HIV Counselling Handbook for the Asia-Pacific

A comprehensive guide to:

- Voluntary counselling and testing
- Provider-initiated testing and counselling
- Treatment and care counselling

unicef
unite for children

fhi Family Health International

World Health Organization
South-East Asia Region Western Pacific Region

HIV Counselling Handbook for the Asia-Pacific

A comprehensive guide to:

- Voluntary counselling and testing
- Provider-initiated testing and counselling
- Treatment and care counselling

unicef
unite for children

fhi
Family Health
International

World Health
Organization
South-East Asia Region
Western Pacific Region

UNICEF East Asia and Pacific Regional Office
Tel: (66 2) 356 9499 Fax: (66 2) 280 7056
E-mail: eapro@unicef.org
Website: www.unicef.org/eapro

Design and Layout by: Keen Media (Thailand) Co., Ltd.

Printed in Thailand

Cover photos:
The Maternal and Child Health staff, mother and child: G.Pirozzi /UNICEF PNG/2006
Teacher and children: unknown/UNICEF PNG/2004
Group counselling: Family Health International – Bangladesh
Female counselling a female: Family Health International – Asia and Pacific Regional Office
Male counselling a male: Family Health International – Indonesia
Transgender being counselled: Family Health International – Indonesia

ISBN: 978-974-685-112-1

Acknowledgements

This handbook was developed for trainers, counsellors in training, and working counsellors to assist them in delivering high-quality HIV testing and counselling services. It highlights the important contribution of counsellors to HIV prevention, care, and support activities and forms one of three parts of the *HIV Counselling Resource Package*, which also includes trainer's session plans, participatory learning activities, and an HIV counsellor's toolkit. This handbook could not have been developed without the help of many people working in HIV counselling, care support, and treatment throughout the Asia and Pacific regions. We are truly grateful for their creative inspiration, technical input, practical guidance, and editorial review.

Dr Kathleen Casey, Family Health International (FHI) Asia and Pacific Regional Office (APRO), wrote this handbook, with contributions from technical writers Greg Carl of the AIDS Research Centre, Thai Red Cross and Dr Anne Bergenstrom of the United Nations Office on Drugs and Crime (UNODC).

These other individuals provided technical review, editorial assistance, cultural advice, and guidance: Dr Ying Ru Lo, Dr Donna Higgins, and Vincent J. Wong (consultant), World Health Organization (WHO) Headquarters; Dr Mukta Sharma, WHO South-East Asia Regional Office (SEARO); Dr Massimo Ghidinelli, WHO Western Pacific Regional Office (WPRO); Wing-Sie Cheng and Shirley Mark Prabhu, UNICEF East Asia and Pacific Regional Office (EAPRO); Dr Lutfa Ashraf, FHI Bangladesh and Shahnaz Begum, GTZ Bangladesh; Li Ling, FHI China; Dr Zhu Qiuying and Dr Guo Ningzhen, Guanxi Center for Disease Control, China; Binod Mahanty, WHO India; Radhika Srinivas, and Sushma Mehrotra, consultant, India; Dr Ratna Mardiati SpKJ, Indonesia; Dr Dahsriati, Dr Endang Budi Hastuti, Sista Ersanti, Astrid Wiratna, and Marcel Latuhaimalo, consultant, Indonesia; Kekek Apriana, FHI Indonesia; Durga Bhandari, FHI Nepal; Batool Fatima, WHO Pakistan; Rvipa Vannakit, WHO Thailand; and Luu Thi Nguyet, ATS Viet Nam.

This handbook builds on information presented in *HIV Counselling and Testing: A Reference Guide for Counsellors and Trainers* (Arlington, USA: Family Health International, 2004) and the *Voluntary HIV Counselling and Testing Manual for Training of Trainers, Part 1* (New Delhi, India: WHO SEARO, 2004).

Layout and design was done by Sunee Sarif, and editing and proofreading by Shanthi Noriega Minichiello, FHI APRO and WHO WPRO.

This work was funded by UNICEF EAPRO with a grant from the Swedish International Development Agency and further contribution from Family Health International.

Preface

HIV Counselling Resource Package for the Asia Pacific Region

Antiretroviral treatment offers hope of arresting a communicable disease that was once untreatable and remains incurable. The prospects of surviving HIV and living longer should in many ways lessen the fear of HIV testing and the consequent discovery of HIV-positive status. Yet, the advent of antiretroviral therapy and new drugs have not provoked wide test-seeking behaviour, and the uptake of voluntary and confidential counselling and testing services has been slow.

In 2005, in some countries, particularly those in sub-Saharan Africa, 12%–25% of women and 8%–24% of men living with HIV learnt of their HIV status only after participating in a survey. An estimated 0.1% of adults in Asia and the Pacific have been tested, and it is believed that less than 10% of those living with HIV are aware of their status.

The urgent need to help more adults and children, especially in vulnerable, marginalized communities, find out their HIV status and receive treatment is beyond question. But HIV testing–whether client- or provider-initiated–is more than simply uncovering HIV cases. The quality of counselling and respect for the right to opt out of testing, as well as support measures for coping with the results, are just as important. Counselling, before or after testing, should increase knowledge of HIV prevention and enhance primary health care and positive prevention, as well as curative care when positive status is confirmed. The quality of counselling also shows itself in the quality of referrals, follow-ups, treatment adherence, and care, including nutritional, psychosocial and medical support, such as cotrimoxazole prophylaxis, to sustain the well-being of adults and children living with HIV.

This comprehensive HIV counsellors resource package answers the pressing need to improve the quality of counselling as countries step up their drive to contain the AIDS epidemic. Prepared over two years by WHO and UNICEF with technical assistance from the Family Health International Asia-Pacific Regional Office, it is designed to equip trainers, counsellors in training, and working counsellors in the Asia Pacific Region with essential skills and knowledge to deliver high-quality HIV testing and counselling services in a range of approaches and settings. The HIV counsellors handbook, trainer's session plans, participatory learning activities, and HIV counsellor toolkit found here were updated from the *Voluntary HIV Counselling and Testing Manual for Training of Trainers* (2004) prepared jointly by the WHO South-East Asia Regional Office and the UNICEF East Asia and the Pacific Regional Office.

The newer features of the current package reflect the new types of tests being used by health care providers. The provider-initiated testing and counselling approach is based on the UNAIDS/WHO Policy Statement on HIV Testing (2004), which was drafted after numerous rounds of consultations to deal with the low uptake of Voluntary and Confidential Counselling and Testing worldwide.

The expansion of client- and provider-initiated testing and counselling services in health care settings must be carefully considered. HIV testing and counselling strategies, particularly for high-risk and vulnerable populations, must be implemented in an ethical manner that respects human rights. Utmost priority must be given to training and supervising health care providers, particularly in counselling clients, obtaining their informed consent, keeping HIV test results confidential, referring clients for treatment and giving them better access to appropriate services, and reducing stigma and discrimination. Understanding of the role and effectiveness of HIV counselling and counsellors-an area that deserves further support and investment-must improve.

We hope that this comprehensive resource package informs and inspires greater efforts to upgrade HIV prevention, care and support and that it strengthens the capacity and quality of health care, as well as its links with communities and families affected by AIDS, towards greater universal access and the fulfillment of the Millennium Development Goals.

Dr Shin Young-soo
WHO Regional Director
for the Western Pacific
Regional Office

Anupama Rao Singh
Regional Director
UNICEF East Asia
and the Pacific
Regional Office

Dr Samlee Pliangbangchang
WHO Regional Director
for South-East Asia
Regional Office

Dan Toole
Regional Director
UNICEF South Asia
Regional Office

Acronyms

ADC	AIDS dementia complex
ADLs	activities of daily living
AIDS	acquired immune deficiency syndrome
ARV	antiretroviral
ART	antiretroviral therapy
BBV	blood-borne virus
CDC	US Centers for Disease Control and Prevention
CNS	central nervous system
EIA	enzyme-immune assay
ELISA	enzyme-linked immunosorbent assay
ESSE	exit, survive, sufficient, enter
FBO	faith-based organization
FTM	female to male
HAART	highly active antiretroviral therapy
HBV	hepatitis B
HCV	hepatitis C
HCW	health care worker
HIV	human immunodeficiency virus
HLA	human leukocyte antigen
HPV	human papilloma virus
HTC	HIV testing and counselling
IDU	injecting drug user
MARA	most-at-risk adolescents
MARPS	most at risk populations
MSM	men who have sex with men
MTCT	mother-to-child transmission
MTF	male to female
NGO	nongovernmental organization

NNRTI	non-nucleoside reverse transcriptase inhibitor
NRTI	nucleoside reverse transcriptase inhibitor
OI	opportunistic infection
OST	opioid substitution therapy
OVC	orphans and vulnerable children
PCR	polymerase chain reaction
PCP	Pneumocystis carinii pneumonia
PEP	post-exposure prophylaxis
PI	protease inhibitor
PITC	provider-initiated testing and counselling
PLHIV	people living with HIV and AIDS
RIPA	radioimmunoprecipitation assay
STI	sexually transmitted infection
SSRI	selective serotonin retake inhibitor
SW	sex worker
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VCT	voluntary counselling and testing
WHO	World Health Organization
ZDV	zidovudine

Contents

ANNEXES

Overview

The *HIV Counselling Handbook* is a generic document that should be adapted to the specific sociocultural context of the reader. It should be considered a living document to be revised as often as needed in order to provide up-to-date information for delivering high-quality HIV counselling. The handbook is one part of the *HIV Counselling Resource Package*, which also includes trainer's session plans, participatory learning activities, and an HIV counsellor's toolkit. For training purposes, the contents may be supplemented with additional resource materials to tailor the course to the local culture.

Why is this handbook necessary?

Many reference guides and training packages address HIV counselling but few are oriented to the epidemic context in the Asia and Pacific regions. In particular, many resources do not guide the reader in meeting the specific needs of individuals from socially marginalized populations that are often most at risk of HIV and other sexually transmitted infections. Most resources also address only the provision of pre-HIV test and post-HIV test counselling.

Who will use this reference guide?

This reference guide is intended for trainers, counsellors in training, and working counsellors. Its users may include:

- Nurses, doctors, social workers, and other care providers;
- Counselling professionals (including psychiatrists, psychologists, drug counsellors, and family therapists); and
- Community-based workers and lay counsellors, including home-based care providers.

What are the objectives of this guide?

The handbook is intended to provide counsellors with a quick reference to the key basic counselling process and procedures in HIV counselling. As no single handbook can adequately deal with all of the complexities of client counselling, readers are referred to other sources of detailed information in the resource guide, which can be found at the end of the handbook.

This handbook provides the following:

- an orientation to the role of an HIV counsellor within HIV prevention, treatment, and care initiatives;
- guidance on practice ethics, including responses to common ethical challenges in HIV counselling;
- a step-by-step guide to pre-HIV test counselling for individuals or couples, and group pretest information sessions;
- assistance to individuals from marginalized sub-populations in reducing HIV transmission, adapting to an HIV diagnosis, and improving the quality of their lives;
- ethical strategies for facilitating client disclosure of HIV status to partner(s) and family;
- assistance to clients in overcoming treatment adherence challenges;
- strategies in support of health-care workers who have sustained occupational exposure;
- guidance in tailoring counselling to the diverse and specialized needs of clients affected by HIV throughout the Asia and Pacific regions; and
- guidance in establishing and implementing a peer supervision support network.

How should this guide be used?

This handbook is intended to be broadly adaptable to specific country and epidemiological settings and to function as both a reference and a learning tool. Within the resource package, the handbook complements the *Toolkit for HIV Counselling* and its annexes. Together, these materials may be used in a modular fashion, allowing trainers to select sections for specific trainee requirements, counselling target groups (injecting drug users, men who have sex with men, etc.), and course duration requirements.

Background

HIV presents health workers, and counsellors in particular, with unique challenges. While many health workers have worked with life-threatening illnesses, prior to the HIV epidemic few had to meet the challenge of working in an area of such sociocultural sensitivity.

In the Asia and Pacific regions many clients and patients come from marginalized groups with a range of psychosocial issues including histories of drug or alcohol use, sex work, and gender and sexual identity issues. Besides the varied backgrounds of clients presenting at services, HIV counsellors and mental health service providers themselves come from diverse professional backgrounds, and are often challenged by a complex array of HIV-related psychiatric and psychosocial conditions. Counsellors are expected to reduce transmission, facilitate knowledge of HIV status, provide psychosocial support, and address treatment adherence in the context of a highly stigmatized disease. In the Asia and Pacific regions, HIV counsellors must meet these objectives with large numbers of clients, often with limited HIV counselling training, personnel support, and clinical supervision.

What HIV counsellors need to know about HIV, STI, and TB: The basics

1

Chapter 1

What HIV counsellors need to know about HIV, STI, and TB: The basics

Your work as an HIV counsellor will require you to understand and communicate to clients a number of facts about HIV: how it is transmitted, how it is diagnosed, how the disease progresses, and how HIV treatments work. It is also important that HIV counsellors understand how sexually transmitted infections (STIs) are transmitted, treated, and relate to HIV. As HIV fuels the tuberculosis (TB) epidemic, it is important that counsellors understand the relationship between HIV and TB, and the role counselling plays in addressing TB-HIV co-infection.

This guide assumes that counsellors have the opportunity to consult with or make referrals to a doctor or medical officer for clinical problems.

What is AIDS? How is it different from HIV?

AIDS is an acronym for ″Acquired Immune Deficiency Syndrome″. *Acquired* means ″transmitted from person to person″; *immune* is the body's system of defence; *deficiency* means a ″lack of″ or not working to the appropriate degree; and a *syndrome* is a group of signs and symptoms. AIDS is the advanced stage of HIV infection. The human immunodeficiency virus (HIV) causes AIDS in humans. Researchers have identified two types of HIV: HIV-1 and HIV-2. HIV-1 and HIV-2 are transmitted in the same way and are associated with similar opportunistic infections, though they differ in the efficiency of transmission and rates of disease progression. HIV-1 accounts for the majority of infections in the world; there are more than 10 genetic subtypes. HIV-2, found primarily in West Africa, appears to be less easily transmitted and progresses more slowly to AIDS than HIV-1. A person can be infected with both types of HIV simultaneously.

What is the immune system?

The immune system is a collection of cells and substances that defend the body against foreign substances, also known as *antigens*. An antigen is a substance (such as HIV) that, when introduced into the body, stimulates the production of an *antibody* (the word antigen is short for ″antibody generating″; antibodies fight antigens). Antibodies form in a person's blood when HIV or other antigens enter the body. Usually antibodies defend against disease agents. The replication of HIV in the body over time, and especially without pharmacological intervention, breaks down the immune system to the point where it can no longer fight disease. The immune system can be compared to an army guarding the borders of a state and protecting it from foreign invasion. As long as the army is strong, the state has little to fear. But if the army is weakened or encounters a stronger enemy, the state becomes vulnerable and can no longer defend itself against attacks, even from smaller neighbours.

The immune system functions in a similar way. It is composed of cells (called *T-lymphocytes* and *B-lymphocytes*) that perform the role of defending army. Among the T-lymphocytes are cells that carry what are known as *CD4 receptors*. These cells are called *T4 lymphocytes* (or *T-cells* or *CD4 cells*).

HIV infects a person's CD4 and T-cells and uses them to make copies of itself–a process known as *replication*. In a person infected with HIV, CD4 cells are progressively destroyed. As these cells are destroyed, an infected person's immune system is weakened and the person is more likely to develop opportunistic infections (OIs) and certain cancers. Any other infection that stimulates the immune system is likely to accelerate this destruction, making the person more vulnerable.

How is HIV transmitted?

HIV is found in blood, semen, vaginal fluids, and breast milk. It can be transmitted in any of four ways:

- through sexual contact with an infected person;
- from infected mother to baby before or during birth or through breast-feeding after birth;

- through infected blood and blood products (transferred via blood transfusions and organ transplants); or
- through the sharing of needles, syringes, and other injecting equipment (including tattooing equipment).

The chance that a person will become infected with HIV varies greatly depending on the type of exposure he or she has had. For example, the risk of becoming infected with HIV through a blood transfusion with infected blood is very high compared with the risk of becoming infected from an accidental needle prick in the health-care setting. Similarly, there is less risk of acquiring HIV from unprotected oral sex than from unprotected anal or vaginal sex.

It is important that your clients understand that HIV may be present in and transmitted by semen, vaginal fluids, breast milk, and blood. In order for your clients to reduce risk they will need to understand that different behaviours carry different levels of risk. HIV counsellors must assess each client's understanding and impart relevant information depending on his or her needs and level of knowledge. Clients and patients must be encouraged by counsellors to make informed decisions about testing and behaviour change. Such informed decisions require a clear understanding of the modes of transmission, the risk involved, and the implications of an HIV test result, as well as the correction of clients' misconceptions. About 70%-80% of global HIV transmission occurs through unprotected sexual intercourse between infected persons and their partners. The sexual contact may be heterosexual or homosexual. Heterosexual vaginal intercourse is the predominant mode of transmission in many developing countries. While the probability of transmitting HIV in a single sexual act is quite low, even a lower-risk activity can get people infected if it is done often enough. Furthermore, the risk of infection can increase dramatically because of several factors, including the presence of a prior STI (sometimes manifested in genital sores or discharge) and unprotected intercourse with sexual partners.

Transmission in clinical settings, injecting drug use, and tattooing

HIV infections resulting from the transfer of infected blood account for about 5%-10% of all HIV infections. Transmission can occur through transfusion with contaminated blood or blood products, the use of contaminated injecting equipment, the exchange and reuse of needles or contaminated syringes, and surgical operations where equipment previously used on an HIV-positive patient has not been sterilized. Organ transplants from infected donors can also transmit the infection. Additionally, HIV can be transmitted through direct contact with instruments that have been contaminated with infected blood and not sterilized before reuse, in circumcision, tattooing, and other rituals, for example.

Transmission during pregnancy, delivery, and breastfeeding

A mother can transmit HIV to her child during pregnancy or delivery, or through breastfeeding (table 1.1). The rates of HIV-1 transmission from mother to child range from 25% to 40% in less-developed countries, and from 15% to 25% in more-developed countries. The risk of transmission is affected by factors related to the virus, the mother, the delivery process, the baby, and infant-feeding practices. These factors explain the differing rates of HIV transmission between more-developed and less-developed countries. During pregnancy and delivery, the mother's health, disruption of the placental barrier, preterm delivery, and haemorrhage are significant predictors of the child's infection. Viral, bacterial, or parasitic placental infections are other factors that increase the opportunity for transmission during this period. Most infants who acquire HIV during delivery have been exposed to maternal blood or cervical secretions that contain the virus. Prolonged membrane rupture and invasive delivery techniques have also been associated with higher risks of mother-to-child transmission (MTCT) during labour and delivery. The risk of MTCT increases if a woman has a higher viral load, which occurs if she becomes infected or reinfected with HIV during pregnancy or if she becomes ill with AIDS. After delivery, breast-feeding is the most significant risk factor. Without treatment, it is estimated that one of every seven infants breast-fed by an HIV-positive mother becomes infected through breast milk. The risk of transmission is greater when HIV-positive women do not breast-feed exclusively for the first six months, or if complications develop from poor breast-feeding techniques (e.g., mastitis, cracked and bloody nipples).

Table 1.1: Timing of transmission of HIV from mother to child

Period	Population with no breastfeeding	Breastfeeding through 6 months	Breastfeeding 18-24 months
During pregnancy	5%-10%	5%-10%	5%-10%
During labour	10%-20%	10%-20%	10%-20%
Through breastfeeding	–	–	–
Early (first 2 months)	–	2%-10%	2%-10%
Late (after 2 months)	–	1%-5%	5%-10%
Overall risk of MTCT of HIV	15%-30%	25%-35%	30%-45%

Source: Source: de Cock K. et al. Prevention of mother-to-child HIV transmission in resource-poor countries: Translating research into policy and practice. JAMA 2000, 283: 1175-1182.

How is HIV diagnosed?

The diagnosis of an HIV infection is most often based on the detection of antibodies to the virus. An antibody test is rarely 100% *sensitive* (correctly able to categorize an infected person as positive) and 100% specific (correctly able to categorize a non-infected person as negative). Therefore, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO), and the US Centers for Disease Control and Prevention (CDC) jointly recommend that all positive test results be confirmed by retesting, preferably using a different testing method. Your local training programme should provide you with information on the the testing procedure at your HIV testing and counselling (HTC) service.

All testing done at HTC centres should be subject to external quality assurance. Usually 5%-10% of all samples–venous samples or samples collected through a filter-paper method (commonly referred to as *dried blood-spot* specimens)–should be sent out for external quality assurance testing. For example, one out of every 10 positive samples and one of every 20 negative samples may be sent quarterly to a national reference laboratory for quality assurance. Quality assurance measures will most often be determined by a country's national HIV programme guidelines, which define testing protocols or algorithms to guide individuals administering tests. The protocols depend on national testing policies, HIV prevalence, the purpose of testing, and the number of different HIV tests available in a particular setting.

The window period

For an HIV-infected individual, the *window period* is a common term used for the time between the initial HIV infection (the *acute infection*) and the development of a measurable immunologic (or *antibody*) response to the infection. During this period, a person infected with HIV could still have a negative HIV test result. Within this time frame, however, HIV is replicating in the blood and lymph nodes. The virus can be detected in this early phase only by laboratory tests used to identify the virus itself.

The window period varies from person to person and can range from as little as two weeks to as long as three months. Thus, if a person tests negative to HIV antibody tests, he or she may still be within the window period; if infected, that person's immune system has not yet begun making a detectable amount of antibodies against the virus. A person in the window period will test positive for HIV only if a virological test (described below) is used.

However, virological testing is often not available or affordable. Post-test counselling should therefore be optimized to detect persons who may have an acute HIV infection. This is best done through retesting for HIV. When to retest those who are most at risk of infection or have had a recent incidence of exposure is generally determined by national guidelines.

Types of tests

There are two main types of HIV tests: antibody tests (e.g., enzyme-linked immunosorbent assay [ELISA], simple/rapid tests, saliva assays, urine assays, and the Western blot) and virological tests (e.g., HIV antigen test, polymerase chain reaction test, and viral culture).

Antibody tests

HIV antibody tests detect antibodies against HIV; they do not directly detect the virus itself. Once HIV enters the body, it infects white blood cells, known as T4-lymphocytes or CD4 cells. The infected person's immune system responds by producing antibodies to fight the new HIV infection. The presence of the antibodies is used to determine the presence of HIV infection.

In the Asia and Pacific regions the most commonly used antibody tests are the enzyme immunoassay (EIA) or ELISA and simple/rapid HIV tests. The Western blot is better than other tests at identifying HIV infection but is also more expensive than other tests. In addition, the radioimmunoprecipitation assay (RIPA), a confirmatory antibody test, is used when antibody levels are very low or difficult to detect, or when the results of the Western blot are uncertain. RIPA is an expensive test that requires time and expertise to perform.

EIA and Western blot tests that use urine instead of blood have also been developed. Tests of urine for HIV are not as sensitive or specific as blood tests. These urine tests must be ordered by a physician, who must communicate the results to the patient or client.

Rapid HIV testing. Rapid HIV tests are antibody tests that generally produce results in less than 30 minutes, and require only a few steps and a limited amount of training. While blood-based rapid tests (using blood drawn from a vein or taken from a finger-prick) are the most common, there are also rapid tests that use oral fluid samples.

In most rapid tests, whether blood-based or using serum or plasma, a sample is generally introduced into a cartridge or at the base of a strip (known as a lateral flow assay) and absorbed through or along a membrane. If a patient has antibodies against HIV, these will be captured on the membrane and a latex- or gold-based indicator will be added to make the antibodies visible-usually as a band or a dot. Most assays also include an additional control band or dot that becomes visible if the test was properly done.

Saliva-based tests determine the presence of HIV antibodies in a sample of oral fluid (saliva). A trained specialist must usually collect the sample from between the lower cheek and the gum. Tests of saliva specimens for HIV antibodies are convenient and accurate, but blood tests are more accurate. When both tests are available, clients may be allowed to choose between the two.

As with all antibody tests, a positive result in any rapid test must be confirmed through another method of testing before a diagnosis is made.

Virological tests

The antibody tests discussed above are those most commonly used in HIV testing and counselling. Under special circumstances (e.g., in a recently infected individual, during the window period, or in the case of a child born to an HIV-positive mother), more direct diagnostic methods may be used. Unlike antibody tests, virological tests determine HIV infection by directly detecting the virus itself. There are three types of virological tests:

- viral antigen detection tests (also known as p24 antigen tests);
- nucleic acid-based tests (specialized tests that look for genetic information on HIV through polymerase chain reaction or PCR); and
- virus culture, which isolates the virus.

Virological tests are rarely used to diagnose HIV in developing countries because they require sophisticated laboratories and are expensive. They may be used to monitor the progress of infection or response to therapy (e.g., by measuring viral load).

HIV tests on infants and children

The diagnosis of HIV in infants is problematic because infants born to HIV-positive mothers will test positive for antibodies acquired from their mothers for up to 18 months after birth through the transfer of antibodies from mother to child during pregnancy, delivery, or breast-feeding. A positive result with an antibody test only identifies infants who have been exposed to the mother's antibodies against HIV; these children may not be infected with the virus itself. For this reason, identifying infected and uninfected infants born to HIV-positive women is difficult. Only virological tests, such as PCR, viral culture, and p24 antigen testing, will determine whether an infant is infected. Clinical evaluation with repeated testing over at least the first two years of life has been the primary means of establishing a diagnosis in these children.

Interpreting HIV test results

Only suitably trained and authorized personnel should interpret and provide the test results. Such personnel are generally identified in national HIV testing policies and may vary across different countries. All counsellors should, however, understand and be able to explain the meaning of a test result to a client.

A negative test result means that HIV antibodies were not detected in the person's sample, either because the person is not infected or because the person is still in the window period. The client must understand that a negative result does not necessarily mean that he or she is uninfected or immune to HIV infection. An HIV-negative person who engages in risky behaviour is still vulnerable to HIV infection. A person who tests negative but has practiced unsafe behaviours during the window period may be infected with HIV and infectious to others.

A positive test result means that HIV antibodies were detected in the person's sample. The person is infected with HIV and can transmit the virus to others if he or she engages in risky or unsafe behaviours. It does not necessarily mean that the person has AIDS. Neither the presence nor the absence of HIV antibodies is confirmed by an indeterminate test result, for any one of three possible reasons:

- The person may be seroconverting (he or she has had an exposure risk within the window period).
- The person may have had an earlier inoculation that is cross-reacting with the HIV antibody test (cross-reactivity does not necessarily mean that HIV is present).
- The person may have a prior medical condition that is affecting the test (for example, arthritis or autoimmune problems).

False-negative results

A false-negative result occurs in an infected person when the blood test gives a negative result for HIV antibodies even though it should have showed positive. The likelihood of a false-negative test result must be discussed with clients if their history suggests they have engaged in behaviour likely to put them at risk of HIV infection. Repeated testing over time may be necessary before the client can be reassured that he or she is not infected with HIV. Most often a false-negative result arises among individuals who are newly infected and are not yet producing HIV antibodies. It is important to remember that someone who has rightly tested negative-because he or she is not infected with HIV-can become infected at any time afterwards.

False-positive results

The HIV antibody tests that are now available are extremely sensitive, and false-positive rates are appreciable, particularly in low-prevalence populations. All clinical HIV testing strategies nevertheless require repeated HIV antibody assays. A false-positive on one assay is unlikely to also test positive on a second, different, type of assay. False-positive results may be due to technical error, repeated thawing and freezing of sample, and cross-reactivity. In ELISAs and rapid tests, human leukocyte antigens (HLAs) can cross-react, resulting in false-positives among persons with:

- rheumatoid arthritis,
- multiple sclerosis,

- systemic lupus erythmatosus,
- type 1 diabetes mellitus,
- Addison’s disease,
- ankylosing spondylitis,
- chronic hepatitis,
- cancer (particularly lympho-proliferative malignancies), or
- severe kidney disease

and in persons who have had:

- a flu shot in the past 30 days,
- a gamma globulin injection, or
- a recent transfusion or organ transplant.

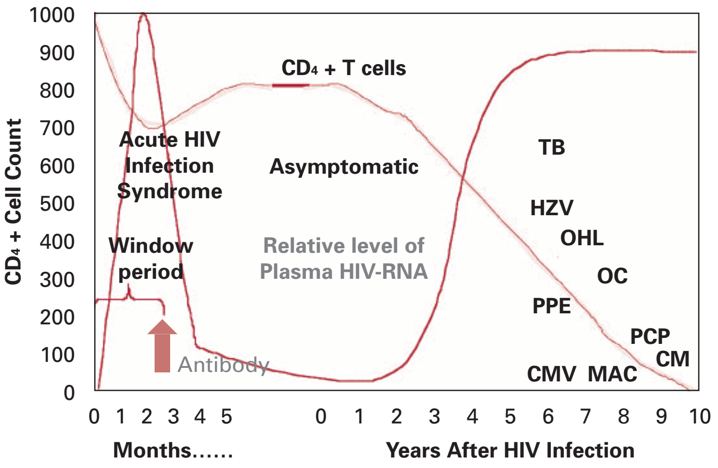
Confirmatory tests usually rule out false-positive results.

