

Counseling people about HIV testing

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José's story

José is a truck driver in Mexico. He is married and has six children. He works long hours driving his truck from his home in Uruapan to Mexico City. When he is in Mexico City he often has sex with women and men there. A truck driver friend of his is now sick with diarrhea and a cough and has been asked to leave his job. José has become worried that it is because of AIDS. He thinks he might have HIV too and is afraid he may have to tell his wife about his having sex with other people. José wanted to be tested for HIV months ago but did not know where to go. He recently saw a sign for your HIV outreach program, which comes to a truck stop on his route every Friday. This afternoon José comes to visit you and learn about the test. He asks, “Do you need to take a lot of blood for the HIV test? How long does it take to get the result? If I have HIV, do I have to tell my wife? What will my family do if I become ill?”

Assessing HIV risk

Each person has a different risk of having HIV. Talking about a person's risk will help her decide whether to take the test. More importantly, it will give her ideas about how to lower her chance of getting HIV in the future. In areas of the world where many people already have HIV, most people are probably at risk, and it can be difficult to know whose risk is highest and who should be tested. In these areas, for example, nearly everyone who has had sex is at high risk of having been infected with HIV. However, some behavior puts people at

Who should be offered an HIV test?

Not everyone who wants an HIV test should have one. People may worry about HIV and ask to be tested even though they are not at risk. By asking some questions, you can find out whether a person is at risk and should be tested. There are three things that it is important to talk about with each person: sexual history, drug use, and whether or not the person has ever had a blood transfusion. You may want to ask some of the following questions, adapting them to your particular area and situation.

1. Why do you think you might have HIV?
2. Have you ever had sex? If so:

What type of sex have you had—vaginal, oral, or anal? (HIV is more likely to be spread by anal than vaginal sex; it is least likely to be spread by oral sex. See Chapter 5.)

Have you had sex with someone you know has HIV?

Have you had sex with anyone you think could have HIV? For example, with a sex worker, with a man who has had sex with other men, with someone who has had a blood transfusion, or with someone from an area with a high rate of HIV infection?

How many sexual partners have you had in the last year?

How many sexual partners have you had in your lifetime?

Do you use condoms during sex? All the time or sometimes?

3. Have you had any sexually transmitted diseases such as syphilis or gonorrhea?
4. Have you ever been given a blood transfusion?
5. Have you ever been given a shot with a needle that had been used on another person without being cleaned afterward?
6. Have you ever been stuck by a dirty needle or medical instrument?
7. Have you ever injected illegal drugs? If so, have you ever shared needles?
8. Have you ever had herpes zoster (also called shingles) or tuberculosis?

If the person answers "yes" to any of these questions, she should probably get tested for HIV.

higher risk even in these areas. This behavior includes visiting sex workers, having many sexual partners, having sex with someone who is known to have HIV, and having had other STDs.

Counseling before the test

The HIV test provides a special opportunity for counseling. Sometimes it is the only chance to speak to people in depth about the ways HIV is spread. Because it can be hard to decide to take the test, people are often ready to think about changing behavior that puts them at risk. Offering testing will attract people to your other HIV services, such as treatment for sexually transmitted diseases, family planning, or social services.

Before people are tested for HIV, you can have them develop a plan of action for after they get the test result, whether it is positive or negative. What will they do? Who will they tell? How will they bring it up? What parts of their life will they change? If they have HIV, how will they avoid spreading the virus to other people? You can discuss with them who should take the test, how the test works, and how to avoid HIV. Additional counseling should be done after the test.

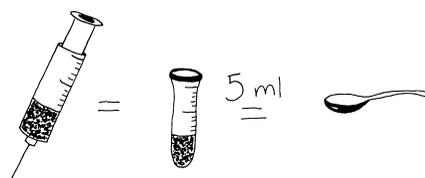
It can be helpful to counsel couples together, both before and after the test. This encourages both members to talk about HIV and what they will do with the test results. Sometimes pre-test counseling sessions are done in groups to save time. Although this can be useful, people may be less likely to bring up personal questions in a group than if they are counseled alone or with their partner.

Introductions are important to set the tone for the session. A simple, open-ended question, such as “What brings you here?” or “How can I help you today?” shows you are ready to listen. Later, you can ask more specific questions that will help you understand a person’s knowledge of HIV and AIDS. Listen carefully to a person’s concerns and questions. Use the time to get a sense of her background and needs.

