

American Indians and Alaska Natives and HIV/AIDS

In 1981, a new infectious disease, AIDS (or acquired immunodeficiency syndrome), was identified in the US. Several years later, the causative agent of AIDS—human immunodeficiency virus (HIV)—was discovered. This discovery coincided with the growing recognition that AIDS in the US was part of a global infectious disease pandemic.

Currently, HIV/AIDS has been reported in virtually every racial and ethnic population, every age group, and every socioeconomic group in every state and most large cities in the US. HIV/AIDS remains a significant cause of illness, disability, and death in the US, despite declines in 1996 and 1997. (US DHHS, 2000). In 2001, an estimated 29,723 AIDS cases were diagnosed among minority racial or ethnic groups, which accounted for more than 70% of all AIDS cases diagnosed that year in the US. (CDC, 2002).

“American Indians and Alaska Natives represent a unique population within the US, not only because of their oppression suffered in the development of this country but also because of their ongoing struggle to gain recognition in the HIV/AIDS epidemic. American Indians and Alaska Natives are not so unique, however, that they are protected from the same behaviors that put all people at risk for HIV infection.” (Rowell and Bouey, 2002).

- **Prevalence and Incidence**
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- **Strengths and Protective Factors**
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Adherence Factors

- Many American Indian and Alaska Native tribes emphasize **living each day as it comes**. This perspective can influence how American Indian and Alaska Native patients adhere to pharmacotherapies—for example, whether they are feeling well or poorly on a given day. (Oropeza, 2002).

Recommendation

Explain to your American Indian and Alaska Native patients how HIV progresses in the body and how antiretroviral therapies work over time. (Oropeza, 2002).

Questions to Promote Adherence

- Do you have any questions about what I explained?
 - Do you understand what I am recommending?
 - Is there anything that would make it difficult to follow my recommendations?
 - Is there anything that you think should be changed?
- (MSH, 2003b).

Providers should:

- Acknowledge bias.
 - Value diversity and difference.
 - Look for cultural strengths.
 - Recognize the interaction of race, culture, and gender.
 - Know that culture is important to the clinical encounter.
- (MSH, 2003b).

Communication: Verbal and Nonverbal

- **Handshake.** A firm handshake in Anglo-American culture is a symbol of strong character, but in some American Indian groups, a limp hand is culturally appropriate and is a symbol of humility and respect. (HRSA, 2003b).

Recommendation

To enhance provider-patient communication, build culturally competent care elements into clinical practice guidelines. For example, use the mnemonics BATHE, ETHNIC, and ADHERE. (HRSA, 2003d).

- **English language.** More than 1 in 20 American Indians and Alaska Natives lives in a household in which no adolescent or adult speaks English “very well.” (Smedley et al., 2003).
- Some American Indians and Alaska Natives exhibit a **style of communication that is reserved** and may be interpreted as unfriendly. Many American Indian and Alaska Native people also exercise caution in personal communications with others. Information or problems may not be readily shared.

Recommendation

Do not interpret a failure to volunteer information as an indication that nothing is wrong. An American Indian or Alaska Native patient is more likely to share information if you have developed trust. (Oropeza, 2002).

- **Slow down.** American Indian languages have some of the longest pause times compared with other languages, especially English. Silence is valued, and long periods of silence between speakers is common. (Hendrix, 2002).

Create an Atmosphere of Open Communication

Perhaps the most important thing a provider can do to ensure that a patient adheres to recommended treatment is to create an atmosphere of open communication. The patient needs to trust that the provider is acting in his or her best interests. The patient needs to understand the purpose of the treatment and be confident that the provider has used good judgment in recommending it. What many providers overlook is that the patient needs to be able to tell the provider when he or she does not understand something about the recommended treatment—most importantly, when the treatment conflicts with the patient’s beliefs or lifestyle. Cultural factors may interfere with the provider’s ability to understand what the patient means or needs. (MSH, 2003b).

Communicate Effectively

- Listen to **how the client describes** his or her condition.
- Learn to **ask questions appropriately.**
- Learn to **observe nonverbal behavior.**
- Ask the client for **his or her views.**
- Know when to involve **family members.**
- Know when to use **interpreters.**

(MSH, 2003b).

- **How to refer to American Indians.** Although there is no agreement about appropriate labels, when speaking generally of American Indians rather than of a specific nation, using the word *people* (Indian people, Native people, indigenous people, First Nation people) may be most appropriate. When speaking of a specific nation such as Lakota, Onondaga, or Nez Perce, use of these specific labels is generally preferable to a broader term. (Weaver, 1998).

Recommendation

When working with a specific client, ask about that client’s preferred terms. Doing so communicates respect. (Weaver, 1998).