HIV disease progression

After HIV enters a person’s body, it infects the person’s cells (essentially CD4 T cells and macrophages) and starts replicating. HIV induces the body’s immune system to produce antibodies specific to HIV. As explained above, the period between the acquisition of the infection and the production of detectable HIV antibodies is called the *window period* and it can last anywhere from two to 12 weeks. During this period an individual may have an *acute HIV infection* (AHI), also sometimes referred to as a *primary HIV infection* (PHI). Here an infected person can be highly infectious despite having a negative HIV test result. At the time of infection, 30%-50% of people have a recognizable acute illness characterized by fever, lymphadenopathy (enlarged lymph nodes), night sweats, skin rash, headache, and cough.

HIV-positive individuals may remain without symptoms (*asymptomatic*) for up to 10 or more years. In this phase they are potentially a critical factor for the transmission of HIV, as they are infectious but can be identified only through blood screening for HIV antibodies. After a period that varies from person to person, viral replication resumes and with it the destruction of CD4 lymphocytes and other immune cells, resulting in a progressive immune deficiency syndrome. Progression depends on a number of factors: the type of HIV infection, the person’s age, other infections, and possibly genetic (hereditary) factors. Infections, diseases, and malignancies occur among HIV-infected individuals and are related to the degree of immune suppression. These include morbidities such as TB, oral hairy leukoplakia, oral candidiasis, pruritic papular eruption, *Pneumocystis carinii* pneumonia (PCP), cryptococcal meningitis, cytomegalovirus retinitis, and *Mycobacterium avium* complex infection (see figure below).

Natural course of HIV infection and common diseases



CM = cryptococcal meningitis, CMV = cytomegalovirus retinitis, MAC = *Mycobacterium avium* complex infection, OC = oral candidiasis, OHL = oral hairy leukoplakia, PCP = *Pneumocystis carinii* pneumonia, PPE = pruritic papular eruption, TB= tuberculosis.

WHO clinical staging

In developing countries, the clinical diagnosis of HIV infection is based most often on serological testing (blood test), an indirect diagnostic method designed to reveal the presence of HIV antibodies in the blood. For people who present with clinical symptoms, diagnosis is usually based on the WHO clinical staging system, a four-stage classification system that combines signs, symptoms, and diseases, plus a physical activity framework using a performance scale (included in the toolkit). Clients are classified according to the presence of clinical conditions or performance scores belonging to the highest stage. The staging is hierarchical; once a stage is reached, the client cannot revert to a lower stage but can only progress to a higher stage. Some countries have modified these criteria. Though counsellors are not expected to make diagnoses, they must be aware of clinical staging to facilitate referral to medical providers for clinical management.

What does clinical management involve?

Individuals who are diagnosed with HIV should be referred to a specialist HIV physician for ongoing medical follow-up. This follow-up may include regular immune system monitoring, antiretroviral therapy (ART), prophylaxis of OIs, the management of HIV-related neurological and psychiatric conditions, the management of common co-infections including tuberculosis and hepatitis B and C, clinical examination, family planning, and general health care.

Immune system monitoring tests

Immune system monitoring tests are performed as part of HIV care and treatment and may include viral load and CD4 tests. The CD4 cell count is an indicator of the level of immune function at any given time, while the viral load is a measurement of the level of circulating virus in the blood. As the virus reproduces, it destroys CD4 cells and reduces the CD4 count. In general, the higher the viral load, the more quickly the CD4 cells are destroyed. Like CD4 counts, viral load measurement is important for disease staging and prognosis. Persons with a high viral load are more likely to progress rapidly to AIDS than persons with a lower viral load. Both tests are useful in guiding the use of ART, staging HIV disease, and determining a patient's prognosis.

Antiretrovial therapy

ART refers to medication that stops or inhibits the replication of HIV. Antiretroviral treatment in general is aimed at prolonging and improving the quality of life by maintaining the maximal suppression of HIV replication for as long as possible. Four types of ART drugs are taken in combination to suppress different stages of the life cycle of the virus. Tool 8.2 contains a discussion on how ART works.

Prevention and management of opportunistic infections

An individual with a low CD4 count is susceptible to OI. The prevention and treatment of OI decreases the mortality risk of HIV infection. Individuals with low CD4 counts are prescribed preventive medications called *OI prophylaxis*. Common OIs in HIV are:

- TB;
- septicaemia;
- pneumonia (usually PCP);
- recurrent fungal infections in mouth and throat;
- meningitis;
- other skin diseases (e.g., Kaposi's sarcoma); and
- other STIs.

The three most commonly reported OIs in Asia are TB, PCP, and extra-pulmonary *Cryptococcus* (usually meningitis). Another common OI in southern China and parts of Southeast Asia (e.g., Thailand and Viet Nam) is *Pencillium marneffei*.

The clinical management of OIs may also involve nutrition counselling and treatment of HIV wasting and severe weight loss, chronic or intermittent fever, and chronic or intermittent diarrhoea.

Management of HIV-related neurological and psychiatric conditions

HIV-related neurological and psychiatric disorders are the result of direct or indirect effects on the brain of either HIV or complications from the suppression of the individual's immune system, such as OIs. These disorders may include one or more of the following:

- mania;
- depression;
- personality change;
- psychosis;
- HIV minor cognitive disorder; and
- HIV dementia (also referred to as AIDS dementia complex), HIV encephalopathic disorders that affect motor skills, coordination, and balance.

While new treatment strategies have resulted in marked improvements in health, mental health care is increasingly recognized as crucial to the overall health of all people with HIV. Psychological well-being affects one's overall health and, importantly, also ensures that treatment decisions are adequately considered, adherence to ART is optimized, and behaviour changes needed to reduce HIV transmission can be initiated and maintained.

Management of tuberculosis co-infection

TB co-infection is common in the Asia and Pacific regions. HIV promotes progression to active TB both in people with recently acquired TB infections and in those with latent TB infections. Up to 60% of people with HIV develop active TB during their lifetimes, compared with about 10% for those uninfected. It is therefore important that HIV services, such as HTC, help to detect more TB cases. TB is spread through the air from person to person. People with active TB are most likely to transmit it to those they regularly spend time with, including partners, family members, and co-workers. Counsellors should ask clients if they have had symptoms of TB. All clients with the following symptoms should be referred for a TB assessment:

- a persistent cough that lasts longer than 2 weeks; or
- persistent fever, unexplained weight loss, severe undernourishment, suspicious lymph nodes (larger than 2 centimetres), or night sweats.

If either of these symptoms is present, sputum samples should be submitted. The patient should be referred to a district doctor or medical officer if he or she is not producing sputum or if nodes are present.

As HIV may reactivate latent TB, counsellors should encourage all HIV-positive clients to discuss TB screening with their HIV physician.

Management of sexually transmitted infections

STIs are particularly prevalent in developing countries and among sexually active young people. Some of the most common are gonorrhoea, syphilis, genital herpes, chlamydia, human papilloma virus (HPV), and trichomoniasis. Different pathogens are responsible for each STI. If left untreated, STIs can have serious consequences for men, women, and newborn children. STIs are a powerful co-factor in HIV transmission. Their presence makes a person more vulnerable to HIV by a factor of 15%-20%. Genital lesions or inflammation caused by STIs enables HIV to enter and establish itself in the body. STIs, particularly if they are ulcerative, increase one's risk of contracting HIV because they may cause ruptures or micro-lesions in mucous membranes. Thus, to reduce the risk of HIV infection, one must avoid contracting other STIs. If other STIs do occur, they must be treated promptly and effectively to minimize the risk of acquiring or transmitting HIV. We will take a closer look at STIs later in this chapter.

Management of hepatitis B and C co-infection

Hepatitis B (HBV) and hepatitis C (HCV) co-infection are common in the Asia and Pacific regions. HBV transmission is similar to HIV transmission. HCV, on the other hand, is transmitted by infected blood products and donated organs and through the sharing of injecting equipment. Both HBV and HCV cause liver inflammation, which may complicate the patient's HIV treatment. Counsellors should therefore urge their clients to be tested for the presence of these infections. Patients with HBV or HCV should be counselled to avoid or limit their alcohol intake to prevent liver damage.

STI counselling

For the reasons discussed above all HIV counsellors should be familiar with STI counselling, treatment, and care. STIs are acquired through heterosexual or same-sex relations. Another means of transmission is from mother to child during pregnancy (syphilis) or delivery (gonorrhoea, chlamydia). The same behaviours that put individuals at risk of HIV infection also expose them to risk of acquiring other STIs: having multiple sex partners or high-risk partners, and engaging in unprotected sex. Thus, the prevention methods are the same.

Clinical manifestations of STI

Many STIs have similar clinical manifestations, with minor variations. Consequently, STIs can be categorized by either their signs and symptoms or their causative agents. Classification according to signs and symptoms has facilitated *syndromic treatment*, which does not rely on laboratory tests. This approach is useful in resource-constrained settings. Table 1.2 summarizes the signs and symptoms of the six most common STI syndromes.

Table 1.2: Six most common STI syndromes

STI Syndrome	Signs/symptoms	Common causes
Urethral discharge (in men)	Urethral discharge Urethral itching Pain on urination Frequent urination	*Neisseria gonorrhoeae* *Chlamydia trachomatis*
Scrotal swelling (complication of untreated urethral discharge)	Scrotal pain and swelling	*Neisseria gonorrhoeae* *Chlamydia trachomatis*
Genital ulcer disease syndrome (GUD)	Genital ulcer with or without pain Swelling of inguinal lymph nodes Abscess and/or fistula	*Treponema pallidim* *Haemophilis ducreyi* *Genital herpes* *Klebsiella inguinale* *Chlamydia trachomatis* (serovars L1-3- Lymphogranuloma venereum
Inguinal bubo	Swelling of inguinal lymph nodes Abscess and/or fistula	*Haemophilis ducreyi* *Chlamydia trachomatis* (serovars L1-3- Lymphogranuloma venereum)
Vaginal discharge syndrome (in women)	Vaginal discharge Painful urination Dyspareunia Vaginal itching Frequent urination	*Neisseria gonorrhoeae* *Chlamydia trachomatis* *Bacterial vaginosis* *Candida albicans* *Trichomonas vaginalis*
Lower abdominal pain syndrome (complication of untreated endocervitis)	Pelvic pain Abdominal tenderness Fever	*Neisseria gonorrhoeae* *Chlamydia trachomatis* *Anaerobic bacterial infection*
Neonatal conjunctivitis	Purulent eye discharge Swollen eyelids Baby unable to open eyes	*Neisseria gonorrhoeae* *Chlamydia trachomatis*

STI care and treatment should consist of:

- correct early diagnosis, followed by treatment with antibiotics;
- counselling and education for behaviour change; and
- treatment of all partners (sexual contacts).

STI counselling and clinical management pose several challenges. Counsellors should consider the following in supporting STI treatment and care:

- It is difficult to change sexual behaviour. Knowledge does not automatically lead to behaviour change. STI control is difficult because sexual practices are rooted in everyday life and culture. Counsellors should let their clients know that they can help them make these changes.
- People find it embarrassing to discuss sex. Sometimes people are shy about asking for the information they need, slow in seeking treatment, or reluctant to discuss the issue with their partners. People can feel uncomfortable talking about sex, and the subject is sometimes taboo. Counsellors should carefully explain to the client or patient why discussing these sensitive issues is so critical.
- Many people with STIs exhibit no symptoms. People with STIs can spread infection even without knowing they are infected. Counsellors should refer all clients presenting with transmission risks for STI screening.
- Treatment is not always available, easy, or effective. Counsellors can support clients in initiating and maintaining treatment adherence (see box 1.1 below).

Box 1.1: Key STI messages for clients and patients

- If you have multiple partners have a check-up every three months. You can have an STI without having symptoms!
- Having an STI can put you at greater risk of getting HIV or giving it to others.
- DO NOT ENGAGE IN SELF-TREATMENT! Specific drugs are needed for specific STIs. Therefore, only a trained STI doctor will know what medication is right for you and your condition.
- Take your STI medication for the entire course even if your symptoms disappear. Otherwise, your STI may come back. Also, take the medication in the correct dose, in the correct way, at the correct time.
- Find a way to tell your partners! If you are treated, but your partner is not treated and you have sex with them, you are at risk of getting the STI again (reinfection). Partner treatment is essential.
- Many STIs can be transmitted from mothers to babies and can cause serious health problems in the infant.
- When you have HIV it is even more important for you to have regular STI check ups. Let your HIV doctor know what STI medications you are taking.

2

Key elements of ethical and effective HIV-counselling practice

Chapter 2

Key elements of ethical and effective HIV-counselling practice

This chapter gives the reader an overview of what is involved in ethical and effective HIV counselling, and reviews some basic counselling micro-skills and counselling service documentation.

What does HIV counselling involve?

The key aims of HIV counselling are:

- to prevent HIV transmission by providing information about transmission risks (such as unsafe sex or needle sharing);
- to assist people in developing the personal skills needed to negotiate safer practices;
- to provide psychological support to people who are infected with and affected by HIV in improving their emotional, psychological, social, and spiritual well-being; and
- to support clients in treatment adherence.

HIV counselling may also include one or more of the tasks outlined in the sections below. While counsellors engage in direct client counselling as a major part of their key role, they are also often required to act as interagency liaison, conduct behavioural or clinical research and welfare assessments, train and supervise volunteers, prepare HIV community service plans, and engage in client advocacy, among other roles and duties.

Types of HIV counselling

HIV prevention counselling: HIV transmission risk reduction

The counsellor assists infected and uninfected clients in identifying and exploring the difficulties involved in reducing transmission risk behaviour. Counsellors may use a variety of strategies ranging from the simple provision of information to the more therapeutic evidence-based strategies that can include motivational interviewing, structured problem solving, interpersonal and brief psychotherapy for risk reduction, cognitive behavioural therapies, relationship counselling, and infant-feeding counselling. Prevention counselling is employed in pre-HIV test and post-HIV test counselling and in counselling across the disease continuum. It is recognized that it is difficult for clients to sustain changes in behaviour over extended periods of time. When providing counselling across the disease continuum, counsellors must continually assess the challenges that will face their clients as they strive to maintain behaviour changes, and provide practical strategies that can help address these challenges. To change behaviour in the context of drug or alcohol dependency, for example, counsellors must assess whether the client is dependent (addicted) and whether he or she can implement harm reduction and substance dependency management strategies…

Pretest counselling

Pretest counselling is confidential counselling that will enable an individual to make an *informed choice* about being tested for HIV. According to WHO guidance, this decision must be left entirely to the individual and must be free of coercion. To make an informed choice about testing, an individual needs to consider the potential benefits and risks associated with testing. His or her personal risk history must also be considered. The counsellor supports the client in managing the potential risks and difficulties by considering the possible psychosocial, legal, and health implications of knowing the client's serostatus. The counsellor also assesses the client's capacity to cope with the possibility of a positive HIV antibody test, provides information on HIV, and engages in prevention counselling, mainly to reduce transmission risk behaviour and thereby reduce the risk of HIV transmission.

While individual one-to-one counselling offers the best standard of support to clients, alternative models of providing pre-HIV test information are also available. Pre-HIV test counselling may be offered to couples; this is discussed at greater length in chapter 4. In some situations where there are many clients or where the HIV test is offered as part of *provider-initiated testing and counselling* (PITC) and opportunities for one-on-one counselling are limited (because of time or human resource constraints), *group pretest information* may be offered. Information can be given in a group, but the informed consent component must always take place in a one-on-one setting to ensure that the patient's choice is autonomous and not coerced. These alternative forms of receiving pre-HIV test counselling are discussed further in chapter 4.

Post-HIV test counselling

Post-test counselling is done primarily to ensure that individuals understand the meaning and implications of their test results. If the client tests positive for HIV antibodies, post-test counselling must make it easier for him or her to adapt to life with HIV and STI infection. Suicide presents a significant challenge to counsellors. There are two periods when people with HIV are more likely to attempt suicide. When the person is first diagnosed, suicide may occur as an impulsive response to the emotional turmoil that follows. The second period of high risk occurs late in the course of the disease when complications of the nervous system resulting from AIDS develop, capacity to earn income declines, and people feel they are a burden to family members and carers. Consequently, after the diagnosis counsellors are required to conduct suicide risk assessments and to manage suicidal thoughts throughout the course of illness.

Post-HIV test counselling is typically provided by the counsellor who conducted the pretest counselling. However, a counsellor may have to provide counselling to an individual who was tested without his or her knowledge and consent. Counsellors providing post-test counselling under the latter circumstances may report having to manage client anger, which is often projected onto the counsellor.

Ongoing counselling for people affected by HIV

The chronic and progressive natural history of HIV infection means that the psychosocial issues confronting both infected and affected individuals change throughout the course of the illness. In addition to issues directly related to HIV, patients may present with a range of psychosocial problems that are pre-morbid or only indirectly related to HIV. For many, becoming infected with HIV reactivates previously unresolved issues such as acceptance of sexual orientation, specific traumatic events such as sexual assault, or unresolved relationship problems. Infected and affected individuals may also need practical assistance such as referral to welfare services, liaison with caregivers, the preparation of wills, and the organization of substitute care for children. Counsellors must work with multiple clients who present a range of problems that vary across the disease continuum.

Treatment adherence counselling

Patients are confronted with many difficulties when required to take medication. Those taking medication for HIV, TB, STI, or hepatitis in particular must deal with many psychological, physical, and practical barriers to treatment adherence. Non-adherence can lead to inadequate suppression of bacteria and, in the case of HIV, viral replication. Counselling for treatment is provided to improve the patient's knowledge of both the disease and the medications and their side-effects. Counselling helps the patient set goals, develop positive beliefs and perceptions, and increase self-efficacy in maintaining treatment.

Paediatric counselling

HIV infection has a profound impact on the lives of children and their families. Not only do children have to cope with the physical aspects of ongoing illness due to HIV immune-related deficiency and its associated treatments, but they also suffer from the emotional and social effects of chronic illness and impending death. Counsellors must often provide support to children, assisting them in coping with separation and loss issues related to the parents' or the child's own illnesses. Other common presentations seen in children with HIV infections are behavioural disturbances, cognitive and motor impairment, and poor treatment adherence. Counsellors caring for HIV-positive and HIV-affected children often have to support them in responding to stigma and discrimination. Furthermore, in many endemic areas counselors must assist children who have taken on a parental role to care for younger orphaned siblings. HIV counsellors provide various forms of support to a child to ease his or her entry into substitute-care settings. The tasks may include working with substitute carers to understand how to give emotional support to children who have experienced not only the death of parents but also societal rejection or discrimination. Additionally, the counsellors are often required to facilitate HIV testing and counselling of children to be adopted. Those found to be infected with HIV often fail to be adopted or fostered once they are diagnosed with the disease.

Children who present with HIV may have other psychological conditions associated with child sexual assault, child trafficking (including the selling of children into child labour), or experience in the military or with prostitution. In some situations physical abuse in association with the disclosure of the child's HIV status within communities and schools is also an issue.

Where is HIV counselling provided?

HIV testing and counselling may be offered in a diverse range of settings including testing and counselling centres that are free-standing or integrated into hospitals, sexual health centres, churches, outpatient clinics, blood donation centres, drug treatment centres, family planning clinics, prisons, community health centres, and a diverse range of health outreach or community-based programmes. Counselling alone may also be offered as part of mobile or outreach services.

Who can provide HIV counselling?

Not every person who practices counselling skills can be considered a counsellor. Two broad groups of people use counselling skills: those who engage in counselling as a distinct occupation and those who use counselling skills as part of another occupation. The wide range of people who may play a role in providing HIV counselling services includes:

- nurses, doctors, social workers, and other care providers who have been specially trained in HIV counselling;
- full-time counsellors (including psychiatrists, psychologists, and family therapists) who have been trained in HIV counselling;
- community-based workers whose work consistently entails appropriate handling of confidential information and emotional issues; and
- people living with HIV and AIDS (PLHIV).

It is essential, however, that counsellors have the specific training needed to support the different services they will have to provide. Increasingly, governments are requiring prospective counsellors to undergo standardized national training irrespective of their professional background.

Developing your skills in effective HIV counselling

We have discussed the various types of HIV counselling and the tasks of counsellors. In order for counsellors to perform these tasks effectively, they must first understand what counselling is and what it is not, and also develop some basic skills. It must also be emphasized that counselling skills cannot be learned simply by reading a text. These skills must be rehearsed in a specialized training programme under the supervision of an experienced counsellor.

Counselling is goal-oriented interaction

Counselling is interaction between a counsellor (helper) and another person or persons whom the counsellor offers the time, attention, and respect necessary to explore, discover, and clarify ways of dealing with a problem. In the context of HIV and AIDS, counselling is a confidential dialogue between a client or patient and a counsellor aimed at enabling the client to cope with stress and make personal decisions related to HIV.

- Counselling is based on a set of techniques and skills that the counsellor brings to the interaction to help the client to explore and better understand a problem, deal with related feelings and concerns, evaluate alternatives, make choices, and take action.

- Counselling is an issue-centered and goal-oriented interaction. It involves carrying on a dialogue and providing options for decision-making and behaviour change. Effective counselling helps another person to be autonomous (able to choose, decide, and be responsible for his or her own actions).

Elements of ethical and effective counselling

Effective counselling has several agreed elements, as discussed below.

Ample time

Providing the client with adequate time is important from the very beginning. The counselling process cannot be rushed. It takes time to build a supportive relationship.

Acceptance

Counsellors should not be judgemental of clients. Rather they should try to accept clients, regardless of socioeconomic, ethnic, or religious background; occupation; sexual orientation; gender identification; and drug or alcohol use.

Accessibility

Clients need to feel they can ask for help at any time. Counsellors need to be available to clients at appropriate times and should have systems in place to respond to clients' needs as appropriate (e.g., provide services after hours or work during lunchtime on a rotating system). It is important that counsellors maintain appropriate boundaries in their after-hours contact with clients. They must also maintain appropriate professional distance (e.g., counsellors should not provide their home contact information to clients), and should not enter into non-professional relationships with their clients, especially sexual relationships.

Consent

Clients must be given an opportunity to consent to or decline HIV testing, treatments, or procedures in an informed and voluntary manner. Counsellors facilitate the informed decision-making of their clients by offering clear and accurate information, and assisting clients in weighing the perceived benefits and risks of each intervention offered.

Consistency and accuracy

Information provided through counselling (e.g., about HIV infection, infant-feeding options, infection risk, risk reduction, and treatments) should be consistent with recognized scientific research and national HIV guidelines.

Confidentiality

Trust is the most important factor in the counsellor-client relationship. It enhances the relationship and improves the odds that an individual will act decisively on the information provided. Given the discrimination, ostracism, and personal recrimination that an individual diagnosed with HIV may have to face, it is all the more important to guarantee confidentiality. Where the counsellor is required by law or public health policy to provide information to a third party against a client's wishes, he or she should discuss with the client the reasons for doing so, along with the relevant process and procedures.

Sociocultural considerations

Effective and ethical counselling must recognize the impact of culture on a client's perception of the world. Counsellors should take a holistic view of clients and their sociocultural background, including beliefs about HIV, sexual mores, traditional healing practices, gender inequalities, marriage practices (e.g., monogamy, polygamy), customs, and social practices. Counsellors should keep in mind that culture and tradition shape attitudes and beliefs, particularly regarding illness and death. Thus, they should be sensitive to and respect cultural differences. A counsellor should refer clients to another counsellor if differences of gender, race, ethnicity, religion, sexual orientation, disability, or socioeconomic status interfere in any way with counselling.

The goal of counselling is to explore, discover, and clarify ways of living more resourcefully. To achieve this goal, counsellors need certain interpersonal and communication skills.

Interpersonal skills

Interpersonal skills are the skills that we employ to establish relationships.

Establishing rapport

Establishing rapport with clients is crucial in all counselling situations and is key to developing a trusting relationship. Developing rapport demonstrates the counsellor's interest in and respect for a client's issues and concerns. Building rapport is an ongoing process that can be facilitated through:

- clarification of the counsellor's role by the counsellor during the first counselling session;
- respect and non-judgemental attitude;
- the presence of common or complementary goals;
- open verbal and non-verbal communication; and
- mutual trust.

To establish rapport, one useful technique is to ask questions such as, ″What's the worst thing that could happen?″ or ″If we could deal with only one thing today, what would be most important to you?″ Such questions help define and prioritize a client's agenda and may be particularly appropriate at the start of a session. Furthermore, through this process the counsellor is able to encourage the client to be explicit in describing sensitive issues, including sexual behaviour patterns.

Ensuring privacy and confidentiality

Cross-cultural research indicates that clients in all cultures need to be assured of privacy and confidentiality. The counsellor can ensure privacy and confidentiality by:

- providing adequate and appropriate space for counselling to take place;
- understanding that no information about a client can be divulged without the client's consent;
- maintaining adequate records of any work with a client and taking all reasonable measures to preserve the confidentiality of the information;
- ensuring that colleagues, staff members, and trainees understand and respect the need for confidentiality in counselling services; and
- being aware that notions of shared confidentiality and partner notification often raise an ethical dilemma in the context of HIV counselling. (The term *shared confidentiality* refers to confidentiality that is shared with a limited number of people, such as family members, loved ones, caregivers, and trusted friends. This is provided only with the consent of the person undergoing testing, counselling, or treatment.)

Showing respect

Counsellors need to understand that each person perceives and copes with predicaments in uniquely personal ways determined by numerous factors including culture, social class, and personality. Recognizing the fundamental rights, dignity, and worth of all people is critical. This can be achieved when counsellors are aware of cultural and role differences in gender and gender identity, race, ethnicity, religion, sexual orientation, disability, and socioeconomic status, and work to eliminate their own personal prejudices and biases about such differences. Counsellors must not participate in or condone discriminatory practices based on these differences. They must respect clients' views and beliefs.

Furthermore, counsellors should be aware that their own attitudes and actions can convey respect or the lack of it. The following actions help demonstrate respect for clients:

- helping clients make informed decisions about their lives and supporting them through the process (without, however, making demands or telling them what to do);
- keeping appointments and apologizing for being late or failing to keep an appointment;

- being a *guide/facilitator* and not a *preacher*;
- showing concern for clients' welfare;
- seeing each client as a unique individual;
- seeing clients as capable of determining their own fate; and
- assuming that they can count on the good will of their clients unless and until the clients demonstrate otherwise.

Showing empathy

The ability to empathize is one of the most essential counselling skills. Empathy involves identifying with the client, understanding his or her thoughts and feelings, and communicating that understanding to the client. For a counsellor to communicate understanding of a client's world, he or she must *enter that world* (understand the client so well that the counsellor feels like the client). Simply stated, this means that counsellors *should put themselves in their clients' shoes*. Empathy requires sensitivity and a moment-to-moment awareness of a client's fear, rage, tenderness, confusion, or whatever else the client may be experiencing. To understand what the client is feeling, the counsellor must be attentive to his or her verbal and non-verbal cues. The counsellor needs to ask himself or herself, What feelings is the client expressing? What experiences and behaviours underlie these feelings? What is most important in what the client is saying to me?

Acknowledging difficult feelings

The presence of difficult feelings is a substantial and unavoidable component of counselling. To help address difficult feelings, counsellors should:

- be aware of their own feelings;
- acknowledge clients' feelings and realities;
- understand that it is not the counsellor's job to ″remove″ or ″fix″ feelings;
- articulate and respond to non-verbal messages; and
- normalize and validate clients' feelings.

While counsellors may want to resolve problems and ″fix″ feelings, most often this is neither possible nor desirable. Rather, such negative feelings need to be acknowledged. Examples of statements that acknowledge a client's feelings are: ″This must have been hard to deal with″ and ″So you believe that he cares for you, but it hurts to think about him having sex with someone else.″

Offering acceptance

For clients to be honest in describing their problems and concerns during counselling, it is critical that he or she feel accepted. The counsellor can facilitate this by being non-judgemental and accepting, irrespective of socioeconomic, ethnic, or religious backgrounds; occupation; sexual orientation or behaviour; or personal relationships. Counsellors should appreciate the stress caused by the fear of being infected or the need to change behaviour, and accept the consequent emotions and reactions. Even if hostility is directed towards the counsellor, he or she should recognize that they are not the real target and refrain from reacting (except to avoid physical harm). To validate acceptance, the counsellor recognizes feelings such as anger, sadness, and fear in a direct, unemotional way, indicating in words and behaviour: ″Your feelings are very strong. I accept them, and I accept you.″

Counselling communication skills and techniques

A major component of a counsellor's job is communicating with clients. This exchange is a two-way dialogue using both verbal and non-verbal communication methods. To identify a client's needs and provide appropriate information, counsellors must have solid communication skills. They must hear and understand the client's message and be clear in their own communication with the client. The following skills are important in building effective communication.

Developing your attending and listening skills

The term *attending* refers to a counsellor's ability to pay close attention to the client by limiting distractions and demonstrating that he or she is giving full attention to the client. Attending involves using responsive non-verbal skills such as listening, eye contact, relaxing, and natural hand movements. Responding to the client by nodding affirmatively and using key words such as "yes" and "I see" when appropriate demonstrates attentiveness. Maintaining eye contact shows that the counsellor is engaged with the client (though clients who are annoyed, nervous, or embarrassed might try to avoid it), and will increase the client's confidence and facilitate better communication. The counsellor should, however, distinguish between eye contact and staring, which could make the client feel uncomfortable.