Next you can discuss basic facts about HIV. Ask each person what he knows about HIV: “How do people get HIV? How can people avoid HIV? Why do people get sick from HIV?” This way, time is not wasted teaching something a person already knows. This also gives you a chance to teach new facts about HIV. Afterward, ask the person to repeat what he has learned; this will help you know if he understood what you were saying. Ask frequently if he has any other questions and listen for an answer. Silence is fine; it often helps bring out important questions or feelings. Sometimes a person’s biggest concern is brought up at the end of a meeting.

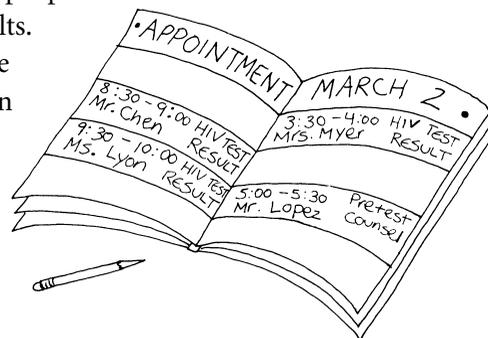
Letting people know what to expect

Explain to people that only a small amount of blood is needed for the test, just one teaspoon (five milliliters) or less for a finger stick test. The body is able to make this amount of blood very quickly, so a person being tested should not feel tired or weak after the blood is taken.



Amount of blood needed for HIV test

Let people know how long they will have to wait for their test results. If they need to wait a few days or a week or two, make a follow-up appointment. Do not use the mail or telephone (where available) for giving test results. By coming to the clinic, people can hear about their test result in a supportive environment where their questions can be answered. They can also receive information about services available to them if they have HIV. Appointments should be made in the same way for people who have positive and negative results. For example, do not schedule people whose results are negative to come in for a five-minute appointment and people whose results are positive to come in for a 30-minute appointment. Rumors can spread about what the length of an appointment means and people may not return for their test results.



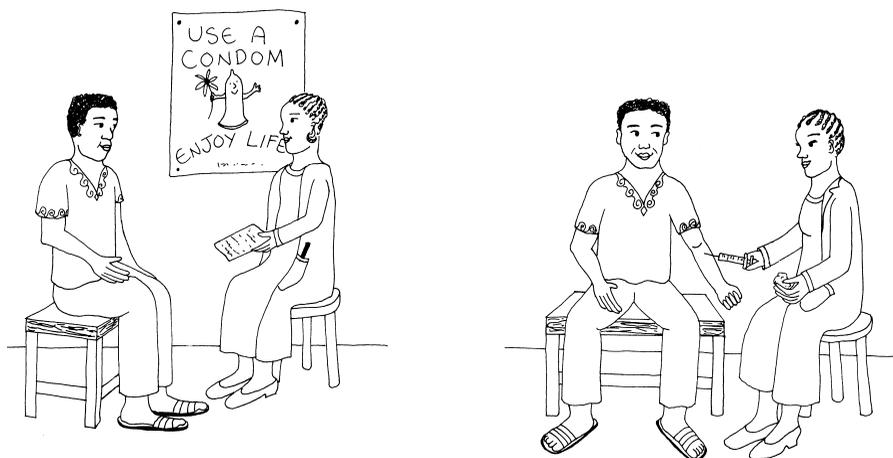
Privacy

People may be treated unfairly when it is learned that they have HIV or AIDS. Because of this, information about HIV should be kept in strict confidence. When possible, medical records should be locked in a safe place where only health workers can read them. Counseling should be done in an area where you cannot be overheard. You should consider limiting what is written in a person's records about HIV or diseases specific to AIDS. This helps avoid having information about someone spread to people who do not need to know it and who might discriminate against the person.

People should be told whether their test results will be confidential or anonymous, and what that means (see Chapter 7). How the information is kept may affect whether someone decides to take the test or not.

The meaning of the test

Before the test, explain the meaning of each possible test result. This will help avoid confusion later, when you tell a person the result of his own test.



Explain what different test results mean before drawing blood.

