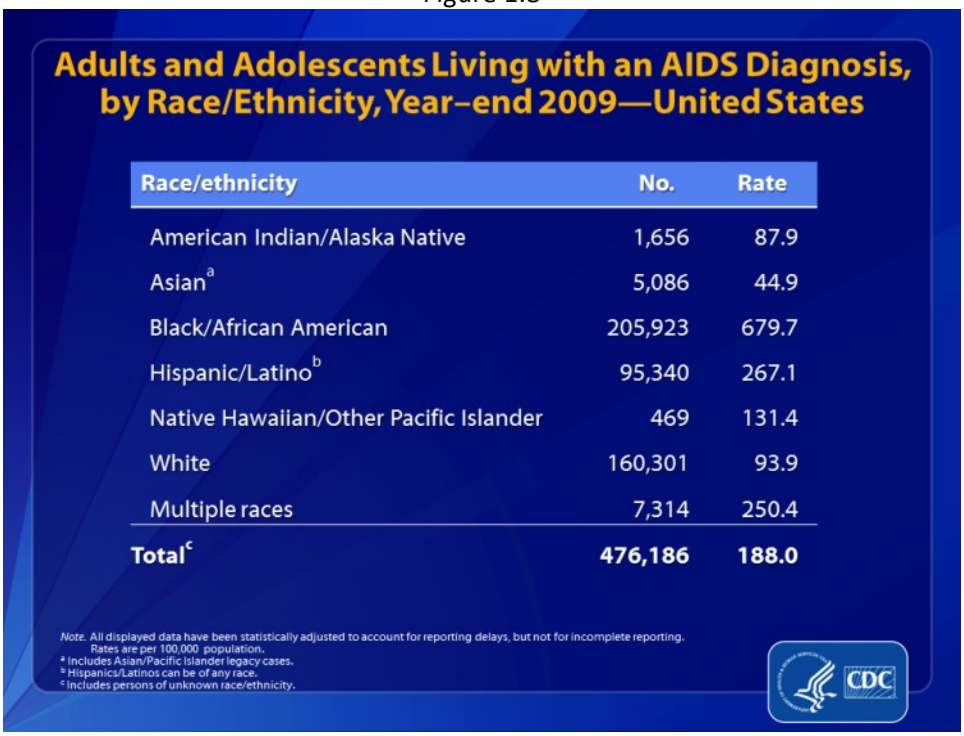
Figure 1.7



Source: CDC, 2011

Figure 1.8 illustrates, at the end of 2009 an estimated 476,186 US adults and adolescents were living with an AIDS diagnosis, for an overall rate of 188.0 per 100,000 population. The rate for American Indians/Alaska Natives was 87.9.

Figure 1.8



Source: CDC 2010

As the following figure shows, among Native American males, male-to-male sexual contact (MSM) and/or MSM plus injection drug use (IDU) are by far the most common modes of HIV transmission, followed by IDU alone (Figure 1.9). Among Native American females, however, the majority of HIV transmissions occur via heterosexual contact, followed by IDU.

Figure 1.9

Source: CDC 2011

Overview of HIV Epidemic Among the Transgender Community

Precise data regarding the number of persons in the US population who identify as transgender are not available, although there have been some efforts to estimate the numbers. In part, this is due to the somewhat fluid definitions of the meaning of "transgender." The data concerning the size of the

transgender Native American population are far from precise. Moreover, the CDC has not compiled information specifically on the numbers of transgender individuals who have been diagnosed with HIV or AIDS.

Nevertheless, the findings of some studies offer at least a glimpse of the extent of the HIV epidemic's impact among transgender persons. Based on analysis of data from the 2006-2008 National Survey of Family Growth, the 2009 California Health Interview Survey, and federal data such as the US Census and the American Community Survey, Gates has estimated that there are nearly 700,000 transgender individuals in the United States, or approximately 0.3% of the adult population.[Gates How Many 2011] In the absence of HIV surveillance data for the transgender population, data compiled by local health departments and researchers studying transgender people indicate that HIV infection rates are high:[CDC Transgender 2011]

- In 2009, out of 2.6 million HIV testing events, approximately 4,100 were conducted for someone who identified as transgender, with 2.6% of the tests in transgender persons revealing previously undiagnosed HIV infections versus 0.9% of non-transgender males who were tested and 0.3% of non-transgender females. The highest percentages of newly identified HIV infections among transgender persons were among African Americans (4.4%) and Latinos (2.5%).
- In New York City, from 2005 to 2009, there were 206 new diagnoses of HIV infection among transgender persons, 95% of whom were male-to-female (MtF). Newly HIV-diagnosed transgender persons were more likely to be in their teens or twenties than were non-transgender persons. Among newly HIV-diagnosed individuals, 50% of transgender women had documentation in their medical records of substance use, commercial sex work, homelessness, incarceration, and/or sexual abuse, versus 31% of those who were not transgender.
- Findings from a meta-analysis of 29 published studies showed that 27.7% of MtF transgender women tested HIV-positive (4 studies), but only 11.8% of MtF transgender women self-reported being HIV-positive (18 studies). In one study, 73% of the transgender women who tested HIV-positive were unaware of their status.[Herbst 2008]

HIV Epidemic Among Transgender Native Americans

Neither the CDC nor any other group has compiled surveillance data on the numbers and rates of HIV infections specifically among transgender Native Americans. For that reason, there are no epidemiologic data that can provide a clear summary of size of the affected population or of their access to HIV testing and medical care. Nevertheless, in light of the significant risks for HIV transmission and linkage to care among transgender populations and of the multiple healthcare challenges faced by Native Americans, the risks for HIV transmission, the presence of unidentified HIV infections, and inadequate access to care among transgender Native Americans are likely to be significant. Therefore, practitioners should become knowledgeable in and apply all of the appropriate cultural competence approaches to understand these patients' backgrounds and healthcare needs. (For a detailed discussion of this topic, please review the curriculum, "Understanding and Implementing the CLAS Standards.")

Summary

The CDC has not compiled HIV surveillance data specifically regarding transgender Native Americans (American Indians/Alaska Natives) who are HIV-positive, and represent a very small and distinct subpopulation among Native Americans. During the period between 2007 and 2010, approximately 1% of HIV diagnoses were among Native Americans; and the rate of new infections among Native

Americans was approximately 18 per 100,000 population. Relatively few deaths occurred among Native Americans, although the rates (4.3 per 100,000 population) were the third-highest, after African Americans and Latinos.

Among Native American males, MSM and/or MSM plus IDU are the most common modes of HIV transmission, followed by IDU alone. Among Native American females, approximately three quarters of HIV transmissions occur via heterosexual contact, with the remainder caused by IDU.

Precise data regarding the number of persons in the US population who identify as transgender are not available. The best available current data suggest approximately 0.3% of the population self-identifies as transgender. Several studies have indicated that a variety of factors are associated with elevated risk of HIV transmission and inadequate access to care among transgender persons. The significant HIV risks and treatment challenges found in both Native American and transgender communities suggest that the HIV epidemic has likely had a disproportionate impact on transgender Native Americans.

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Assessment Questions

1. Which of the following represents the percentage of all US HIV diagnoses that was reported among Native Americans during 2007 to 2010?

A. 45%

B. 1%

C. .10%

D. 30%

E. None of the above

2. Which of the following represents the rate of new HIV diagnoses per 100,000 population among Native Americans in 2010?

A. 44

B. 116

C. 18

D. 14

E. None of the above

3. Is the following statement True or False?
The Centers for Disease Control and Prevention began to compile data on the number of transgender Native Americans in 2010.