Attending to the client is also improved when the physical counselling space is comfortable. A comfortable seating plan, with a culturally appropriate distance between counsellor and client, can improve the space. Minimizing distractions, such as noises or disruptions, can also help create a facilitative atmosphere.

The term *listening* refers to the ability of the counsellor to actively listen to the client when he or she is talking. Listening signals concern for the client's problems and allows the counsellor to detect common themes and revealing omissions in the client's remarks. For instance, a client may say, "I'm worried and I want to know my status. I know that my partner has another sexual partner." The common theme here is that a client perceives himself or herself to be at risk of HIV and AIDS because of the partner's behaviour. The *revealing omission* here might be that the client is not using condoms, or that the client fears rejection, violence, or abandonment if he or she were to introduce condoms into the relationship.

While listening, the counsellor should pay attention to the following:

- **The client's experience**–what the client sees as happening or not happening to him or herself;
- **The client's behaviour**–what the client does or does not do;
- **The client's feelings**–the emotions that arise from experience and behaviour;
- **The client's problems and worries**–client explanations rather than counsellor assumptions;
- **The counsellor's body language**–the gestures, facial expressions, intonation, distance, etc., that indicate the counsellor is listening and understands what the client is saying; and
- **The client's perceptions**–the client's point of view when talking about his or her experience, behaviours, and feelings.

To demonstrate listening, the counsellor should reflect briefly on what the client has told him or her, paraphrasing the client's words aloud. If the client hears no comments for two to three minutes, he or she might conclude that the counsellor has lost interest, disapproves of what was said, or does not understand the client. Counsellors can use a formula that expresses the client's principal feeling, such as, "You feel… because…" (e.g., "You feel relieved because you now know your HIV status and are able to change your behaviour to remain negative").

Showing immediacy

In the context of HIV counselling, immediacy refers to the ability of a counsellor to deal with a situation affecting the way he or she and a client relate to each other at a given moment (e.g., if the client is exhibiting hostility towards the counsellor). Immediacy involves the ability to:

- reveal how another person is affecting you;
- explore your own behaviour towards the other person;
- share observations about the other person's behaviour towards you, or point out discrepancies or distortions; and
- invite the other person to explore the relationship with a view to improving it.

Using an appropriate language level

When communicating with clients, it is important to note that distressed clients often remember little of what they are told. Among the most common reasons for lack of recall is a counsellor's use of technical or unnecessarily complicated language. Counselling is more effective when the counsellor:

- uses simple and culturally appropriate language;
- ensures that clients feel that they are understood and that a common level of communication is used;
- explains important points more than once–the main message first, then specific details, and finally the message summed up and repeated; and
- puts important points in writing, when appropriate, or uses visual diagrams or printed materials, such as pamphlets or brochures, as memory aids that clients can refer to after a session.

Using impersonal statements

In making a general point, impersonal statements (also known as the *third-person technique*) can be helpful in reflecting clients' unspoken, but nevertheless perceived, feelings. This technique is very useful in acknowledging, reflecting, and normalizing the client's feelings and keeping him or her from being on the defensive. Examples of third-person statements are:

- ″People can feel a lot of confusion and guilt when they hear information about HIV.″
- ″Sometimes when I give HIV test results to clients, they want to talk about what they can do to keep themselves healthy and where they can go for help.″
- ″People often feel uncomfortable and guilty when you talk to them about their drug use.″
- ″Some of my clients want to know how they can stay in good health and where they can find help.″

Counselling communication skills

Body language

- Good eye contact with clients especially when we are talking about sensitive issues.
- Sitting "with" the client, and not behind a desk
- Sitting a culturally appropriate distance from them and facing them
- Sitting in a relaxed but professional way (not too formal, not too casual)
- Not looking at our watch, or taking phone calls or doing other distracting things whilst the client is talking

Non-verbal skills – It is important how we say it

- Not responding to the clients in a way that shows our frustration or displeasure e.g. grunts, sighs or groans.
- Not giggling or sounding surprised when a client says something that embarrasses us
- Talking in a calm manner (not too bossy or directive)

Showing we have listened to the client and understood them

Paraphrasing involves restating, in your own words, the essence of what the client has said. The client says, *"I feel so helpless. I can't get the housework done, get the children to school on time, or even cook a meal. I can't do the things my wife used to do."* Then the counsellor says, *"You are feeling overwhelmed by having to do things you did not have to do in the past when your wife was alive."*

Reflecting emotions is similar to paraphrasing except that the focus is on the emotions expressed by the client e.g. the client says, *"I don't know what to do. Before he died I promised my husband that I would take care of his mother for the rest of her life. But I no longer have the energy. I cannot seem to get myself sorted out to do anything. He knew that his mother and I did not get along and that the situation would be miserable. Why did he die and leave me in this mess?'* The counsellor reflects, *"You seem to be feeling very low and helpless right now, but at the same time you seem to be feeling guilty and angry about your promise to your husband."*

Consider how we ask questions

Closed questions: Can be answered with only a one word response "Yes or No" e.g. "Do you practice safer sex?" This could give us misleading information. The client may say yes but what they think is safe sex may be different to what we consider safe.

Leading questions: Tell the client what we would like to hear e.g. "You always use a condom don't you?" Clients who are asked these types of questions may give you inaccurate answers.

Open questions Start with "how" "what" "where" e.g. *"Many clients have trouble using condoms what are some of the problems you have?"* These questions allow the client to explain or describe a situation.

Use silence – do not talk too much

Silence is important because it gives the client as it

- time to think about what to say,
- the chance to experience his or her feelings,
- the ability to proceed at his or her own pace,
- time to deal with ambivalence about sharing, and
- freedom to choose whether or not to continue.

Behaviour-change strategies in HIV counselling

3

Chapter 3

Behaviour-change strategies in HIV counselling

What does it take to change behaviour?

Individuals' lifestyles and behaviours have a major impact on physical and emotional health. Behaviours that affect health include eating, personal hygiene, sexual activity, physical activity, smoking, and drug or alcohol abuse. Because these behaviours are often deeply ingrained, they are not easy to change. Yet unless harmful behaviours are changed, they can result in preventable illness, poor quality of life, and possibly a premature death. Unhealthy behaviours must be unlearned. This is most always a complex process; if the intent is to change behaviour, simply providing clients with information is rarely sufficient. Let us look at an example that illustrates this point in box 3.1.

Box 3.1: Information alone rarely leads to behaviour change

The client is a doctor who has worked in a large public hospital and has seen the effects of smoking on his patients' health. He is aware of the scientific evidence about the harmful effects of smoking on his health, yet he continues to smoke. He has a chemical dependency on nicotine, he is overworked, and he smokes when he experiences stress. He also indicates that he is in the habit of holding a cigarette when he drinks alcohol at social functions, when he talks on the phone, and when he is writing up his patient records.

The client clearly knows that his behaviour is harmful. However, a number of other factors contribute to his smoking habit. He has a physiological dependency on a substance in cigarettes. He has situational behavioural triggers, which have become entrenched behaviours (e.g., phone in one hand and cigarette in the other). He is also stressed and perceives smoking to be stress-reducing. He will not give up smoking until he sees that the benefits of not smoking outweigh the benefits of smoking, unlearns automatic behaviours such as smoking to keep an empty hand occupied while talking on the phone, manages his symptoms of nicotine withdrawal, and finds substitute strategies for coping with stress.

To change behaviour, the individual needs to:

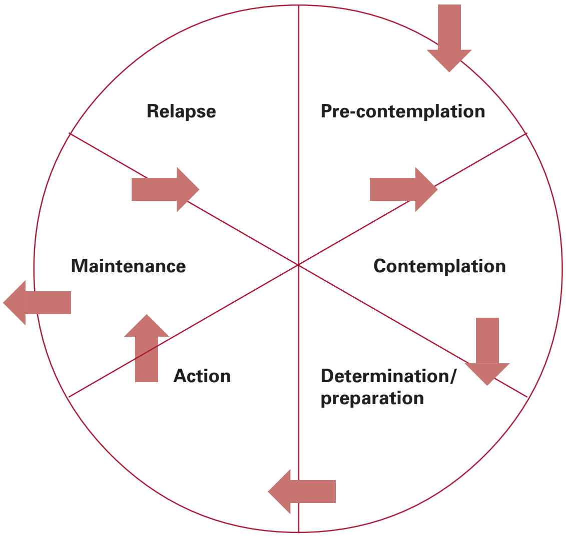
- identify the behaviour as harmful;
- understand available alternatives;
- be able to act on that knowledge; and
- receive the support needed to maintain the behaviour change.

HIV-related behaviour-change counselling

In STI and HIV counselling, sexual behaviour, drug or alcohol use, and poor treatment adherence are probably the most important behaviours to consider in relation to HIV transmission risk. Reducing HIV transmission in the community and helping HIV-positive clients stay healthy are essential components of the counselling process. The counsellor's job is to support clients in recognizing which behaviours are a transmission risk (see chapter 1: How is HIV transmitted?) and to assist clients in choosing and sustaining safe and healthy behavioural patterns. The counsellor must explain the advantages and disadvantages of behaviours such as the use of alcohol, tobacco, and other drugs; sexual activity; and eating habits. The counsellor facilitates change by:

- helping the client to anticipate challenges to behaviour change;
- working collaboratively with clients to develop effective strategies to meet the anticipated challenges; and
- reinforcing the achievements.

Stages of Change



Source: Prochaska JO, DiClemente CC, Norcross JC. In search of how people change. Am Psychol 1992;47:1102-4 and Miller WR, Rollnick S. Motivational interviewing: preparing people to change addictive behavior. New York: Guiford, 1991:191-202.

Supporting behaviour change is a complex interaction between the counsellor and client that requires a great deal of insight into human nature and motivation. It requires the counsellor to help clients recognize behaviours that are harmful to their health and to acknowledge the difficulties that changing behaviours will present.

No single strategy for behaviour change can address all harmful behaviours. The three strategies presented here–risk elimination, risk reduction, and harm reduction–can be thought of as tools for assessing clients and their concerns. In this chapter we will primarily address behavioural strategies for reducing STI and HIV transmission. Strategies for managing treatment adherence will be addressed in chapter 8.

How do I get a client to want to change his or her behaviour?

Decisions to change certain behaviours, for example, by abstaining from drug or alcohol use or starting to use condoms, are difficult to make. Clients don't often state openly that they would like to change these behaviours. Often they are in a state of ambivalence and fluctuating motivation before deciding to make a change. If a client is either not ready or ambivalent about change, advice in the form of demands or attempts to use heavy persuasion may put him or her on the defensive and increase the resistance to change. The concept of stages of change developed by Prochaska and Di-Clemente[1] (see figure above) shows that, for most persons, a change in behaviour occurs gradually, with the patient moving from being uninterested, unaware, or unwilling to make a change (*pre-contemplation*) to considering a change (*contemplation*) and deciding and preparing to make a change. Genuine, determined action is then taken and, over time, attempts to maintain the new behaviour occur. Relapses are perceived as almost inevitable and become part of the process of working towards sustained change.

Motivational interviewing is a non-confrontational approach to counselling. Studies have found it to be highly effective with clients in the pre-contemplation or contemplation stages of behaviour change related to drug, alcohol, or tobacco use, as well as safer sex practices. The goal is to explore the clients' ambivalence towards change and to encourage them to express their concerns and individual reasons for change. The key concept in motivational interviewing is resolving ambivalence about the need for change. First let us take a look at the summary table of interventions appropriate to each stage of change in relation to drug use. Then we will look at motivational interviewing strategies in more detail.

---

[1] Prochaska JO, DiClemente CC, Norcross JC. In search of how people change. Am Psychol 1992;47:1102-4, and Miller WR, Rollnick S. Motivational interviewing: preparing people to change addictive behavior. New York: Guiford, 1991:191-202.

Behaviour change counselling strategies for the states of change, as applied to drug users

Stage of change	Behaviour-change counselling strategies
Pre-contemplation The client does not perceive that he or she has a problem or that it is an immediate problem.	• Find out whether the client is experiencing life problems such as lack of money or a relationship breakdown. • Find out the health impact of the behaviour from the client's perspective. • Ask the client how much drug use is affecting or contributing to his or her problems. • Provide *personalized* information about general health problems resulting from continued drug use. • Provide *personalized* information about the client's HIV status and the risk taking associated with drug use (lack of safer sex practices, unsafe injecting, etc.). For example: "You have had several HIV tests because you have not been able to inject safely or use a condom. Each time you have been anxious about the result. Do you want to continue going through this?" Or, if the client is already HIV-positive: "Now that your doctor has recommended that you start treatment." In both cases you should provide the client with information. (provide information)
Contemplation The client is seriously considering giving up drugs in the next six months.	• Acknowledge the client's ambivalence. • Ask the client what he or she (not the counsellor) sees as the benefits and problems of continued drug use, and the benefits of and barriers to stopping. • Help the client to see potential solutions to the various barriers raised (loneliness, common practice among friends, withdrawal symptoms, etc.). • Help identify potential resources (e.g., detoxification facility services, recovery groups, treatment buddies).
Preparation The client intends to quit within the next month; has tried to quit in the past year or has made behavioural changes (e.g., tries to use clean injecting equipment or reduce use).	• Establish an action start date. • Help client develop awareness of practice of keeping a habit diary (if illiterate, interview and do the recording, or use low-literacy self-recording), noting issues such as when he or she uses drugs, who with, how much, etc. If the client is illiterate, interview and do the recording. • Establish degree of dependency. Use ICD 10 or other standard diagnostic criteria. • Interview the client about past attempts to stop using drugs. Determine the process with the client, including detox, gradual withdrawal, oral substitution therapy. • Interview the client to establish why the client uses drugs (social use, depression, strategy for coping with sex work, etc.).
Action phase	• Help the client develop a plan of action. • Facilitate referrals or preliminary visits to drug treatment services. • Support skills rehearsal, e.g., informing partner of wish to enter a methadone programme.
Maintenance phase The client is free of drugs or in recovery programme for six months.	• Anticipate and normalize relapse. • Review triggers for relapse and coping strategies. • Support progress and monitor health and highlight positive consequences of changes (e.g., increased condom use during sex; less STIs; improved appearance; improved relationships with partners, families; new friends; better financial situation).
Termination The client is 100% confident in all trigger situations.	• Congratulate the client and again remind him or her that you are available for follow-up.

HIV = human immunodeficiency virus, STI = sexually transmitted infection.

Getting started with motivational interviewing

Counsellors should select the strategy for a given session depending on the patient's readiness for change. More than one strategy can be used in a session. The counsellor works through the list of strategies in box 3.2 as the client becomes more ready to change.

Box 3.2: Strategies used in motivational interviewing

- Opening strategy: lifestyle, stresses, transmission risk behaviour, and substance use
- A "typical day" / Session review
- The good things and the less good things about change
- Information provision
- The future and the present
- Concerns about change
- Help with decision making

Example: Your client uses injecting drugs and shares injecting equipment and does not use condoms for sex

- The skills you will primarily use here are reflective listening and open questioning. Your job is simply to develop an understanding of the client's feelings without criticism, judgement, or blame. Use an opening strategy such as talking about the client's life and the current stresses he or she is facing: " How is your life at the moment?"; "What's happening in your life right now?" You do this even if the client has come in about a specific health problem like an STI or for an HIV test.

  At this point the client may discuss the positive aspects of using drugs and say that he or she is in control of the use of drugs.
- The counsellor could then say, "How do you see your drug use affecting your health?", or talk about whatever issues the client raises (e.g., relationships, financial situation). The main point is to build rapport with the client and assess his or her readiness for change.

  Avoid using terms such as "problems" or "concerns" and do not assume that a given issue or circumstance is a "problem" for the client. Do not confront resistance or denial at this stage and simply say something like, "I can see how this does not feel like a problem for you right now."
- The counsellor then begins to focus on the events of the day and how the client feels about them. Questioning shifts to inquiries such as, "Tell me about a typical day in your life… How about last Friday?"; "After you got up in the morning, how long was it before you had your first hit that day?"; "How did you feel after it?" Explore a typical day in the life of the client. The counsellor mainly asks simple, open-ended questions. The aim here is to raise the client's awareness of the relationship between drug use and what is happening in his or her life. This strategy is particularly useful for pre-contemplators.
- The next step, either in the same session or in a later session, is to ask the client about the good things and the things that are not so good about drug use and then to respond with a reflective statement that links the two responses. For example: "So your use of heroin helps you relax when you are having sex with clients." Or: "On the other hand, you say that sometimes clients hurt you, don't pay you, or have sex with you without using condoms because you are relaxed."
- Providing information about drugs is routine in health services, especially with people at risk of or living with HIV. The important issue here is the way the information is exchanged. *The information should be impersonal and neutral*. For example, you may want to say something like: "Using drugs can cause liver problems and make it difficult for people to protect themselves from sexually transmitted infections. It can even make it difficult for people with HIV to use and benefit from the new HIV treatments." Or: "Sharing injecting equipment and engaging in unprotected sex as well as missing some doses of medication can make people resistant to treatment." This should be followed up with a simple open question such as: "How do you feel, or what do you think about that information?"

- The strategy called *Future then Present*, about the future and the present, can be used with clients who are becoming concerned about their behaviour. The counsellor can focus on the present behaviour and how the client would like to behave in the future, thus indicating a discrepancy. This can provide the motivation to change behaviour. Ask: "How would you like things to be in the future?" Once future goals have been elicited, a counsellor can return to talking about the present, asking for example: "What's stopping you right now from having or doing those things?" Listen, and then ask: "How is your drug use affecting you right now?" This will lead to a direct exploration of the concerns and problems that drug use is causing the client, and to a discussion of behaviour change.

Motivational interview strategies can be used effectively when integrated with the stages-of-change model. Knowing which stage of change the patient is in gives you a place to start when deciding which strategy to employ. Let us take a look at strategies for our injecting-drug-using client, as presented previously in the summary table on page 26.

Strategies for the action and maintenance phases

Using a simple structured problem-solving approach

Once the client decides to make a change, the counsellor's role is to facilitate behaviour by collaboratively engaging the client in structured problem solving. This approach can be summarized as:

- describing the problem that results in HIV transmission;
- brainstorming about the options for behaviour change–selecting the risk elimination, risk reduction, or harm reduction approach (discussed on page 29);
- critically evaluating the options–asking the client to consider the benefits and potential problems associated with each strategy; and
- developing an action plan with opportunities for a "provisional try".

As a counsellor you must then offer support in developing the skills needed to fulfil the action plan. This may include, for example, role-plays that involve condom negotiation, practice in using condoms, or training in cleaning injecting equipment.

Reviewing options

The client reviews the advantages and disadvantages of different ways of altering behaviour. The counsellor asks the client to brainstorm about the advantages and disadvantages of different options. In our example of *risk elimination for a drug user*, this may include abstinence, brainstorming about the gradual reduction in drug use, or considering oral substitution therapy. In the case of *sexual transmission risk reduction*, options might include abstaining from sex, using condoms for sexual partners other than a tested regular partner, and choosing sexual activities with a lower transmission risk. Three broad strategies that relate specifically to choices for transmission risk reduction are presented later in this chapter.

Risk elimination: "Abstaining from sex and refraining from injecting drugs is best"

Risk elimination relies on abstinence to eliminate the risk of HIV infection. According to this strategy, the client should abstain from sex and refrain from injecting drugs. The risk of infection is eliminated because the behaviours that lead to it are eliminated. Examples of prevention education messages based on risk elimination are the *sexual abstinence* and *just say no to drugs* campaigns. Both campaigns have failed to reduce HIV or change the behaviour that leads to HIV infection.

While adherence to risk elimination guarantees 100% safety from infection attributable to those behaviours, it is often the least-useful behaviour-change strategy because most people find it extremely difficult to do away with risky activities such as drug injection or sex. This strategy does not acknowledge that certain behaviours are pleasurable and it does not allow for alternatives.

Risk reduction: ″Use a condom and do not share injecting equipment″

Realizing that many people cannot stick to the risk elimination strategy, some counsellors and educators opt for *risk reduction*, a strategy that realistically acknowledges that some individuals will continue to engage in risky behaviours. Assuming that abstinence is not a realistic alternative, the risk reduction strategy advises individuals to engage in ″safer″ behaviours–using condoms during sex or when engaging in low-risk sexual activities, and not sharing needles when injecting drugs.

The risk reduction strategy, however, cannot offer a 100% guarantee that a person will remain uninfected. For example, if a condom breaks during intercourse, the client will be at risk.

Harm reduction: ″Follow a step-by-step process of change″

The harm reduction strategy recognizes that risky behaviours not only occur but also have meaning. This strategy assumes that risk is a part of life and ranks an individual's risk of HIV infection among other life issues, such as illness, unemployment, and drug use. The harm reduction strategy rejects the all-or-nothing approach to behaviour change. Instead it conceives of change as incremental and taking place over time. Any positive change brings the individual one step closer to healthy behaviour. The counsellor works with the client to identify risky behaviours, understand the reasons why he or she may continue to engage in them, and identify what the client can do to move towards healthier behaviours. Needle-exchange programmes, for example, acknowledge that some clients engage in risky behaviour (injecting drugs). Eliminating the behaviour that puts them at risk might not be an immediate goal of this strategy, but for some it can be a long-term objective.

These three strategies, and many others, are available to HIV counsellors and educators. Elements of different strategies may be appropriate at different times for the same client. Most importantly, HIV educators and counsellors must be familiar with these strategies and know how best to use them–not as absolutes but as tools for interacting with clients. Educators and counsellors should also keep in mind that they can adapt each strategy to their own style and culture.

Developing an action plan with a timeline

The action plan should be a clear list of tasks associated with the behaviour change; each task should include a date (e.g., visit potential detoxification centres, or buy condoms). The strategy should be built up in steps so that small changes can be rewarded or acknowledged. For example, this may involve setting a goal of asking one person to use a condom in week 2 or to enter a detoxification programme and join an anonymous anti-narcotic support group.

Making a provisional try (an initial attempt at behaviour change)

The provisional try takes place when a client leaves the counselling session and attempts a step towards changing behaviour. Though provisional tries may not always be successful, the minimal attempt at behaviour change can be considered a success and must be supported by counsellors. Counselling strategies during the provisional-try stage include:

- reinterpreting the concept of ″failure″ (″This was an experiment and we just wanted to see what happened so we could plan for problems″);
- asking ″why″ in a positive way (″Let's look at what happened so we can carefully plan″); and
- providing closure (″Different strategies work differently for different people; we can try something else″).

Preventing a relapse

Relapse prevention strategies are an important part of behaviour-change interventions. Clients should not feel they have failed. Planning for a relapse makes them aware that a relapse is likely to occur as it is a natural part of the behaviour-change process, and that it does not mean failure or even a setback.

Relapse prevention strategies

- Identify high-risk situations (triggers)
- Develop trigger management skills
- Rehearse trigger management skills
- Engage in structured problem solving
- Get back on track after a relapse

Most relapse prevention plans call attention to possible triggers that can bring forth the old behaviour (e.g., send a drug or alcohol abuser back to his or her drug of choice, or let somebody share injecting equipment or not use a condom during sex). The client is encouraged to come up with a list of potential triggers that need to be avoided or addressed once they occur. The counsellor can ask the client to monitor his or her drug use, for instance, or contexts where it may be harder to use condoms. If the client cannot keep a record, then the counsellor can ask questions that will elicit this information.

The principles and strategies outlined in this chapter can be applied to a range of target behaviours. Behaviour-change counselling may not always be about changing adverse behaviours; it can also be about developing new behaviours–improving diet or developing an exercise habit.

Counselling in association with the HIV test

4

Chapter 4

Counselling in association with the HIV test

Section 1: Approaches to HIV testing and counselling

There are different approaches to testing individuals for HIV. UNAIDS distinguishes between the following models on the basis of who initiates the offer of an HIV test. In the Asia and Pacific regions, testing is commonly initiated by a provider, although some individuals may seek testing on their own. In any case, HIV testing and counselling should be voluntary and always undertaken with informed consent, counselling, and confidentiality (the *three C's*).

Client-initiated HIV testing and counselling

In this model, sometimes referred to as *voluntary counselling and testing* (VCT), individuals actively seek HIV testing and counselling at a facility that offers these services, perhaps as a result of provider referral. Client-initiated HIV testing and counselling usually emphasizes individual risk assessment and management by counsellors, addressing issues such as the desirability and implications of taking an HIV test and the development of individual risk reduction strategies. Client-initiated HIV testing and counselling is conducted in a wide variety of settings, in health facilities and stand-alone facilities outside health institutions, through mobile outreach services, in community-based settings, and even in people's homes.

Provider-initiated HIV testing and counselling

This refers to HIV testing and counselling that is recommended by health-care providers to persons attending health-care facilities. If someone were to present to health facilities with symptoms or signs of illness that could be attributed to HIV, for instance, it is a basic responsibility of heath-care providers to recommend HIV testing and counselling (also often referred to as *diagnostic testing*).

Provider-initiated HIV testing and counselling is also done to identify unrecognized or unsuspected HIV infection in persons attending health facilities that provide services to populations engaged in behaviours that may put them at risk of HIV. Thus, HIV testing and counselling would be recommended to tuberculosis patients and those suspected of having TB, given the frequency of this disease as an OI. Even if they do not have obvious HIV-related symptoms or signs, such patients may nevertheless have HIV. Knowing their HIV status may induce them to seek specific preventive or therapeutic services.

Section 2: Pre-HIV test counselling

Where possible, pretest counselling of individuals or couples is desirable. Such counselling is intended to:

- review the client's risk of infection;
- help the client understand why the test is needed;
- explain the test and clarify its meaning;
- psychologically prepare the client for a potential HIV-positive result;
- explain the limitations of the test and the various results that can be obtained; and
- obtain informed consent.

To meet these objectives counsellors need to strike a balance between collecting and offering information by listening to and meeting the client's own needs.

Step 1: Introduce the service

The first step in pretest counselling is for you to establish a relationship with the client. This phase involves clearly explaining your role. The client should be told how much time is available for counselling. The reasons for note-taking should also be explained. This explanation should be accompanied by a brief overview of how you and the organization you are working for will protect their confidentiality. The HIV counselling toolkit has sample pre-HIV test and post-HIV test forms. Your country may require you to complete a standardized form.

Once you and the client have become acquainted, the counselling session begins. First, the counsellor obtains the client's basic biographical information. This may include his or her name or code name (if a code name is used, no address is recorded), age, sex, telephone number, occupation, education, and marital and economic status. The information collected will vary across different HTC settings. Often programmes require service monitoring data such as sexual orientation, or information on whether the person is engaged in one or more risk behaviours (e.g., sex work or injecting drug use). The request for this kind of information in some cases can make clients feel uncomfortable and is therefore best kept until the end of the session, when the client has developed a sense of trust. It is also likely that by the end of the counselling session you will already have much of this information.

Step 2: Clarify information on HIV/STI transmission

It is important for you to ascertain the client's level of knowledge about HIV and AIDS and the HIV test and also identify misconceptions and misunderstandings so that they can be corrected.

Briefly discuss the ways HIV can be transmitted and how STIs can facilitate HIV transmission. Also discuss how HIV is not transmitted.

Briefly outline how having an HIV test can give people who are HIV-positive access to treatment, and how the knowledge of their infection can allow them to make decisions that can improve their health and protect their partners and children. At this point, the client should also be told about the implications of the window period and HIV testing. Let us look at an example in box 4.1.

Box 4.1: Sample explanation of the window period

When HIV infects a person's body, the body realizes that HIV is a virus that should not be there. The body's immune system will then begin to develop something called antibodies to try to fight against HIV and protect the person. The test used to check for HIV looks for these antibodies in the blood. It is called an antibody test.

It can take from two to 12 weeks after infection with HIV for these antibodies to develop. This time period is called the window period.

Importantly, if you have the HIV test too soon after a potential exposure, then the test cannot tell us for sure whether or not you are infected. In other words, if you have been recently exposed to HIV, even though your results say that you are HIV-negative, you could still be infected.

Step 3: Conduct a personal HIV/STI risk assessment

Making a risk assessment can be a culturally sensitive and difficult issue for many counsellors and their clients. It may cause clients to feel embarrassed or worried about how you will feel about them.

After you have explained something about HIV transmission, the HIV test, and the implications of the window period, it is important to tell the client that you need to discuss some sensitive issues with him or her. It is suggested that counsellors use the four reasons found in box 4.2.

When conducting a risk assessment counsellors should:

- provide a private consultation area;
- see each individual separately, with no other person present unless consent has been sought and given (couples should be interviewed separately; we will discuss this later in the section on the counselling of couples);
- use clear and simple language;
- use models or drawings if needed.;
- obtain detailed information;
- discuss all practices with all people; and
- use counselling communication micro-skills such as reflecting the client's emotion, paraphrasing, and using open questions.

Box 4.2: The Four Reasons

"I need to discuss some things with you today that we would not normally talk about with others."
We need to discuss these things to:

- give you realistic feedback about your risk of being infected–you may be worrying unnecessarily;
- make sure you know how to keep yourself and your partners safe–different practices have different risks;
- see if you have other potential health problems that this test will not identify–I may need to do other types of tests as well;
- if you have been infected, to know when you most likely became infected–it may make a difference in the type of treatment we offer. We can only know this if we know what you have been doing and when.

