

Big Issues In Brief

Scaling up responses to HIV/AIDS

Counseling and HIV/AIDS



The issue.

HIV/AIDS counseling is a vital weapon in the fight against HIV/AIDS. It is a key component of HIV prevention—the first line of defense. HIV/AIDS counseling also supports improved health outcomes and adherence to HIV treatment regimes. It enables people to live with hope. The major limitation to this powerful strategy in the fight against AIDS is the dire shortage of trained counselors. Who will counsel clients and the community? How will we train, supervise, and support the counselors?

Why is it important?

HIV/AIDS counseling is a crucial component in the response to HIV/AIDS. It is an essential part of HIV testing—the entry point to prevention as well as to care and treatment. HIV/AIDS counseling also plays a vital role in programs focusing on the prevention of mother-to-child transmission. In general, counseling is said to help make people living with HIV/AIDS—and everyone else—feel and live better, and grow personally. But what do we really mean when we say “HIV/AIDS counseling”?

“HIV/AIDS counseling is a confidential process that enables individuals to examine their knowledge and behaviors in relation to their personal risk of acquiring and transmitting HIV infection. Counseling helps clients to make decisions on whether or not to be tested and provides them with support when they receive the test result.”¹ The specific nature and scope of HIV/AIDS counseling depend on the situation in which it is being used. However, some general principles apply to all types of HIV/AIDS counseling. HIV/AIDS counselors should:

The people and organizations highlighted in the shaded boxes in this document were identified in field reports as “success stories.”

- Establish a helping relationship with the patient or client
- Employ active listening skills to make it possible for clients to tell their own stories
- Have correct and appropriate information about a client's condition and make existing resources available to support those affected by it
- Help clients make their own informed decisions
- Assist clients in identifying their strengths and support them in developing a positive attitude toward life

Ethiopia

The Hareg Project works with U.S. government support to extend services for the prevention of mother-to-child transmission throughout Ethiopia. Dr. Yonas, head of the Addis Ketema Health Center in Addis Ababa, says his patients' main requests are for psychological support and medication. HIV/AIDS counseling could help fulfill this need. How well are we meeting this demand?

People who provide HIV/AIDS counseling must remember that it is not acceptable to judge, blame, interrogate, or make decisions on behalf of clients. Preaching and lecturing, making promises that cannot be kept, and arguing or imposing one's own beliefs are not helpful behaviors and can be very harmful. HIV/AIDS counseling can help people who are worried about being infected or who have learned that they or their family members are HIV-positive to come to terms with the emotions and challenges they face. Counseling can also be an important opportunity to help clients understand how they can avoid HIV infection or reinfection. Counselors can provide information that will help clients to make choices and decisions that could prolong and improve the quality of their lives. These are some of the common ground rules of HIV/AIDS counseling. The challenge then is to integrate these basic counseling practices into the variety of situations in which HIV/AIDS counseling and testing are taking place.

What is known about HIV/AIDS counseling?

HIV counseling and testing

Everyone is now encouraged to learn about his or her HIV status. Knowing whether one has the virus can help prevent the infection of others. Counseling allows access to treatment and support for those who are HIV-positive, and helps people who do not know their status to make informed decisions about whether to take an HIV test. Until recently, this has been described as "voluntary counseling and testing for HIV/AIDS," or VCT. VCT also helps clients understand why it is important to wait or return for results, and how long it may take.

Rwanda

A young couple, Andre and Jeanne, live in Kigali. When Jeanne became pregnant, she went to the Masaka Health Center for prenatal care. “The nurse told all pregnant women at the clinic that we should get tested with our husbands, and she gave me an invitation to take home to Andre,” explained Jeanne, who was surprised to see how eager Andre was to be tested. He said, “I have wanted to be tested for three years.... I was finally able to be counseled and tested because it was offered on a Saturday. Thankfully, we are both HIV-negative.”

Couple counseling and testing can have the advantage of allowing couples to support each other and to make plans for the future together. While this is an ideal situation, it is not common and may not be the best arrangement for all couples.

In busy settings in many African countries, pretest counseling is being replaced by health education in groups, through the use of videos and other materials, to ensure that every person receives a basic package of information about HIV testing. Pretest counseling in groups can be both cost- and time-efficient. It also has the potential to reduce AIDS stigma in communities. It should be noted that a reduction in individualized pretest counseling does not diminish the need for informed choice in HIV testing (the “voluntary” in VCT) and considerably increases the need for good-quality posttest counseling.