A. True

B. False

Module 2—HIV Transmission and Treatment Risk Factors

Learning Objectives

- List the risk factors associated with the disproportionately high HIV infection rates among Native Americans
- List the risk factors associated with the incidence of HIV infection among transgender individuals

Pre-training Assessment

1. Which of the following is (are) risk factors for HIV infection among Native Americans?

A. Relatively low rate of individuals having high school education

B. High rate of alcohol use

C. High rates of sexually transmitted infections

D. All of the above

E. A and C only

2. Which of the following is (are) risk factors for HIV infection among transgender individuals?

A. Participation in commercial sexual activity

B. Alienation from family and community members

C. High rates of substance use

D. High levels of financial difficulties

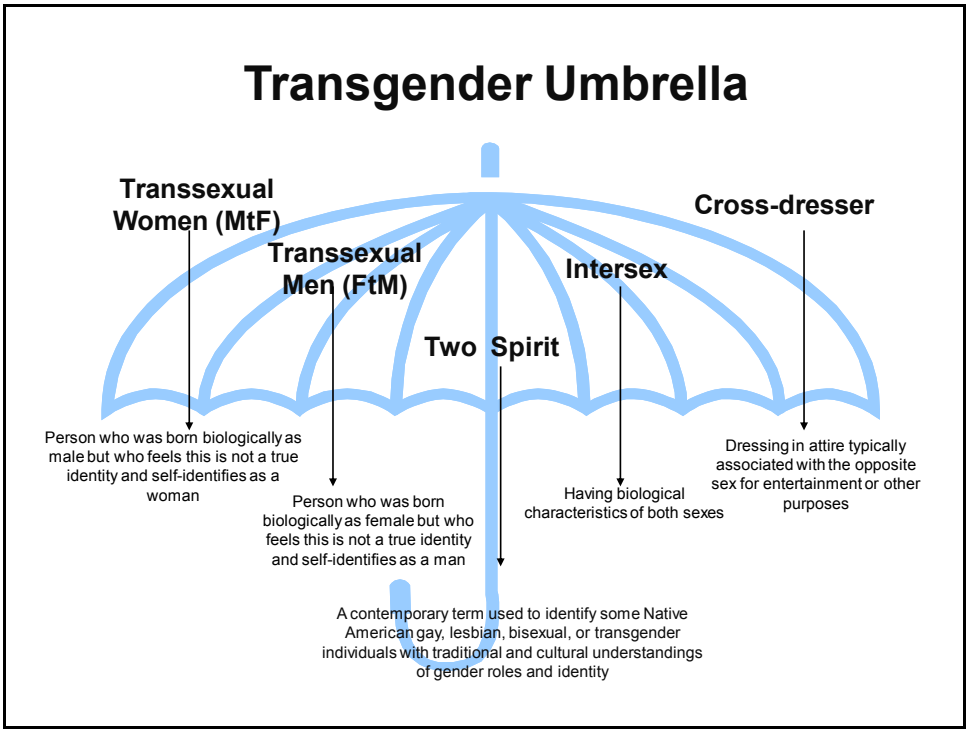
E. All of the above

F. A and C only

Introduction

Increasingly, the term "transgender" has come to be regarded as an umbrella term (Figure 2.1) encompassing a range of gender-variant, gender-diverse, or gender-nonconforming individuals whose self-identification or self-expression falls outside societal norms regarding what is male or female or whose gender identity differs from that with which they were identified at birth. Gender identity, gender expression, and sexual orientation are distinct concepts, none of which is necessarily linked to one's genital anatomy.[CDC HIV transgender 2011] "Gender identity" refers to a person's basic sense of self, of identifying as male, female, or some other gender (e.g., transgender, bigender, or intersex). Transgender individuals include people who self-identify as a gender different from what their biological gender at birth- male-to-female (MtF) or female-to-male (FtM), as well as other gender variant identities. Transgender people include but are not limited to transsexuals, genderqueer, third gender, and two-spirit individuals.

Figure 2.1 Transgender Umbrella



Source: Jacobs 1997

"Two-spirit" is a contemporary term of self-identification used by some Native Americans that can include individuals who may be gay, lesbian, bisexual, transgender, or other terms traditional to their tribal affiliation. The term "two-spirit" was adopted in 1990 at the International Native Gay & Lesbian Gathering. For some Native Americans, the term "two-spirit" provides a way to maintain continuity with their cultural traditions, in which some individuals manifested a balance of both feminine and masculine energies and attributes, making them inherently sacred people. However, the term "two-spirit" originated primarily in urban contexts and may not be suitable for translation into Native American languages, where the term may have a different meaning or may be inappropriate.[Jacobs 1997]

Because the literature on HIV risk and treatment management specifically for transgender Native Americans is extremely limited, this module will discuss these issues separately, first for Native Americans and then for transgender individuals.

Factors Associated with Increased Risk for HIV Infection Among Native Americans

As other curricula in this series have discussed, race and ethnicity in and of themselves are not associated with greater risk for acquiring HIV infection. However, Native Americans often face cultural and socioeconomic factors that are associated with risk for HIV transmission and for inadequate care.

Socioeconomic Issues

Issues related to poverty—such as lower education levels, unemployment and underemployment, and insufficient access to high-quality healthcare services—can contribute to Native Americans' risk for HIV infection. Socioeconomic factors such as poverty coexist with epidemiologic risk factors for HIV infection in Native American communities. The 2010 US Census reported that 28.4% of Native Americans—almost twice as many as the national average of 15.3%—were living in poverty.[Census Comm. Survey 2010] In addition, the proportion of the US Native American population who had a high school diploma, GED, or the equivalent (77%) in 2010 was less than the national average (86%).[Census Comm. Survey 2010]

According to the 2010 American Community Survey, 29.2% of Native Americans lacked health insurance coverage—nearly twice as many as the 15.5% percentage among the US population as a whole.[Census Bureau. Facts 2010] Besides lower rates of health insurance coverage, Native Americans also experience disproportionate burdens of other serious diseases in addition to HIV infection. Cardiovascular disease, cancer, unintentional injuries, diabetes mellitus, and cerebrovascular disease are the five leading causes of death among Native Americans.[IHS Disparities 2012] Native Americans experience disproportionately high rates of death than other Americans from tuberculosis (500% higher), alcoholism (514% higher), diabetes (177% higher), unintentional injuries (140% higher), homicide (92% higher), and suicide (82% higher). As a result of such disproportionate health conditions, Native Americans have a 5.2-years shorter life expectancy compared with the overall US population (72.6 years vs. 77.8 years, respectively). Factors such as these illustrate the vulnerability of Native Americans to a host of serious health problems, including HIV infection.

STI Rates

The presence of a sexually transmitted illness (STI) has been associated with increased risk of acquiring or transmitting HIV infection.[Fleming 1999] According to 2005 STI surveillance data by race/ethnicity, the second-highest rates of gonorrhea and *Chlamydia trachomatis* infection and the third-highest rate of syphilis occurred among Native Americans.[CDC STD Surveillance, McNaghten 2005] These STI rates suggest that the types of sexual behaviors that can also facilitate HIV infection are relatively common in this population.

Substance Use

Both casual and habitual use of a variety of illicit drugs and alcohol abuse are associated with greater likelihood of participating in behaviors, such as unprotected sexual activity, that can increase the risk of HIV transmission. Sharing injection drug equipment increases risk. (For more detailed discussion of the associations between substance use and HIV disease, please review the curriculum, "Culturally

Competent Care for Substance Users Diagnosed with HIV Disease.") The 2005 National Survey on Drug Use and Health reported that the rate of current use of illicit drugs was higher among Native Americans (12.8%) than among members of other races or ethnicities (9.7% among African Americans, 8.1% among whites, and 7.6% among Latinos).[DHHS 2005 National Survey]

Native Americans' use of alcohol, however, was comparable to the rates of other minority populations (47.3% for persons reporting at least 2 races, 42.6% for Latinos, 42.4% for American Indians/Alaska Natives, 40.8% for African Americans, 38.1% for Asians, and 37.3% for Native Hawaiians/Pacific Islanders), but significantly lower than that reported by whites (56.5%).[DHHS 2005 National Survey]

HIV Testing Issues

Limitations on access to HIV testing facilities present a risk for missed diagnoses and lack of linkage to appropriate care among Native Americans, in part because of geographic access and in part for reasons of confidentiality. For example, at the time of receiving an AIDS diagnosis, more Native Americans, compared with individuals of other races/ethnicities, lived in rural areas, where access to HIV testing facilities or services is often limited, resulting in lower testing rates.[Bertolli 2004] In addition, Native Americans may be less likely to seek testing because of concerns about confidentiality in close-knit communities, where someone who seeks HIV testing may be more likely to encounter a friend, relative, or acquaintance at the facility where testing is available.