"As you can see there are some good reasons for us to talk openly about these things, even though it may be uncomfortable."

Clients who are being assessed for the first time should have a detailed personal risk assessment (see figure below). A detailed assessment is designed to inform the client about how each potential exposure risk can result in HIV transmission and how to reduce the risk for each behaviour, and to ascertain whether, when, and what type of specific exposure risk has occurred. While this method is more time-consuming than simply asking clients a series of questions about their risks, clients are more likely to provide an accurate and detailed account of their behaviour when they get information and can see the reasons such detailed and personal questions are being asked. Clients who are frequently tested can simply be asked a series of questions about their risks.

Steps in a detailed risk assessment

Information	→	Risk reduction	→	Question
"Vaginal sex: HIV can be transmitted during vaginal sex. HIV can be found in the fluids of the woman's vagina, in the fluids in semen, and in the fluids that lubricate the man's penis during sex."	→	"You can reduce the risk of vaginal sex by using a condom. It is important that the condom be put on the penis before it enters the woman's body."	→	"Have you had vaginal sex without a condom?" If the answer is yes, then ask: "Can you tell me the last time this happened?"

Step 4: Demonstrate condom use and discuss safe injection

Clients should be able to demonstrate that they can properly apply a condom to a penis model. You could first demonstrate this and then ask the client to try to do the same. Safe injecting skills should be reviewed together with a discussion of how to gain access to safe injecting equipment and how to avoid sharing injecting equipment or drawing from a common supply of drugs.

Step 5: Explore psychological coping resources

It is important to screen for any current or pre-existing psychological disorders such as depression, anxiety, or psychosis, as well as patterns of drug or alcohol use that may adversely affect the client's ability to reduce transmission risk and to cope with a positive HIV test result (see box 4.3). While this screening could be done at the time you provide the result, clients who are in crisis are often unable to provide the necessary information adequately. Chapter 6, section 2, offers suggestions on how you can assess and support clients with psychological disorders.

Box 4.3: HIV testing and counselling for drug- and alcohol affected clients

Before starting HTC you must assess and consider whether a client's understanding of the process and procedures is likely to be impaired by drugs or alcohol, making it difficult for the client to listen, provide information, and cope with emotions that are typically elicited by the HIV testing and counselling process. Assess the client's ability to comprehend information by:

- ensuring that the client is oriented to time and place; and
- asking the client questions and checking to see that he or she answers coherently.

If you think that the client's ability to participate fully in counselling and informed consent to testing may be compromised, it is suggested that you:

- discuss this with the client in a supportive way;
- acknowledge that you understand that this is a stressful situation; and
- assert that you cannot proceed while the client is heavily under the influence of drugs or alcohol.

In pretest counselling you may need to ask the client to wait in a waiting room or to come back later that day when he or she is better able to understand the process of HIV testing and counselling. During pretest counselling clients should be informed that a result can be provided only to clients who fully comprehend what they are told. This may mean that they have to limit the intake of drugs and alcohol before post-test counselling.

Step 6: Assess anticipated support from partners and family

Again, while this information can be collected at the time the results are given, it is better to have a prior understanding of the client's potential support. Clients with significant risks may wish to discuss with their partner or family the fact that they are having a test and to include them in the pre- and post-test counselling. The client must be consulted and consent obtained before the partner or family is involved in test result provision.

Step 7: Discuss test procedure and obtain consent

The client should be given basic information on how blood will be collected and results provided. He or she should be reminded of the limitations posed by the window period and consent to the test should be obtained. Depending on your local health policy the consent can be given in writing or orally. If written consent is not required you should simply note on the counselling form that the client gave oral consent.

Clients should be told about the measures taken during blood collection and laboratory testing to ensure that the result they receive is accurate. Sometimes clients refuse to accept a positive test result, convinced that, because of some laboratory mix-up, it really belongs to somebody else.

Section 3: Providing pre-HIV test information in a group

Individual pretest counselling may allow the health provider or counsellor to build a relationship with the client and to engage in a detailed risk assessment, but it is not always possible. In many settings the demand for HTC is high and resources are limited. If a large number of individuals have to be tested, *group pretest information* may be offered instead of individual pretest counselling. The information components of pretest counselling could be provided in a group setting while issues specific to the individual could be discussed one-on-one in a shorter session (see the following table on page 36). I*nformed consent to the test should always be obtained individually*.

Elements of pretest HIV counselling for groups and individuals

Group	Individual
• Confidentiality and privacy; • Basic information about HIV; • Basic information about HIV transmission and HIV risk reduction; • Demonstration and discussion of condom use; • Benefits of testing, and potential issues; • Testing and result provision procedures; • General information about reproductive health.	• Personal risk assessment and feedback of individual risk; • Informed consent.

How is window-period exposure assessed during group counselling sessions?

Where individual pretest counselling is not possible, and no pretest personal risk assessment is done, window-period exposure must be assessed when the test results are provided. All results must be given individually, in a post-test counselling session. Similarly, where individual pretest counselling cannot be provided (and therefore coping strategy is not assessed) this information must be collected in the post-HIV test counselling session when the HIV-positive result is provided.

Pre-HIV test counselling for couples

Such counselling should be encouraged, not only for those planning to get married but also for those already in a relationship who wish to make informed decisions about having children and planning a family, and generally for those who want to work on their relationship and plan their future. However, couples should not be coerced into being counselled together. It is always wise to have separate individual risk assessments to reduce the risk that transmission risks will not be acknowledged, as they might not be in a joint counselling session. Confidentiality is important and couples should be told about what is covered and what the limits are. These points are discussed further in chapter 9.

You should listen attentively to the couple as they explain why they have come to be tested. Each partner should be given equal opportunity to talk and ask questions, and the counsellor should be non-judgemental and respectful in responding to the couple. Couples should be given relevant and accurate facts about HIV and AIDS to help them make informed decisions.

They should be supported in exploring the likely implications of their test results for their relationship, marriage, sex life, family planning, and child-bearing plans. Each partner should be given the opportunity for individual counselling, as some may find it threatening to explore their sexually risky behaviour in the presence of their partner. Together, couples should also look into the practicality of any changes in their sexual practice such as abstinence, condom use, or non-penetrative sex. The majority of studies on couple counselling among *discordant* couples (only one of the partners is infected) report success in changing behaviour to avoid infecting HIV-negative partners.

Section 4: Post-HIV test counselling

The foundation of good post-test counselling is established during a client's pretest counselling session. If pretest counselling is done well, then good rapport has already developed between the counsellor and the client. However, under PITC you may often find yourself required to provide a result to clients whose testing process was initiated by a doctor. Additionally, the client may have only group pretest information or may have been told that the HIV test was to be done by a doctor.

In other circumstances you may encounter a client who is unaware that he or she has been tested. You will need to first introduce yourself and explain your role and try to establish rapport before providing the test result. When another health provider has initiated the testing process it is important that you establish what information has already been provided by that service provider. Ideally you should clarify directly with the initial provider what information was given to the client, and more importantly whether the client was informed that an HIV test was to be administered. Unfortunately, counsellors are sometimes asked to provide an HIV-positive result to a client who was not told he or she was to be tested, and therefore did not give consent. Giving results in such a situation will be discussed below in the section on providing results to an HIV-positive client or patient.

Key procedural considerations for post-HIV test counselling

- **Cross-check all results against client files**. This should be done before the counsellor meets with the client, to ensure that the correct result is provided.
- **Provide results to the client in person**. Providing results to the client in person ensures not only that the appropriate person receives the results and confidentiality is protected but also that the client adequately understands the results and receives sufficient support.
- **Be aware of the manner in which you call clients from the waiting area**. A counsellor may unwittingly convey results to clients and others in the waiting area through verbal and non-verbal behaviour when calling clients in to receive their results.
- **Provide written test results**. Sadly in many settings test results may be misused, deliberately or not. Positive test results may be used to gain access to services that are inaccessible to others in the community, and therefore become a commodity to be traded. HIV-negative results, on the other hand, may be offered to sexual partners and mislead them about their exposure risk. For that reason providing written results to clients, whatever the HIV status indicated, is generally inadvisable.

If a result is required for employment or immigration purposes and HTC is not offered as an anonymous testing service it is recommended that clients be asked for proof of identity at the time of testing and again at the point of issue of the results. All results provided under these circumstances should contain a disclaimer clearly informing the reader that the results may not accurately reflect the status of the individual as he or she may have had exposure within the window period or after taking the test. A client who wishes to share the result with a partner should be advised to make an appointment together with the partner, who may then be shown the result in the client's presence.

Reading post-HIV test results

- For a negative result, say, ″Your test result was negative. That means we did not detect any antibodies for HIV.″
- For a positive test result, say, ″Your test result was positive. That means you are infected with HIV.″
- Before proceeding, it is important to make sure that the client has understood the test result and absorbed the information mentally and emotionally.

Detailed steps to follow when providing HIV-negative results

- **Review the client pretest counselling notes**. Check all laboratory results and client codes to reduce the possibility of providing incorrect results or information.
- **Begin the post-test session by asking how the client has been feeling since he or she had the blood sample drawn**. Congratulate the client for returning or waiting for the results.
- **When the client is ready, give the test results in a neutral tone of voice and wait for the client to respond before proceeding**. Say, ″Your test result was negative. That means we did not detect any antibodies for HIV.″ Before proceeding, it is important to make sure the client has understood the test result and absorbed the information mentally and emotionally. Sometimes clients misunderstand ″negative″ to mean that the test is flawed or that the news is bad and they have HIV.
- **Check for possible exposure in the window period, one that was undisclosed in pretest counselling or that may have occurred since then** (if same-day results are not provided). Though clients may be HIV-negative, according to an antibody test result, they may still be HIV-infected and in the window period, and may therefore be highly infectious. A client who has had an exposure risk that necessitates a retest should be provided with a date for retesting (based on national HIV testing guidelines). Clearly communicate to the client that he or she may be infected and able to pass on HIV and therefore needs to have a follow-up test.

- Reinforce information on HIV transmission prevention strategies and personal risk reduction plan. Some clients who have engaged in high-risk behaviour without becoming infected may think they are immune and may therefore see no need for any behaviour change. Review and explore any safe-sex constraints and infant-feeding issues (if the client is breast-feeding), or discuss the impact of drug or alcohol use on commitments to reduce future HIV and STI transmission risk. Review information contained in the Behaviour-Change Counselling section (chapter 3) of this handbook.

Clients who disbelieve their negative test results

Many clients find it difficult to believe an HIV test is actually negative, especially if they have engaged in high-risk behaviour or in activities that they feel are wrong. A negative test result cannot reduce their deep-seated anxiety and belief that they are actually infected with HIV. They may therefore become frequent testers, presenting at health services and discussing the presence of symptoms they believe to be HIV-related.

It is important to clarify whether the client has an undisclosed HIV risk or is continuing to engage in risky behaviour. Sometimes this is why people find it hard to accept an HIV-negative result. If reassurance does not reduce anxiety and the client repeatedly asks to be retested, consider referring the client to a mental health specialist for follow-up treatment and shift the focus of counselling from a discussion of HIV and its symptoms to a discussion of the impact of worry on the client’s life.

Detailed steps to follow when providing HIV-positive results

- **Begin the post-test session by asking how the client has been feeling since he or she had the blood sample drawn.** Congratulate the client for returning or waiting for the results.
- **If the client is known to have a history of drug or alcohol use, assess whether he or she is sufficiently alert and coherent to receive the result.** It is not uncommon for individuals who are awaiting results to manage their anxiety by self-medicating.
- **When the client is ready, let him or her know the test results in a neutral tone of voice and wait for the client to respond before proceeding.** Say, ”Your test result was positive. That means you are infected with HIV.”
- **Give the client time to absorb the information before proceeding.** Make sure that he or she has understood the test results and absorbed the information mentally and emotionally. A prolonged silence or no response could be due to shock, denial, or helplessness. Check to see if the client understands the result: ”Can you tell me what this means for you?” You may also want to ask, ”I’m wondering what you’re thinking or feeling right now…” Often, however, clients will not be able to tell you what they are feeling and may instead simply react in one of the following ways:
    - **Crying**: If the client starts crying, it is important to let the crying continue. Give the client space to vent the feelings. Offering a handkerchief is one way of showing that it is all right to cry. Comment on the process: ”This must be difficult for you. Would you like to talk about it?”
    - **Anger**: The client may start swearing or let anger burst out in other ways. Do not panic, stay calm, and give the client space to express his or her feelings. Acknowledge that the feelings are normal and let the client talk about what is causing the anger: ”I understand that you are angry, shocked, and upset…”
    - **Denial**: Counselling should acknowledge the client’s difficulty in accepting the information. Let the client talk about his or her feelings. Then gently review with the client the exposure risks that he or she reported during pretest counselling. The client can also be reminded of the precautions taken during blood collection to ensure that the blood sample was not wrongly labelled.

- **Assess the client's ability to cope with the diagnosis in the next 48 hours**. The assessment will include support available to the client and the risk of suicide (these will be covered in detail in chapter 5).

  How much you discuss partner or family disclosure with clients at this point requires careful consideration. Most clients will be too distressed for a detailed discussion. Briefly emphasize the importance of disclosure, going into details only if the client desires support in doing this immediately and if his or her emotional state will allow disclosure planning. It may be necessary to make further appointments. Chapter 7 of this handbook addresses partner disclosure counselling.

- **Provide only brief information on HIV treatment and care and advice on healthy living**. Most clients will not be able to absorb information at this point. You could have information leaflets available for the clients to read when they wish and set up a further appointment to discuss this information.

- **Provide follow-up appointments and referrals**. All newly diagnosed clients should be referred for medical consultation as soon as possible. Even in areas where ART is not available, HIV-positive clients can be referred to services that offer medical prevention and treatment of OIs such as TB or PCP. Counsellors should encourage HIV-positive clients to seek early treatment if they become ill, particularly with STIs.

  Offer follow-up counselling sessions to assist the client in adapting to the diagnosis as soon as possible. Where possible, provide an after-hours emergency contact phone number. This should not be your personal phone number but rather the contact number of rostered ″on-call staff″, the local crisis services, or even the local hospital accident and emergency department. Encourage clients who have tested positive to contact other HIV-positive individuals (through a network or support group or individually).

- **Ensure client safety by asking how he or she plans to travel home**. Often clients are in a state of shock and may put themselves and others at risk if they travel home in that state. Clients who seem disoriented can be offered tea, coffee, or even a place to sleep if possible. You could walk around the perimeter of the facility with the client until you are sure the client can negotiate traffic on foot or in a vehicle. Alternatively, you could ask the client if you should call somebody to take him or her home. This may, however, require some explanation to the other party and should therefore be considered carefully.

5

Working with suicidal clients

Section 1: Conducting a suicide risk assessment

Section 2: Suicide management interventions

Chapter 5

Working with suicidal clients

Suicide risk in HIV

There are two periods when people with HIV are more likely to attempt suicide. The first is when the person is initially diagnosed and suicide may be an impulsive response to the emotional turmoil that follows. The second period of high risk occurs late in the course of the disease, when complications of the central nervous system resulting from AIDS develop, capacity to earn income declines, and people feel they are a burden to family members and carers.

Section 1: Conducting a suicide risk assessment

How do I identify suicidal clients?

Many health workers fear explicitly addressing suicide with clients in the belief that this may ”give the client ideas”. On the contrary, sensitively inquiring whether a client has suicidal thoughts will communicate that you care for the client, and that you understand that sometimes life crises seem overwhelming. You can help prevent suicide only if you know it is a risk.

How do I raise the issue of suicidal thinking with clients…

You need to consider the various points of client consultation and how discussions of suicidal thoughts can be sensitively initiated.

…during pre-HIV test counselling? It is important to determine as early as possible in the HTC process who may be at risk of suicidal thinking. Many clients come for HIV testing with predisposing risk factors and crises that are evident before HIV diagnosis. This early collection of information provides valuable information that may help you provide positive results in a carefully planned fashion.

A sufficient history should be taken to determine whether the client has common risk factors such as drug or alcohol use, pre-existing psychological disorders, or other life-threatening illnesses such as chronic hepatitis that might predispose him or her to suicide. It is also imperative to ask the client whether he or she could disclose a confirmed positive result to others and whether significant others (partners, relatives, or friends) would be supportive. Research indicates that individuals who have little or no support at the time of diagnosis or who are likely to experience rejection from significant others may be at greater risk of suicide.

In addition, clients should be asked how they would react if they received an HIV-positive result. While many clients may not be able to predict accurately how they would respond, the information elicited may indicate that they are at risk of suicide. Clients could respond to this question by indicating that they would take their lives. When clients respond in this way, counsellors must make inquiries as to whether clients have, under other circumstances, attempted suicide. Clients who make such statements in anticipation of an HIV-positive result should be reminded that their results may show that they are not infected, and that if they are infected support will be available to them.

…when providing indeterminate results? Some clients who receive indeterminate (or inconclusive) results are convinced that the follow-up test will confirm that they are infected. Such clients should be reminded that they have not been diagnosed HIV-positive. Counsellors should assess the clients’ coping strategies and directly raise the issue of whether they intend to harm themselves or attempt suicide while waiting for further testing.

Clients who indicated during pretest counselling that they are at risk of suicide or whose history shows predisposing risk factors should be asked explicitly whether the result has left them feeling that life is not worth living or whether they would commit suicide.

…when providing confirmed positive results? When HIV-positive results are provided suicide risk assessment should be conducted with all clients irrespective of whether they indicated suicide risk during pretest counselling.

Clients who indicated during pretest counselling the intent to harm themselves if the result was positive should now be gently reminded about this. The counsellor could say: ″During pretest counselling you told me that you would kill yourself if you received a positive result… Do you still think that this is what you will do?″

While many clients may express this intent in pretest counselling, many do not mean to follow through on that intent. Even so, it is important to assess the suicide risk further. If a client denies entertaining suicidal thoughts despite the intentions expressed earlier, you must explore why he or she would not attempt suicide now after receiving the positive results. You can thus determine whether suicide is a continued risk. Clients who cannot say why they would not attempt suicide may still be at risk.

For clients who did not indicate during pre-HIV test counselling that they would attempt suicide, the counsellor should consider the background information they supplied and explicitly explore whether being diagnosed HIV-positive has given them suicidal thoughts. The counsellor may say, for example: ″When I give positive results to people, they sometimes indicate that they feel as if their life is over, or they want to harm themselves or even end their lives. I am wondering how you are feeling right now…if you feel like this or fear that you may feel like this in the near future.″

Long-term follow-up of HIV-positive clients

Many counsellors working with HIV-positive clients implement routine psychosocial assessment screening, which assesses mood, relationship and social supports, and financial and living difficulties regularly every three to six months. This allows counsellors to identify psychosocial stress factors early and to work with problems before the client starts contemplating suicide.

Such an assessment should alert you to the following predisposing risk factors for suicide:

- a pre-existing mood disorder (depression, anxiety, or mania)–all of your HIV-positive clients should be screened routinely for these conditions (common signs and symptoms of clinical depression are listed in box 5.1);
- a current psychiatric disorder such as schizophrenia or bipolar disorder;
- the presence of other psychosocial stress factors (e.g., a relationship breakdown);
- drug or alcohol use or withdrawal;
- inadequate pre-HIV test and post-HIV test counselling;
- inadequate support network; and
- discomfort with sexuality or gender.

Clients are confronted with stigma, discrimination, family relationship breakdowns, loss of income, and many other social problems directly or indirectly related to the course of their illness. An explicit suicide risk assessment should be part of this routine psychosocial assessment. You could make this risk assessment during the routine follow-up by asking questions in the following way: ″Many people living with HIV feel that the problems that face them are overwhelming and that they cannot cope. Some even say that their life is not worth living and that they want to end it all… Do you ever feel this way?″

Box 5.1: Signs and symptoms of a clinical depression

Depression is an internal "stress state". To an outsider, the symptoms seem to be a form of agitation or withdrawal. However, each depressed person experiences the condition differently. The symptoms vary in severity by individual and over time. Some people exhibit only a few of the following symptoms while others have many:

- persistent sad, anxious, or "empty" mood;
- feelings of hopelessness, pessimism;
- feelings of guilt, worthlessness, helplessness;
- loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex;
- decreased energy and fatigue;
- difficulty concentrating, remembering, and making decisions;
- insomnia, early-morning awakening, or oversleeping;
- appetite and weight loss, or overeating and weight gain;
- restlessness, irritability;
- persistent physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic pain;
- thoughts of death or suicide, suicide attempts.

Source: National Institute of Mental Health website: www.helpguide.org/mental/depression_signs_types_diagnosis_treatment.htm

Therapeutic assessment interview. A good assessment interview is part of therapy. Often it is enough to change suicidal thoughts, especially when clients are impulsive and responding to an immediate emotional crisis such as a recent HIV diagnosis or a precipitating life event such as a marital breakdown or infidelity. Once you have established the presence of suicidal thoughts or you have noted a number of the previously mentioned common predisposing risk factors in the client's history you should conduct a detailed therapeutic assessment. A summary of this assessment is provided in box 5.2.

Box 5.2: Suicide risk assessment process summary

- Establish the presence of suicidal thoughts and their frequency.
- Find out the extent of planning for suicide (giving away of property, specificity of plans, etc.), including access to the means (pills, guns, etc.). Explore details of past attempts. Ask:
  - Were these impulsive, planned, carried out while using drugs or alcohol?
  - How did this attempt change the client's life?
  - How did others respond to the attempt?
- Check for history of clinical signs of depression (refer to box 5.1)
- Explore other problems – HIV will rarely be the sole problem; often there will be other problems that confront the client.
- Explore what would make the client change his or her mind and want to live.
- Ask the client to consider the adverse impact of the suicide on others. Often clients think their death will bring relief to others; counsellors need to challenge this notion.
- Develop a management plan and set goals for the client.
- Document your interview and determine the level of suicide risk.

Key procedural considerations in working with suicidal clients

- When a counsellor is dealing with a suicidal client, it is important to first clear the client medically. Before starting counselling always find out from the client whether he or she has taken anything poisonous. Do not be too quick to sit down and give counsel when the client could have ingested something toxic.
- In some cases the client comes in a crisis and requires urgent attention; he or she may be alone or accompanied by a relative. The counsellor should see the client alone at the start. Many suicidal clients feel powerless and often unwilling to be frank and open about their problems in front of other members of the ″problem system″.
- It is important for medico-legal reasons to document your assessment of the client and your determination of suicide risk. You may have to justify action or lack of action at a later stage.
- Counsellors should never leave a suicidal client unattended in a room during the counselling session. If you need to get a file or speak with another colleague stay in the room with the client and have another staff member assist you.

Documenting the assessment process. For medico-legal reasons the counsellor must retain records showing that the client was assessed through standard clinical operating procedures.

The most appropriate form of documentation is a standard set of interview questions with the client's responses recorded against each item.

Determining the level of risk. All suicide risk assessments must gauge the level of risk; this will form the basis of your intervention. For medico-legal reasons the counsellor must determine the level of risk against standard indices or assessment protocols. Two such instruments-the *suicide risk assessment interview* and the *suicide matrix*–may be found in the *Tools for HIV Counselling*. Choose the instrument that you feel matches your ability to assess the risk of the client. Professional counsellors, psychologists, and medical personnel should use the more detailed assessment tool. Documenting the level of risk is important as it may be used to justify action taken by the counsellor and other staff. For example, under mental health legislation clients may be detained against their wishes when there is a clear danger of harm to themselves or others. Similarly, breaches of confidentiality may be justifiable when clients' life is at risk.

Section 2: Suicide management interventions

What do I do after I complete the assessment? After determining the level of risk, it is important to provide feedback to the client and make an attempt to engage him or her in the development of an action an. The action plan will depend on the client's level of suicide risk.

Key interventions for low-risk clients

- **Provide feedback** to express your continued concern about a possible resurgence of suicidal impulses.
- **Ask the client to choose one person** (a family member, partner, or friend) **with whom the thoughts of suicide can be shared**. The counsellor could offer to meet with the client and the person chosen. Remind the client that there is no need to explain his or her HIV status. The other person simply has to be told that the client has been under a great deal of pressure and has thought of ending his or her life.
- **See to it that the individual has immediate 24-hour access to suitable clinical care** (e.g., crisis team, extended-hours team, general practitioner, hospital, or telephone support). Give the individual a list of contact numbers and provide explicit contingency plans in case these contacts are unavailable (see box 5.3). The client could become suicidal again, so these are important considerations
- **Remove all available means of suicide** (e.g., guns, pills, chemicals, car keys, knives, rope, other weapons). If the individual requires medication, limit access to the medically required amount and ask family or a friend to supervise.
- **Get the client to identify and monitor early-warning signs of a resurgence in suicidal thoughts.**

- Establish a suicide contract: try to delay the individual's suicidal impulses. For example, make a ”contract” with the individual in which he or she promises not to attempt suicide within an arranged (short) period of time. Also, provide other options for the individual to use at times when he or she is on the verge of attempting suicide (e.g., suggest that the individual call someone reliable for help, such as yourself, a trusted family member or friend, a doctor, or a crisis hotline).
- Restore hope. Encourage the view that all problems can be managed if not solved. Identify, explore, and validate the client's ability to cope with past crises or difficulties. Use a structured problem-solving method (discussed in chapter 3) as an important skill for the individual to learn.

Box 5.3: Providing emergency services after clinic hours

Believing that you are the only one who can help a client can be gratifying, but it is also unrealistic and harmful.

- Do not under any circumstances promise to always be available to clients. Clients should be encouraged to involve family member, friends, religious personnel, and other community agencies in caring for them.
- Encourage the formation of a support network (e.g., family, friends, and agencies).
- Encourage the use of community resources (e.g., crisis hotlines, peer support and community clubs, and medical centres) in case you are not available when the client needs you.
- Clients may need referral to specific agencies for assistance (e.g., legal aid, welfare organizations supporting unmarried mothers, single parents).

Counsellors are advised to give only professional, and not home, contact information to clients. If after hours crisis contact is required by the counsellors' employer, the latter should provide a special mobile phone and only this number should be given to the client on the understanding that the counsellor may not always be available but a trained counsellor will always be on hand to answer the phone. Different counsellors on a crisis after-hours roster may take this phone.

Key interventions for clients who display little emotion after diagnosis or precipitating crisis

Clients who display little emotion or who express sentiments like ”I feel dead already” show serious immediate risk of suicide. These clients are often frank about intending to kill themselves eventually, but they will sometimes deny this intent in order to be released from the counselling centre. Some clients are in total denial of anger; in most cases these have a history of childhood abuse. These clients need to be referred where possible to a qualified psychotherapist, clinical psychologist, or preferably a psychiatrist.

Key interventions for moderate- to high-risk clients

How you respond and the degree of your involvement in supporting these clients will largely be determined by your professional background, the availability of other mental health services, and mental health legislation. The following steps are only intended to guide your response.

- Counsellors should always **provide feedback to clients** they believe to be significantly at risk of suicide to let them know that they care for them and see that they have reason to live.
- A counsellor who wishes to refer a client for **further assessment by a specially trained mental health professional** should let the client know. The counsellor should always gain the consent of the client. It is always best if the client were to voluntarily seek admission to mental health services or hospital for supervision.
- If the individual is believed to be at high risk of doing harm to himself or herself and will not accept help, it may be necessary to talk to a psychiatrist or general practitioner about the possibility of **involuntary admission to a hospital under existing mental health or public health legislation.** Counsellors should be fully aware of local mental health policies and legislation.

- **Where there are no suitable options for inpatient supervision, counsellors should contact family members and seek their supervision and support**. The issue of confidentiality will be overridden to some extent if the counsellor believes the individual is acutely suicidal. *Confidentiality about HIV status may be preserved; however, the counsellor who has a client at high risk of suicide must inform others of the client's suicide risk*.

Challenging client situations

There will always be individuals who are more difficult to help than others. Some special problems that may be encountered are discussed below.

Clients who refuse to talk. An individual may refuse to discuss a previous suicide attempt or current thoughts or plans for fear of being:

- stopped from committing suicide;
- embarrassed by suicidal thoughts or attempts;
- labelled "mentally ill";
- sent to hospital; or
- exposed if details of the interview become known to others

or simply because the individual is being contrary or manipulative.

Naturally, the individual is correct in thinking that he or she may be prevented from committing suicide. Furthermore, if the counsellor believes that the individual is acutely suicidal and will not accept help, the issue of confidentiality will be overridden to some extent. The counsellor in that case may have to talk to a psychiatrist or general practitioner about the possibility of having the client admitted to a secure mental health facility or supervised inpatient hospital under national mental health legislation.

With regard to the other reasons for refusing to talk, the counsellor can convey willingness to help and reassure the client about the confidentiality of the interview. A non-judgemental manner will be extremely important. If the client is still reluctant to talk, make sure he or she knows how to contact a clinician at any time of the day if the client should decide to seek help.

Clients who repeatedly attempt suicide. These individuals often feel lonely and isolated and may be trying to get attention. Alternatively, they may threaten or attempt suicide to control or use others to their own advantage. Other individuals may simply lack more appropriate coping techniques. Regardless of the reason, all suicide attempts need to be taken seriously. Counsellors must remember that the individuals are in distress and may lack more appropriate ways of dealing with their emotions.