Keys to Communicating with American Indian Patients

1. **Greet** your patient warmly, smile, shake hands, and be friendly. The return handshake may feel softer or gentler than what you are used to.
 2. **Eye contact** is expected at first greeting, but prolonged eye contact may be considered disrespectful.
 3. **Do not appear to be in a hurry.** Your patient may have traveled a great distance at great expense to see you. If you spend only a brief amount of time, your patient may get a negative impression of the value of the visit.
 4. During the visit, **avoid medical terms that may not be understood.** Do not speak “down” to your patient, however.
 5. When you have finished speaking, **give your patient time to reflect** on what you have said. Do not be afraid of silence.
 6. Your patient may not understand what you mean if you ask him or her to identify a specific location of pain. Rather than asking, “Where is the pain?” **ask the patient to point to the area of most intense pain.**
 7. Patients may wish to perform certain **tribal healing ceremonies**, such as smudging (see the Complementary and Alternative Medicine section), even in the hospital. Try to accommodate these practices.
 8. Great respect is given to the elderly. **Treat the elderly with kindness and respect** and do not appear to criticize or scold them.
 9. Poverty, distance from the medical facility, and taboos against dying in the home may put a strain on the family of a patient who needs long-term or terminal care. **Discuss different care options with the family** and decide together what option is most appropriate.
 10. The **extended family** plays an important role in health care decision-making. Several family members may accompany a patient when he or she arrives to be admitted to the hospital. Try to make accommodations so that family members can be close to the patient’s room or close to the hospital.
 11. Work with your patients and their families to determine how best to remember to **take medications at prescribed times or return for appointments** when needed.
 12. Indian culture discourages competitive behavior and encourages giving, sharing, and cooperation. **Generosity and doing things for others** are regarded highly.
- (Adapted from Diversity Resources, Inc., 2001).

Communicating with Elders

- **Listening is valued over talking** by most older American Indians. Calmness and humility are valued over speed and self-assertion. (Hendrix, 2002).
- Elders frequently complain that **English speakers “talk too fast.”** (Hendrix, 2002).
- **Interrupting a person who is speaking is considered extremely rude**, especially if that person is an elder. (Hendrix, 2002).
- **Nonverbal communication.** A distance of several feet is the usual comfort zone. Body movements are minimal. Except for a handshake, touch is not usually acceptable. (Hendrix, 2002).

Suggestions

- Avoid the “invisible elder” syndrome and ask for the elder’s help in understanding the current situation and in planning the components of care to show respect for the elder’s experience.
- Adapt questions to the patient’s age and acculturation level. Slow down when communicating with an Indian elder, especially during initial encounters and when explaining treatments, medications, or health care decisions.
- Frame questions carefully to convey the message of caring rather than idle curiosity about the patient’s culture or cultural practices. (Hendrix, 2002).

Decision-making

Recommendation

Address the individual’s health problems in the context of his or her family. In many cultures, an individual’s health problems are considered the family’s problems, and it would be improper and disrespectful to exclude family members from medical interactions. Family members can provide valuable information about the patient’s diet, health behavior, daily activities, and types of alternative medications used. Their involvement in a treatment plan may be vital to the patient’s ability to adhere to the recommended treatment. Families may decide what the patient eats, when he or she takes medication, whether he or she exercises, and when he or she seeks medical attention. (MSH, 2003b).

A culturally competent provider discusses with the patient the patterns of decision-making in his or her family. Understanding and respecting the complex and often delicate interactions that exist between family members enable providers to use the patient’s family as a valuable resource, rather than seeing it as an intrusion into the provider-patient relationship. Working with the family often means working with the extended family (aunts, uncles, grandparents, etc.). (MSH, 2003b).

- **Family often extends** beyond the sphere of the traditional nuclear family. Because health care decision-making may include members of the extended family and the community, providers should consider familial influence on treatment decisions. (HRSA, 2003b).

- **Wisdom of elders.** The presence of elders is critical to the provision of culturally competent services. Elders can provide specific advice and emotional support and can guide the approach to counseling or other forms of intervention and prevention from an American Indian and Alaska Native perspective. (MSH, 2003).

Diet

Encouraging Adherence to Recommended Dietary Changes

Getting a patient to change his or her diet is difficult under ordinary circumstances, but cultural factors can complicate a patient's ability to adhere to recommended changes. Diet is so closely related to culture that failure to incorporate a patient's dietary customs is a recipe for noncompliance. Many cultures follow food guidelines based on religious beliefs. Some cultures have strict beliefs about the kinds of food a woman can eat during pregnancy or after giving birth.

Ask the patient about any dietary restrictions. Get a sense of the patient's usual diet and the way foods are prepared at home. Show interest, respect, and understanding for the patient as an individual and as part of a cultural tradition, and you will be rewarded with information about dietary beliefs and traditions that will help you find suitable and appropriate ways to get the patient to make the dietary changes you propose. (MSH, 2003b).

Historical Distrust

- **Past injustices** may cause American Indian and Alaska Native patients to distrust their providers. (HRSA, 2003b).
- **Suspicion and mistrust** are natural outcomes and important survival skills for people who have experienced genocide. Practitioners and program planners who seek to work with American Indian people must realize that their helping interventions may be viewed in this context. (Weaver, 1998).

Suggestion

Patience, perseverance, and working with clients around concrete issues are ways that social workers (and health care providers) can begin to establish trusting relationships with American Indian clients. (Good Tracks, 1973).

Interpretations of Disease and Disability

- Physicians have many ideas about disability. For example, most doctors believe that treatment should include intervention and that biological anomalies should be corrected. However, **some cultures believe that the "disability" is spiritual rather than physical or that the "disability" itself is a blessing** or reward for ancestral tribulations. (HRSA, 2003b).
- Western physicians are well indoctrinated about the dangers of "invisible" diseases such as hypertension and high cholesterol, but people in other cultures may not be as willing to intervene **when there are no symptoms**. (HRSA, 2003b).

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