During the period between 1997 and 2000, 50.5% of Native Americans who responded to the Behavioral Risk Factor Surveillance System survey reported that they had never been tested for HIV infection. In the Southwestern states 58.1% of the Native Americans reporting never having been tested.[Denny 2003]

Factors Associated with Increased Risk for HIV Infection Among Transgender Persons

Transgender individuals experience many circumstances that are associated with increased risk for HIV infection:[CDC HIV Transgender 2011]

- Low self-esteem
- Difficult economic status
- Substance use
- Lack of social support

Self-esteem and Social Support Issues

Transgender individuals often feel that they lack appropriate social support, due to rejection by peers and family members and to lack of relationships with gay, lesbian, and bisexual communities. Bockting and colleagues found that transgender persons reported the lowest levels of support from their families in a study of risk factors among sexual minority groups.[Bockting 2005] Alienation from family and peers may increase individuals' sense of psychological and social vulnerability, which, in turn, may increase their risk for HIV infection.[Nemoto 2005] For example, condoms may be perceived as undermining intimacy with primary partners. Sex with casual partners and a willingness to engage in unprotected receptive anal intercourse may provide a sense of gender validation and of attractiveness that transgender individuals may not find from friends, family, and members of their larger communities.[Nemoto 2004]

Mental health concerns. Studies have found that transgender individuals are more than 1.5 times as likely as nontransgender men to experience depression and nearly twice as likely as nontransgender

men or women to have considered or attempted suicide.[Nemoto 2005, Bockting 2005] A meta-analysis of risk behaviors among transgender individuals found that 35% of MtFs had experienced anxiety and 44% had experienced depression.[Herbst 2008]

Economic Status

Lack of economic opportunities among transgender persons can occur because of individual or institutional discrimination, stigma, and lower education levels. Studies have identified the following economic difficulties in this population:

- More than one-third of MtFs have experienced job discrimination.[Bockting 2008]
- More than one-fifth of MtFs reported income below the federal poverty level.[Bockting 2005]
- Nearly two-thirds of 16-to-25-year-old MtFs were unemployed.[Garofalo 2006]

Economic difficulties such as these may lead some MtFs to engage in commercial sexual activity to earn money. Herbst and colleagues found that 42% of MtFs reported that they had participated in commercial sex work[Herbst 2008]. Garofalo and colleagues reported that 59% of transgender youth had done so.[Garofalo 2006] The findings of a study by Operario and colleagues underlined the great HIV risk involved in this activity—transgender sex workers were found to have rates of HIV infection as much as 4 times higher than those of female sex workers.[Operario 2008]

HIV risk among MtFs is not limited to exposure through sex work—sexual practices and partnership arrangements also play a role. Concurrent sex partners and unprotected receptive anal intercourse (URAI)—the sexual activity having the highest risk for HIV transmission—are common among MtFs. A study by Herbst and colleagues found that more than one-third of MtFs reported having multiple sex partners and nearly half reported engaging in URAI during casual sex.[Herbst 2008]

Substance Use

Nemoto and colleagues reported that, among a group of San Francisco MtFs of color, unprotected receptive anal intercourse with either primary or casual sex partners was associated with drug use before sexual activity.[Nemoto 2004] Many of these individuals begin to use alcohol and other drugs as a means of coping with discrimination, stigma, and the difficulties involved in the sex-work environment. For example, another San Francisco study found that the majority (57%) of transgender participants had a history of using non-injected drugs, including marijuana (90%), cocaine (66%), and methamphetamine. In addition, 34% had a history of injecting drugs, nearly half of whom had shared syringes—an activity having very high risk for HIV transmission.[Nemoto 2005]

Summary

Currently, "transgender" encompasses a range of gender-variant, gender-diverse, or gender-nonconforming individuals whose gender self-identification does not conform to societal norms regarding what is male or female. Poverty-related issues—lower education levels, unemployment, and lack of health insurance and access to quality healthcare services—pose fundamental challenges for HIV-positive Native Americans. Certain sexually transmitted infections—including gonorrhea and chlamydia—that are associated with higher rates of HIV infection occur disproportionately among Native Americans. Illicit drug use, which is associated with behaviors that can facilitate HIV transmission, occurs at higher rates among Native Americans than other races/ethnicities. Finally, geographic isolation and confidentiality concerns may prevent some individuals from accessing HIV testing and care.

Many similar risk factors for HIV infection also confront transgender individuals, including:

- Poverty, job discrimination, and unemployment
- High rates of the use of substances associated with unsafe sexual practices.

Financial difficulties are associated with disproportionate rates of participation in commercial sex work among transgender persons, often involving risky sexual practices. In addition, many transgender individuals feel that they do not have adequate social support, often because of rejection or discrimination by community and family members. This can result in behaviors associated with risk for HIV infection and lack of access to healthcare services for those who are HIV-positive.

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Assessment Questions

1. Which of the following is (are) risk factors for HIV infection among Native Americans?

A. Relatively low rate of individuals having high school education

B. High rate of alcohol use

C. High rates of sexually transmitted infections

D. All of the above

E. A and C only

2. Which of the following is (are) risk factors for HIV infection among transgender individuals?

A. Participation in commercial sexual activity

B. Alienation from family and community members

C. High rates of substance use

D. High levels of financial difficulties

E. All of the above

F. A and C only

Module 3—Cultural Competence Barriers and Challenges

Learning Objective

- Describe the challenges of providing HIV testing and access to and retention in care for transgender Native Americans

Pre-training Assessment

1. Which of the following is (are) among the challenges in providing culturally competent care for Native American patients?

A. Most Native Americans live on reservations or in designated tribal areas.

B. Many Native Americans migrate regularly between rural and urban areas.

C. Rates of health care insurance coverage among Native Americans are lower compared with rates among the general population.

D. All of the above

E. B and C only

2. Native Americans are commonly misclassified as members of which of the following racial/ethnic groups?

A. African American

B. Latino

C. White

D. A, B, and C

E. B and C only

3. Is the following statement True or False?
Almost all transgender individuals self-identify as female.

A. True

B. False

Intersecting Challenges Between Native Americans and Transgender Persons

Introduction

Although exact data on the number of transgender Native Americans who are HIV-positive are not currently available, many of the risks and challenges involved in diagnosing and managing this population overlap with those found in Native Americans who are HIV-positive. These overlaps include financial difficulties, discrimination and social marginalization, high rates of comorbid conditions, and disproportionate rates of substance use—each of which contributes to increased risk of HIV transmission and increased challenges to clinical management of HIV-positive individuals. Therefore, a convergence of all these factors can develop, leaving transgender Native Americans vulnerable to acquiring HIV infection and experiencing less than optimal treatment outcomes.

Challenges in the Management of Native American Patients

Discrimination and Distrust of Authority

Racial and ethnic discrimination has placed Native Americans at a serious disadvantage regarding economic opportunities, healthcare, and education virtually since the first arrival of European settlers in North America. In addition, due to a lengthy history of broken treaties, lost territories, the reservations system, enforced attendance at government boarding schools, and the urban relocation program, Native Americans have a long-established distrust of government programs and activities. This distrust often includes public-health officials, both because they are government agents and because of specific tribal histories of receiving inadequate or no healthcare services.

Demographic Challenges

Identifying members of the population and where they reside is one of the most important challenges to providing culturally competent care for transgender Native Americans who are HIV-positive. The 2010 US Census reported that there were 5.2 million Native Americans (1.7% of the total US population), including individuals who described themselves as belonging to more than one ethnicity.[Census Bureau. Facts 2010] Native Americans are a diverse group:

- There are 334 federally and state-recognized American Indian reservations.
- Native Americans belong to 565 federally recognized tribes.
- 28% of Native Americans at least 5 years of age speak a language other than English at home, versus 21% of the population as a whole.
- 22% of Native Americans live in American Indian areas or Alaska Native Village Statistical Areas, which include federal reservations and off-reservation trust lands.