Regardless of how people are informed and counseled before deciding to take the HIV test, results must be given to individuals privately (or to couples choosing to be informed together). Individuals, couples, or groups seeking to know their status must receive the right information, and client confidentiality must always be respected. Counselors must help clients to understand the meaning of all test results. Receiving a negative HIV test result is an important opportunity for addressing how to avoid infection in the future, through explanation of risk-reduction behaviors such as practicing safer sex.

If test results are different within a couple, the couple is said to be “discordant.” When any person receives an HIV-positive result, the possibility that his or her regular sexual partner is still HIV-negative must be addressed, along with discussion of disclosure of HIV status to the regular partner. Many women fear rejection or violence if they disclose that they are HIV-positive. However, experience in many settings indicates that the fear of rejection and abuse is greater than actual rejection and abuse experienced after disclosure.² Thus, counseling must address fear of disclosure and how to know when it is safe to disclose, as well as what to do in an abusive situation. A discordant couple may experience particular issues, such as feelings of guilt or blame, and concerns about how to plan for having children. Counselors must be skilled in recognizing and addressing danger signs or potential for violence. Both partners need support, with referrals to ongoing social services and support organizations.

When individuals or couples are told of positive HIV test findings, it is important for counselors to remember that everyone reacts differently to this information. Some people may experience disbelief, anger, fear, or feelings of doom. The counselor should allow clients to express their feelings. At the same time, the counselor can provide support to clients in a variety of ways. Counseling on practicing safer sexual relations to protect others from infection and to limit reinfection of those already HIV-positive must be addressed. Referral to other existing health and social services is crucial. Perhaps most importantly, counselors should develop skills that help HIV-positive clients to recognize their ability to have hope and to live well.

Good and promising practice

HIV/AIDS counseling at traditional family planning service sites

Many women are participating in HIV counseling and testing services provided at family planning and antenatal care settings, making these services points of entry to HIV prevention, care, and support. Although these service sites are traditionally considered “women’s places,” the introduction of HIV counseling and testing services and the extension of clinic hours to accommodate partners’ work hours have proven successful in encouraging participation of a greater number of men in programs such as prevention of mother-to-child transmission. This, in turn, provides a good opportunity for partners to consider HIV counseling and testing. The Masaka Health Center outside Kigali, Rwanda, provides an example of a good practice for encouraging greater couple participation in antenatal care and HIV testing. Since 2003, pregnant women counseled and tested for HIV at the clinic were invited to return to weekend sessions with their partners. During these sessions, nurses counseled clients with messages designed for couples. More men were able to participate in this HIV counseling and testing service because it was on a weekend. They appreciated that the process went rapidly because no other services were offered in the clinic at that time.

People involved in HIV/AIDS counseling in family planning, antenatal care, or prevention of mother-to-child transmission settings must possess a great deal of HIV/AIDS-related information in order to meet the needs of pregnant women and couples who test HIV-positive. The content of pretest counseling can be relatively routine, informational, and carried out in groups. Posttest counseling for positive pregnant women, however, requires special attention. The HIV-positive pregnant woman needs counseling to reach decisions about medication, nutrition, infant feeding, disclosure, and other aspects of living with HIV. Counselors must be knowledgeable about all these subjects or know where to refer patients for further help. It is vital that patients be referred and linked to ongoing psychosocial and medical support as soon as possible, when available.

Challenges

Confidentiality versus secrecy

Confidentiality is an ethical principle that acknowledges a person’s right to privacy and is the basis of many professional-client relationships. Within the health care field, confidentiality is an important aspect of relationships between patients and health care providers. Respect for confidentiality is also a key determinant of the effectiveness of many public health interventions. For example, patients who must take medication regularly and be monitored for its effects are much more likely to return to clinics if they have a trusting and respectful relationship with staff. HIV/AIDS counselors should be held to a strict code of confidentiality. When counselors break confidentiality, they risk losing the trust of their clients, and this may undermine the very health interventions recommended to limit the spread of HIV. If potential clients believe that counselors or staff at the HIV testing centers cannot be trusted to maintain confidentiality, individuals will not come to be tested. If members of the community do not come to be tested, those who are HIV-positive will not be treated, and the epidemic will spread.

