



Counselling and HIV/AIDS



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UNAIDS *Best Practice Collection*

At a Glance

- Various studies have proved that good counselling has: assisted people to make informed decisions—such as whether to have an HIV test; helped many other people living with HIV or AIDS to cope better with their condition and lead more positive lives; and helped prevent HIV transmission.
- However, many decision-makers and service managers—such as policy-makers in government ministries, directors of hospitals or heads of nongovernmental organizations (NGOs)—are doubtful about the effectiveness of counselling. Their scepticism is a major obstacle to the development and provision of good counselling services. The resulting inadequacies include:
 - lack of policy approval for establishing counselling services;
 - insufficient space or resources provided for counsellors;
 - unreasonable demands on the time of counsellors;
 - difficult access to the service for clients;
 - intimidating or inappropriate atmosphere within counselling clinics;
 - a lack of privacy and confidentiality;
 - no follow-up support for those infected with HIV and their families, spouses and partners.
- Disseminating the results of studies on the beneficial impact of counselling can help overcome the scepticism and strengthen the support given to counselling.
- For an effective counselling service, a number of things are needed, including:
 - careful selection of trainees who will be able to provide counselling services;
 - training that includes supervised placement after initial training, and follow-up training after a period of work experience;
 - retention of trained counsellors, by providing them with sufficient space and reasonable working hours; sufficient administrative support, professional support and support from their colleagues;
 - the creation of appropriate settings for counselling, avoiding an environment which prevents clients from freely expressing personal concerns; confidentiality for clients; and ensuring that informed consent is always given and counselling offered before an HIV test;
 - referral systems that link counselling services with medical clinics and with a range of other services—such as social support, legal services and the supportive care available through religious communities—usually provided by NGOs.

UNAIDS *Best Practice* materials

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is preparing materials on subjects of relevance to HIV infection and AIDS, the causes and consequences of the epidemic, and best practices in AIDS prevention, care and support. A *Best Practice* Collection on any one subject typically includes a short publication for journalists and community leaders (Point of View); a technical summary of the issues, challenges and solutions (Technical Update); case studies from around the world (*Best Practice Case Studies*); a set of presentation graphics; and a listing of key materials (reports, articles, books, audiovisuals, etc.) on the subject. These documents are updated as necessary.

Technical Updates and Points of View are being published in English, French, Russian and Spanish. Single copies of *Best Practice* materials are available free from UNAIDS Information Centres. To find the closest one, visit UNAIDS on the Internet (<http://www.unaids.org>), contact UNAIDS by email (unaids@unaids.org) or telephone (+41 22 791 4651), or write to the UNAIDS Information Centre, 20 Avenue Appia, 1211 Geneva 27, Switzerland.

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1. Acquired immunodeficiency syndrome—prevention and control
2. Counselling

WC 503.6

Background

HIV counselling has been proved effective in various ways. An evaluation of The AIDS Service Organisation (TASO) in Uganda has shown that it helps people accept and cope with the knowledge of being HIV-positive, and furthermore encourages acceptance from families and communities. A Rwandan study has proved that HIV counselling can help people make decisions about HIV testing, as well as reduce HIV transmission. Yet there is a reluctance among some policy-makers and service managers to give counselling its proper due as a discipline in which trained practitioners can produce measurable, useful results. For this reason it is under-resourced and not fully appreciated.

The counselling process

HIV counselling is a confidential dialogue between a client and a counsellor aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process includes evaluating the personal risk of HIV transmission, and discussing how to prevent infection. It concentrates specifically on emotional and social issues related to possible or actual infection with HIV and to AIDS. With the consent of the client, counselling can be extended to spouses, sex partners and relatives (family-level counselling, based on the concept of shared confidentiality). HIV counselling has as its objectives both prevention and care. A counsellor is a person trained in the skills of the job: listening to the client, asking supportive questions, discussing options, encouraging the client to make his or her own informed decisions, giving practical information and suggesting follow-up.

Counselling should be a process involving a series of sessions as well as follow-up. It can be done in any location that offers peace of mind and confidentiality for the client. Two types of

counselling, according to site, are practised. Clinic-based counselling is counselling provided in a formal session—in a hospital, health centre or clinic—by a trained professional, such as a doctor, social worker, nurse or psychologist. Community-based counselling is given in a non-formal environment, in a village or urban neighbourhood—by one community member trained in counselling to another community or family member.