Misclassification. Although the total number of HIV diagnoses among Native Americans is relatively low, racial misclassification may result in under-reporting of HIV incidence in this population. Misclassification of Native Americans as members of other racial/ethnic groups is a concern throughout the healthcare system—in part because many are of mixed heritage and may be classified as African American, Asian/Pacific Islander, Latino, or white.[Oropeza 2001] Burhansstipanov and colleagues found that Native Americans in general are undercounted by 38% nationwide.[Burhansstipanov 2000] Misclassification may vary by region. In Alaska, 3% of Native Americans who are HIV-positive were

misclassified as belonging to another race; in Los Angeles, 56% of Native Americans diagnosed with AIDS were racially misclassified.[Alaska 2003; Hu 2003]

Language. Native Americans are widely dispersed geographically. Many speak languages other than English [Census Bureau 2011. Native American community beliefs and practices are diverse. This spectrum of beliefs includes of the idea of two-spirit individuals. Indigenous terms for two-spirit individuals include:

- Lakota: *wíŋkte*
- Navajo: *nádleehé*
- Mohave: *hwame*

Two-spirits. The term two-spirit was coined only in 1990, adapted from an Anishinabe word meaning "to have both female and male spirits in one person." "Two-spirit" is often meant to describe individuals who have traditionally performed a variety of roles in many Native American communities. Although some two-spirits may wear clothing of the opposite sex (more commonly wearing a mixture of clothing) or engage in activities typically associated with the opposite sex, that is not an essential part of the definition of two-spirit. Roles traditionally performed by two-spirits in some tribes included: artisans and craftspeople, child-care workers, healers, and counselors and arbiters. In addition, much of the respect in which two-spirits have been held derived from being considered to be associated with spirits and often endowed with abilities associated with shamans.

Traditional Healing Practices

In native cultures, traditional healers can assist individuals in their efforts to achieve overall well-being. Many patients may consult them because they typically are more accessible to individuals who live on or near a reservation.[Oropeza 2002] In some cases, patients who are HIV-positive living in an urban environment may wish to return home to participate in traditional medicine practices. Traditional healing can include a range of plants, herbs, other substances, and ceremonies with which most HIV practitioners are unfamiliar. Although there are some overlapping practices, different tribes often have their own particular traditional medicines and healing practices. This is consistent with the common Native American belief in a holistic approach to health—in contrast to mainstream medicine's tendency to focus on a specific set of symptoms or a particular organ system. Traditionally, Native Americans consider health to represent the harmony of mind, body, and spirit with nature, with illness implying an imbalance within the individual and between the individual and nature. This attitude toward health suggests that the whole person must be treated, rather than just one problem or set of symptoms.

It is important for clinicians to understand patients' perspectives on health and healing and the role of traditional healers in their treatment planning. Clinicians should discuss these practices with patients and, if possible, coordinate care with traditional healers. This approach helps to protect patients from potential dangerous interactions between traditional and conventional drugs. It also can facilitate patient-clinician communication. Clinical management that reflects patient perspectives will increase patient engagement and adherence to recommended treatment protocols.

Migration Habits

Some Native Americans are accustomed to migrating between reservation/rural areas and urban areas. Depending on distance and the purpose, these migrations can occur daily, weekly, or several times a year. The motivations for this may include family visits, participation in tribal ceremonies, job and educational opportunities, substance abuse, and accessing healthcare services:

- Because employment and educational opportunities in tribal areas tend to be limited, some individuals may travel long distances to an urban area to work or to obtain an education.
- Substance users may travel to cities, where access to alcohol or drugs is easier. Some reservations prohibit the sale or use of alcohol.
- A substance abuser may need to travel to an urban area to participate in a drug or alcohol treatment program.
- A person living in an urban area who has a medical condition may choose to return home to receive care from family or community members or to have access to traditional healing practices.
- Some individuals need to travel or even relocate from a reservation/rural area to an urban area to receive more comprehensive, mainstream healthcare services. This can include access to HIV specialty care.

Such migration habits make identifying need for and providing appropriate healthcare to Native Americans who are HIV-positive challenging. They can also facilitate the transmission of HIV infection and other diseases between urban areas and reservations.

Communications Styles

Native Americans' communication style can be reserved, which some practitioners may be tempted to interpret as unfriendly.[Oropeza 2002] When addressed, some Native Americans may look away or down in deference to another person's authority, and some communities may consider direct eye contact to be a sign of disrespect. Native Americans often speak slowly and deliberately, which can be mistaken as a lack of education.

Many Native American are cautious when communicating with other people—in part because some communities discourage sharing information or problems about oneself and family members. Distrust of authority and concerns for confidentiality also contribute to the habit of not disclosing personal information. On the other hand, Native Americans typically listen carefully and keenly observe nonverbal communication, such as facial expressions, gestures, or vocal tones. Practitioners should not interpret Native American patients' failure to volunteer information as meaning that there are no health concerns. It is critical to develop trust with each patient and to encourage information sharing.

Sexual Orientation Issues

Many Native American tribes have a history of accepting alternative gender roles and sexualities that dates to before the arrival of European settlers, whose Christian beliefs influenced these indigenous social systems and beliefs regarding gender roles and sexuality. Some tribes did not have such accepting attitudes., Native American individuals and communities are capable of exhibiting homophobic attitudes that are similar to those prevalent in mainstream society.[Oropeza 2002] As discussed previously, however, some gay, lesbian, bisexual and transgender Native Americans have adapted the "two-spirit" identity as a way to reclaim the historical, more inclusive alternative gender roles and traditions.

Provider-Related Challenges

As discussed previously in this curriculum, clear epidemiologic data on the number of transgender Native Americans who are HIV-positive are lacking. The total number of individuals who belong to this

specific population is likely small, given the relatively small total number of Native Americans who are HIV-positive and the low incidence of transgender persons in the general population. This lack of epidemiologic data presents a challenge for healthcare providers who serve this population. Providers may be unfamiliar with these patients' unique needs, and patients may be challenged to identify providers able to address those needs.

Economic Barriers

As discussed in Module 2 of this curriculum, Native Americans face a set of serious and pervasive economic barriers. Poverty-related issues—low income, unemployment, inadequate education—exacerbate Native Americans' risk for acquiring HIV infection. According to the 2010 US Census, 28.4% of Native Americans lived in poverty. Fewer Native Americans (77%) had a high school diploma, GED, or the equivalent than the general population as a whole (86%).[Census Facts, 2010
The US Department of Health and Human Services' Indian Health Service (IHS) provides or pays for care for approximately 1.5 million Native Americans, with service providers located mostly on or near tribal reservations. More than half of Native Americans live in urban areas, without easy access to IHS facilities. In addition, according to the 2010 American Community Survey, 29.2% of Native Americans had no health insurance coverage,[Census Bureau. Facts 2010] and approximately 17% receive health insurance coverage through Medicaid.[Kaiser. American Indians 2004]

Besides lower rates of health insurance coverage, Native Americans also experience disproportionate burdens of other serious diseases in addition to HIV infection. Cardiovascular disease, cancer, unintentional injuries, diabetes mellitus, and cerebrovascular disease are the 5 leading causes of death among Native Americans.[IHS Disparities 2012] Native Americans experience disproportionately high rates of death from tuberculosis (500% higher than general population), alcoholism (514% higher than general population), diabetes (177% higher than general population), unintentional injuries (140% higher than general population), homicide (92% higher than general population), and suicide (82% higher than general population). As a result of such disproportionate health conditions, Native Americans have a 5.2-years shorter life expectancy compared with the overall US population (72.6 years vs 77.8 years, respectively). Factors such as these illustrate the vulnerability of Native Americans to a host of serious health problems, including HIV infection.

Inadequate HIV Testing
Access to HIV testing and confidentiality issues are important concerns among many Native American communities. Native Americans are more likely than members of other races/ethnicities to live in rural areas.[Bertolli 2004] Rural residents may be less likely to be tested for HIV infection because their access to testing facilities is likely to be limited. Native Americans who live in close-knit communities also may be reluctant to seek testing due to concerns about confidentiality and the likelihood of encountering a friend, relative, or acquaintance at the facility.

Between 1997 and 2000, 50.5% of American Indians and Alaska Natives who responded to the Behavioral Risk Factor Surveillance System survey reported that they had never been tested for HIV. In the southwestern United States, 58.1% of Native Americans reported never having been tested.[Denny 2003] Late diagnosis of HIV infection has been associated with higher rates of diagnosis of HIV-related conditions and greater mortality.[CDC. Late HIV Testing 2009]

Challenges in Management of Transgender Persons

Many cultural, socioeconomic, and health factors contribute to the challenges of providing appropriate HIV prevention and treatment services to transgender individuals; and many of these overlap with the challenges facing Native Americans.