A positive test result means that a person has HIV. He could have been infected at any time in the past when he took part in risky behavior—even years earlier. A child may have been infected at birth. A negative test result means that a person does not have HIV. Very rarely, a person with a negative HIV test may still have HIV, because it takes 3 weeks from infection for a person to develop enough antibodies to make the test positive. The person may want to take another test in a month, especially if he or she has recently engaged in any risky behavior.

Waiting for results

Usually people have a lot to think about before getting their test results. They may need to wait as little as an hour or as much as two weeks, depending on the type of test used. The wait usually seems long, whether it actually is or

not. While waiting (and worrying), people may think seriously about how they act and how they can change their behavior or living situation to avoid getting HIV in the future. They may think about how they can avoid infecting others if the test turns out to be positive. This is one reason why it is better to do most of the teaching and talking before the test, saving the post-test session for dealing with a person's response to the results. Often when people get their results, they are so nervous or dazed that they are unable to learn new information.



Right after hearing their test results, people may not listen to counseling.

Counseling after the test

Imagine for a moment that after a two-week wait you are on your way to the clinic to hear your HIV test result. You hope to see the familiar face of your counselor. Maybe you will sit in the same chair you sat in two weeks ago. You are nervous as you open the clinic door. What are you thinking at this moment? Do you wonder what your test result is? Do you wonder who will tell you the result? Do you wonder how the news will change your life? Do you wonder if it would be better not to know?

The counseling appointment after the test gives a supportive setting for hearing the news. If the test is negative it gives a person time to ask questions and think about ways to lower their risk of getting HIV in the future. If the test is positive the person will have a chance to talk with someone who knows about HIV and can help them with the bad news.

Counseling people with positive test results

It is hard to give someone news of a positive test. It is difficult to tell someone bad news. However, most people with positive results already guessed that they had HIV; a positive test may be less of a surprise than you think. Fortunately, you will probably give more negative results than positive ones. Prepare beforehand for telling someone a test result; this will make the experience better for you and for the person who took the test. You can do this by

thinking carefully about what you are going to say and what the person's responses might be.

Breaking the news

Ask a person what she has been thinking about since taking the test. Find out what worries or questions she has. Arrange for enough time to talk about the issues she raises. When you give the result, use a neutral tone of voice. You might simply say, "Your HIV test was positive," and then wait for the person to respond. A neutral tone and a moment of silence allow someone to feel her own feelings rather than respond to yours. People have many different responses to both positive and negative results. For this reason, let each person set the tone and pace of the discussion according to her own needs.

First reaction

The first feelings that people have after finding out they have HIV may include denial, anger, fear, sadness, hopelessness, and guilt. Most people will be upset, and some may talk about hurting themselves or other people. Help avoid a crisis. Be supportive. Let them know that strong emotions are understandable, but that they should not give up hope. Acknowledge feelings by using simple statements such as "This is probably a scary time for you."

Sometimes people will not accept the results of a positive test. They will insist that they are negative and that there has been a mistake. Do not argue with them. Tell them that the test is almost never wrong but you are willing to discuss the possibility of a second test. People who deny the truth are often the most in need of support; ask them to return for another meeting.

While you should not deny people's worries, it is helpful to talk about things positively. For example, many people believe that having HIV means they will die very soon. Talk about how long it usually takes to become ill. Some people have lived for over fifteen years with the virus. Teaching people ways to stay healthy will build feelings of strength at a time when they may feel powerless. Research is being done that may lead to new treatments for HIV and AIDS.

If you know the person you are counseling, you might talk about difficult times in the past that he handled well. Try to help the person overcome harmful thoughts and focus on solving problems. Help people plan for the future. Talk about the plans they made during the pre-test counseling session. This will remind them that they will not die tomorrow, and it can help change feelings of fear or hopelessness into feelings of strength. Help people find a health worker who knows about treating people with HIV—maybe you!

People will want to talk about their health, their relationships with friends and family, and how to have safer sex to protect sexual partners. By talking openly about these things you will help people accept the fact that their lives

are changing. People with HIV should practice safer sex, not only for their sexual partners' protection, but also for their own. Having unsafe sex puts a person at risk of getting sexually transmitted diseases, many of which are more severe in persons with HIV. Additionally, exchanging body fluids with another person who has HIV may make a person sicker, because one person's virus may be more dangerous than another's.