Pre-test counselling

HIV counselling is often given in connection with a voluntary HIV test. Such counselling helps to prepare the client for the HIV test, explains the implications of knowing that one is or is not infected with HIV, and facilitates discussion about ways to cope with knowing one's HIV status. It also involves a discussion of sexuality, relationships, possible sex- and drug-related risk behaviours, and how to prevent infection. It helps correct myths and misinformation around the subject of AIDS. Whenever resources permit, pre-test counselling should be made available to those who desire it. People who do not want or do not have access to pre-test counselling should not be

prevented from taking a voluntary HIV test, however. In contrast, informed consent is always required before an HIV test where the individual's name will be linked to the result.

To allay anxieties while awaiting the test result, some individuals may seek support not only from their own families or a knowledgeable community worker.

Post-test counselling

Post-test counselling helps the client understand and cope with the HIV test result. Here, the counsellor prepares the client for the result, gives the result and then provides the client with any further information required, if necessary referring the person to other services. The two usually discuss ways to reduce the risk of infection or transmission. HIV test results should always be given with counselling.

The form of post-test counselling will depend on what the test result is. Where it is positive, the counsellor needs to tell the client clearly, and as gently and humanly as possible, providing emotional support and discussing with the client on how best to cope, including information on relevant referral

Background

services. Ongoing counselling will help clients accept their HIV status, and take a positive attitude to their lives. Through ongoing counselling the infected person may choose to invite a trusted family member to share confidentiality and participate in the counselling—enabling the family to start practising family-level counselling.

But counselling is also important after a negative result. While the client is likely to feel relief, the counsellor must emphasize several points. First, because of the “window period”, a negative result may not mean absence of infection, and the client might wish to consider returning for a repeat test after 3-6 months. Second, counsellors need to discuss HIV prevention, providing support to help the client adopt and sustain any new safer practices. (For further information on counselling related to testing, see Key Materials, *Source Book for HIV/AIDS Counselling Training*, WHO, 1994.)

Counselling for behavioural change

The availability of HIV counselling, even without HIV testing, may create a private environment for discussing sexual matters and personal worries. Counselling augments AIDS education by making HIV-related information personally relevant. Counselling of this type for behavioural change has been successfully provided in

the Medical Research Council project in western Uganda (see Mugula F *et al.*, A community-based counselling service as a potential outlet for condom distribution, paper WeD834 presented to 9th international conference on AIDS and STD in Africa, Kampala, Dec. 1995). Here, community-based counselling in a small rural community increased condom use from 2000 to 7000 per month.

Counselling for children

In many places, children are increasingly affected by the epidemic. Apart from those themselves infected with HIV, they include children where one or both of the parents are either living with HIV or AIDS or have died of AIDS. These children have special counselling needs, such as the emotional trauma of seeing their parents being ill or die, discrimination by other children and adults, and emotional worries about their own continuing illness. Older children may need counselling related to sexual issues, and on the avoidance of risk behaviour.

Counselling for pregnant women

Counselling can benefit pregnant women—or women wanting to become pregnant—who are either HIV-positive or unaware of their HIV status. It facilitates their making informed decisions about whether to become pregnant

if HIV-infected; whether to take a test before pregnancy; and, if pregnant, whether to terminate the pregnancy, where abortion is legally available. For those already pregnant, counselling can also discuss the use of zidovudine (ZDV, also known as AZT), where available, to reduce the risk of transmitting HIV to the unborn child, and breastfeeding and other infant feeding options (see UNAIDS Technical Update on mother-to-child transmission). Where possible, and when the woman agrees, it is advantageous to involve her male partner in the counselling sessions. Ideally, women should have counselling available to them before they become pregnant.

Couple counselling

Counselling is sometimes provided to a pair of sex partners, who agree to attend sessions together. It can help resolve misunderstandings between the two people—such as over worries when one of them is tested HIV-positive—that can lead in some cases to violence, particularly against women. Couple counselling can also be given to a client and his or her sex partner or spouse, before or after an HIV test. It is also provided as part of pre-marital counselling.

For the development of appropriate counselling services, see Key Materials, *Counselling for HIV/AIDS: a key to caring*, WHO, 1995.