Identification of transgender persons

Determining who is or is not transgender can be a challenge, both because people use a range of definitions and because some individuals who meet certain definitions do not self-identify as transgender. Because many individuals self-identify as simply male or female, and because few epidemiological data sources provide more than these categories, data may not include information on whether respondents are transgender. Many individuals may not wish to identify as transgender because of the potential for stigma and discrimination. One source of stigma is some providers' requirement of a "gender identity disorder" diagnosis to be eligible for services. To avoid the label of a psychiatric disorder and the often lengthy associated evaluation process, some transgender people engage in risky self-treatment such as street hormone use or injection silicone use.[SF AIDS Foundation. Transgender2009]. National Coalition for LGBT Health 2004]

Practitioners should not make assumptions about sexual orientation and behavior based on gender identity alone. Considerable diversity in sexual orientation and behavior occurs among transgender people, with some identifying both as transgender and as gay, bisexual, or lesbian. The US Institute of Medicine has recommended that behavioral and surveillance data for transgender individuals should be collected and analyzed separately, rather than grouped with MSM data.

Discrimination and stigma

Many transgender individuals encounter various forms of discrimination and social stigma, which can hinder their access to education, employment, and housing opportunities. One study reported that transgender individuals were more likely than MSM or heterosexual women to live in transient housing and to have lower education levels. Discrimination may lead some transgender individuals to pursue high-risk activities, such as commercial sex work, to meet basic survival needs. Another high-risk activity associated with discrimination is participation in unprotected receptive anal intercourse, which some transgender persons may agree to due to fear of sex partner rejection or need to affirm their gender identity. Discrimination and stigma may contribute to high rates of depression, emotional distress, loneliness, and social isolation—sometimes resulting in suicidal thoughts and suicide attempts among transgender individuals.[CDC Transgender 2011]

Practitioners' insensitivity and lack of knowledge

Healthcare providers' lack of knowledge, experience, and skills regarding many aspects of transgender identity, sexual behaviors, and health needs can inhibit HIV-positive transgender persons from seeking appropriate healthcare services. Studies have shown that similar proportions of HIV-positive transgender MtFs and other HIV-positive individuals have health insurance coverage, but that transgender patients were less likely to receive HAART.[CDC Transgender 2011]

In addition, health insurance policies typically do not offer coverage that is specific to transgender individuals' needs—e.g., medically unsupervised injections of silicone and hormones—leaving many at risk for less than adequate medical care, including HIV prevention, and treatment.[Bockting 2008]

Summary

Many of the risks and challenges involved in diagnosing and managing transgender Native Americans who are HIV-positive represent a convergence of similar factors found among Native Americans who are HIV-positive:

- Financial problems
- Discrimination and stigma
- Presence of comorbidities
- Increased rates of substance use

This convergence means that HIV-positive transgender Native Americans a likely to experience several risk factors for acquiring HIV infection and experiencing poor treatment outcomes.

Because no specific demographic data on the precise size of this population are available, practitioners who manage transgender Native Americans who are HIV-positive must depend on information about Native Americans and about transgender people to estimate demographic data. Providing HIV prevention, testing, and care for these patients will involve awareness of the complex factors many Native Americans must navigate between traditional beliefs and practices and modern evidence-based healthcare services. It also is critical for practitioners to understand transgender patients' specialized medical needs.

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Assessment Questions

1. Which of the following is (are) among the challenges in providing culturally competent care for Native American patients?

A. Most Native Americans live on reservations or in designated tribal areas.

B. Many Native Americans migrate regularly between rural and urban areas.

C. Rates of health care insurance coverage among Native Americans is lower compared with rates among the general population.

D. All of the above

E. B and C only

2. Native Americans are commonly misclassified as members of which of the following racial/ethnic groups?

A. African American

B. Latino

C. White

D. A, B, and C

E. B and C only

3. Is the following statement True or False?
Almost all transgender individuals self-identify as female.

A. True

B. False

Module 4—Implementing Culturally Competent Care for Transgender Native Americans

Learning Objective

- Identify key elements of culturally competent HIV treatment and prevention approaches for transgender Native Americans

Pre-training Assessment

1. A productive cultural competence framework in managing diverse patient populations includes which of the following elements?

A. Discussing what HIV means to the patient

B. Asking the patient about his or her preferences regarding healthcare

C. Inquiring about sources of stress in the patient's life

D. All of the above

E. A and B only

2. Studies have demonstrated that which of the following factors is (are) associated with greater risk of poor adherence to HAART?

A. Active substance use

B. Depression

C. Race or ethnicity

D. All of the above

E. A and B only

3. Which of the following is (are) important components of culturally competent treatment in managing Native Americans who are HIV-positive?

A. Input from Native American community organizations

B. Presence of a staff member who is fluent in the American Indian language

C. Understanding the history of Native Americans' experience with federal and state government agencies

D. Awareness of Native Americans' more indirect style of personal communication

E. All of the above

F. A, C, and D only

4. Is the following statement True or False?
Native Americans who have received most of their healthcare through the Indian Health Service may feel disoriented by mainstream healthcare systems.

A. True

B. False

5. Which of the following is (are) important components of culturally competent treatment in managing transgender patients who are HIV-positive?

A. Providing the full range of safer sex recommendations

B. Determining by what name the patient wants to be addressed

C. Prescribing hormone therapy for all patients who request it

D. Assessment by a mental healthcare professional

E. A, B, and D only

F. All of the above

Introduction

As the modules on epidemiology, risk factors, and prevention and treatment challenges in this curriculum discussed, the precise makeup and size of the population of transgender Native Americans who are HIV-positive is uncertain. This is due primarily to two factors:

- The small number (compared to other racial/ethnic groups) of Native Americans who are HIV-positive
- The somewhat fluid definition of "transgender," which may include individuals who self-identify as members of a different gender from their birth gender, those who have undergone sex reassignment treatments, those who identify as two-spirit Native Americans, and others

There is no set of HIV treatment guidelines devoted specifically to transgender Native Americans. No peer-reviewed publications on that subject were found in a search conducted for this curriculum. Until such resources are developed, practitioners with patients who self-identify as transgender Native Americans need to be knowledgeable about culturally appropriate treatment of both Native Americans and transgender persons. This module will discuss the needs of each group separately and point out where the needs of both groups may intersect.

Elements of a Cultural Competence Framework

One widely published HIV clinician has proposed that clinicians who treat patients from a variety of racial/ethnic and cultural backgrounds use "a cultural competence framework" so as to provide care that is appropriate for each patient's particular needs.[Stone 2004, Carrillo 1999] This framework, outlined below, offers the advantage of not requiring a clinician to know all of the specific beliefs and practices associated with each different group. Rather, it utilizes a structured provider-patient dialogue that allows the patient to introduce issues that are important to her or him, whether involving culture, lifestyle, religion, sexual behavior, or other factors. This type of adaptable, interactive framework can be particularly useful during clinical encounters with patients who have complex backgrounds that have been shaped by discrimination, social marginalization, and mental health challenges. The preceding modules in this curriculum have shown that these circumstances are common among both transgender people and Native Americans.

The steps involved in this cultural competence framework are:

- Identify the patient's core cultural issues by asking about values and preferences regarding healthcare, while watching for any spoken or nonverbal hints about these preferences. The latter point can be especially important in interacting with Native American patients.
- Explore what HIV means to the patient by asking what the patient believes might have caused it and how it affects his or her life. This can elicit information about the patient's perspective, values, and culture. Inquire about the patient's social situation:
    - To what extent does the patient feel in control of her/his life? Are there financial or other material constraints that could affect health choices?
    - Has the patient experienced any change in environment, such as immigration or relocation?
    - What is the patient's preferred language; and what is her or his literacy level?
    - What kind of support systems does the patient have, including sources of stress, living situation, religious affiliation, family and friends?

- Negotiate with the patient to develop a treatment plan that is agreeable to both patient and practitioner.

This framework allows a practitioner to learn the key issues that are important to the patient. It provides information about the extent to which a patient adheres to traditional cultural values or is more acculturated to mainstream US society. This information is valuable for developing a treatment plan that engages the patient and encourages adherence.

Improving Communication in the Clinic

Several studies have identified inadequate or ineffective communication as a key component of non-white patients' dissatisfaction with the healthcare services that they receive. The amount of time spent with a practitioner can be a valuable predictor of patient satisfaction[Warde 2001]. Transgender Native Americans who are HIV-positive may require more time than members of some other groups to understand and make decisions about HIV treatment options. To the extent possible, clinicians should try to spend more time with these patients, particularly focusing on listening to them. Clinicians can enhance patients' comprehension by assessing their understanding in a sensitive, non-condescending manner. Examples include asking, "Does that make sense to you?" or asking the patient to repeat back the treatment plan that has been agreed upon. Providing written materials in the patient's preferred language and at an appropriate literacy level can enhance comprehension. Clinical staff such as nurses, physician assistants, case managers, and peer counselors can be assigned to spend more time with the patient and answer additional questions.