Telling other people

A person with HIV will think about whether to tell other people that she has the virus. The information will affect her relationships with sexual partners, friends, family, employers, and health care providers. More and more people are being taught about HIV and AIDS, but there is still a lot of misunderstanding and fear of the disease. Each person should be warned of the risks and benefits of telling people she has HIV. The goal is to gain support from friends and family while decreasing the risk of discrimination.

People with HIV should start by telling those people who will be the most supportive and those who may also be at risk of having the virus. Everyone with HIV should be strongly urged to tell past and present sexual partners about having HIV. Sexual partners need to know so that they can be tested and can protect *their* partners from infection. When counseling a person with HIV, you should ask him about his sexual partners and how he plans to tell them. Role playing is a useful way to help a person with HIV practice how to tell others (see Chapter 11).

If the person with HIV can tell her partners, this keeps her sexual partners' names confidential. However, some people are reluctant to tell their partners. This can be especially true for women who fear being yelled at, beaten, or thrown out of the house by their partners. In such cases, the person with HIV may ask a health worker to tell the partners that they might have HIV. The name of the person with HIV can be kept confidential or the couple can be counseled together. The health worker can teach the partners about HIV and AIDS and encourage them to be tested.



When someone you are close to has HIV

The following list describes some emotions families or friends may feel when someone they care about tells them that he has HIV. Health workers can talk about some of these possible reactions with people who have a positive test. It will help them prepare for difficult situations. If the health worker has HIV herself, talking about some of her personal experiences can be especially helpful.

Shock. Family members may be shocked and ask, “Why us?” They may be surprised to find out about the situation that put their loved one at risk; for example, a husband or wife may not have known that the other was having sex outside the marriage.

Anger. Families and sexual partners may be angry with a person who has HIV. They may feel betrayed if the person had sex outside the relationship, or they may feel abandoned because the person they love will become ill. The anger may get worse as the person with HIV becomes ill and health workers do not have much medical help to offer. The family or partner may become frustrated. Try to help them understand some of the reasons they might be angry, and let them know that it is natural to be frustrated in the face of these issues.

Fear of infection. Family members and sexual partners may think that they gave HIV to their loved one, or they may worry that their loved one will infect them in the future. It is important to talk with family members about how the virus is and is not spread. HIV is not spread by casual contact, so they do not have to worry about living with someone with HIV or being friends with him, but they should think about changing their sexual behavior to lower the chance that the virus will spread. Sexual partners should think about being tested for HIV themselves.

Fear of being alone. Families and friends may worry about being left alone or isolated from the rest of the community. A serious illness often causes the community to withdraw. Health workers can offer support and let families and friends know that they are not alone. If there are support groups in the community for families and friends of people with HIV, tell people about them.

Guilt. People who are close to others with HIV but don’t have the virus themselves may feel guilty about the fact that they do not have the virus. Some people react to this by taking more risks because they care less about their own lives. Other people may think that they or someone in their family did bad things in the past, and that their gods or spirits are now punishing them by giving them HIV.

Shame. Some families or friends may feel ashamed that a person has HIV. They may think that HIV brings dishonor to the family. Families may have less contact with the community because they fear rejection. Explain that no one should feel ashamed to have someone with HIV in the family.

Helplessness. Family and friends may feel helpless in the face of disease. Learning more about HIV and volunteering for an HIV organization can give them a sense that they can help other people and help slow the spread of HIV and AIDS.

The next step

Hearing about positive HIV test results can bring up many strong feelings; a person may not be able to concentrate and may not hear what you are saying. Try to give written information to each person who is able to read, so that she can later read about what she did not hear or understand in your post-test counseling session. Make an appointment for her to come back so that you can talk about health services, support groups for people with HIV, crisis counseling services, and programs for people who use drugs or alcohol.

Counseling people with negative results

A complete counseling session is also important for people who have a negative HIV test. Counseling a person with a negative result is, in many ways, like counseling someone who is positive. The session can start with general questions about what the person has thought about since the last visit. Ask if he has any questions before you tell him the result. After giving the result, give him time to respond with his own feelings and thoughts.

If a person has a negative result, remind him that a negative test only means he does not have HIV now. He can still get HIV in the future.

Most people will feel relieved to receive a negative test result. Sometimes, however, people feel sad or guilty, especially if they have lost friends or loved ones to AIDS.