The Challenges

Various obstacles stand in the way of HIV counselling being provided effectively wherever necessary.

An underlying problem is the fact that counselling may not be given its proper due by policy-makers and service managers—in part, because of the inherent difficulty of measuring its quality and impact on psychological stress reduction and behaviour change. Because of this, priority is often not given to the proper planning of counselling services and counsellors may not receive the official approval and resources they need to do their job effectively. Another major constraint is the lack of good counselling training schedules that are applicable to local circumstances.

Poor selection of trainees for counselling

People are sometimes put on training courses simply because they are “due” for another course, or to fill up the course, and not because they will be taking up positions as counsellors. This is one reason why those trained in counselling often do not continue to practise it.

Lack of supervised practice and follow-up after training

Because counselling is a skill dependent on the personal qualities of warmth and understanding, it is often mistakenly assumed to require little in the way of preparation

and practical training. For this reason, a 2-3-day workshop, without any supervised practice, is sometimes felt to be enough to produce a trained counsellor.

Inadequate resources, facilities and organization

Problems frequently encountered relating to poor organization or insufficient resources include the following.

- Counselling is not considered an essential social service, and there are therefore no clear policies on funding.
- There is a lack of confidentiality.
- The setting of the service is inappropriate for clients because of lack of privacy during counselling sessions, inconvenient opening times or difficult physical access.
- The procedure of the service is intimidating—for example, clients may be interrogated by reception staff.
- Counsellors often have an established job—such as nursing—which is regarded as taking priority over counselling. Without priority or proper resources being given to counselling, many counsellors have to carry out home visits in their spare time, as a voluntary activity. The consequent frustration can result in burnout.
- Clients are not referred at the right time. For example, clients may not have been offered pre-test counselling—

or possibly have not even given informed consent to testing—and may come to the counsellor, panic-stricken, on learning they are HIV-positive. The counsellor is then required to sort this situation out. If this happens repeatedly in spite of the counsellor’s complaints it may burn out the ability to cope. Often, counsellors are able to provide only a single post-test counselling session and do not make follow-up plans because they are overwhelmed with other duties, or because they lack transport for home visits.

Burnout

Burnout is a state of emotional exhaustion, that results when the counsellor has reached his or her limit to deal with HIV and the emotional stress it causes. This may lead to a state of irritability and anger, often directed at supervisors, colleagues and even clients. The counsellor may also feel despair at the limited number of sources of social or medical support that can be suggested to the client, especially in communities starved of resources. The counsellor may have a privileged awareness of issues directly affecting the client’s ability to cope and reduce future risk behaviour, and feel responsible for the client’s welfare. However, because of lack of formal recognition and resources, counsellors may find they have few options to assist the client.

The Responses

Establishing the role of HIV counselling

One way counselling can be accorded its proper respect is by conducting studies on its *delivery, quality and impact*. Research findings on counselling can help convince decision-makers and service managers to endorse and provide resources in support of counselling services.

- In Uganda, TASO (The AIDS Service Organisation) conducted a study on 730 HIV-positive clients to whom it had given long-term counselling. Counselling appeared to help these clients cope with their infection. Of the clients sampled, 90% had revealed the fact of their infection to another person, with 85.3% telling relations. The study also showed a high level of acceptance of HIV-positive people within families (79%) and in communities (76%), as reported by the TASO clients who had received regular counselling (see Key Materials, TASO Uganda—the inside story, 1995). After results were discussed at each hospital where TASO operated, the hospital managers provided more space for counsellors and encouraged doctors to refer clients to TASO counsellors.
- In 1992, a study in Rwanda examined the impact of preventive counselling. It was shown that for the women whose partners were also tested and counselled, the annual incidence of new HIV infections decreased from 4.1% to 1.8%. Among women who were HIV-positive, the prevalence of

gonorrhoea decreased from 13% to 6%, with the greatest reduction in those using condoms. As a result of these findings, counselling was recognized as a mainstream intervention and the funders of the study established a project for counselling and discordant couples in Zambia (see Key Materials, Allen *et al.*, 1992).

Proper selection of trainees for counselling

Candidates for a counselling training course should satisfy a number of conditions. They must be given a job description that specifies that they can provide counselling. They must have the necessary agreed professional background—this may be as a social worker, health worker, teacher, community worker, or a volunteer from a group of people living with HIV/AIDS. They should be good listeners, respected by others, motivated and resilient, and have warm and caring personalities.