Importance of Staff Diversity

According to an analysis from the HIV Cost and Services Utilization Study (HCSUS), racial concordance between patients who are HIV-positive and their providers is associated with decreased disparities in time to starting HAART for minority patients.[Stone 2004] Such findings confirm the important potential benefit of diversifying the staff who are involved in providing care for patients who are HIV-positive. Although recruiting HIV-specializing physicians can be quite challenging, adding other patient-facing staff who are Native American can substantially increase patients' comfort level. Such staff may include front-desk staff, medical assistants, and others. Furthermore, both current and new staff members at all levels should receive regular cultural competence education and training. (Please review the curriculum "Understanding and Implementing the CLAS Standards" for a more thorough discussion of the types of trainings that are available and who should participate in them.)

Optimizing HIV Care and HAART

Since the early years of the HIV epidemic, disparities in care, including in the receipt of antiretroviral therapy, have been reported among patients belonging to racial/ethnic minorities. For example, nonwhite patients often experience a longer average delay after being diagnosed with HIV infection before they access HIV care. Once linked to care, these patients are less likely to receive HAART than white patients.[Stone 2004, Cunningham 2006, Dennis 2011]

Practitioners who serve transgender Native Americans should become familiar with this pattern of disparities and should establish clinical strategies to optimize the probability that HAART will be recommended to these patients and that patients will adhere to the recommended regimen. Such strategies include working to build trust in the patient-provider relationship, ensuring that the patient

participates in decisions about his or her own care, and providing enough time and information—from other clinical staff members if there is not adequate physician time to do so—for the patient to make an informed decision and understand the importance of taking the medications as directed.[Stone Perspectives 2004] Practitioners should develop approaches to manage comorbidities such as hepatitis C coinfection, substance use disorders, or mental disorders and patients' concerns about antiretroviral adverse effects or other medication-related toxicities. This can help to minimize the risks of nonadherence and to optimize the likelihood of attaining full virologic suppression.

Enhancing Adherence to HAART

Researchers and clinicians have known for many years that patient adherence to HAART is critical to achieving full virologic suppression and good immune reconstitution. Once this became well established, interest began to grow in whether certain factors could be associated with predicting adherence and whether certain patients might be at greater risk for nonadherence and treatment failure. Investigators have found that a patient's demographic characteristics generally cannot be used to predict adherence to HAART when other key predictors of nonadherence are considered.[Stone 2001, Battaglioli-DeNero 2007] Studies of HAART adherence have demonstrated that only a limited number of patient factors can reliably be associated with inadequate adherence:[Malcolm 2003, Alfonso 2006, Malta 2008, Cohn 2011]

- Depression
- Active alcohol abuse
- Active injection drug use (former users seem to have adherence rates similar to patients with no substance use history)
- Low health literacy

Depression, substance use. Depression and substance abuse are both common in persons who are HIV-positive; some patients experience both types of concerns.[Angelino 2001, Angelino 2008, Tegger 2008, Starace 2002] Depression may be more difficult to diagnose in nonwhite than white patients. Practitioners who manage HIV-infected patients should perform routine screening for depression in all patients before initiating HAART. Likewise, all patients—not just those who likely became HIV-positive via injection drug use—should be screened for potential substance abuse issues. (For more detailed discussion of this subject, please review the curriculum, "Culturally Competent Care for Substance Users Diagnosed with HIV Disease.") Before prescribing HAART for patients in whom depression, substance use issues, or some combination of these is identified, clinicians should develop a management plan. The risk of poor adherence is greater if these issues remain unaddressed. HIV practitioners should make an effort to collaborate with patients' mental healthcare or drug treatment providers to optimize both HIV treatment and mental health and substance use outcomes.[Stone 2004]

Health literacy. Clinicians should endeavor to assess patients' health literacy levels and to correct any misconceptions.[Corbie-Smith 2002, Kumar 2009, Armstrong 2007, Zekeri 2009] Although a patient's racial/ethnic background has generally not been found to be predictive of adherence, some highly charged emotional factors may disproportionately affect nonwhite patients' willingness and ability to adhere to HAART. These include distrust of traditional healthcare practices and concerns about potential harm associated with medications that some may regard as toxic, experimental, or ineffective.[Corbie-Smith 2002, Kumar 2009, Armstrong 2007, Stone 2004, Cunningham 2000] Support groups, peer educators, and treatment buddies are some of the strategies that clinical staff can use to help patients develop more positive attitudes about their treatment.

Cultivating a trusting clinician-patient relationship before beginning HAART can enhance adherence. Several studies of adherence have shown that the quality of the patient-provider relationship is one of the most important predictors of adherence, particularly for nonwhite patients.[Stone 2004, Simoni 2008, Malcolm 2003] Logistical supports—such as directly observed therapy—can significantly enhance patients' adherence to HAART if a practitioner observes indications that a patient may be at risk for poor adherence.[Moitra 2011, Mitty 2002, Goggin 2007]

Improving Use of HIV Testing and Access to Care

Within a cultural competence framework for managing patients who are HIV-positive such as Stone's outlined above, there are several broad strategic approaches that are key to improving care for transgender Native Americans who are HIV-positive.

Increasing the number of transgender Native Americans who are aware of their HIV status is a critical first step. Studies have shown that individuals who know that they are HIV-positive typically reduce risky sexual behaviors, thereby reducing HIV transmission and community viral load.[Colfax 2002] HIV-positive persons who are not aware of their status are the primary cause of new HIV infections.[Marks 2006] Efforts to expand the number of transgender Native Americans who are aware of their HIV status will require that both patients and healthcare providers become knowledgeable about the Centers for Disease Control and Prevention's current guidelines for HIV testing.[Branson 2006] (For more detailed discussion of testing issues, please review the curriculum, "Promoting HIV Testing in Diverse Populations.") Similarly, healthcare providers and facilities need to develop and implement approaches that take into account the risks and challenges discussed in Modules 2 and 3 of this curriculum so as to link transgender Native Americans who are HIV-positive to HIV care, and to ensure that they are retained in care.

Cultural Competence and the Native American Community

Although many urban areas across the United States have programs and community-based organizations that serve the needs of either Native Americans who are HIV-positive or transgender individuals who are HIV-positive, ones that specifically target transgender Native Americans who are HIV-positive are virtually nonexistent. Therefore, the section that follows will briefly describe the cultural competence approaches designed to serve each population group.

Burks et al. conducted a survey of gay, bisexual, and two-spirit Native American men to determine what respondents would like from HIV prevention and care services designed to serve them.[Burks 2011] An important study finding was that participants thought that HIV prevention and care efforts would be more effective if Native American outreach workers were involved in condom and information distribution and in peer and community education. The participants would also like to see a national HIV service organization, run by Native Americans that could foster a sense of community ownership as well as reintroduce traditional Native American healing practices. As a model, the authors cited the now-defunct Native American HIV services organization, Ahalaya, which offered its clients traditional healing and spirituality services, referral services, case management, and social and psychological support. An evaluation of Ahalaya found that participants in the program reported significant improvement in quality of life and HIV knowledge, as well as reduced risk behaviors.

Diversity Among Native Americans

Practitioners who are responsible for managing HIV testing, prevention, and treatment programs for Native Americans should recognize that the term "Native American" encompasses a broad range of beliefs, values, and practices. Therefore, HIV programs should take into consideration the cultural perspectives held by the individual Native American patient.

Cultivating trust and rapport with Native American tribal leaders and elders, who serve as the gatekeepers for community health issues, is critical. Knowing the local history of the Native American community and its experiences with the US and state governments is important. Practitioners who manage the care of Native Americans who are HIV-positive can benefit from becoming familiar with Native American history, both nationally and within the population that a particular practice serves. For example, many Native American nations self-identify as sovereign entities, and therefore not part of the jurisdiction of a local health department. This may mean that certain public health activities such as HIV name reporting and partner notification may pose barriers to patient trust and access. In the view of many Native Americans, the US government, including some health and social policy agencies, has not always maintained full fidelity with its treaties and other agreements with Native American tribes.[National Alliance 2004]

Practitioners should also become familiar with the relevant language and terminology used by members of the particular Native American communities that their practices serve. Examples include:

- Some communities have different preferences for the terms that describe their communities—Native American, Indian, American Indian, or a Native-language word.
- Some Native Americans refer to their nation/tribe using a word from their native language rather than the English term—e.g., Haudenosaunee instead of Iroquois, or Lakota instead of Sioux.
- Some Native Americans also self-identify according to the name of their clan or extended family.