Although a clearly defined management plan should be established and followed, other crises will sometimes interfere with it despite the best intentions. In some cases involving individuals with a psychiatric disorder, such as a *borderline* personality disorder, certain behaviours or *crises* may need to take precedence over the management plan or other goals that the counsellor and the individual have agreed on. These behaviours, listed in order of importance, are as follows:

- suicide threats, suicide attempts, and other life-threatening behaviours;
- behaviours that interfere with the process of treatment (e.g., missed sessions, excessive demands, angry outbursts, repeated admissions to hospital);
- behaviours that seriously interfere with the individual's quality of life (e.g., drug or alcohol abuse, antisocial behaviours).

The rate of suicide completion among individuals with this personality type, although lower than that among people with schizophrenia and affective disorder, is substantial. Therefore, all suicide attempts need to be taken seriously even if they appear to be intended to manipulate others and seem unlikely to be lethal. As suggested above, the first target of management will always be high-risk suicidal behaviours. It has been argued that previous suicide attempts are among the best predictors of suicidal behaviour. There are suggestions that problems in interpersonal relationships, depression, and drug and alcohol abuse are also risk factors in this population.

Suicidal threats or ideas need to be assessed immediately and actively. Once the individual's safety is assured, the goal of any intervention will be to replace suicidal behaviours with more adaptive ways of solving problems. Engaging the client in collaborative and structured problem solving may be a more constructive way of addressing his or her need for attention.

Making suicidal behaviour a management priority with these clients has several advantages. First, it reduces the likelihood of future suicidal behaviour. Second, it communicates the fact that the counsellor or clinician takes such behaviour very seriously. Third, the individuals themselves soon learn that if they engage in such behaviour, they will spend their time with the counsellor or clinician discussing this behaviour and applying the problem-solving model rather than discussing other topics. Fortunately, suicide completion in these individuals becomes less likely as they get older.

Follow-up monitoring and counselling for suicidal clients

Low- to moderate-risk clients. You must organize follow-up assessment visits with clients. Low-risk clients should be seen and assessed for suicide risk regularly. If your service does not provide ongoing counselling, the client should be referred to an agency that provides such support. It is preferable that you either accompany the client on the initial visit to the agency or arrange for a family member or friend to do so with the client's permission.

Clients who have been prescribed antidepressants by a doctor. Antidepressants usually start to lift depressive mood symptoms after a period of two or more week after initiating the treatment. However, the psychomotor retardation that is often associated with depression tends to lift before the mood improves. Consequently, there is a period of time when the individual remains depressed but becomes more alert and active and during this time may attempt suicide.

If the individual has just been started on antidepressants and is being managed within the community, his or her family or carers should keep a close watch and avoid leaving the individual unattended during this critical management phase. The individual should also be made aware of the antidepressant time lag. At first, he or she may notice only side effects; it may be useful to explain that these indicate that the medication is starting to work.

Clients who acknowledge recent failed suicide attempts. Some methods of suicide seem ″less″ harmful but may cause serious complications. For example, an overdose of paracetamol can lead to liver failure and subsequent death. Unfortunately, some individuals overdose on paracetamol only to get help and attention without intending to kill themselves. Deaths among these individuals are especially tragic. After a suicide attempt the individual's physical health will need to be closely assessed and monitored by a physician. Relapse into suicidal thinking is common among clients who have attempted suicide in the past.

Remember:

- Always review the precipitating risks and trigger for the past attempt at suicide.
- Always review the thoughts and emotions (feelings and body sensations) that may be the client's early-warning signs of depression. Ask the client to call the counselling service or a trusted family member or friend if a relapse seems imminent.

Introduction to HIV care counselling

6

Section 1: HIV and mental health

Section 2: Developing a post-diagnosis support plan

Chapter 6

Introduction to HIV care counselling

Care counselling is provided to people living with HIV to allow them to have a better quality of life and avoid passing on the infection to others, while improving the efficacy of treatment. Care counselling respects the rights and needs of HIV-positive people to enjoy sexual relationships, make reproductive choices, and live full and healthy lives.

Role of counsellor

Key counselling tasks are as follows:

- periodic review of the client's commitment and ability to reduce transmission risk-the difficulty of sustaining behaviour change should be acknowledged;
- encouragement and facilitation of voluntary disclosure of HIV status to partner and family (chapter 7);
- counselling for treatment adherence (chapter 8); and
- periodic psychosocial assessments to assess the quality of life of the client (including the client's mental health and ability to gain access to emotional support) make appropriate referrals for treatment, and provide financial and social support (a routine psychosocial tool, the post-diagnosis follow-up form, is provided in toolkit T6.1).

Section 1: HIV and mental health

Individuals infected with HIV and their significant others such as partner or partners, family, and friends can experience profound emotional, social, behavioural, and medical consequences. Adjustments will have to be made in partner relationships, family life, sexual and social relations, work and education, spiritual beliefs and needs, and legal and civil rights. The psychosocial issues are dynamic and are often different at different stages of the disease continuum. The HIV disease demands a great deal from the infected individuals and their significant others, and health workers must constantly adapt and adjust to meet these demands. Psychiatric disorders in persons living with HIV have been associated with poor treatment adherence, increased transmission risk behaviour, increased drug and alcohol use, and poorer quality of life.

Counsellors providing support to people living with HIV need to be aware of the complex, and sometimes subtle, psychiatric and psychosocial issues facing patients living with HIV. A psychosocial assessment, of the client's well-being and the risk of future psychiatric problems, as well as the client's social welfare needs, should be done routinely at least every six months or (preferably) quarterly. Most HIV-related psychiatric conditions can be treated with appropriate medications and psychological counselling and, if not cured, at least controlled.

Key considerations in supporting HIV-positive clients and their families are as follows.

Presence of a pre-existing mental illness or disorder

Research shows us that those individuals with a pre-existing history of psychiatric disorders may be more vulnerable to HIV because of their lifestyle and their limited capacity to modify transmission-related behaviour.

Psychological reaction to living with HIV

The emotional reactions of clients may be a psychological reaction to the life changes that living with HIV brings. These changes include relationship break-ups, stigma and discrimination, loss of employment, and fear of death and bereavement.

HIV-related psychiatric or neurological disorder

This type of disorder is an effect of the virus on the brain or central nervous system (CNS). The most-common psychiatric or neurological disorders related to HIV are depression, anxiety (social phobia, health anxiety), psychosis, mania, and HIV-associated dementia.

Mood and behaviour changes related to poor diet and nutrition

When clients eat poorly or have difficulty absorbing nutrients because of vomiting and diarrhoea, they may present with symptoms consistent with depression: apathy and inattentiveness, and problems with concentration and memory. People with some HIV-related neurological disorders often have these symptoms.

Side-effects of HIV and other treatments

Some antiretroviral (ARV) and other treatments can cause sleep disturbances, depression, agitation, and, in rare cases, even mania. Additionally, prescribed and non-prescribed drugs used together can interact and cause symptoms that could be misunderstood as signs and symptoms of a psychiatric illness.

Impact of HIV

HIV can be diagnosed at any stage of the illness. Indeed, in the Asia and Pacific regions many individuals do not learn their HIV status until the later stages of the disease. The following is a summary of the key considerations occurring at different points in the course of the disease.

Post-initial diagnosis. Diagnosis of HIV is often accompanied by feelings of shock, anger, disbelief, and even denial. After diagnosis, clients will go through an *adjustment phase* of mild to moderate intensity and limited duration. However, evidence indicates that among some individuals adjustment disorders will be more significant. Clients may present with depressed moods and anxiety, and initiate or increase drug and alcohol use. Some of these conditions may, however, precede infection and could be associated with behaviours that put a person at risk of acquiring HIV. Suicidal thinking is common around the time of the initial HIV diagnosis; these feelings may continue for up to six months (and sometimes even longer). Another condition diagnosed in individuals during this phase of illness is post-traumatic stress disorder, a severe form of anxiety particularly prevalent among individuals with HIV acquired through sexual assault.

Many of the psychological problems at this stage respond to simple counselling interventions to help the client with specific tasks. These interventions include the following:

- assessing and managing suicidal feelings (see chapter 5);
- supporting clients in disclosing their HIV status to their partner or family (see chapter 7);
- supporting behaviour change to reduce HIV transmission and maintain health (see chapters 3 and 9); and
- responding to specific problems that are related directly or indirectly to living with HIV.

All clients who are newly diagnosed must be referred for medical follow-up to a doctor who has been trained in HIV treatment and care. The client may also need STI or TB assessment and treatment, along with interventions to prevent mother-to-child transmission (see chapter 9).

At this stage you will need to acknowledge the very real challenges confronting clients living with HIV. Fluctuating emotions will have to be normalized. Statements of understanding can be helpful; for example: "I understand this is difficult for you. Many clients I see experience a wide range of emotions at different times as they adjust to this diagnosis. Many clients tell me they move in and out of crying to feeling angry, feeling hopeless and then hopeful. These feelings are not comfortable but it is normal to respond in this way. You are not losing your mind. You will not always feel this way."

Asymptomatic phase. The asymptomatic phase of the illness can last up to 10 years in treatment-naive patients (those who have not begun HIV treatment) or much longer among those with access to early intervention treatment. During this phase individuals are typically symptom-free or experience only mild symptoms but may present with difficulties related to coping with lifestyle changes and living with an infectious disease. Some may develop health anxiety and misinterpret minor non-HIV-related health symptoms as indicators of disease progression. People in this stage may also have to deal with issues related to the disclosure of status, rejection, and discrimination. In HIV-prevalent areas, some people may suffer multiple bereavements as partners, family, or friends die from HIV and may develop anticipatory loss reactions related to their own sero-status. The diagnoses most commonly provided during this phase of the illness are adjustment disorder, depression, drug and alcohol misuse, panic disorder, personality problems, and either psychogenic or HIV-related sexual dysfunction.

Symptomatic phase. The third phase occurs typically within five to 10 years after initial infection. People living with HIV experience significantly more psychological issues as they progress to this third phase of the disease. High levels of anxiety and depression are noted with the onset of HIV-related symptoms. Other common diagnoses are:

- organic brain syndromes such as HIV dementia;
- delirium related to opportunistic infections;
- drug and alcohol dependency and misuse;
- mood disorders related to metabolic disturbances;
- chronic pain; and
- HIV-related constitutional illnesses.

In addition, HIV-related sexual dysfunctions are more likely to be reported during this phase of the illness and these may present challenges to HIV transmission risk reduction.

Specific counselling tasks include the following:

- assessing and managing suicidal feelings (see chapter 5);
- providing clients with support related to partner or family disclosure (see chapter 7);
- supporting behaviour change to reduce HIV transmission and maintain health (see chapters 3 and 9);
- responding to specific problems that are related directly or indirectly to living with HIV;
- screening for HIV-related psychiatric and neurological conditions;
- counselling for treatment adherence (see chapter 8); and
- grief and bereavement counselling (see chapter 10).

Acquired immune deficiency syndrome. AIDS is the final stage of HIV disease. The mean survival rate without ART is about two years after an *AIDS-defining illness* is diagnosed. In this phase of the disease, organic brain syndromes such as AIDS dementia complex, HIV mania, and organic mood disorders may be the dominant presenting problems in psychiatric consultations. During this phase clients may experience adjustment disorders related to disease onset, loss of autonomy, grief and loss, and increased suicidal thoughts. Psychological assessment diagnosis in HIV requires the practitioner to consider the relative contribution of metabolic disturbance, constitutional illness, pre-morbid conditions, iatrogenic effects, and psychosocial factors to mood and behavioural disturbance.

Many of the issues and tasks for counsellors will be the same as in the previous phases; however, the emphasis may shift to these other tasks:

- finding financial, housing, and social support for clients who can no longer work;
- providing grief and bereavement counselling (see chapter 10);
- advising and supporting families, friends, and health workers in managing challenging patients with HIV-related psychiatric and neurological conditions;
- preparing adults and children (see chapter 9) for periods of inpatient hospital treatment;

- arranging for substitute care and long-term care of dependent children (see chapter 9); and
- gaining access to home-based care and support services.

A summary of common signs and symptoms of HIV-related psychiatric disorders can be found in annex 3.

Mental health assessment

Conducting a post-diagnosis review. First and foremost, review your client's pre-HIV test and post-HIV test counselling notes. If your client has been referred from another agency and counsellor you may not have access to his or her records and must therefore conduct a psychosocial assessment. A tool for post-diagnosis counselling can be found in *HIV Counselling Tools* (with this handbook). This tool will guide counsellors in assessing how the client adjusts to their diagnosis.

Using standard mood assessment inventories. A number of scales can be used to screen for possible psychiatric problems. The most widely available and used in the Asia and Pacific regions is the "General Health Questionnaire" (GHQ-28), which has been widely translated. General screening tools are used not to diagnose but to identify clients who need more detailed follow-up assessment with more specific diagnostic tools such as a depression scale.

Diagnosing and referring clients for assessment and management of psychiatric disorders. Diagnosis of HIV-related psychiatric conditions should be conducted only by appropriately trained individuals including clinical psychologists with training in clinical diagnosis, psychiatrists who can prescribe medication, and neurologists. Many specific diagnostic tools are licensed for use only by trained mental health practitioners. Among these are specific mood disorder diagnostic tools, the International Classification of Diseases (ICD 10), and the *Diagnostic and Statistical Manual of Mental Disorders (Revised)* (DSM IV R)[k1]. The References section of this handbook lists some useful clinical diagnostic tools. As discussed earlier, some psychiatric conditions that counsellors will see in clients will not respond to simple counselling and problem solving alone and will require medication. For this reason, clients need to be referred to a medical practitioner with mental health training. In most cases these clients will be prescribed medication and may be referred back to you for counselling or referred to peer support. In some cases clients will require inpatient treatment to stabilize their mental or medical condition. A series of flow-charts have been included in the toolkit to assist clinical diagnosis. Again these flow-charts must be used with caution; they are intended only to assist in diagnosis and referral.

Psychiatric referral and treatment, social welfare counselling, and peer support all play an important part in post-diagnosis care, support, and treatment plans. Counsellors will need to bring to their interventions with clients an atmosphere of empathy, respect, and encouragement. Many clients will present to us with a sense of ambivalence about whether they can trust a counsellor or whether a counsellor can really help them, and some may even appear defensive about needing our assistance.

Section 2: Developing a post-diagnosis support plan

A client will have many emotional, spiritual, and economic needs. To address these needs, it is important to develop an individual action plan and, where feasible, to identify a case manager (the preferred term is *client support coordinator*), social worker, or counsellor who can provide continuous care and support and assist the client in negotiating complicated medical and social service systems. Case management involves assessing needs, developing an individual action plan, and providing follow-up services.

Remember:

- A trusting relationship between the case manager or counsellor and the person living with HIV and AIDS is integral to providing adequate assistance and follow-up services.
- The case manager or counsellor should be sensitive to the individual needs of each client when providing assistance and developing action plans.
- The case manager or counsellor should have extensive knowledge of available clinical, community, and social service systems, along with a basic understanding of counselling skills.

Developing follow-up and referral plans

In the context of HTC, referral is the process of assessing and prioritizing immediate client needs for prevention, care, and support services, and assisting clients in gaining access to these services (e.g., by making appointments or providing transportation). Referral should include the basic follow-up necessary to facilitate initial contact with care and support service providers.

Clients' care and support needs change as HIV infection progresses. Although counsellors cannot fulfil all client needs, they can mobilize additional resources to reinforce the care and support they offer. This requires the involvement of the family, community, religious groups, self-help groups, nongovernmental organizations (NGOs), development partners, health-care facilities, and others. Counsellors should refer clients to services that address their highest-priority needs and are appropriate to their culture, language, gender, sexual orientation, age, and developmental level.

Counsellors must be aware that there are limits to the services they can offer. These limitations should be explained to clients clearly so they do not feel rejected if the counsellor makes a referral. Counsellors can refer clients during the pre- or post-test sessions (or at any other time) and must know how to make appropriate referrals with clear plans for discharging clients.

Reasons for referrals. Clients may have complex needs that affect their ability to adopt and sustain behaviours that will reduce their risk of transmitting or acquiring HIV. They may need referrals for medical evaluation, care, and treatment of OIs and communicable diseases (e.g., TB, hepatitis, and STIs). Referrals may also be needed for clients who need:

- treatment of a drug or alcohol addiction;
- care and treatment because of mental illness, developmental disabilities, or difficulties coping with an HIV diagnosis or HIV-related illnesses;
- legal services to prevent discrimination in employment, housing, or public accommodation;
- individual counselling;
- relationship counselling;
- family counselling;
- spiritual counselling;
- access to social services;
- home-based care; or
- family planning services.

HIV-positive pregnant women and HIV-affected families with orphans and vulnerable children may need to be referred as well.

Assessing clients' referral needs

Counsellors should identify the key factors that are likely to influence a client's ability to adopt or sustain behaviours that:

- reduce the risk of transmitting HIV or acquiring STIs;
- promote health; and
- prevent disease progression.

The assessment should include an examination of the client's willingness and ability to accept and complete a referral (see box below regarding measures intended to preserve confidentiality in the referral). Service referrals that match the priority needs identified by the client himself or herself are most likely to be completed successfully. Counsellors may refer a client to clinical or community support groups, depending on the client's needs and responsiveness to counselling.

Making a successful referral

- Work with clients to decide what their immediate referral needs are.
- Outline the health and social service options available and help the client choose those most suitable (in terms of distance, cost, and client's culture, language, gender, sexual orientation, age, and developmental level).
- In consultation with the client, examine the factors that may make it difficult for the client to attend the referred service (e.g., lack of transportation or child care, work schedule, cost) and address those factors.
- Make a note of the referral in the client's file. Follow up and monitor the referral process.
- Give the client a list of other services with addresses, telephone numbers, and hours of operation.
- Ask the client for feedback on the quality of the services to which he or she has been referred. Be aware of community support groups near the counselling site, the services they offer, their hours of operation, and contact persons.

In certain cases it may be most appropriate to refer clients (with their consent) to a family member, friend, or sexual partner. The counsellor should discuss the matter of identifying a suitable party with the client. If possible, the counsellor should meet with that person before sending the client to meet with him or her.

Ensuring consent for release of information

Some services ask clients to sign a release-of-information form to allow the exchange of information between services. This form is one way of demonstrating to clients that you are serious about respecting their wishes and protecting their confidentiality. It also emphasizes to the receiving agencies the need to respect confidentiality. Some agencies have a prepared form for referral information. Where appropriate, the referral information is documented on the referral form and signed copies of the form and the release-of-information form are either sent directly to the agency or placed in an envelope that the clients take with them to the service. Copies of the referral and release-of-information forms should be stored in the clients' file. Sample referral and release-of-information forms (T4.6 Referral form and T4.7 Consent-for-release-of-information form) are included in *HIV Counselling Tools* (with this handbook).

Section 3: Mapping out the client's needs

Review your client counselling notes and assessments, determine the key issues, and then, one by one, identify specific intervention strategies. Let us look at an example in the case study below.

Case study. The client is a woman who was brought to the clinic by a female co-worker from the factory where she is employed. The woman has known she is HIV-positive since her first husband died two years ago. After her husband's death, her family sent her to live in your city with a relative. She met another man and they were married.

She has not told her husband that she has HIV and does not know that this is an HIV service. She also says that there is pressure from her husband and his relatives to start a family. She reports she is not using contraception at present and has unprotected vaginal sex with her husband.

Often unwell, she complains of recurrent diarrhoea and weight loss, loss of appetite, and decreased sexual desire. In addition, she has a smelly vaginal discharge and itching. She also reports that she has a persistent cough and recently coughed up blood, and she finds it difficult to sleep at night. Her situation, she says, is hopeless. Her employer is upset because of the increasing time she is taking off work for illness. She no longer wants to talk to her friends at work. She has not had any HIV follow-up and has only limited knowledge of treatment options.

Refer to the sample client support plan in the table below.

Key issues (case study)

Issue	Strategies
Brought to the clinic by co-worker after crying at work; was not aware this facility was for HIV and now fears people suspect she has HIV.	• Suggest strategies for responding to questions from her co-worker regarding the clinic visit (e.g., "How did it go?") • Discuss how she can negotiate with this co-worker to maintain confidentiality
Reporting STI, HIV, and TB-related symptoms	• Refer to local TB service and medical doctor trained in HIV care and treatment • Refer for STI treatment if local HIV service does not offer service • Link to treatment and care team or case manager
Husband and family unaware of her status	• Provide counselling in support of disclosure to partner and family
No contraception, and unprotected sex with her husband	• Discuss risk of MTCT if she becomes pregnant • Offer pregnancy test or refer for pregnancy test • After partner disclosure offer to refer couple to family planning service • Discuss safer-sex strategies and the need to protect her from STIs, and other infections; offer condoms for contraception after disclosure to partner
Pressure from partner and family to have a child	• Obtain client's consent to conduct PMTCT counselling of partner and family after disclosure
Loss of appetite, decreased sexual desire, unwillingness to talk to friends at work, sleeping difficulties	• Assess/Refer for depression and drug and alcohol use • Teach relaxation exercises to assist with sleep disorders
Lack of appetite and weight loss	• Refer to nutrition counselling service
Time off work due to illness	• Discuss strategies for explaining absences at work • Refer to NGO for financial assistance if required
Increasing social isolation	• Offer referral and introduction to peer support

HIV = human immunodeficiency virus, MTCT = mother-to-child transmission, NGO = nongovernmental organization, PMTCT = prevention of mother-to-child transmission, STI = sexually transmitted infection.

7

Supporting HIV disclosure

Chapter 7

Supporting HIV disclosure

This chapter deals with partner and family disclosure between adults. The disclosure of HIV status to a child is discussed in chapter 9, section 2, of this handbook.

Section 1: Counselling for HIV status disclosure

Counsellor's role in ethical partner disclosure

One of the most challenging HIV prevention and care activities that a counsellor will engage in is facilitating partner disclosure.

Partner disclosure counselling has long been part of the public health response to STIs other than HIV, such as syphilis and gonorrhoea. In the history of partner counselling for HIV, there are no clear data indicating that the mandatory counselling of partners is more effective in preventing transmission than voluntary counselling. But it does appear that when people think that they will be forced to tell their partners, or that their status will be revealed without their consent, they choose not to come in for HIV testing, counselling, or other prevention and care services. This is true in the case of syphilis and gonorrhoea, which are curable, unlike HIV, and therefore cause much less fear than HIV and AIDS. It is even more likely that a policy of mandatory partner counselling will increase the fear of testing and disclosure because of the serious stigma and discrimination involved and thus discourage people from using HIV testing and counselling services. Furthermore, mandatory partner counselling is neither possible nor practical to implement on a large scale. People cannot be forced to test for HIV, to retest periodically after exposure in the window period, and to continue to tell their partners. Nor do people always know, or remember, the names of their sexual partners, and they cannot be forced to reveal those names. Finally, it is very costly to hire and train staff to trace and counsel all those whose names are given. Contact tracing is traditionally done for STIs only. We will discuss the various strategies available to you for STI contact tracing later in this chapter.

What about clients who put their partners at risk by refusing to disclose their status?

In a voluntary partner counselling programme, the few cases where persons refuse to tell their partners can be taken care of individually. UNAIDS offers guidelines to countries on the steps that could be taken when individuals refuse to disclose their HIV status to partners and knowingly place them at risk. Later in this chapter (see box 7.2) we will offer advice on how to manage this situation.

Clients may sometimes refuse to disclose their status because of a fear of violence. A protocol for dealing with this barrier is provided in annex 6.

When should I raise the disclosure issue with clients?

The best time to start discussing disclosure with clients is when they attend pretest counselling or a group pretest information session. When reviewing a client's exposure risks the potential need to discuss their status with partners should be addressed if they receive an HIV-positive test result. You should indicate that support would be offered to them in this area. As discussed in the HIV post-test counselling section of this handbook (chapter 4), a counsellor may gently raise the issue when the HIV diagnosis is provided. It is also important to bring up partner disclosure during the regular counselling follow-up visits that are offered to individuals in the course of their HIV infection.

Initiating the discussion. Counsellors should indicate to clients that they understand that telling partners is difficult. Acknowledge that HIV disclosure is often followed by major, life-changing consequences. After recognizing that disclosure is difficult, you can mention its general benefits, which are listed in table 7.1 below.

Facilitating decision making. Counselling is not telling people what to do. Rather it is encouraging them to think through the advantages and disadvantages of options and helping them come to an infomed decision. It also is about helping them overcome the barriers that they may encounter. Research demonstrates that when solutions are imposed on clients, they are less likely to stick to them. We can let our clients know that we need to work together to overcome any anticipated difficulties in order to:

- allow partners to have early access to treatment and care;
- reduce HIV transmission to uninfected individuals;
- prevent reinfection with HIV and STIs; and
- reduce the risk of resistance to treatment.

A counsellor can assist clients in considering the benefits of disclosure to them as individuals and to their relationships with others, as well as its negative consequences. Because disclosure is a very private and individual decision, all relevant personal circumstances should be considered. Common advantages and disadvantages of disclosure and non-disclosure (table 7.1) should be weighed and compared. If the clients can read and write, it is helpful to draw up a matrix and have the client brainstorm about advantages and disadvantages. Alternatively, the counsellor could make notes as the client answers aloud, and then provide an oral summary: "You listed the following as advantages…and the following as disadvantages…"

Table 7.1: Disclosure or non-disclosure (a sample decision matrix)

Option	Advantages	Disadvantages
Disclosure of HIV/STI status	• Burden of secrecy is lifted • Emotional support is available • Health care and medications are more accessible (no need to hide them) • Symptoms and worries can be discussed freely • (If disclosing to spouse or partner) Safer-sex and family-planning choices can be discussed freely • Reasons for specific activities (e.g., breast-feeding, replacement feeding) can be shared freely • Partner can be tested and treated • Other	• Person is distanced or rejected outright by partner, spouse, friends • Job loss is possible* • Children are shunned in school* • Promiscuous label is attached to person • Person is discounted because of fatal illness* • All signs or symptoms are assumed to be HIV-related* • Others fear for their safety around the person* • Person is at risk of mental or physical harm • Other • *Associated with HIV discrimination and stigma*
Non-disclosure of HIV/STI status	• Status is kept secret • Status quo ("normalcy") or current situation is maintained • Person is protected against stigma, isolation, rejection, loss of income, violence, blame for change in social status • Person is not prevented from having children in the future • They are not forced to seek medical care that they do not need • Other	• Secret is a burden • Anxiety builds because of fear of involuntary disclosure • Social support is inaccessible • Person is isolated • Sexual partners are put at risk • Access to medical care is delayed • Trust of children, family is lost • Other

How clients consider and evaluate the advantages and disadvantages of disclosure is determined by their personality and their past and current life experiences.

Offering a menu of disclosure options. Another powerful way to support decision making around disclosure is to offer the client a menu of disclosure options (see box 7.1). Often clients feel that they cannot make the disclosure themselves, while others feel it would only upset their partner to hear the news from someone other than themselves. As a counsellor you should support the client's decision making by presenting him or her with a menu of disclosure options and encouraging the client to discuss the advantages and disadvantages of *each option*.

Box 7.1: Partner disclosure options

- Client discloses to partner
- Client brings partner/family to clinic and discloses with counsellor present
- Client brings partner/family to clinic and counsellor discloses in front of client
- Client authorizes counsellor to disclose without the client
- Client discloses to a key trusted family or community member who discloses to partner
- Client hands out referral cards to sexual contacts

Once the client has decided on his or her preferred disclosure option, you can offer support in a number of different ways.

Preparing the client for disclosure, including self-disclosure. One key way to assist the client is to help him or her think through the why, when, where, how, and what of disclosure. While this is important for all of the disclosure menu options, it is particularly critical for client *self-disclosure*.

- **Why**: You need to make sure that clients think through why they are making the disclosure and what response they anticipate.
- **When**: Encouraging clients to consider the appropriate time for the disclosure is important. You need to have the client make the disclosure when no one else is present in the house to see the distress of the partner (e.g., the children are asleep). Clients should avoid making a disclosure during an argument.
- **Where**: Helping clients consider the place that they feel will give them the time for a confidential discussion and offer some security to both parties is an important consideration.
- **How**: You need to encourage the client to think about the disadvantages of different methods of self-disclosure (face-to-face or by telephone, email, or letter).
- **What**: Plan with the client how to initiate the conversation and anticipate the partner's likely response. You can then plan with the client a constructive response to the partner's reactions. Role-play can be an extremely useful technique to employ. When getting the client to anticipate how the partner will respond you can take on the role of the partner in the dialogue.
- **Planning for next steps**: Plan with the client how to get the partner support, HIV testing and counselling, and how to manage the relationship issues arising from the disclosure.

Partner disclosure by the client in the presence of the counsellor

Role-play rehearsal is again important if the client will be making the disclosure himself or herself. All of the planning discussed for self-disclosure should be discussed before the session with the client.

As the partner may have questions for the counsellor during the session, it is important that you clearly plan with the client in advance what can and cannot be disclosed during the session. It may be a good idea to document the permissible and non-permissible disclosure items in the counselling record form agreement.

Consider the following disclosure options:

- full disclosure–nothing is barred, client gives full consent; or
- partial disclosure–some things can be discussed (HIV status) but others cannot (e.g., sexuality; the way the person became infected; risky practices such as injecting, sex work).