In order to select people with good qualities for counselling, TASO uses the following approach. First, prospective trainees must have a job placement where they can see clients who require counselling. Second, TASO conducts a one-day AIDS counselling awareness workshop for a large group of people being considered for training. This awareness workshop must be conducted separately from training on the technical skills of counselling. During the awareness workshop, a number of issues concerning AIDS—including controversial matters such as

compulsory partner notification—are brought up. The trainers observe the attitudes, reactions and interpersonal interaction skills of the prospective trainees, and based on this, select people for the actual skills training. In order to choose the right type of people to become counsellors, those selecting trainees should have a good understanding of the cultural context in which counselling is to be delivered.

Training workshop, followed by supervised practice

Most of the current effort in training takes the form of a single workshop, with no follow-up supervision. Instead, after the initial workshop the trained person should be placed in counselling work, with support and good supervision, and should participate in a second training workshop later.

Such an approach has been followed in several places. The Zambian national AIDS programme, for instance, has set up a countrywide programme for training in HIV counselling. This begins with a basic workshop, followed by placement in a work situation, which is later followed up by an advanced workshop.

Retention of trained counsellors

In Tanzania, a study showed that of those who had received counselling training, less than a quarter were reported to be practising counselling. Counsellors often leave their jobs, most probably because of burnout and lack of proper support. If counsellors are given

The Responses

proper support, the stresses which can build up and cause burnout can be reduced. Such support can take three forms:

- administrative support, including the provision of better working facilities and timetables, and job descriptions that accommodate counselling;
- professional support, where a supervisor discusses cases with the counsellor or provides emotional support;
- peer support from colleagues.

Service development and support

Once the heads of service sites and AIDS programmes are convinced of the importance of counselling, then one can get down to establishing the basics for a good service (see *Key Materials, Counselling for HIV/AIDS: a key to caring*, WHO, 1995).

- Excessive workloads on counsellors that lead to burnout can be reduced by using trained part-time volunteers and a well-planned system of shifts—for example, a nurse may do counselling for four hours in the morning, and then work at the nurse station in the afternoon.
- The location and opening hours of the service should take into account the needs of the particular community. Counselling has been carried out in STD clinics, hospital outpatient departments and hospital wards. Some nongovernmental organizations (NGOs) have set up counselling centres inside hospital compounds. Others have established counselling services on their own premises, or in centres specially dedicated

to HIV counselling (see *Key Materials, Strategies for Hope No. 9, 1994*). Counselling services for sex workers, as well as condom supplies, are sometimes offered in the vicinity of night clubs, and operate at night.

- HIV/AIDS educational campaigns should include details on how, where and when people can obtain counselling.
- Reception staff should be trained to adopt a supportive and sympathetic attitude, and sensitized to the need for confidentiality.

- If resources permit, counselling services for asymptomatic individuals, as well as preventive counselling, should be located separately from care services for AIDS patients. This enables those living with HIV but who have not yet developed AIDS to receive counselling without being depressed by seeing very ill AIDS patients.

- Counselling sessions need to be well planned so that, for instance, informed consent is always sought and counselling offered before a client takes an HIV test.
- Counselling should be integrated into other services, including STD, antenatal and family planning clinics.
- Community-based counselling services can be initiated and expanded quickly and at little expense.

Referral systems

The existence of good support for counsellors is directly related to the existence of a good referral system. A referral system should be developed in consultation with NGOs, community-based

organizations, hospital directors and other service managers, as well as with networks of people living with HIV and AIDS. An efficient referral system will enable AIDS service organizations and other NGOs to refer clients requiring medical care to hospitals and clinics. At the same time medical services should refer clients to specialized NGOs for ongoing counselling, home care and social support, such as the provision of food and housing.

In Abidjan, Côte d'Ivoire, NGOs such as *Espoir* work closely with Treichville University Hospital to provide medical, nursing and psychosocial care to inpatients and outpatients with HIV/AIDS. *Espoir* also operates a free, anonymous HIV counselling and testing centre.