Secrecy both results from and encourages fear, shame, and a sense of vulnerability. In the context of HIV/AIDS, reasons for maintaining secrecy include fear of rejection, stigma,³ and discrimination. Relationships between health and social-care providers and people living with HIV/AIDS that are built upon confidentiality will more likely benefit all parties. Secrecy, while still the prerogative of people living

with HIV/AIDS and their families, does not help break down the stigma and discrimination experienced by so many. Though only those affected can break down the secrecy, we are all responsible for challenging stigma and discrimination in our communities. Respect for confidentiality is a starting point and a vital step in challenging secrecy and stigma.

Mozambique

When Alzira Mendes went for her first prenatal checkup, Nurse Flora counseled her about HIV transmission and prevention. Nurse Flora then performed the HIV test with a rapid testing kit. Alzira's test was positive. She became very concerned about the health of her baby. Nurse Flora explained that the chances of the baby's having HIV would be reduced if Alzira took medication (nevirapine) during her labor and if the baby got a dose after birth. Nurse Flora referred Alzira to the program on prevention of mother-to-child transmission and to the hospital where she could receive care and treatment for her HIV.

In this case, the person who counseled, educated, and conducted the HIV test, Nurse Flora, was the same person who referred the patient to care and treatment. Because many staff in health care settings carry out multiple functions—including HIV counseling—these staff must be supported with ongoing training.

Who are the counselors?

The important work of counseling falls on many different people in a variety of settings. While trained counselors and therapists are ideal, in reality, the availability of trained professionals is a luxury. Staff working in health facilities and social services can become good HIV counselors with training and supervision. In practice, very few staff in health care settings are exclusively counselors. As nurses, doctors, health educators, and social workers all function as HIV/AIDS counselors at certain times, they all need basic training in HIV/AIDS counseling. As programs for HIV counseling, testing, and prevention of mother-to-child transmission expand, the increased demand for counseling and testing skills will require that greater numbers of health care staff be trained, and that training and protocols be standardized. Overall, more health care workers are needed for all aspects of HIV/AIDS care, and an essential component of their training must include HIV counseling skills.

In Tanzania, traditional birth attendants (TBAs) have been trained to encourage women to test for HIV. Further training for TBAs is needed in order for them to provide ongoing counseling and support to HIV-positive women after delivery on infant feeding, early detection of complications, and referrals. TBAs have always been traditional "counselors" within their communities. Providing appropriate information on HIV/AIDS to TBAs, village elders, and others viewed as "wise people" within the community will help validate their roles and get the messages out more effectively. Partners, mothers, sisters, brothers, and friends all function as counselors at times in our lives. We can all benefit from the empathy and active listening skills that counseling brings, and we can offer these to others. Regarding HIV/AIDS, these skills need to be developed further and must include correct information about HIV, as well as knowledge of appropriate resources. Community-based HIV/AIDS education can be the source of improved awareness, strength, and support to affected communities. Lessons learned include the notion that counseling skills are not limited to one setting, but apply across life activities.

Cotê d'Ivoire

To promote human capacity development in Cotê d'Ivoire, The President's Emergency Plan for AIDS Relief is supporting rapid expansion of a pool of expert trainers and providers trained in the prevention of mother-to-child transmission and the integration of prevention of mother-to-child transmission training at national institutions. An important part of this effort is standardized training materials developed by JHPIEGO, a not-for-profit international public health organization affiliated with Johns Hopkins University in Baltimore, Maryland, in the United States.