Counsellor disclosure in the presence of the client

If the plan is for the counsellor to make the disclosure in the presence of the client then this should be role-played with the client after he or she has briefed the counsellor in what to disclose and what not to disclose. Again, list what may be discussed by the counsellor with the partner and what may not. Consider planning with the client:

- how you will introduce the disclosure to the partner;
- how the partner could react (check for the possibility of violence);
- how you will manage items that are not to be disclosed (e.g., how your client got infected);
- his or her role during the session (e.g., will the client answer questions?); and
- how he or she will initiate future conversations with the partner after the disclosure.

Counsellor disclosure without the client

This type of disclosure is often referred to as *voluntary third-party disclosure*. A counsellor must first gain written consent from the client before disclosing his or her HIV status to partners. Counsellors are advised to make a list as to what can be discussed with the partner and what cannot.

This type of contact is sometimes better done by an independent counsellor with only limited knowledge of the client's history, to prevent inadvertent breaches of confidentiality.

Issues to consider include:

- where the disclosure is to take place (e.g., at home, the clinic)–if the disclosure is to be made at the client's home, at least two counsellors should be present and consent for this should be obtained; if the disclosure is to take place at the clinic, consider the strategies or excuses the client will have to use to get the partner to come over;
- whether there is potential violence related to the disclosure (either towards the client, or the client to the partner) ; and
- how the client will manage himself or herself with the partner after the disclosure, and what form of communication with the partner will be needed.

Disclosure by a key trusted family or community member on behalf of the client

This is another form of third-party voluntary disclosure where the client nominates a trusted family, religious, or community member or leader to make the disclosure on the client's behalf. Usually the person chosen has the respect of the partner or the client's parents or whoever else the disclosure is to be made to. This person needs to be counselled on what should and should not be disclosed. Care must be taken to support the client in fully exploring the willingness and capacity of the selected individual. Should the client decide to proceed with this method, the counsellor could offer to assist the client in briefing and rehearsing the third party.

Box 7.2: When HIV clients refuse disclosure and knowingly place partners at risk

UNAIDS guidance on ethical partner notification also takes into account the serious consequences of not letting partners know about the possibility of HIV infection. These consequences require ethical weighing of the benefits and harms that are likely to occur if and when an HIV-positive person (e.g., one who has been a victim of domestic violence or has had threats to his or her life) refuses to disclose his or her HIV status to partners.

In that case, the public health legislation of the country should authorize, but not require, health care professionals to decide whether to inform their client's sexual partners of the status of the cliient. This decision should be based on the individual case, taking ethical considerations into account, and should be arrived at only if the HIV-positive person:

- has failed to achieve appropriate behaviour changes despite thorough counselling;
- has refused to disclose his or her HIV status to the partner(s), or consent to such disclosure;
- poses a real risk of HIV transmission risk to partner(s) (current or future sex with partner, sharing of needles, etc.); and
- could have his or her identity concealed from the partner(s), if this is possible.

Follow-up support should then be provided to those involved, including the client who refused to make the disclosure. The decision to conduct third party involuntary disclosure should not be made by the counsellor alone but should be discussed with the counsellor's supervisor and should conform to national policy.

Source: Adapted from UNAIDS. *Opening up the HIV/AIDS epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling and appropriate use of HIV case surveillance reporting.* UNAIDS/00.42E. Geneva, 2000

Section 2: Partner contact strategies for other STIs

Often in STI services the counsellor is also the doctor treating a client. If the counsellor is not an STI doctor, all clients arriving at the service should be seen by a physician. The counsellor must discuss with the client strategies for effective ethical contact with partners. If the purpose of partner management is to treat as many of a client's sexual partners as possible, there are three ways of contacting sexual partners:

- through the client himself or herself (*client referral*);
- through a service provider (*provider referral*); or
- through a third party, without revealing the identity of the client (*conditional referral*).

Client referral

In this option the client takes responsibility for contacting partners and asking them to come to the clinic for treatment. Many clients may be unwilling or unable to discuss the STI with partners, so the service provider should help him or her decide what to do. A client might approach partners in several ways:

- by talking directly about the STI infection and the need for treatment;
- by accompanying the partner to the health centre or asking him or her to come to the centre without saying exactly why; or
- by giving the partner a card asking him or her to come to the centre.

Provider referral

The partners of a client with STI are contacted by a member of the health team–perhaps the counsellor or health-care provider who treated the client, or someone else with a particular role connected with searching for and treating partners. The provider obtains the names of the sexual partners but gives the client time to counsel them himself or herself before the provider asks them to come to the clinic for treatment.

Conditional referral

This is a *third-party referral*, where the provider counsels the partners without naming the source client concerned.

On the surface, all approaches to partner management suggest some advantages; you might like to spend a few minutes working out what they are. Considering the advantages and disadvantages summarized in table 7.2.

Table 7.2: Partner management approaches

Approach	Advantages	Disadvantages
Client referral	Client has control over decisions, so they are both voluntary and confidential No cost to the centre	Depends on willingness of client to refer partners Client may need support from service provider
Provider referral	If referral succeeds, more partners can be contacted and treated more efficiently.	Depends on willingness of client to divulge names Cost, time, and practical problems of tracing partners More, highly trained staff will be needed May be perceived by clients as a threat to confidentiality
Conditional referral	Partners who accept referral and test positive can be treated May reduce further transmission by the partner	Trust in health worker may be destroyed May distress the couple's relationship and reduce trust

Because of the expense of provider referral and the perceived threat to client confidentiality, the more practical option is client referral. This is also the approach recommended by WHO.

Box 7.3: Client scenario

A young man comes to the clinic and tells you that a girlfriend asked him to come over to have an STI treated. He does not know the name of the syndrome and shows no symptoms or signs of any infection. The name he gives for his friend is not in your centre's records, so you have no way of identifying which syndrome to treat him for.

Client referral cards

Given the high proportion of partners with no STI symptoms, the scenario described in box 7.3 is not implausible. It is an example of failed partner management. If the partner shows no symptoms or signs of an STI, and the original client's syndrome is not known, the partner cannot be treated.

Client referral cards can help resolve this problem, and are used for this purpose by many health centres.

Sample client referral card A

Card No. ______________________________

Date of Issue: __________________________

Diagnostic Code: ________________________

Partner's name and details: ________________

Card No. __________ Date of Issue: ________

Issuing Clinic: Townville Clinic, New Town

Name: ________________________________

Please come to Townville Clinic at 23 Smith Street, Townville

Please bring this card with you.

The card above has two parts. After the necessary details are written in, it is cut along the vertical line and the right half is given to the client to hand to the partner named on the card. The remaining half is kept in the centre's records. Cards like this can be linked with the record systems of several different health centres. More importantly, they allow the centre to record the names of partners who come for treatment, as well as those who don't, together with their contact information. This information would be useful when contacting partners through provider referral.

Sample client referral card B

Townville Clinic, Townville

Tel. 456 834

Opening hours

Monday	9:00 am–3:00 pm
Tuesday	9:00 am–3:00 pm
Wednesday	9:00 am–3:00 pm
Friday	9:00 am–1:30 pm

9/3/97 **Referral ABC**

This second card is much simpler, yet it contains the information needed to treat a partner. In the sample above the service provider has merely written in the date and a code for the client's STI syndrome, "ABC", which could stand for any of the seven STI syndromes. Clients know the card is in general use at the centre; hence, no stigma is attached to carrying it around. It also contains no personal details on the client or the partner. The use of such a card, in short, has no disadvantages and can be part of an administrative records system (e.g., for monitoring the success of client referral).

Summary

A referral card can be extremely useful in helping counsellors identify the appropriate treatment for anyone referred to an STI clinic by a client with an STI. The card may include any extra needed information, but should never breach confidentiality or put anyone at risk of being stigmatized.

8

Providing treatment adherence counselling

Chapter 8

Providing treatment adherence counselling

ART is a complex treatment with multiple medications that, once started, need to be taken over the long term. Studies have shown that an adherence rate of over 95% is associated with the optimal response to treatment for the control of HIV replication. For ART to be effective, a patient must take all the prescribed medications regularly and at the same time every day. Some medications have other requirements: for example, they have to be taken before or after a meal, or with a certain liquid. Suboptimal adherence to the ART regimen can result in treatment failure, continued destruction of CD4 cells, and resistance to antiretroviral (ARV) medication. ARV resistance, aside from causing regimen failure, will compromise future treatment options and increase the risk of mortality. Non-adherence to medication requirements may also diminish their effectiveness.

How treatment resistance develops

In order to understand treatment resistance it is important, first of all, to understand ART. Multiple ARVs are used to interrupt the life cycle of the virus. *Viral load*–the level of virus in the blood–is dramatically reduced and arrest the immune system damage through a cocktail combining at least three ARV drugs of various classes.

The development of viral resistance to treatment is a complex process. There may not be enough of the drug in the body because of incorrect or missed doses, by malabsorption caused by dietary or other problems such as diarrhoea or vomiting or other more complicated issues related to the natural history of the virus.

The counsellor's role

Your role as *adherence counsellor* is to provide key information about: how ART works; how treatment can fail; and how the common challenges to adherence can be overcome.

Clients need to know that if they do not take the ARV medications with a very high degree of adherence the medications will stop working, both for the individual and for the whole community over time, as a result of resistance. First-line treatment is the most effective and easiest to take (with fewer side effects than second-line treatment). First-line treatment can give years of life to the patient, assuming near-100% adherence. Second-line treatment is harder to take and more expensive.

In many cultures one commonly shares what one has with others who are in need. In relation to ARV medication, infected patients have been known to share their drugs with an uninfected partner to keep him or her from catching the infection, or with other HIV-positive family members who are asymptomatic and do not yet need ART, to prevent illness. Clients should be warned against sharing drugs with others, as this may result in insufficient levels of the drugs in the body and the development of ARV resistance.

How to support treatment adherence and minimize the chances of treatment resistance

It is extremely important that clinical services establish a system where they take time to assess and prepare individuals for long-term treatment. In particular, counsellors will need to consider the diverse needs of individuals from most-at-risk populations. The general principle is that the individual does not commence therapy until he or she:

- has emotional and practical life support systems (e.g., family members, friends, community volunteers, or members of PLHIV clubs) to support him or her;
- can work his or her treatment regimen into a daily routine;
- understands that non-adherence leads to resistance and that this can be passed to others through unprotected intercourse or the sharing of injecting equipment;
- recognizes that all doses *must* be taken as prescribed (the correct dose in the correct way at the correct time);

- understands that traditional medicines and special dietary supplements may adversely affect ART and health, and that their use should be discussed with the treating physician;
- feels comfortable taking treatment drugs in front of others (has disclosed to others or has a prepared explanation for taking the pills);
- keeps clinical appointments;
- knows ”alarm signs” and when to see a doctor about them;
- understands the interaction and side-effects of ARVs in combination with illicit drugs and, where applicable, oral substitution therapies; and
- knows how to manage common side-effects of the medications (e.g., nausea, vomiting, diarrhoea).

Throughout adherence counselling, the counsellor will need to work in close collaboration with the doctor, nursing staff, and home-based care team.

ART adherence counselling and prevention of HIV and other STIs

It is difficult for patients to adhere to HIV ART if they cannot disclose their status to their partners and family members who live with them. You must raise the importance of disclosure to partner and family and facilitate the process. It is also important to support your clients in encouraging their partners to be tested for HIV if they do not yet know their status.

Counselling seroconcordant couples

The potential risk of HIV superinfection has been used to support recommendations for the correct and consistent use of condoms even when both partners are already infected with HIV. Though the issue is a complicated one, it is difficult to find strong evidence to support condom use among monogamous, seroconcordant, HIV-infected couples to reduce the risk of superinfection. If either partner has sex with others, however, then the correct and consistent use of condoms is strongly advised for the couple to avoid STIs.

Concordant HIV-infected couples should use condoms consistently if needed to avoid STIs and unintended pregnancy. Not enough is known about HIV superinfection, however, to recommend consistent condom use specifically to prevent superinfection.

Pretreatment preparation counselling

At least three preparatory adherence counselling visits to discuss the aforementioned topics should be made before the start of ART. *Continual adherence counselling after the start of ART is required*. The preparatory visits should be spaced one week apart to allow short-term reinforcement of key points about adherence and treatment, and practice with mock pills and other medications. After the final preparatory visit, the treating physician and nurse-counsellor should jointly consider the patient’s readiness to start treatment.

During each visit some of the information provided in the previous visit can be reviewed and the client’s understanding should be assessed.

Visit 1 summary

- Have the client undergo clinical assessment by a doctor.
- Explore the client's knowledge and understanding of HIV and his or her own health status.
- Briefly introduce the concept of ART and other treatments to the client.
- Explain the consequences of non-adherence.
- Explore potential barriers to adherence.
- Explain the transmission of resistance and review the client's personal plan for reducing transmission risk.
- Discuss the concept of having a "treatment buddy" selected by the client or a trained volunteer appointed to assist with the client's permission.

Visit 2 summary

- Have the doctor give feedback to the client on the medical assessments conducted during the previous visit.
- Review the client's understanding of information provided in the previous visit and assess the client's understanding of the feedback from the doctor.
- Review the potential barriers that the client anticipated in the previous visit and offer strategies for addressing the barriers (see Tool T8.3 "Barriers to ADH").
- Review the treatment plan with the client (the correct dose in the correct way at the correct time).
- Offer the client an opportunity to conduct a test run of the treatment regimen using empty capsules. Ask the client to record missed doses, identifying what caused him or her to miss the doses (e.g., forgetting to take pills on out-of-town travel for work).
- If the client has selected a "treatment buddy", ask him or her to bring that individual to the next session.

Visit 3 summary

- Review the client's understanding of information provided in the previous two sessions. Reinforce the fact that there is a much to remember and that you understand that it is not easy.
- Review client problem-solving strategies and familiarize the client with the counselling treatment reminder cue cards and adherence recording tools.
- Review the treatment plan again, as in visit 2.
- Assess the client's readiness. You can facilitate this assessment simply by asking the client to answer your questions about the regimen and what the client proposes to do when there are problems.
- Provide feedback on the client's readiness to the medical team.
- Meet with the client's "treatment buddy" to review his or her role and discuss how to make follow-up arrangements with clients. Establish a "buddy support" start date.

The impact of psychiatric and neurological disorders

As discussed earlier, psychiatric and neurological disorders are common in HIV and can pose substantial challenges to maintaining treatment adherence. Difficulties with planning and scheduling daily activities, attention and memory problems, and poor motivation–features of many of these disorders–may keep the individual from adhering to the treatment. In HIV-related dementia, psychosis, or mania, individuals may refuse to take medication, believing it to be poison. Individuals who experience paranoid thinking may resist the support offered by others.

Counsellors should screen for the presence of the disorders using the adherence pretreatment screening tools ("Pre-ART adherence screening tool (T8.4)". It is important that you discuss the findings of this assessment with the patient's doctor. Further reading on this topic is essential; recommended references can be found at the end of this handbook.

Managing common barriers to treatment adherence

The individual client may be inhibited from adherence for any of the following reasons:

- a lack of understanding of the treatment regimen and goals;
- barriers to motivation and memory;
- support and logistical barriers; or
- treatment side-effects.

Barriers to understanding originate from poor communication, language barriers, low literacy, lack of knowledge and erroneous beliefs about HIV as a disease, and lack of awareness or mistrust in the effectiveness of ART. On the other hand, barriers to motivation and remembering can stem from forgetfulness, depression, or other psychiatric conditions, from active drug or alcohol use, or from an inability to set longer-term goals. Finally, lack of support or logistical difficulties include fear of disclosure of HIV status, difficult and unstable living conditions, and poor access to transport and to continuous supply of the ARV medications.

The "Barriers to ADH (T8.3) and problem solving (ART) (T8.7)" in *HIV Counselling Tools* lists common barriers to treatment adherence and suggests specific ways of overcoming them. There is also a tool for managing ARV side-effects.

Supporting adherence by drug and alcohol users

ART for PLHIV should be introduced in the same way as ART for HIV-infected patients. ART is rarely emergency treatment; therefore, patients using drugs or alcohol should first be carefully assessed, properly informed and motivated, and have their potential adherence barriers addressed before they start ART.

Drug and alcohol dependency should be assessed and managed. Opioid-dependent patients who participate regularly in *methadone maintenance* treatment programmes have been shown to be more likely to use highly active ART (HAART), and to use it more consistently or with closer adherence. In addition, the following should be facilitated:

- stabilization of living conditions;
- management of psychiatric disorders (pre-morbid and HIV-related); and
- stabilization of serious medical conditions.

The management of prescribed and non-prescribed drug interactions and the adjustment of drug doses require close medical supervision. Dispensing medication in small amounts at frequent intervals will:

- provide opportunities to detect and address adherence problems before they lead to drug resistance; and
- limit treatment disruption or misuse.

Once-daily options, a low pill burden, and fixed-dose combinations (FDC) may be of benefit in this early stage of treatment. Again it is important to make sure that drug and alcohol users understand that their use of drugs and alcohol complicates their treatment because of complex drug interactions. Health issues such as poor nutrition and substance-related illnesses may add to this challenge.

You should assess and ensure that the client's drug and alcohol use–the type, frequency, and context of use–is documented and determine if the client has a dependency issue.

Other treatment medications

Complex treatment regimens that include TB, OI, and STI medications, as well as ARVs, will need to be clearly "mapped" for clients. They will need to know what drug to take, when to take it, and what to do if they miss a dose. They will also need instructions on the side-effects of each of these drugs.

Support during ART

The individual should have a follow-up adherence counselling visit within one to two weeks and continuous adherence counselling at regular intervals throughout ART. Adherence barriers can change over time and individual patients will need different levels of support as their life circumstances change and as they become accustomed to their treatment, experience side-effects, feel better or worse, and face new challenges. Adherence support therefore needs to change over time as well. Ongoing adherence counselling and continuing interactive communication are the keys to providing effective adherence support to the patient on ART.

In addition to adherence support, the adherence counsellor or physician should perform *adherence monitoring and assessment*. Adherence should be assessed on a basic level by all members of the multidisciplinary team at all counselling visits.

A typical follow-up counselling session involves:

- reviewing the treatment experience of the client;
- assessing any need for referral back to the doctor (usually related to side-effects);
- monitoring adherence (over a defined period);
- reviewing and finding solutions to barriers to adherence;
- reviewing adherence to transmission risk reduction; and
- conducting a psychosocial assessment.

Adherence assessment and monitoring

Adherence is difficult to measure, as it cannot be assessed accurately by any single method. Therefore, several approaches are used to assess adherence. Some measures in current use are client self-reporting, electronic monitoring, pill counts, provider estimation, and measurement of medications in the bloodstream. All methods have their strengths and weaknesses; none offer the security of a totally accurate account of the individual's adherence.

HIV Counselling Tools provided with this handbook contains tools for pretreatment preparation, treatment follow-up, and treatment adherence monitoring (tools T8.1, T.8.2, T8.3, T8.4, T8.5, and T8.6).

Summary of the ART adherence counselling session

Pretreatment session 1

- Clinical assessment (by doctor)
- Assessment of potential barriers to adherence
- Review of basic understanding of HIV and AIDS
- Transmission prevention counselling

Pretreatment session 2

- Feedback from health investigations
- Problem solving of potential barriers
- Discussion of preliminary treatment plan and regimen
- Provision of dummy pills for "provisional try"
- Transmission prevention counselling
- Facilitation of partner or family disclosure
- Nomination of family or volunteer "treatment buddy"
- Reinforcement of transmission risk reduction

Pretreatment session 3

- Review of previous two sessions
- Detailed treatment planning
- Final assessment of patient readiness
- Family/Buddy support meeting
- Collection of client contact information
- Transmission prevention counselling
- Arrangements for next visit

Treatment follow-up sessions

- Review of treatment experience of client
- Assessment of any need for referral back to doctor
- Monitoring of adherence
- Review and problem solving of barriers to resistance
- Review of adherence to transmission risk reduction plan
- Psychosocial assessment

Addressing special needs

9

Section 1: Pregnant women, new mothers, and their partners

Section 2: Children and adolescents

Section 3: MSM

Section 4: Transgender and intersex clients

Section 5: Male, female, and transgender sex workers

Section 6: Drug and alcohol users

Section 7: Health workers after accidental exposure

Chapter 9

Addressing special needs

This chapter addresses the special issues that you may be called upon to address in the course of providing pretest and post-test counselling, adherence counselling, or ongoing psychological support to individuals living with HIV.

Section 1: Pregnant women, new mothers, and their partners

HIV can be transmitted from mother to child during pregnancy, delivery, or breast-feeding. Without specific interventions, HIV-infected women will pass the virus to their infants during pregnancy or delivery in about 15%-25% of cases, and an additional 5%-20% of infants may acquire postnatal infection during breast-feeding, for an overall risk of 30%-45%. But this means that almost one-third of children born to HIV-positive women will be infected with HIV.

Reducing HIV transmission from HIV-infected pregnant women to their infants requires a range of interventions beginning with HIV testing and counselling and including ART for eligible pregnant women or ARV prophylaxis for women and newborns, safer obstetric practices, and counselling and support for safer infant feeding.

Ideally, all women and their male partners should receive HIV testing and counselling before deciding to become parents (refer to ”Couple counselling” in chapter 4).

HIV testing in pregnant women

Routine testing during antenatal care is an important way to reach women with information about HIV and AIDS, to identify women with HIV so that they can gain access to services and participate in interventions to prevent MTCT, and to prevent infection in women without HIV.

It is important to provide essential HIV and AIDS information at the first antenatal care contact, to be sure that as many women as possible receive the information and are routinely offered HIV testing. This can be done through a group information flipchart and through key pretest information from the individual provider seeking informed consent for the HIV test.

The advantages of HIV testing should be explained. Women must understand that there are clear advantages to being tested for HIV. Pretest counselling and group information sessions should address HIV transmission and the risks associated with MTCT during pregnancy, birth and breast-feeding.

Retesting in the third trimester

If the woman is considered to be at *high-risk of HIV transmission*, she should be retested in third trimester.

Managing women who decline

If a woman refuses to get tested, spend extra time with her to find out why she refuses and see if you can help her with any problems that keep her from accepting testing.

Some women may be afraid to get an HIV test, do not want to know their HIV status, or do not want to discuss results with their partner. Stigma and discrimination against pregnant or breast-feeding women who are known to be infected with HIV is a serious problem in many communities. Counselling women about the benefits to themselves and to their infant of knowing their HIV status can usually help to overcome fear of stigma and discrimination, and other barriers.

Allowing women to express their concerns is also important. Fear of negative outcomes is more common than actual negative outcomes for most women; most who disclose their HIV status report positive outcomes, support, and understanding. When counselling, it is important to assist women in evaluating the real chances of adverse outcomes and help them make a plan to minimize those outcomes.

If a woman does not accept HIV testing at her first visit, ask again at each future visit whether she is not ready to be tested. At each clinic visit briefly review the benefits of knowing one's HIV status and emphasize the care that is available to HIV-positive women and their infants to help her decide.

Counselling pregnant women who test positive for HIV

If a pregnant woman tests positive for HIV, counsellors should discuss the following:

- the risk of being reinfected and of infecting someone else in attempting to become pregnant;
- the risk of mother-to-child transmission of HIV;
- the need for clinical staging of an HIV infection to assess eligibility for ART to benefit the woman's health; and
- options for the prevention of MTCT.

Drug and alcohol using pregnant women who have been diagnosed HIV positive should be advised that that using such substances during pregnancy can be harmful to the baby and can cause birth defects or the baby being born addicted to the substance. Inform the client that it is important to their infant's health that the antenatal care clinic doctor knows that they have HIV and that they are using drugs or alcohol so that the right treatment can be offered to you and your baby. Counselors should not offer advice to the mother to immediately cease using the drugs or alcohol as to do so may actually create serious health problems for the mother and her baby if the mother is substance dependent. Counselors' should refer the mother to an antenatal care clinic and indicate in the referral that the mother is using substances. The counselor should discuss the need to share this information with the doctor and gain the client's consent.The woman should be referred to a physician who can conduct the medical assessment and offer more specific medical advice applicable to her health status.

Encouraging partner testing

In some countries only one of the partners in up to 25% of couples is infected and the other is not (discordancy). The partner should be encouraged to have an HIV test. The discordant couple should be told about the risk of HIV transmission in unprotected sexual intercourse and the issue should be explored in a counselling session for the couple. A case example is presented in box 9.1.

Box 9.1: Case example

A young married HIV-negative woman and her HIV-positive husband visited a clinic today and spoke of their desire to start a family. The husband asked for advice on how to minimize the risk of transmitting HIV to his wife and how to prevent the baby from becoming infected.

In the case example presented in box 9.1, the counsellor should discuss the following with the clients:

- HIV transmission between the husband and wife;
- HIV transmission in the womb, during delivery, and during breast-feeding;
- the high viral load during the period when HIV is newly acquired (seroconversion), placing the woman at greater risk of infecting the unborn child;
- an offer to have the woman undergo HIV testing if she has not recently been tested or if the couple have been having unprotected intercourse; and
- referral of the clients to a antenatal care physician who can offer the couple specific advice tailored to their needs and health status.

Counselling to prevent mother-to-child transmission

Counselling should address the three primary transmission risk strategies that can be employed to reduce mother-to-child transmission:

- use of ARVs;
- safe obstetric practices; and
- infant-feeding options and support.

ARV prophylaxis and ART

The administration of ARV medicines for prophylaxis or treatment involves a number of different services, including family planning and infant-feeding support. Therefore, women undergoing ART will require detailed explanations, monitoring, and follow-up. Essential adherence to prophylaxis or an ART programme can be enhanced if both the health worker and the woman clearly understand the regimen and its benefits. Often clinics working with pregnant women report very low rates of adherence to, or completion of, the regimen. It is therefore important for the counsellor to go beyond simply providing information and assess the constraints on a woman's potential adherence to the programme and ways to overcome those constraints. *HIV Counselling Tools* (with this handbook) includes tools that can help you do this. You will need to explain that ARV intervention does not always succeed in reducing transmission. With ART, the number of infants who contract HIV is greatly reduced. Those who are infected will need continuing medical care, and their mothers and families will need social and emotional support.

Counselling on delivery methods

In many cultures women commonly give birth at home or within the community. In these settings, it is important that pregnant HIV-positive women understand the benefits of delivering a child within a service that can support safe delivery and minimizes HIV transmission risk. Most infants who acquire HIV during delivery are infected through exposure to maternal blood or cervical secretions that contain the virus. Prolonged membrane rupture and invasive delivery techniques have been associated with higher risks of MTCT during labour and delivery. Strategies for reducing transmission during labour and delivery include:

- minimizing invasive procedures and avoiding artificial rupture of membranes and routine episiotomies;
- minimizing the use of forceps and vacuum-assisted deliveries;
- treating any signs of infection;
- managing postpartum haemorrhage and ensuring safe blood transfusions;
- minimizing aggressive suction of the infant's mouth;
- clamping and cutting the umbilical cord only after it has ceased pulsing, to avoid spraying infected blood; and
- providing a short course of an ARV drug, according to national guidelines.

Infant-feeding counselling

All women who are considering pregnancy or already pregnant or breast-feeding should understand that breast-feeding carries a risk of HIV transmission to the child. Women with HIV infection have the virus in both their blood and breast milk. Counsellors should provide advice that is consistent with their local national guidelines. WHO offers extensive advice and resources on infant feeding (refer to the "Additional online resources" section of this handbook).

Breast-feeding should be discontinued as soon as feasible to minimize the risk of HIV transmission. Always consider local custom, the individual woman's situation, and the risks of replacement feeding (which can include an increased risk of other infections and malnutrition).

Counsellors should provide full facts about the risks of breast-feeding and be able to discuss alternative infant-feeding options. If facilities for special counselling on infant-feeding options are available, they should be offered. This special counselling can help a woman make an informed decision about how to feed her infant. *HIV Counselling Tools* (with this handbook) contains some useful tools to assist you in providing information to clients on breast-feeding.

If HIV-positive women have access to safe, consistent, and affordable breast-feeding alternatives and the means to use them, the risk of death and illness from HIV and other infections can be kept to a minimum. Keep in mind that HIV-positive women may face stigma from their families and communities if they do not breast-feed their infants. If breast-feeding alternatives are not available, the health risk to infants who are not breast-fed is six times greater than the health risk to those who are, so breastfeeding remains the better option.

The risk of MTCT during breastfeeding is greater when an HIV-positive woman does not exclusively breast-feed for the first six months, or if complications develop (e.g., mastitis, cracked and bloody nipples) from poor breast-feeding techniques. The risk of transmission also increases if the mother becomes infected with HIV while breast-feeding. The duration of breast-feeding is also associated with the level of transmission risk: after six months, the risk of HIV transmission may be greater than the benefits of breast-feeding. Counsellors, in collaboration with the clients' doctor, should inform HIV-positive women of the alternative options listed in box 9.2. If none of these options is possible, women should continue breast-feeding, seek prompt treatment for any breast problems, and treat any case of thrush in the infant.