At the Thai Red Cross Society, clients of the Anonymous Counselling Center are referred to the Wednesday Friends' Club (a support group for people living with HIV and AIDS) and the Chulalongkorn Hospital Immune Clinic for follow-up on treatment and care.

Referrals should always be confidential, and clients should be advised to contact named individuals at the referral site, rather than being given a general referral note. A referral system can only function well if the referring caregiver discusses with the client the reasons why he or she is being referred and the services which are available at the referral site. It is suggested that regular meetings should be held among service providers to review and improve the referral system.

Key Materials

Allen S, Serufilira A, Bogaerts J, Van de Perre P, Nsengumuremyi F, Lindan C, Caradl M, Wolf W, Coates T, Hulley S. Confidential HIV testing and condom promotion in Africa: impact on HIV and gonorrhoea rates. *Journal of the American Medical Association*, 1992; **268**(23): 3338-3343. Study on impact of HIV testing and counselling on self-reported condom and spermicide use and on corresponding HIV seroconversion and gonorrhoea rates in urban Rwandan women.

Sittitrai W. *Reproductive health and HIV/AIDS. Myanmar training manual: a community-based approach for youth and women*. Yangon, UNICEF, 1995. Designed to help community workers in rural Myanmar raise awareness of and develop life skills related to HIV/AIDS. Covers all associated issues, such as care among youth and women. Topics are approached in practical, user-friendly manner. Focuses on importance of involving community, friends and family.

UNAIDS policy on HIV testing and counselling. Geneva: UNAIDS, 1997. UNAIDS/97.2. Statement encourages provision of voluntary HIV testing and counselling, and increasing women's voluntary access to them; stresses importance of informed consent and confidentiality; urges increased quality assurance and safeguards against potential abuse, especially of home collection and home self-tests; and warns against mandatory testing.

Source book for HIV/AIDS counselling training. Geneva:

WHO, 1994. WHO/GPA/TCO/HCS/94.9. Intended for use in training counsellors. Deals with initial training and refresher courses, for those needing to act as counsellors in the course of their professional duties (nurses, midwives, social workers) and for those specialized in counselling.

Counselling for HIV/AIDS: a key to caring. For policy-makers, planners and implementors of counselling activities. Geneva: WHO, 1995. WHO/GPA/TCO/HCS/95.15. Explores programmatic and policy issues with regard to planning and setting up counselling services. Describes counselling, situating it in context of overall response to the epidemic, and ways counselling is organized. Examines counselling aimed at specific population categories. Also examines role of policy-makers and planners.

Keys to Counselling. *AIDS Action Newsletter*, Issue 24. London: AHRTAG, 1994. Special issue of newsletter devoted to counselling. Counselling is presented as an essential part of voluntary HIV antibody testing programmes.

"I feel much better now": HIV and AIDS counselling. 45-min. video for Eastern Europe. Geneva: WHO/UNAIDS, 1996. [En, Ru]. Depicts application of counselling strategies to four different case scenarios where issue of HIV infection is raised. Intended for training counsellors and other health care professionals. Can be used as stand-alone resource or part of structured training. Highlights key issues relevant to HIV counselling, with emphasis

on providing services which are client-centred and flexible to individuals' needs.

Candle of hope: the AIDS programme of the Thai Red Cross. Strategies for Hope Series No. 9. London: ActionAid, 1994. Provides overview of Thai national response to HIV/AIDS epidemic. Includes descriptions of efforts and experiences of Thai Red Cross and Wednesday Friends' Club in providing anonymous, voluntary HIV testing and counselling, disseminating AIDS education, and providing health care, support services, and sense of hope for those living with HIV.

Filling the gaps: care and support for people with HIV/AIDS in Côte d'Ivoire. Strategies for Hope Series No. 10. London: ActionAid, 1995. Describes work done by various NGOs in providing counselling, testing services and outpatient health care for infected persons. Also actions and efforts of HIV-positive support groups that provide support services and disseminate AIDS information and prevention material.

TASO Uganda—the inside story: Participatory evaluation of HIV/AIDS counselling, medical and social services, 1993–1994. Kampala: TASO, 1995. WHO/GPA/TCO/HCS/95.1. Describes participatory evaluation of The AIDS Support Organisation (TASO), carried out in 1993 with technical assistance from WHO/GPA. Evaluation results and recommendations on counselling, medical and home care support, and social support services are discussed.

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