Incorporating Native Perspectives and Staff

Some Native American healers are reluctant to work with a non-Native caseworker. When an HIV-positive patient who has been assigned a non-Native caseworker wishes to use indigenous healing practices, a community-based agency serving Native Americans may be able to provide assistance in accessing a traditional healer or even provide transportation to the place where the healer practices. This again underlines the importance of seeking input from Native American community agencies when developing HIV services for any members of that community, including transgender Native Americans who are HIV-positive. For example, practitioners may benefit from learning the findings of community organizations' HIV needs assessments. Practitioners can use results to develop and implement services that address community needs.

Creating a Sense of Empowerment

Practitioners who serve Native American patients need to cultivate in their patients a sense that they can understand and be in control of their own healthcare. This can begin when taking a patient's history, by asking where he/she grew up and whether traditional healing practices were part of a patient's background. If a patient indicates a history of using such practices, providers should be nonjudgmental, while encouraging the patient to access both mainstream and traditional medical practices whenever possible, emphasizing that the two can be more effective when used together.[Oropeza 2002]

Compiling a comprehensive patient history allows practitioners to begin to create an empowerment narrative, with the goal of optimizing HIV treatment outcome. One component of this narrative is asking patients to talk about how they successfully overcame difficulties in the past. This can be particularly helpful for patients who feel that they have little or no control over the course of their HIV disease. Offering patients treatment options, while discussing the advantages and disadvantages of each can empower them to make their own decisions and to be involved in every step of their own care.

Importance of Direct Communication

Many Native Americans are not comfortable with and do not engage in direct communication, and providers should become familiar with Native American patients' communication styles (see Module 3 in this curriculum). For patients who communicate in this way, practitioners may need to read non-verbal cues and subtle language to discern patients' concerns. Providers should explain to patients that they will ask direct questions to help appropriately assess and serve their needs and that the intention is not to be insensitive. Citing examples of direct and indirect questions and answers may help patients understand the difference. When questioning patients or explaining treatments, practitioners should use standard medical terminology, followed by any known slang or lay terms that may be used in the community and should encourage patients to ask questions when unfamiliar medical terminology is used.[Oropeza 2002]

Practitioners can further help overcome Native American patients' distrust and reliance on indirect communication by telling them about their own experiences in managing other patients who are HIV-positive, emphasizing the goal of optimizing patient well-being. It is important that patients understand that practitioners will discuss treatment options with them and will involve them in the decision-making process. The trust and direct communication cultivated in this way will support patient adherence to treatment plans.

Pacing the delivery of information. Medical terminology can be intimidating, and in some patients' minds it can become overshadowed by psychosocial issues related to integrating HIV into a patient's identity. Practitioners can approach this concern by providing information to patients gradually and by confirming that they understand before proceeding. Providing too much information at one time can cause some patients to withdraw from further discussion and become isolated from the healthcare system.

Enhancing familiarity with the healthcare system. Those Native Americans who have received most of their healthcare through Indian Health Service (IHS) or tribal clinics may feel disoriented by mainstream healthcare systems. Practitioners should educate these patients about how the healthcare system works, using diagrams or directories of services, if available. This should include an explanation of the provider/patient relationship, including the roles both of the primary care provider and of other providers who will be involved in the patient's care. Encouraging patients to advocate for themselves and to question providers and others involved in their healthcare when more information is needed can also be empowering.

Integrating HIV Diagnosis Into Self-Identification

When patients first learn that they have been diagnosed with HIV infection, it can take time to accept the reality of the diagnosis and to integrate it into their self-identification. A newly diagnosed Native American patient may be in denial about his/her HIV status, may not want to discuss it with others, or may be reluctant to access HIV services. Use of direct questioning—rather than indirect questions about

thoughts and feelings—can provide the most productive way to help Native American patients integrate their HIV diagnosis into their self-identification.[Oropeza 2002]

The following are the types of questions that can help the patient with this integration process:

- What do you know about your HIV diagnosis?
- What treatments or services, including traditional ones, have you sought since you were diagnosed?
- Do you have an HIV case manager?
- Do you know about federal or state benefits programs?
- Who else knows about your diagnosis?
- Do you try to avoid thinking about HIV, or do you find that you cannot stop thinking about it?
- Do you practice safer sex?

Linkage to Other Services

Practitioners should be prepared to refer patients to HIV support groups or similar services, where they may have the opportunity to meet other HIV-positive individuals. Native Americans who are HIV-positive may feel isolated and alone, especially if HIV support services are not available in the area where they live. Practitioners may want to consider developing these support systems in their clinics so that patients have a safe environment where their confidentiality will be secure.

Some patients will need or want further support from a variety of social service providers, particularly ones that serve Native Americans. Practitioners should be knowledgeable about local resources. These can include HIV-case management programs, support groups, and substance abuse programs. Native American social service providers can act as advocates and intermediaries to interpret and support patients' treatment plans.

Cultural Competence for the Transgender Community

Practitioners must be knowledgeable about the unique medical and other needs of transgender persons, as well as those of Native Americans who are HIV-positive. The section that follows provides a concise review of the elements of culturally competent care of transgender individuals who are HIV-positive. A subsequent curriculum in this series will provide a comprehensive discussion of the epidemiology, challenges, and practice of providing culturally competent care to HIV-positive transgender patients of all races/ethnicities.

Many transgender individuals do not access the healthcare services necessary to prevent and manage HIV infection. Moreover, they bring to any clinical encounter a set of unique physical and psychosocial healthcare needs. By developing culturally sensitive and appropriate practices, healthcare providers can reduce the barriers to care and help transgender patients achieve optimal health outcomes. Below are some of the core components of creating a practice environment that is transgender-friendly.[Williamson 2010]

Patient Health History

Intake forms should include "transgender" and "other" in addition to "male" and "female." Intake forms and all patient-facing staff should use gender-appropriate language as initial indicators of the healthcare practice's sensitivity to the special needs of transgender patients. For example, an individual who was

assigned a male name at birth may now choose to be called by a female name. Some basic questions can help further clarify this issue:

- Do you self-identify primarily as male or female?
- How long ago did you realize that your body and your self-identification did not match?
- Have you ever received hormones?
- Have you used needles to inject hormones, silicone, narcotics, or other drugs?

Sexual health. Practitioners should ask about sexual behaviors, such as the use of condoms and preferred sexual partners (male, female, or both), because transgender persons may self-identify as gay, heterosexual, or bisexual. Since behavior, rather than gender or orientation, is the key factor in the risk for HIV transmission, practitioners should inquire whether a patient has participated in unprotected receptive intercourse with biological males. By obtaining an accurate sexual health history, a provider can offer safer sex recommendations that are culturally appropriate and useful to each individual patient.

Mental health. Practitioners should determine whether transgender patients have seen a mental healthcare professional, especially regarding gender issues. Transgender individuals often experience feelings of depression, frustration, social isolation, and anxiety as they develop their sense of self-identification. Mental healthcare professionals can provide clinicians with an assessment of whether a transgender patient is suitable for hormone therapy, if the patient is considering that approach. If a mental healthcare provider has diagnosed a patient with a serious coexisting mental disorder, a clinician may decide against prescribing hormone therapy at that time.

Physical examination. Many transgender persons avoid complete physical examination for long periods of time, due to reluctance to discuss their gender identity or to concerns that a practitioner would be unqualified, uncomfortable, or judgmental. After taking other measures to reassure the patient, the clinician should ask transgender patients when they last had a complete physical, which should include the chest and genital areas. Use of neutral terms such as these is preferable to terms like breast or testicular exam, which may cause discomfort to some transgender patients whose feelings about their anatomical incongruity are still ambivalent. Clinicians' findings from a physical exam can vary widely, depending on whether a patient has received hormone or cosmetic surgical treatments. In addition, some MtFs may dress in women's clothes, yet have entirely male anatomy.