Box 9.2: Alternatives to breast feeding

- Exclusive use of commercial infant formula;
- Exclusive use of home-prepared formula (modified animal milk or dried milk powder and evaporated milk);
- Exclusive use of non-modified cow's milk;
- Exclusive use of modified breast milk (mother expresses milk, boils it briefly to kill the virus, then cup-feeds); or
- Government regulated breast milk banks, functioning according to WHO/UNICEF established standards

Counselling male partners

Men need information on how to prevent transmission of HIV to their female partners, particularly during their partner's pregnancy and during breast-feeding. In all counselling contexts, especially when men present for HIV tests, counsellors should take the opportunity to ask if they have female partners and address HIV prevention strategies to reduce MTCT. Male partners of pregnant women should be explicitly warned about the risk posed to both the mother and the child when they share injecting equipment, or have unprotected sex with other female or male partners during their partner's pregnancy. Men should also be advised to refrain from such behaviour while their partner breast-feeds. It is noted that in the Asia and Pacific regions many MSM have female partners of child-bearing age. It is therefore essential that services offering counselling to MSM explicitly address the issue of preventing MTCT.

It is further recognized that it is important to increase the male partner's involvement in antenatal and postnatal care. Partners should be invited to consultations where appropriate and feasible. Innovations such as "new father" clubs can support the effort to reduce MTCT, and improve family relationships. Just as many antenatal care services offer prenatal classes to women, similar classes can be offered to couples or to prospective and new fathers. It is important that men who are diagnosed HIV-positive are offered support in disclosing their status to their partners. Chapter 7 offers specific advice on how this can be accomplished. Men who work during standard clinic hours may not be able to attend clinical and counselling services. The involvement of male partners may necessitate services that have flexible consultation hours and evening information sessions.

Providing emotional support to pregnant women and new mothers

Pregnant women recently diagnosed and those who have deteriorating health are especially vulnerable to depression. Positive women are also at increased risk of postpartum depression. Depression not only reduces the quality of life of infected women but can contribute to poor treatment adherence, and to an inability to bond with, and care for, their newborn baby. It is imperative that counsellors are aware of common signs and symptoms of depression; these are discussed in chapter 5. General post-diagnosis care counselling is discussed in chapter 6.

Postpartum depression

Postpartum depression affects 10%-15% of women who give birth. It is best described as the ”baby blues” that deepen and last beyond the first month. Women who suffer from postpartum depression may feel profound sadness, have obsessive thoughts, and be unable to shake troublesome worries. Postpartum depression can be related to hormone changes in pregnancy and after birth and can also be related to psychosocial stressors.

The appearance of postpartum depression varies from woman to woman. It may appear as depression, anxiety, obsessive-compulsiveness, or any combination of these. Women may be suffering from postpartum depression if they feel depressed, lose interest in daily life and activities they used to find pleasurable, and suffer from at least four of the following symptoms almost continuously for at least two weeks:

- extreme fatigue, sluggishness, or exhaustion;
- feelings of hopelessness and helplessness;
- sleeplessness despite exhaustion;
- changes in appetite (loss of appetite, food cravings);
- anxiety, fear, guilt;
- difficulty concentrating;
- difficulty making decisions;
- heart palpitations, tingling, numbness, or feelings of dread, all of which signal a panic attack;
- impulses to harm baby or self;
- disinterest in personal hygiene or appearance;
- obsession with baby’s health; and
- inability to cope with everyday situations.

Postpartum psychosis

Postpartum psychosis is a rare but severe illness that affects one in every thousand women who give birth. A woman with postpartum psychosis may experience delusions, such as thinking her baby is evil, or hallucinations, which involve seeing, hearing, smelling, or otherwise sensing things that are not really there. Postpartum psychosis usually occurs soon after a woman gives birth, within three to 10 days. Postpartum psychotic episodes are generally brief, lasting for at least one day and less than a month. The new mother may experience periods of relatively normal behaviour. A psychotic episode that occurs more than a month after a woman gives birth is not considered postpartum, but may be caused by other factors.

Besides experiencing delusions and hallucinations, the woman suffering from postpartum psychosis may also:

- be extremely agitated;
- lose weight quickly without dieting; and
- go without sleep for more than 48 hours.

Women suspected of having either postpartum depression or postpartum psychosis require specialized medical assistance; counselling alone will not be sufficient. Referrals should be made to either a psychiatrist or an obstetrician or gynaecologist. The client’s HIV doctor should be alerted, preferably with the client’s consent. If the client refuses to consent to referral and you assess the condition to threaten the life or well-being of the mother or her child then you will need to proceed to make the referral without the consent of the woman. It is important that under this circumstance you explain to the woman why you will take this step. Before taking this step you are advised to discuss the situation with your supervisor.

Section 2: Children and adolescents

The diagnosis of infants and children is discussed in chapter 1. This section will cover the counselling of children and adolescents as it relates to HIV testing, counselling of parents and guardians, and HIV care counselling issues for children and guardians. Grief and bereavement counselling related to children and adolescents are covered in chapter 10.

Understanding the counselling context

There is a need for significant scaling-up of access to counselling and testing services for infants and children in order to enable more children to benefit from antiretroviral treatment, care, and support, and thus a better quality of life. Most-at-risk young children and adolescents are unlikely to seek counselling and testing for HIV and are more likely to be counselled and tested as a result of provider-initiated or caretaker-initiated testing. Given this context, issues of informed consent and rights-based approach are of particular importance. In general, the testing of infants and children occurs in a number of specific circumstances, including:

- children who present in clinical settings with signs and symptoms or medical conditions that could indicate HIV infection including tuberculosis (if HIV prevalence in TB patients is low, HIV testing and counselling would not be a priority);
- HIV-exposed children or children born to HIV-positive women;
- after birth, for early diagnosis of HIV;
- diagnosis of an ill infant or child; or
- upon admission to an orphanage, drug rehabilitation centre, or other similar institution

in cases where the child has been, or could have been, exposed to HIV through:

- mother-to-child transmission;
- sexual activity;
- injecting drug use;
- sexual abuse or rape;
- exposure within a health-care setting (e.g., contaminated needle stick injury or receipt of potentially infectious blood); or
- living or working on the streets.

Early diagnosis of infants and young children has the following potential advantages:

- early identification, and access of, HIV-infected infants and children to timely and optimal treatment, care, and support;
- access to information and services to prolong life, for example, by improving nutrition and taking exercise;
- easier decision-making regarding infant feeding;
- elimination of anxiety and stress of parents of HIV-negative infants, and among HIV-positive children relief of knowing the truth rather than being worried about the unknown;
- reduction of potential stigma, discrimination, and psychological distress among those diagnosed HIV-negative;
- easier life-planning for parents and children who are HIV-infected; and
- among older children who are HIV-positive, a better understanding of the importance of preventing further transmission, including the practice of safe behaviours to avoid infecting others.

If service providers have not been sufficiently trained on what information to share and how to communicate it with a child and his (possibly HIV-positive) parent(s) or guardian(s), *negative outcomes* may include:

- not fully understanding the situation, or only understanding the negative implications;
- disclosing their status without being aware of the possible negative ramifications, such as stigma and discrimination; and
- feelings of anger, resentment, anxiety, hopelessness and depression.

Legal and ethical considerations in testing infants and children

The United Nations Convention on the Rights of the Child (CRC) states that ″States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members″ and further that ″no child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation″. In the context of HIV testing, every child has a right to have his or her HIV test result kept confidential. The CRC's General Comment No. 3 states that ″States parties must protect the confidentiality of HIV test results, consistent with the obligation to protect the right to privacy of children (art. 16), including within health and social welfare settings, and information on the HIV status of children may not be disclosed to third parties, including parents, without the child's consent″.

Counsellors, along with other health-care providers, must be clear about the national laws and policies on counselling and testing of children, and to whom, when, and how best to inform or disclose a child's HIV status. HIV testing of infants and children should be supported only when it is in the best interests of the child. The potential benefits and harms associated with the testing of a child should be balanced along with the reasons for the request or suggestion for testing. You will need to be aware of the following considerations in the context of testing infants and young children:

- Under what circumstances is testing of infants and young children conducive and how is it best conducted?
- Once the results are known, how and what benefits are available for the infant or child who tests HIV-positive?
- How will the knowledge of HIV-positive sero-status be used to ensure access to care and support for the infant or child?
- What is the role of health-care providers and counsellors in supporting parents or guardians?

Consent and confidentiality. In general, HIV testing should be conducted only after an individual is informed of the benefits and risks and voluntarily agrees to test. Children in general, and those under 10 years in particular, present special circumstances for seeking consent, both of which may be affected by national policies, provider judgment, and the maturity of the child. Although parents and guardians often give consent for medical procedures (including HIV testing) on behalf of their children, a child still has a right to ″participate in decisions affecting his or her life″. Mandatory testing of children should not be undertaken in any circumstances and HIV testing or a child's HIV status must not be used to deny access to education, health care, housing, or any other service.

The age at which a child or adolescent may consent to HIV testing without parental or guardian permission varies from country to country. While most have national laws and policies related to counselling and testing for adults, most laws and policies are unclear or ambiguous and sometimes conflicting about HIV testing of minors, in particular about who is authorized to give informed consent and under what conditions. In some cases, age at which a minor may give consent to test is actually higher than the legal age for which they can consent to sex, consent for marriage, termination of pregnancy, or voting rights. Laws and policies on consent do not often give consenting rights to informational caretakers or medical staff, an issue in terms of HIV testing in case of orphans, abandoned infants, and street children.

Counselling children in association with HIV testing

Counselling must be available for any child undergoing HIV testing, including post-test counselling for the child and the parent(s) or caretaker(s). Counselling children infected or affected by HIV and AIDS requires the following skills:

- assessing maturity for understanding the benefits and risks of testing and for providing consent;
- age-appropriate communication;
- disclosure;
- the process of informing a child of his or her HIV status;
- counselling for adherence to HIV medication;
- ability to talk to children about death;
- assessment of sexual abuse and rape;
- parent or caretaker counselling; and
- ongoing psychosocial counselling.

Counselling children involves:

- creating a friendly and private environment (see box 9.3);
- establishing a relationship with children and gaining their confidence and trust;
- helping children to tell their story;
- listening to children in an active manner;
- giving children correct and appropriate information at his or her level of development;
- recognizing that the HIV test may raise different issues for children of different ages;
- giving honest answers without hiding information, even if difficult;
- helping children to make decisions;
- preparing older children and adolescents for safe sexual (or injecting practices), to prevent co-infection with another strain of HIV, and onward transmission of HIV to their sexual or injecting partners; and
- helping children to recognize and build on their strengths to develop a positive attitude towards life.

The foundation for a relationship between a counsellor and a child is good communication. Children should never be forced to tell their ”story”–there may be good reasons when children cannot communicate about something. To help children to communicate freely, a counsellor can use one or more of the following creative and non-threatening tools:

- drawing;
- storytelling;
- drama and role-plays; or
- plays.

Box 9.3: Creating a child friendly environment

- You can give an approximate time to the child about how long the session will last.
- If the parents or guardians are not in the room, inform the child exactly where the parents or guardians will be. Small children may need to be shown where the parents or guardians are waiting.
- Be prepared to sit on the floor with a child or talk while you are playing with toys, or even take a walk with the child (where appropriate and safe to do so).
- Discuss confidentiality and its limitations.
- The child or adolescent is informed that this is "a safe place", a place where the child can relax, talk, and play. The rule is that the counsellor cannot hurt the child, and the child cannot hurt the counsellor.
- Focus on the child or adolescent. Show an interest in his or her life and daily activities. Be curious. Appreciate who he or she is. Find the uniqueness in each child. Find out what is interesting or special about each child that you see.
- Have toys and objects that the child likes and that are age appropriate. Have toys and objects that will help you illustrate your discussion about HIV and what will happen during an HIV test.
- Use age appropriate language.
- Be calm and unhurried. Follow the child's lead. Listen to what he or she wants to talk about and encourage it, as long as it is not destructive or dangerous. You can bring the child back to the main topic if he or she is not talking about it or showing it in his or her play.

HIV and the psychosocial impact on children and adolescents

Chronic illness tends to affect many different areas of a child's or adolescent's life, including school, family, and social and psychological adjustment. Research examining the psychological well-being of chronically ill children has been mixed, but the general consensus is that chronically ill children are at greater risk of developing *adjustment problems*. These adjustment problems have included an increased risk of depressive symptoms, behavioural problems, academic difficulties, and feelings of isolation and withdrawal. Although chronically ill children appear to be at increased risk of developing psychological symptoms, there are a large number of chronically ill children who adjust well to their illness. Given that chronic illness may increase risk of impairment but does not by itself guarantee adjustment problems, the trend in recent research has been to examine variables that may moderate the risk of emotional difficulties. Factors that have been shown to predict adaptation to chronic illness include less family stress, cohesion, and expressiveness. Additionally, low socioeconomic status, coping style, attributional style, and social competence have been shown to predict emotional and adjustment difficulties.

The expression of HIV infection in the central nervous system (CNS) is variable across children and adolescents and among children and adolescents across time. Documented symptoms of CNS involvement include attention and concentration difficulties, language problems (particularly in expressive language) and motor skill deficits, lagging social development, and failure to achieve, or loss of, major milestones. Children and adolescents with HIV and AIDS have been reported to exhibit a number of behavioural and psychosocial difficulties including hyperactivity, attention deficits, social withdrawal, and depression. It is often difficult to ascertain whether symptoms of these disorders are behavioural/emotional or neurological in nature.

Cognitive deficits, learning disabilities, and developmental delay related to CNS symptoms of HIV infection can directly affect academic performance. It is unclear to what extent the behavioural, neuropsychological, and developmental deficits are also related to social circumstances such as maternal HIV infection, impoverished environment, and chronic illness in general. Careful assessments must be used to tease out cognitive, social, and neurological contributions to these problems. Counsellors and mental health personnel may find that a considerable amount of their work involves guiding carers and families in using appropriate behaviour management and parenting/care skills.

Addressing family and care issues

It is important to realize that many families are coping not only with HIV-related issues but also with additional stressors related to inner-city life. These include poverty, violence, and drug abuse. Other concerns reported by families dealing with HIV and AIDS involve interacting with the medical environment and addressing medical concerns. Families must negotiate financial and insurance difficulties and learn to communicate effectively with physicians and health workers. Additionally, they are coping with hospitalizations, clinic visits, and important medical decisions. Caregivers are often required to manage their children's medical condition as well as their own, and possibly, that of other family members. The medical regimen associated with HIV and AIDS can be notoriously difficult to follow. Not only must caregivers adhere to their own medication regimen, they must convince their children to comply with medication that tastes bad and pills that are difficult to swallow because of their large size.

Social isolation

Another unique aspect of HIV and AIDS is the secrecy, stigma, and isolation that accompany it. Despite improvements in the understanding of HIV and AIDS, those who are infected continue to be faced with the possibility of fear, rejection, and prejudice if and when their diagnosis becomes known. Stigma and discrimination may already be experienced by many children and adolescents who live on the streets and engage in illegal or socially disapproved activities. Children and adolescents who cannot disclose their status may experience an internal sense of isolation; those who do make the disclosure may experience stigma and isolation as a result. Where possible, you should seek consent from the child or adolescent and the parent and guardian to refer the child to a children's or adolescents' HIV peer support group.

Facilitating disclosure of HIV status for children and adolescents

Cultural issues may affect communication patterns, attitudes towards HIV infection, and willingness to gain access to social and psychological support systems. Children and adolescents are often not told of their own HIV infection, or that of caregivers, parents, and siblings. Evidence shows that parents and caregivers are uncomfortable discussing HIV status with children for a variety of reasons. One of these is the fear that children and adolescents will be unable to keep the diagnosis a secret from peers and other community or family members, resulting in social rejection of the child and the family. Parents and caregivers also report a desire to protect the child from the knowledge that the parent or child has the illness. This is especially true if one or more close family members or friends have already died from AIDS. Additionally, parents and caregivers report that they are uncomfortable and uncertain how to address questions regarding how the virus was transmitted to a parent or child. Parents may feel guilty or ashamed about the method by which they contracted HIV. Mothers especially may be trying to cope with their own feelings about having transmitted the virus to their child. There is a large body of literature in paediatric psychology addressing the question of disclosing disease status to paediatric patients. A great deal of this literature has been conducted in the area of paediatric oncology. In general, it has been well established that children and adolescents have better emotional adjustment if they are told of their diagnosis and allowed to discuss their condition openly with their family and medical caregivers. This is true even in situations where the child is terminally ill.

Unfortunately, there is little research regarding disclosure of diagnosis specific to paediatric HIV and AIDS. Stigma and discrimination may already be experienced by many children and adolescents who live on the streets and engage in illegal or socially disapproved activities. Children and adolescents may feel isolated if they cannot disclose their status, or experience stigma and isolation as a result of disclosure. Research has not been conducted to assess whether concerns about social ostracism and related psychosocial effects outweigh the need to discuss the child's or adolescent's (or other family member's) HIV or AIDS diagnosis. Some preliminary evidence suggests that children and adolescents with HIV or AIDS who were not told of their diagnosis had higher levels of social isolation than children who knew their diagnosis. Adolescents who are likely to be sexually active should be aware of their HIV status and receive information and support in reducing transmission risk behaviour. Where possible, the child and the child's guardian should be referred to a children's or adolescents' HIV peer support group where available.

Counsellors should attempt to provide families and caregivers with information regarding the benefits and consequences of disclosing HIV status to a child or adolescent. Open communication about health status is generally considered optimal, but this must be weighed against a family's concerns about social rejection. Additionally, families may request help formulating an explanation that is developmentally appropriate and answering difficult questions about disease process, prognosis, and transmission. Situations involving cognitive or developmental delay may not be appropriate for disclosure if a child's or adolescent's ability to keep the diagnosis private, or his or her ability to understand the situation, is impaired. Additionally, disclosure should be undertaken in an environment that is supportive, with adults ready to provide appropriate information and reassurance.

Should children be told they have HIV?

There are no guidelines for the most appropriate or exact age or the most appropriate methods for telling a child about his or her HIV status. Informing a child about his or her HIV infection is a process, not a single event, that moves along as the child's understanding evolves with age. As no concrete guidance on disclosure is currently available, parents, with the advice of caregivers wherever possible, need to carefully assess and then decide for themselves if, when, and how they will make the disclosure. The potential benefits of disclosure to the child should be taken into consideration. These benefits may include:

- helping a child to cope with his or her illness by addressing fears and concerns with the support of parents or caregivers;
- facilitating the child's involvement in planning his or her care and educational and psychosocial needs;
- enabling an adolescent to learn about safer sex practices and to take responsibility; and
- preventing further transmission, if sexually active or injecting drugs.

When informing a child of his or her HIV or health status:

- use age-appropriate or developmentally appropriate language and concepts that the child can understand;
- ask the child what he or she is thinking and what he or she knows about HIV and AIDS;
- use words, pictures, and drawings to explain HIV; and
- ask the child if he or she has questions, and answer them honestly and directly.

Non-disclosure may lead to anxiety, fear, and depression and also deprives the child of support and referral to psychosocial support and activities.

The potential disadvantages of disclosing to a child include stigma and discrimination, and in extreme cases harm by others. The experience in some sub-Saharan countries has indicated that older children prefer to be told by their parents if one or both parents have HIV. It is thought to be beneficial for older children to learn about their parents' HIV-positive status before the onset of illness, though at present most children only learn about their parents' status much later on. When to disclose the parent's HIV status to a child depends on the child's age and maturity, but ultimately is the choice of the parent. It is inevitable that disclosure of an HIV-positive sero-status to a child will have a significant psychological impact on the child. This will be compounded should both parents, or siblings, be infected.

Behaviour change and adolescents

Behaviour change during adolescence is often strongly influenced by peers. It is important to assess the level of pressure your client experiences and discuss this with him or her. Consider evaluating the client's readiness for change and employ motivational interview strategies (discussed in chapter 3). Also taking into account the client's readiness for change, determine what skills training should be provided in strategies for managing peer pressure. Further reading recommendations are offered at the end of this handbook.

Preparing children and adolescents for hospital visits and medical procedures

Sometimes parents and guardians are uncomfortable telling their child about going to a clinic or the hospital. Parents might feel protective or anxious about their child's reaction. Parents or guardians should be advised by the counsellor that ″You can protect your child from the information but you cannot protect him or her from the experience″. At the very least, it is important that the child knows that he or she is actually going to a clinic or the hospital. It can also be helpful if the child knows the reason(s) why (e.g., an outpatient check-up or assessment or an inpatient medical procedure, operation, or treatment).

The child/adolescent should be provided with some basic information about what will happen at the clinic or hospital.

The child's or adolescent's level of development determines the approach.

Young infants (newborn through eight months). When the baby is going to hospital or having an operation, it is normal for parents to find it more stressful. Young infants usually separate easily and can be comforted quickly by the care staff in the hospital. Parents or carers should be advised of this by the counsellor. Often parents or carers can provide a familiar rug or soft toy so that the child can derive comfort from this. Where a drug- or alcohol-dependent mother has delivered a child who is showing signs of withdrawal the mother will require support and counselling in relation to feelings of guilt and distress with the fact that the infant needs specialist drugs for withdrawal treatment.

Older infants and toddlers (from eight months through two years). Most children in this age group will have some difficulty separating from their parents, and older infants can initially behave poorly with care staff. The parent knows the child best and can tell the nurses and doctors how the child might react and what can be done to help the child cope better. Parents are advised that they could start telling their toddler about going to the clinic or hospital a day or two before.

Often the parents of most-at-risk adolescents (MARA) will have limited ability to negotiate with hospital staff. Counsellors can therefore provide support to parents in communicating with hospital staff and managing administrative procedures. This may be particularly important where parents are drug users or sex workers and have had poor experiences navigating the health system and dealing with health professionals.

Preschool and young school-age children (three through six years). Most children in this age group can understand simple explanations about their illness and may need time to express their feelings, draw or play, and ask questions. Parents and guardians could start telling their child a few days to a week before. Playing games like nurses or doctors with dolls, etc., can be helpful. The child especially could role-play the actions of the doctor or nurse and give the ″child″ an injection. Counsellors can provide a syringe without a needle for this purpose and work with parents and guardians to help them prepare the child.

Older school-age children (seven through 11 years). Most children in this age group are able to understand the reason for a hospital stay and what is going to happen to them. Children at this age may have fears about waking up during medical procedures or operations, and about pain and changes in their body. Plenty of reassurance, talking time and play-practice on teddy bears or other toys, and drawing can help. You could start telling and preparing the child a week or more before. Children who have been living on the streets and who normally project a ″streetwise″ demeanour may regress to quite dependent and fearful behaviour. Having treatment support buddies or other supportive carers visit will assist the child in adjusting to this environment.

Adolescents (12 to 17 years). Most adolescents have a good understanding of what is going on in their bodies and the reason for clinical or hospital visits. Including them in discussions or decisions about their care and treatment can increase their sense of control and reduce anxiety. Adolescents often have several worries about clinical visits or going to hospital. They may be concerned about the impact of an illness or medical procedure on their appearance, the reactions of friends, independence and privacy, or sexuality issues. Also, be prepared to discuss the adolescent's fears about dying or disability. The adolescent may need time to think about it, gather information and read, discuss it with you in more detail, talk to other teenagers with HIV, and make plans to be absent from school, work, and social life. Counsellors are advised to discuss this issue with parents and guardians. It is best to start telling and preparing the adolescent a few weeks in advance.

When adolescents are unaccompanied minors they should be encouraged to develop links with peer support groups before hospitalization. In some circumstances hospital buddy support systems can be developed so that the adolescent will have the opportunity to have visitors and support while in hospital.

Helping parents or caregivers talk about the hospitalization

Often a parent can feel nervous about what to say to the child. The counsellor could practice with the parent to increase his or her confidence. Also, role-playing can be a good way to troubleshoot for those unexpected questions and reactions. In many circumstances you will be dealing with a family where the child or adolescent has left home or regularly come and gone. Often there will be family resentments.

Brothers and sisters. If the child has brothers or sisters, the other children may also need explanations, reassurance, and an opportunity to express their feelings. The counsellor's role may be to offer clarification and support.

Grandparents. Grandparents are often closely attached to their grandchildren and can be a very important part of the child's life. Involving grandparents (or other members of the child's extended family) in the preparation and hospital stay can be a big help to the child. This can let your child avail himself or herself of multiple social support and provide a sense of normality.

Talking about medical procedures with younger children

It is most helpful to talk to the child in simple, clear language with words that you know he/she understands:

- ″special pictures″ could mean X-rays or scans;
- ″special medicine or drink″ could refer to medication or tonics; and
- ″special creams″ could be cream-based medications.

Counsellors can be a great help to the parents, nurses, and medical staff by finding more child-friendly ways to explain other common hospital words such as ″injections″, ″drips″, ″plaster″, ″bandages″, ″ dressings″, or ″monitors″.

Giving information about the hospital or clinic in advance

After you or the parents/guardians have gathered information, you may need to spend time talking to the child about the hospital or clinic itself to ″desensitize″ the child. You could try some of the following ideas:

- Describe the hospital or clinic (e.g., a place/big building or house with many children in it). An advance visit to the hospital or clinic might help.
- Tell the child or adolescent about the people who work in the hospital or clinic (e.g., doctors are men and women who help children who are sick). It is useful to have a child-friendly sentence prepared to describe the other staff your child might meet such as the nurse or laboratory technician.
- Talk about what hospital or clinic staff might look like (e.g., the differently coloured uniforms, tissue hats in the operating theatre, name badges).
- Talk about what the hospital ward may be like (e.g., a big room with many smaller rooms with children of all ages in them, or the daily routine). Also, explain that your child might have to share or change rooms with other children while in the hospital or clinic. This can prevent problems of non-compliance and resistance.
- Talk about what the food may be like.

Giving the child a personal reason for the hospital visit or medical procedure can motivate him or her to comply with treatments and help your child make sense out of the experience (e.g., being able to run longer without getting tired, wearing special garments so legs will look better). The reason would depend on the illness or health problem being treated and your child's level of understanding. Tell parents or carers that ″It is important to encourage the child to talk about the hospital or clinic and his or her ability to cope with it″.

Statements of dislike for the hospital made by counsellors, parents, or a guardian to a child are often unhelpful.

Parents should be advised that in general it is best to answer all questions even if this means saying, ”I don’t know but I will find out”. Try to remember to come back later with the answer! Even if it is difficult for you, try to answer questions openly and honestly. Parents should be advised that reassurance is vital. Parents should reassure the child that they and other members of the family will visit as often as possible. The reassurance that the family will be there can help the child cope better and separate easier during absences. Sometimes children’s hospitals have some form of parents’ accommodation so that parents can arrange to stay overnight. Telling the child that you will be doing this can also be reassuring. Parents are advised to try to stay calm; their child may pick up on their own level of fear and concern, and be frightened by this.

Counselling in relation to pain management

Dealing with pain can be difficult for parents and children. Pain can be a feared experience associated with hospital and medical procedures. Parents and caregivers should be advised that if their child asks if a medical procedure hurts, telling the child or adolescent that it will not hurt when it does hurt is not helpful. This false reassurance tends to diminish trust, increase anticipatory fear, and reduce compliance. Often children and adolescents can tolerate more pain when prepared for it, know what to expect, have words to describe it, and are reassured in advance about ways of coping with the pain. Breathing techniques to ” blow away the pain” can be taught to the child or adolescent by a parent or the counsellor. Being prepared for the experience of pain can also improve the child’s sense of pain control. In addition to medical treatments, most hospitals and clinics should offer support for pain management. Children may find it hard to describe pain and so they will need assistance. Smiling and sad faces can help children express how bad the pain is.

☺☺	☺	😐	☹	☹☹
No pain	Feel better	Not sure	Pain not strong	Very strong pain

Alternatively, a picture of the body can be provided and children can draw, or point to, the parts where the pain is.

Section 3: MSM

Who are MSM?

The term men who have sex with men (MSM) is meant to address all men who have sex with men, regardless of their sexual identity. It is used because only a minority of men involved in same-sex behaviour define themselves as gay, bisexual, or homosexual but may more aptly self-identify using local social and sexual identities and behaviours. They do not consider their sexual encounters with other men in terms of sexual identity or orientation. Many men who have sex with men consider themselves to be heterosexual rather than homosexual or bisexual, especially if they also have sex with women, are married, take the penetrative role only in anal sex, or have sex with men for money or convenience.

The term MSM includes various categories of men who may be distinguished according to the interplay of variables such as their:

- sexual identities, regardless of sexual behaviour (gay, homosexual, heterosexual, bisexual, and transgender, or their equivalents, and other identities);
- acceptance of, and openness about, their non-mainstream sexual identities (open or closeted);
- sexual partners (male, female, or transgender);
- reasons for having these sexual partners (natural preference, coercion or pressure, commercial motivation, convenience or recreation, or life in an all-male environment);
- roles in specific sexual practices (penetrative, receptive, or both); and
- gender-related identities, roles, and behaviour (male or female, masculine or feminine/effeminate, cross-dressing, or gender-concordant dressing).

What do counsellors need to know about sexual identity and sexual behaviour?

”Men who have sex with men” has become a popular term in the context of HIV and AIDS, where it is used because it addresses behaviours that put men at risk of infection. It has been argued that the term is too focused on sexual behaviour and not enough on other aspects, such as emotions, relationships, and sexual identity. Some organizations and individuals prefer the term *males who have sex with males* because it indicates a broader group of individuals engaged in sex with members of the same sex. In particular, it does not have the age limitation implied by the term ”men”, and therefore includes boys who are having sex with each other and also sexual relationships between men and boys.