Sometimes people do not believe that they are negative. They know that they had sex with someone who has HIV and they think that HIV is spread every time a person with HIV has sex. You can tell them that this is not true. In any case, this is the time for a person to develop a strong commitment to staying HIV negative.



Counseling people with indeterminate results

An indeterminate HIV test result is confusing. It means that a person is newly infected and has just begun to make HIV antibodies, or that something else in his blood causes a partially positive test by mistake. Suggest that he take another test in a month. He should practice safe behavior while waiting for the next test.

Post-test counseling checklist: Giving test results

Ask, "How have you been since the test? What have you thought about? Do you have any questions?"

Give test result in a neutral tone: "Your test is positive/negative/indeterminate."

Wait for a response.

Talk about the following:

- the meaning of the test result

- telling others

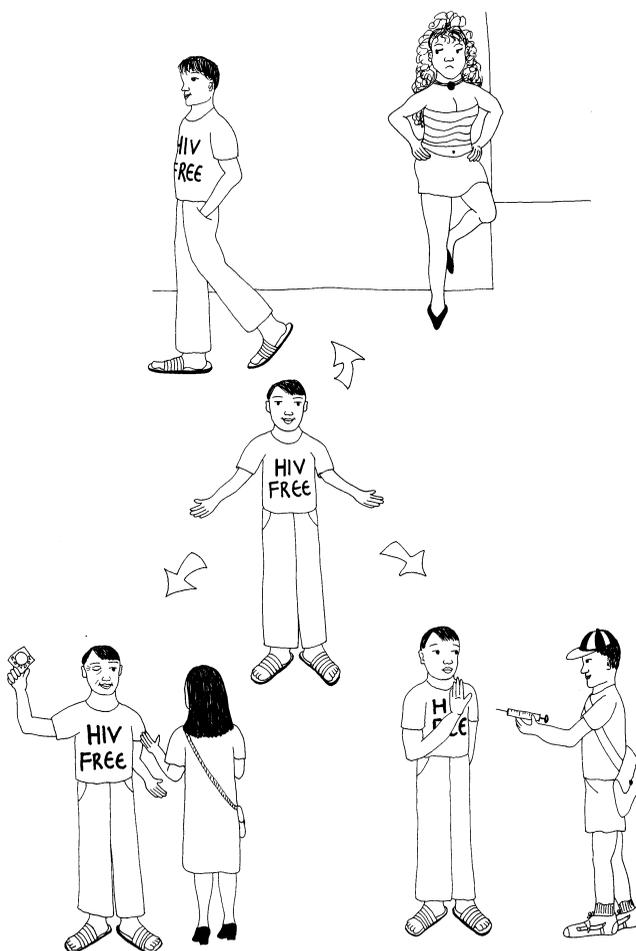
- being safe

- staying healthy

- anticipating problems

Review plan made during pre-test session.

For people with a positive test, hand out written information and schedule a follow-up appointment.



Answering José's questions

“Do you need to take a lot of blood for the HIV test? How long does it take to get the result? If I have HIV, do I have to tell my wife? What will my family do?”

After talking with José, you know there is a chance that he has HIV because he has had unsafe sex with different people. You recommend that he be tested for HIV. Only a little blood is needed, usually about 5 milliliters, or one spoonful. It usually takes between an hour and two weeks to get the result (this depends on the laboratory).

Counseling before and after the test will be helpful whether José has HIV or not. Encourage him to acknowledge his feelings by using simple statements such as “This is probably a difficult time for you.” Let him know before taking the test that he should talk with his wife after receiving the results. A positive result may affect his and his wife’s decision about having more children. If his wife also has HIV, she could pass the virus on to her baby. If she does not have HIV, she may become infected while trying to become pregnant. If José gets sick, it would be harder for his wife to support another child.

If José’s test is positive, he should tell all his other sexual partners as well. They should also be tested. This will help them plan for the future and get early medical care. This is also a chance for you to talk about safer sex at a time when José is likely to listen to you.

José is worried about how his family will survive if he has HIV. These worries often stop people from being tested—they think, “What I do not know will not hurt me.” Discuss how knowing whether he has HIV will help José and his family plan for the future. Help him plan for the future, whether his test result is positive or negative.