Need for standardized training and protocols

Health systems are under tremendous strain, especially in areas of high HIV/AIDS prevalence. In some of the worst affected countries, many deaths attributed to HIV/AIDS are among societies' most valuable assets in the fight against AIDS: youth, health care workers, and teachers.⁴ In light of this crisis, what can be done? First, further infection should be limited through prevention. The campaign for prevention—through HIV/AIDS education and changes in social and personal risk-reduction behavior—is a call-to-arms for everyone. Second, as many people as possible should be enabled to become health and social care workers, and all training of health and social workers should include basic HIV/AIDS-counseling skill development. Third, strong community responses to HIV/AIDS should be facilitated, including improved awareness, reduced risky behavior and HIV stigma, increased home-based caring skills, and strengthened care support networks. All health and social workers should be enlisted in the battle against HIV/AIDS. The most efficient approach to extending and improving the quality of HIV counseling with limited resources is to standardize counseling protocols and supervision. This begins by training the trainers who are deployed to educate other HIV counselors, thus creating a “cascade effect.”⁴ Facilities offering HIV counseling and testing should become “centers of excellence,” where supervision and counseling skill development sessions are regularly held for the benefit of staff from smaller facilities and communities in the area. While counseling approaches will vary between countries, standardized approaches within countries can facilitate performance monitoring and quality-of-service evaluation. In some communities, HIV counseling services are provided by organizations distinct from health care testing facilities. Nonprofit groups and nongovernmental organizations could offer professional HIV counseling and HIV/AIDS health promotion services, which are valuable resources when available.

People living with HIV/AIDS as counselors

Those holding the greatest potential to fill the need for HIV/AIDS counseling are people who themselves have tested HIV-positive. At the Paris HIV/AIDS Summit in 1994, 42 national governments declared that the principle of greater involvement of people living with or affected by HIV/AIDS (GIPA) is critical to ethical and effective national responses to the epidemic. Since then, the GIPA principle has been promoted as a cornerstone of HIV/AIDS prevention, care, and support. People living with HIV/AIDS can be excellent counselors for HIV counseling and testing. They still benefit from counselor training themselves, but their personal experience of testing positive for and living with HIV provides a strong basis for empathy and for addressing the real needs of others. Participation of people living with HIV/AIDS in health care provision reduces HIV stigma and improves the ability of health care services to meet the needs of those affected by HIV/AIDS. People living with HIV/AIDS who participate in health care provision serve as role models for “living positively”⁵ in their communities, and wield the potential to promote dialogue on HIV/AIDS and to challenge stigma.

Zambia

Ida tested HIV-positive in 2002. She can testify to the struggles this condition brings as well as to the benefits of antiretroviral therapy and the importance of having support to cope. Ida was subsequently trained to be an HIV/AIDS educator and counselor, and she has been instrumental in encouraging support groups and helping people living with HIV/AIDS to adhere to medication regimes. Ida's work in the community has been recognized by Martin Brennan, U.S. Ambassador to Zambia, Zambian AIDS activist Winston Zulu, and Oprah Winfrey.

How to support the counselors?

Counselors are regularly confronted by emotional and difficult situations. They need support to be able to maintain good standards of care and to protect their own well-being. Regular supervision meetings or “debriefings” with supervisors trained in the special requirements of counseling supervision are an important support for counselors. Membership in a professional counseling association, if available, can help keep counselors abreast of developments in HIV counseling and to provide a forum for sharing experiences with colleagues. Counselors should be encouraged to participate in social activities outside their work environment, to maintain a good networks of friends, and to relax in their leisure time. Everyone needs acknowledgement for the work they do. People involved in HIV counseling are no different, and they deserve support and appreciation for the valuable services they render. As counselors may not be able to discuss their problems outside of work and may not receive recognition for problems they may have averted at work, health system managers must be vigilant and seek to maintain morale by encouraging respect and by rewarding demonstrated professionalism.

Links

Guide to Promoting HIV Counseling and Testing within Communities

<http://www.coregroup.org>

Endnotes

¹ UNAIDS. May 2000. “Voluntary Counselling and Testing.” *Best Practice Collection, Technical Update*. Geneva: UNAIDS.

² USAID/The Synergy Project. March 2004. “Women’s Experiences with HIV Serodisclosure in Africa: Implications for VCT and PMTCT.” Meeting Report. Washington, D.C.: USAID.

³ The Synergy Project. 2004. “Stigma and HIV/AIDS—A Pervasive Issue.” *Big Issues in Brief: Scaling Up Responses to HIV/AIDS*. Washington, D.C.: Social & Scientific Systems, Inc.

⁴ Family Health International. 2004. “Scaling-Up Voluntary Counseling and Testing in Africa.” *Snapshots from the Field*. Arlington, Virginia: Family Health International.

⁵ The Synergy Project. 2004. “Living Positively with HIV/AIDS.” *Big Issues in Brief: Scaling Up Responses to HIV/AIDS*. Washington, D.C.: Social and Scientific Systems, Inc.