Safer Sex Education

Because transgender patients may engage in a variety of sexual behaviors, practitioners should be prepared to provide patients with the full range of recommendations regarding safer sex practices, so that patients are not put into the position of have to reveal their own personal sexual practices, which some may not feel comfortable enough to discuss. Practitioners should encourage the use of condoms, latex gloves, and other barriers for all types of penetrative oral, vaginal, and anal sexual activities. The overall goal of safer sex practices should be to decrease the risk of all sexually transmitted infections.

Hormone Therapy

Managing hormone therapy in transgender patients who are HIV-positive can present challenges, due to the potential for interactions between the hormones and antiretroviral agents. Hormonal agents often used among transgender patients include testosterone, estradiol, and oral contraceptives. In addition to or instead of hormones prescribed by a clinician, some transgender patients may obtain these agents illegally and self-administer them. Co-administration of antiretroviral agents and hormones in transgender women (MtFs) has not been studied extensively, and clinicians should review the most up-

to-date HIV treatment guidelines from the US Department of Health and Human Services (www.aidsinfo.nih.gov/guidelines) when considering such co-administration.

In Short

Provision of culturally competent healthcare for transgender patients who are HIV-positive requires that practitioners offer a transgender-friendly clinical environment. Clinicians must be knowledgeable about the physical effects of treatments such as hormone therapy and genital-conforming surgery, as well as the potential implications for selection of antiretroviral agents and treatments for any comorbidities. Critical elements to providing a transgender-friendly environment include:

- Staff commitment to eliminating institutional barriers to care
- Collecting appropriate history for each transgender patient
- Presenting treatment information in a way that involves transgender patients in all aspects of decision making about their healthcare

Selected Resources

Native American Resources

American Indian Community House. A nonprofit organization serving the health, social service, and cultural needs of Native Americans living in New York City, including HIV referral and case management services. www.aich.org/.

Changing Directions: Strengthening the Shield of Knowledge. Dickey M, Tafoya T, Wirth W. Available at: www.aidsetc.org/aidsetc?page=etres-display&resource=etres-541. Changing Directions is a 55-page train-the-trainer curriculum designed to aid non–Native American healthcare professionals in developing the skills to increase the quality and effectiveness of HIV prevention and care services for Native Americans. The curriculum covers issues involved in delivering culturally competent care to Native Americans living both in reservations/tribal areas and in urban environments.

Canadian Aboriginal AIDS Network. A nonprofit coalition providing leadership, support, and advocacy for native people affected by HIV, regardless of where they live; includes extensive list of resources in English and French. www.caan.ca/.

Commitment to Action for 7th-Generation Awareness & Education: HIV/AIDS Prevention Project (CA7AE: HAPP). A project of Colorado State University, HAPP provides capacity-building assistance to native communities, tribal health departments, state health departments, and other CDC-funded organizations serving Native Americans. www.happ.colostate.edu/.

Indian Health Service (IHS) - HIV/AIDS Program. Comprehensive HIV portal administered by IHS, which is responsible for providing federal health services to American Indians and Alaska Natives www.ihs.gov/hivaids/index.cfm.

The Indigenous HIV/AIDS Research Training Program (IHART). IHART is a program within the Indigenous Wellness Research Institute, School of Social Work, University of Washington; http://depts.washington.edu/ihartp/. Its goals are:

- To build a network of skilled scholars dedicated to culturally grounded research that contributes to improving HIV and mental health–related disparities among American Indians/Alaska Natives, Native Hawaiians, and other indigenous populations
- To enhance skills development for grants, research, publications, and partnerships of tribal, community, and university-based scholars

Indigenous Peoples Task Force. A nonprofit organization whose mission is to provide HIV prevention and education services to Native Americans and direct services to HIV-positive Native Americans and their family members
www.indigenouspeoplestf.org/.

National Native American AIDS Prevention Center (NNAAPC). This organization's mission is to address the impact of HIV on American Indians, Alaska Natives, and Native Hawaiians through culturally appropriate advocacy, research, education, and policy development. www.nnaapc.org/.

Native American AIDS Project. Nonprofit organization located in San Francisco that offers education and prevention services, day activities program, case management, treatment, mental health services, and more. www.naap-ca.org/.

Project Red Talon. A project of the Northwest Portland Area Indian Health Board, providing HIV/STD prevention education, training, technical assistance, capacity building, and resource materials to federally recognized American Indian tribes in the Pacific Northwest.
www.npaihb.org/epicenter/project/project_red_talon/.

Red Circle Project. This is a program of AIDS Project Los Angeles that provides culturally competent HIV resources and referrals; group interventions for Native gay/two-spirit men and transgender individuals; and mobile HIV testing to urban Native cultural events. http://redcircleproject.org/.

Transgender Resources

Callen-Lorde Community Health Center. This New York City–based organization has developed a set of protocols for hormone treatment of transgender individuals. To request a copy of the protocols, please visit: www.callen-lorde.org.

Center of Excellence for Transgender HIV Prevention. This organization's mission is to increase access to comprehensive, effective, and affirming healthcare services for transgender and gender-variant communities. www.transhealth.ucsf.edu.

National Center for Transgender Equality. This organization is dedicated to advancing the equality of transgender people through advocacy, collaboration, and empowerment by monitoring federal activity and communicating information about it to members around the country, providing congressional education, and maintaining a center of expertise on transgender issues. www.nctequality.org.

Positive Health Project. This agency provides HIV prevention and care services to marginalized populations who are at very high risk of HIV infection and transmission.
http://positivehealthproject.org/.

Transgender Awareness Training and Advocacy. Website of Samuel Lurie, who provides healthcare trainings regarding transgender people to a variety of organizations. www.tgtrain.org/.

Transgender Care. This group compiles information and articles on transgender health issues. www.transgendercare.com.

World Professional Association for Transgender Health (WPATH). WPATH is an international, multidisciplinary professional association whose mission is to promote evidence-based care, education, research, advocacy, public policy, and respect in transgender health. www.wpath.org.

Summary

In managing the care of transgender Native Americans who are HIV-positive, practitioners should understand the key risk factors for HIV transmission and inadequate access to care and the complex set of challenges related to this group's social, cultural, psychological, and health circumstances. This understanding of transgender Native Americans' beliefs, attitudes, and behaviors can be practically applied through a "cultural competence framework," a process that allows a practitioner to become familiar with the issues that are important to the patient and to incorporate this understanding into treatment plans. Effective communication is the key to patients' satisfaction with their healthcare encounters. Practitioners should take appropriate measures to ensure that patients understand and agree with recommended treatment plans. Adherence to HAART is critical to optimal clinical outcomes; and studies have shown that patients' race/ethnicity are not associated with their ability to achieve optimal adherence. Factors associated with greater risk of poor adherence include: depression, active alcohol or substance abuse, and low health literacy. Although specific data and practice guidelines for transgender Native Americans are unavailable at this time, a wide range of resources is available to assist practitioners in understanding HIV-related behaviors, risks, and clinical management among both Native Americans and transgender individuals.

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Assessment Questions

1. A productive cultural competence framework in managing diverse patient populations includes which of the following elements?

A. Discussing what HIV means to the patient

B. Asking the patient about his or her preferences regarding healthcare

C. Inquiring about sources of stress in the patient's life

D. All of the above

E. A and B only

2. Studies have demonstrated that which of the following factors is (are) associated with greater risk of poor adherence to HAART?

A. Active substance use

B. Depression

C. Race or ethnicity

D. All of the above

E. A and B only

3. Which of the following is (are) important components of culturally competent treatment in managing Native Americans who are HIV-positive?

A. Input from Native American community organizations

B. Presence of a staff member who is fluent in the American Indian language

C. Understanding the history of Native Americans' experience with federal and state government agencies

D. Awareness of Native Americans' more indirect style of personal communication

E. All of the above

F. A, C, and D only

4. Is the following statement True or False?
Native Americans who have received most of their healthcare through the Indian Health Service may feel disoriented by mainstream healthcare systems.

A. True

B. False

5. Which of the following is (are) important components of culturally competent treatment in managing transgender patients who are HIV-positive?

A. Providing the full range of safer sex recommendations

B. Determining by what name the patient wants to be addressed

C. Prescribing hormone therapy for all patients who request it

D. Assessment by a mental healthcare professional

E. A, B, and D only

F. All of the above

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