In part the term MSM can be seen as a reaction to the language that has developed in Western cultures to describe or ”medicalize” sexual acts between men. Also, the emergence of the ”gay culture” in Western societies during the 20th century has encouraged the belief that people are either ”gay” (homosexual) or ”straight” (heterosexual). This may be true for some people in some parts of the world, but for many men, having sex with other men is just one part of their sexual life and does not determine their social or sexual identity. Some MSM may be highly visible in the community and can include men who dress as women or wear some items of women’s clothing. However, other MSM may be completely indistinguishable from non-MSM. Where ”homosexuality” is not visible it is sometimes thought not to exist; however, this is probably not the case. In fact, sex between men happens in most, if not all, societies. Public discourse that denies the existence of same-sex activity does not reflect what happens in real life.

Possibly the largest group of MSM in most countries in Asia is that of men who do not accept their non-mainstream sexual behaviour, do not openly self-identify as gay or homosexual, and who have either casual and anonymous sexual encounters or highly clandestine relationships with other men. Some of these men may be married or also have sex with women. A few may self-identify as bisexual. Some men who self-identify as heterosexual or bisexual occasionally have sex with men for pleasure, usually because women are less accessible. Some men may have sex mainly with transgender MSM without self-identifying as gay or homosexual, primarily because transgender MSM are not considered men in their cultural context.

There are men whose natural preference is for women but who have sex with men because of restricted access to women. This can happen in conservative societies that encourage strict social segregation of men and women, or in all-male environments over extended periods of time, such as prisons, military establishments, male migrant labour settings, and all-male educational institutions. Denied access to women, men have to gratify their sexual urges with other men, without self-identifying as gay or homosexual. Many male sex workers across Asia often self-identify as heterosexual and have sex with men mainly to support themselves and their families. They are often married or have girlfriends or female sex partners. There are, however, some male sex workers who do self-identify as gay or homosexual and have sex only with men. Some men prefer to have sex only with men but pressure to get married and start families results in their having sex with women. Some have a preference for men but are not averse to women, and vice versa. Others prefer to have sex only with women but end up having sex with men for money or because they have no access to women. The ambivalent position of male-to-female transgender individuals adds other dimensions to the scenario.

Why do some men engage in same-sex behaviour?

It is not known why, while most people are sexually attracted to the opposite sex, others are attracted to the same sex. Some theories stress biological differences between heterosexual and homosexual adults, suggesting that people are born with their sexuality predetermined. Though experiments and tests have been undertaken to measure differences in hormone levels, genetic make-up, and brain structures of homosexual and heterosexual people, the findings have, for the most part, been unclear. One psychological explanation stresses the importance of life experiences, childhood, and relationships with other people, particularly with parents. A person's assumptions about sexuality and that person's behaviour are influenced by family environment, experiences, and sense of self. Beliefs about sex are initially shaped by family values. Later on these beliefs may be challenged and shaped by pleasant and unpleasant sexual experiences, which also shape their choice of sexual activities and partners. Throughout life a person's sense of who and what he is has a strong impact on sexual development and experience. Another theory suggests that preferring your own sex is a matter of willpower, and that a man who has sex with men does so out of a wish to deviate from established gender roles. However, there is little evidence for either of these theories. Other researchers think that it may be possible that sexual orientation is a mixture of both biology (nature) and social conditioning (nurture).

Key counselling issues and tasks

Although many of the issues surrounding HIV are similar for MSM and for the rest of the population, other issues may arise during counselling. These are discussed below.

Beliefs about masculinity. Healthy and strong men do not get sick or cannot get infected. Such beliefs may be supported by previous experiences of not using a condom. It is important that you acknowledge the difficulties the client experiences with these issues and challenge these beliefs. This indicates to the client that, even if strong and healthy, he is susceptible to HIV and other infections if he does not protect himself.

Diagnosis and treatment of STI. Ideally, counsellors should recognize the genital, oral, or anal symptoms of STI that may be disclosed by the client during the HIV risk assessment. When STI is suspected, clients need to be referred to a properly equipped laboratory for diagnosis and treatment. Doctors and other medical staff must be trained to identify and treat infections of the mouth and anus, as well as the sexual organs.

Internalized homophobia. This is present when a client feels uncomfortable about his sexual identity and sexual behaviour. When the client is unwilling to admit to same-sex behaviour and is therefore unwilling to take protective measures, it is important that you explore the reasons for the discomfort and unwillingness to have protection. Clients who have significant difficulties with their sexuality may find it beneficial to see a counsellor or to review some of the information for clients available on the websites or in the references provided at the end of this handbook.

Poverty. Poverty renders some unable to practice safer sex because of the cost of condoms and appropriate lubricant. Also, because of poverty the need for financial reward can take precedence when a paying partner refuses to use prevention or offers a higher payment for unprotected sex.

Safer-sex strategies. Clients need to gain knowledge and skills in safer-sex strategies specific to male-to-male behaviour.

Sexual dysfunction. Issues of sexual identity, fear of infection, or HIV status may prevent the client or his partner from maintaining an erection, affecting the ability to use condoms. Similarly men may experience difficulties reaching sexual climax (*retarded ejaculation*) and typically respond by removing the condom or avoiding the use of condoms in the first place to maximize stimulation. It is important that you normalize the possibility of these difficulties by saying, "Many men I see report that they have difficulties maintaining an erection or reaching sexual climax and this often results in their not being to use a condom.... Do you experience any of these difficulties?" If the client informs you of these difficulties you can suggest alternative sexual practices or ways to increase stimulation while the condom is in place. A referral to a doctor who can assist the client can also be made. Often sex-worker peer counsellors or educators can assist in these situations.

Sexual violence. More men than we would like to believe are victims of rape or coercive sex. This is seldom discussed out of fear of emasculation. If sexual violence is disclosed or suspected then sexual assault protocols should be followed.

Suicidal thoughts. MSM are at higher risk of suicide because of the double stigma from same-sex behaviour and HIV-positive status. If the client discloses thoughts about suicide, protocols in suicide risk assessment should be followed. All MSM and especially those who indicate that they are having difficulties accepting their sexuality or forming relationships, who experience rejection by partner or family, or who use significant quantities of drugs and alcohol may be at heightened risk of suicide.

Risk reduction counselling among MSM with female partners

When men present for HIV testing they may not volunteer their sexual identity. When conducting a risk assessment it is best to first of all remind the client that the interview is confidential. Then ask them: " When you have sex, do you have sex with men, women or both?" Asking a client if he is heterosexual, homosexual, or bisexual is asking about sexual identity rather than sexual practice. It is also important to understand that men who self-identify as homosexual may not disclose that they also have sexual relationships with women unless explicitly asked. If you only ask questions related to sexual identity you may miss discussing specific exposure risks.

Men who are in relationships with female partners but engage in sexual activities with male partners and who cannot introduce the use of condoms into their heterosexual relationships should be advised to have regular HIV tests and to use condoms with male partners.

The risks associated with MTCT should also be discussed with men who have female partners. During HIV counselling associated with HIV testing, men who have indicated that they are at risk of HIV infection or who test positive should consider how they can reduce the chances of infecting their female partners. Furthermore, you should ask if the partner is pregnant, and if they answer yes, then the men should be offered advice on preventing unplanned pregnancy, as well as referral for family planning. It should be emphasized to them that condoms can not only reduce HIV and STI transmission but also prevent unplanned pregnancies. Men who test positive should be offered support in disclosing their HIV status to their partners, even if they do not wish to fully acknowledge the fact that they contracted HIV through same-sex behaviour. Partner disclosure strategies are discussed in chapter 7.

All men, irrespective of their status, should be warned explicitly about the risks of transmitting HIV through unprotected sex while their partner is breast-feeding.

To understand more about counselling MSM it is important that you go over the materials cited as references at the end of this handbook.

Section 4: Transgender and intersex clients

Understanding the terminology

Transgender is a broad term that designates somebody who does not fit clearly into "male and female" descriptions. The individual rejects the gender assigned to him or her at birth. Transgender is sometimes referred to as gender variant.

The term *transsexual* refers to an individual who feels that his or her gender identity does not match the biological body he or she was born with or the gender he or she was assigned by society. Transsexuals can be referred to as male-to-female (MTF) or female-to-male (FTM). Transsexuals are further described in terms of whether they are "pre-operative" ("pre-op") or "post-operative" ("post-op"). Some describe themselves as "no-operative"("no-op").

Cross-dressing refers to the act of dressing in the clothing typically worn by the opposite gender and may be used in reference to both transsexuals and cross dressers. "Cross-dressers" (also known as transvestites) is a term usually reserved for individuals who like to cross-dress but who do not experience any discord between their physiological appearance and their gender identity. Most cross-dressers are heterosexual men who cross-dress for amusement, role-playing, stress relief, or sexual gratification. Usually biological women are not called cross-dressers, as society allows women a broader range of dressing behaviour (women can wear pants, have short hair, etc.).

Other terms used refer either to how society perceives the individual or to the gender reassignment. Passing refers to the degree to which an individual of one gender is perceived (by others in society) to be of the opposing gender. *Transitioning* commonly refers to the process of moving from one gender to the opposite one. Transitioning is likened to a developmental process that involves many steps.

Increasingly you may hear the term intersex. This term tends to be used by health professionals working in gender orientation. A variety of conditions that lead to atypical development of physical sex characteristics are collectively referred to as *intersex conditions*. These conditions can involve abnormalities of the external genitals, internal reproductive organs, sex chromosomes, or sex-related hormones. Some of these abnormalities are as follows:

- external genitals that cannot be easily classified as male or female;
- incomplete or unusual development of the internal reproductive organs;
- inconsistency between the external genitals and the internal reproductive organs;
- abnormalities of the sex chromosomes;
- abnormal development of the testes or ovaries;
- over- or underproduction of sex-related hormones; or
- inability of the body to respond normally to sex-related hormones.

Intersex conditions are not always accurately diagnosed, experts sometimes disagree on exactly what qualifies as an intersex condition, and government agencies do not collect statistics about intersex individuals. Some experts estimate that as many as one in every 1,500 babies is born with genitals that cannot easily be classified as male or female.

What happens when an intersex condition is discovered later in life?

Babies born with these conditions are generally assigned to the sex consistent with their genitals, just like other babies. Their intersex conditions may become apparent only later in life, often around the time of puberty.

Delayed or absent signs of puberty may be the first indication that an intersex condition exists. For example, complete androgen insensitivity may first become apparent when a girl does not menstruate. Medical treatment is sometimes necessary to help development proceed as normally as possible; for some conditions, surgical treatment may be recommended. Many intersex conditions discovered late in life are associated with infertility or with reduced fertility. The discovery of an intersex condition in adolescence can be extremely distressing for the adolescent and his or her parents, and can result in feelings of shame, anger, or depression. Referral to an experienced mental health professional can be very helpful in dealing with these challenging issues and feelings.

Sexuality of intersex individuals

Most people with intersex conditions grow up to be heterosexual, but persons with some specific intersex conditions seem to have an increased likelihood of growing up to be gay, lesbian, or bisexual adults.

Challenges faced by transgender individuals, people affected by intersex conditions, and their families

Intersex conditions, whether discovered at birth or later in life, can be very challenging for the affected persons and their families. Medical information about intersex conditions and their implications is not always easy to understand. Persons with intersex conditions and their families may also experience feelings of shame, isolation, anger, or depression.

Parents of transgender children or of children affected by intersex conditions sometimes wonder how much they should tell their children about their condition, and at what age. Experts recommend that parents and care providers tell children with intersex conditions about their condition throughout their lives in an age-appropriate manner. Experienced mental health professionals can help parents decide what information is age-appropriate and how best to share it. Peer support groups may be available to assist individuals and their families.

How can I be supportive of transgender and intersex clients?

- Educate yourself about the specific intersex condition of the client.
- Be aware of your own attitudes about issues of sex, gender, and disability.
- Learn how to talk about issues of sex and sexuality in an age-appropriate manner.
- Remember that most persons with intersex conditions are happy with the sex to which they have been assigned. Do not assume that gender-atypical behaviour by an intersex person reflects an incorrect sex assignment.
- Work to ensure that people with intersex conditions are not teased, harassed, or subjected to discrimination.

Gender identity and HIV risk behaviour

Coming to recognize oneself as transgender involves a number of stages of exploration and analysis at an interpersonal as well as an intrapersonal level over the course of many years. A detailed model that describes the process of gender identity formation has been developed and is based on 15 years of sociological field research and social and professional interactions with a wide range of transgender persons, the majority of whom have self-identified as female-to-male transsexuals. In reviewing this model it is important to bear in mind that it cannot possibly apply to all individuals in the same way. Each person is unique. Each person experiences the world in his or her own way. Some people may never experience some of these stages. Other people may pass through some stages quickly, and more slowly through others. While some people may move through these stages in a particular order or may repeat some stages several times, the model may be totally inapplicable to others. It is also important to remember that any person may enter into a process that resembles the one outlined here but may conclude that the best way to live his or her life is to go no further than any particular stage. This model is only intended to provide some insights into a commonly followed path; it is by no means the only path, nor will all who appear to be following it come to the same conclusions.

At various stages of the identity formation process individuals may experience a number of psychological issues; these issues may lead the individual to engage in HIV transmission risk practices. Some individuals, for example, may lack a sense of self-esteem, and therefore consider their life not worth protecting. Often individuals who are depressed do not have sufficient motivation to make the necessary behaviour changes required to protect themselves. When individuals have many other life stressors and health issues, the risk of HIV is just one of many issues they struggle to deal with. Such individuals may benefit from a consultation with a sympathetic clinical psychologist or psychiatrist who can provide appropriate assessment and support at the various stages of identity formation. When there are no referral options you may offer supportive counselling such as providing the client with an opportunity to discuss problems, and engaging him or her in specific problem-solving strategies.

Offering counselling on specific risk reduction strategies

While all people are at risk of contracting the HIV virus regardless of age, gender, or sexuality, people with gender issues may face unique risks that the general prevention literature fails to address. It is important for counsellors to be aware of these and be able to offer specific risk reduction strategies. Below are some precautions that may have particular relevance to transgender and intersex clients.

Rectal douching or neo-vagina douching. Clients who have a neo-vagina (created through surgery) or a natural vagina or engage in receptive anal intercourse may practice douching to keep these passages clean. They should be informed that douching weakens the lining of the anal passage or vagina and removes friendly bacteria and mucous, exposing the porous membranes (surface skin lining) and increasing the risk of HIV transmission. The practice of douching is generally discouraged by health workers. Clients should be reminded that douching and gels are not an alternative to safe sex, and that only condoms can offer protection from the HIV virus and other sexually transmissible infections during intercourse. If clients should douche because they are concerned about vaginal odours, they should see a doctor as these odours may indicate an infection.

Advice on precautions after gender reassignment surgery. If clients are thinking of, or have recently undergone, gender reassignment surgery involving areas of their body that may be exposed to body fluids during sex, then they should be sure to cover the area until it is completely healed.

Water-based lubrication and neo-vaginas. Although a neo-vagina may produce some lubrication during intercourse it may not be enough for comfortable sexual activity. You should counsel clients regarding the use of water-based lubricants such as ”Wet Stuff” and ”KY Jelly”. These will help avoid breaks or tears in the vaginal lining, which occur naturally during intercourse but which also increase the risk of the virus being transmitted.

Hair removal. Your clients should be advised that when they shave or wax the body or pubic hair they must be careful not to cut or scrape the skin. They should be advised to cover any cuts and abrasions before sex and never allow anyone’s body fluids (blood, semen, or vaginal fluids) to touch damaged skin. They should be especially careful if they shave their pubic hair, legs, chest, or armpits and then engage in ”trick sex” (intercourse between closed thighs or under armpits, etc.).

Needles. Some people may use syringes/needles for hormone injections. HIV and other dangerous viruses including hepatitis can be found in a shared needle or syringe. If your clients inject their own hormones or help friends with theirs, they should be advised to keep a clean supply and never share needles or syringes.

Taping, strapping, and tucking. Taping, strapping, or tucking the genitals could create a warm, moist area leading to skin disorders, chafing, and dermatitis. Removing tape roughly could result in damaged or broken skin. Any of these will increase the risk of the virus penetrating skin during sex. Clients should generally be advised to remove tape carefully and remove any traces of adhesive with something gentle and soothing oil.

Section 5: Male, female, and transgender sex workers

Who are sex workers?

The term sex workers encompasses a diverse group of people, so it is therefore difficult to generalize about their behaviours and attitudes towards HIV prevention and care. For example, they may be injecting drug users, married women or men, indentured workers (coerced into sex work and even taken to other countries), college students, or unattached minors. Sex workers may be of all genders (male, female, or transgender). They may work temporarily as sex workers or full-time. Effective HTC interventions need to recognize these individuals not only as sex workers but as partners, wives or husbands, and parents.

Sex workers and HIV risk

Sex workers are especially vulnerable to HIV transmission because of their large number of sexual partners and often-high rates of other STIs. Sex workers often feel disempowered to negotiate safer-sex practices with clients on whom they rely for income. In some cases, sex workers may accept a higher price with a client who refuses to use a condom.

Research in some countries has shown that sex workers differ in how they negotiate safer sex, depending on the extent of the emotional relationship. With new clients sex workers may use condoms; with their regular clients or ”lovers”, with whom they have developed an emotional relationship, they do not think about using a condom. In some situations, the risks from injecting drug use and commercial sex work overlap. Prevention strategies from two separate disciplines–harm reduction for injecting drug users (IDUs) and reduction of sexual transmission–must then be simultaneously implemented in recognition of the two sources of risk among this population. Sex workers have particular needs, and HTC and psychosocial interventions should be tailored specifically to ensure effectiveness. It is crucial that HTC services reach this vulnerable population, both to protect the sex workers from HIV and other STI infections and to prevent transmission to their clients and partners.

HIV prevention counselling for sex workers

Sex workers or their clients may not be motivated to avoid exchanging body fluids during sex, because they do not know about HIV and STDs and therefore do not feel at risk. Counsellors should be careful to fully explore the sex worker's understanding of HIV transmission in relationship to a wide range of sexual practices:

- Sex workers may need money urgently for pressing needs, leading them to neglect sexual health considerations.
- Clients of sex workers may be drunk or may not care about their own sexual health or that of others. Counsellors should assess the sex workers' drug and alcohol use. It can be helpful to acknowledge that sex workers often use drugs and alcohol to help them cope with their work. Where sex workers will not abstain from such use, counsellors can work with them to identify safe or reasonable levels of use, e.g., "I can still think clearly with only one glass of beer."
- Clients may offer more money for unprotected sex.
- Non-penetrative sex or other safe practices may be taboo.
- Condoms and lubricant may not be available, or may be too expensive or of poor quality.
- Some sex workers may work informally or alone, and cannot benefit from the expertise of others or from opportunities to build safe sex into the structure of a more professional transaction.
- Sex business managers may encourage unprotected sex in the belief that this may be more profitable.
- Sex workers cannot keep adequate supplies of condoms and lubricant because they might be viewed as evidence of illegal activities, or because there is nowhere to store them.
- Some sex workers negotiate from a disadvantaged position; for example, negotiations take place in the street or in a place controlled by the client, limiting the ability of the sex worker to negotiate safer-sex practices.
- There may be intense competition between sex workers for clients, making demands for unprotected sex more likely to be met.
- Sex workers may not have adequate negotiation skills, or may not speak the same language as clients. They may be much younger or from a lower class than clients. Female sex workers may be reluctant to talk about sex because of cultural restrictions.

Counselling to prevent transmission can cover a range of strategies and activities to convey information and behaviour-change messages. The objective is to provide the sex workers with knowledge about HIV transmission and ways of reducing the risk of transmission, for example, safer-sex practices, the use of male or female condoms and lubricants, symptoms of STIs, and information to clarify misunderstandings about unsafe traditional practices or beliefs. Furthermore, counselling can play an important role in developing the communication and negotiation skills of the sex workers to enable them to negotiate safer-sex practices successfully with:

- clients;
- partners and other people with whom they have a personal relationship; and
- brothel owners.

In particular, the key behaviour-change message that must be conveyed pertains to consistent condom use. We have noted that condom use differs among the different type of clients or relationships of a sex worker. Some have argued that relationships other than a sex worker's professional relationships may be as risky or even more risky for HIV and STI transmission. This is because they have less control and less negotiation possibilities. There is emotional involvement as the relationship becomes more than just a commercial arrangement and sex workers will put aside their professional attitudes and control. Counselling therefore needs to address the needs of the sex worker holistically, rather than focusing solely on professional sex work activities.

Motivating sex workers to reduce risk

The professional sex worker has a vested interest in working safely because his or her income depends on staying healthy. Counsellors can remind clients of the difficulties they may have if they have sore or painful infections or smelly discharge and require time off work.

Unlike private sex, commercial sexual transactions usually involve negotiating price and other arrangements, providing an ideal time to specify that all services will be carried out in a risk-reducing manner (e.g., using condoms). Sex workers often work in groups, and this means that they can be targeted by health promotion strategies and may be able to agree to encourage and implement safer-sex practices among themselves. Outreach workers can bring clients to an HTC service, where discussion can be facilitated by both a counsellor and a peer educator.

Some key prevention interventions with sex workers

Teaching sex workers to recognize visible symptoms of STIs is important. Photographs can be helpful. They should depict conditions that sex workers are most likely to see rather than pictures of more-extreme symptoms. Of course, it must be stressed that many infections, including HIV and hepatitis, have no visible symptoms.

Advising female sex workers on issues relating to sex, menstruation, and contraception. Some sex workers would prefer not to work during menstruation, but many have no choice. Some women use small sponges to control the flow of blood. These should be taken out and rinsed at appropriate intervals. Sex workers should be reminded, however, that they must use condoms during menstruation and not rely on sponges. It is important that women can confidently offer alternatives to vaginal sex during menstruation.

Taking an oral contraceptive (the Pill) or an injectable contraceptive such as Depo Provera(r) throughout the whole menstrual cycle will prevent bleeding. Advice should be taken from a family planning expert, as menstruation should not be avoided for extended periods of time.

Advising against the practice of douching and cleaning. Male, transgender, and female sex workers use a number of personal hygiene methods. Unfortunately, these often include the use of harsh chemicals and detergents, which are not suitable for use in the anus or vagina because they break down the natural protection against infection. The same is true of vaginal drying agents. Both sex workers and their clients need to be made aware of the possibility of tissue damage from these practices, placing them at increased risk of HIV and other STI.

Advising and referring for advice on microbicides and spermicides. Microbicides are chemicals that kill germs or viral material, including those that may cause many sexually transmitted diseases. Spermicides are chemicals designed to kill sperm. Nonoxynol-9 (N9) is the most commonly used spermicide. Research has been carried out to see if it also has a microbicidal effect. So far, research has shown that N9 does not reduce the risk of HIV transmission. Many people have reported that N9 irritates the skin in the anus or vagina; it might therefore increase the risk of HIV transmission. Most services discourage routine use of N9 because its harmful effects may outweigh any benefits.

Key messages about sex-worker transactions with clients

Counsellors can discuss the following strategies that sex workers can employ with clients:

- Refuse the client ("No condom, no way"). Although this eliminates risk, it obviously leaves the worker with no money or even in debt if expenses have been prepaid. So it is not the option sex workers want to take or can afford to take. It also may result in an unpleasant scene with the client and possible difficulties with managers or others who influence the situation.
- Discuss the matter with the client.
- Persuade the client. Persuasion can be successful, but only if the sex worker has the opportunity (sometimes others negotiate on behalf of the sex worker), speaks the same language as the client, and has good communication skills, confidence, and information. The client must also be reasonable and sober.

Suggesting that sex workers offer an alternative service that does not require a condom is a popular strategy. Clients often visit sex workers for sexual experiences that are different from the "usual". This places sex workers in an ideal position to sell services that are safe as well as interesting to the client, and therefore perhaps generate more income for the worker. Safer-sex activities are those in which no skin is broken and where there is no opportunity for exchange of body fluids. These kinds of activities can be taught by peer educators in both one-to-one and workshop sessions. Some projects among female sex workers in places where women do not speak openly about sex have found ways to discuss these activities with sex workers. For example, peer educators suggest that sex workers develop the skill of putting a condom on a client without his knowledge (perhaps with the mouth) or rubbing the penis between the thighs or moistened hands rather than the vagina or mouth. While these practices avoid the need for negotiation, however, they can make things difficult for the sex worker if the client discovers the deception and is angry about it.

Counselling in association with the HIV test

Providing feedback on the risks associated with potential exposure in the window period is crucial. It is imperative that sex workers understand that they must practice safer sex and avoid sharing injecting equipment (for example) while they are at risk of primary (acute) HIV infection. It is unclear how often sex workers should be offered HIV testing; however, where it is either realistic or affordable sex workers should be encouraged to undergo screening for HIV every three months, especially if they have difficulties employing risk reduction measures.

When HIV-positive test results are provided many health workers will tell sex workers to stop their work and recommend that they do other types of work. This advice, though well intentioned, is rarely feasible. Often sex workers have limited education and work skills training, and have a family to support. While clients can be referred to job skills training or income generation skills, during the immediate post-diagnosis period counsellor interventions should focus on providing emotional support and other transmission reduction strategies.

Messages about the need to inform sexual partners of the sex workers' HIV status also need to focus on support for disclosure to regular personal relationship partners (boyfriend, girlfriend, husband, wife), bearing in mind that sometimes a regular partner may also be a "client".

Supporting HIV-positive sex workers

Research indicates that sex workers often have higher-than-average rates of depression and anxiety, and are often subject to physical abuse from clients. Many sex workers experienced sexual and physical abuse in childhood. Sex workers may be at significantly greater risk of suicide immediately after diagnosis and as they begin to experience illness and develop changes in their physical appearance that result in unemployment. Drug or alcohol use as a coping measure will further predispose them to suicide or accidental overdose. Careful monitoring of psychological well-being is required, along with assessment and involvement in seeking support for drug and alcohol issues.

Sex workers are often considered low-priority targets of HIV treatment and care services. The counsellor should help the client acquire all the services necessary. It is also important to review the potential barriers that sex work may pose to treatment adherence and get the client to collaborate with you to overcome these problems.

Often sex workers have been disowned or rejected, or have actively distanced themselves from their families. When they have to live with HIV or become ill they may seek to reunite with their families and require counselling support.

Counselling for HIV-positive sex workers can assist them in:

- deciding whether to disclose their HIV status;
- discussing in a non-judgemental manner the potential legal implications of continuing to engage in sex work;
- planning strategies for disclosing their status to regular partners;
- ensuring access to treatment and care;
- addressing barriers to risk reduction posed by sex work and drug and alcohol use;

- facilitating family reunions and offering family counselling support;
- providing ongoing support and planning for the future;
- joining peer support programmes;
- taking up income-generating projects; and
- availing themselves of accommodation services as needed.

Section 6: Drug and alcohol users

Drug or alcohol use, especially dependent use, can have a significant impact on a client's health and can complicate the treatment of other conditions. A client who is drug-dependent is more likely to adhere to HIV transmission risk reduction or an HIV, HCV, STI, or TB treatment regime if he or she is being treated for drug dependence. Drug use, and in particular injecting drug use, is a major risk factor for blood-borne virus transmission. Counsellors who work in HIV and other health services may often work with substance users in different ways including:

- providing counselling associated with HIV testing;
- providing counselling to facilitate transmission risk reduction, including counselling and referral to help clients to modify their drug use;
- supporting clients, their partners, and families in adapting to living with HIV;
- supporting the client in achieving adherence to HIV and other medical treatment (including opioid substitution therapy [OST]); and
- offering palliative counselling to clients who are in the final stages of their life.

How to assess drug and alcohol use

You must be aware of drugs commonly used by your clients, their method of use, and the signs, symptoms, and side-effects of their use. When assessing clients for substance use, counsellors should pay close attention not only to signs of dependence but also to the harm arising from substance use. Many clients may show harm from substance use but may not be dependent. When assessing clients, only appropriately qualified counsellors should make a diagnosis of dependence.

Recognizing drug use: signs and symptoms

Drug and alcohol use is commonly underreported and can be missed if you do not directly ask the client about such use. You should be aware of a client's drug use so that you can provide him or her with information and advice on how to reduce this risk. It is important that a drug use assessment be carried out in pre-HIV test counselling as part of the risk assessment, in any behaviour-change counselling session, and in supportive post-diagnosis counselling sessions. Adherence to risk reduction and to HIV and STI treatments require ongoing supervision and support across the disease continuum. It is important to focus on all aspects of drug or alcohol use and not simply on a client's injecting drug use. Clients should also understand the relationship between sexual transmission and all types of drug use.

Different people use drugs and alcohol in different ways. A client may also use drugs or alcohol in different ways at different times of his or her life. To get a clear idea of a client's drug use it is necessary to determine the following:

- what drugs a client *currently* uses;
- what drugs the client has used *in the past*;
- how the client has used these drugs, including the *pattern* of drug use;
- whether the client is *dependent* on these drugs;
- whether this drug use is causing *problems* in the client's life; and
- how the client feels about his or her drug use and whether or not he or she wants to *change* his or her drug-use behaviour.

Because of the stigma associated with drug use a client may be reluctant to disclose drug use because he or she:

- feels embarrassed about the drug use and fears being judged because of it;
- fears being treated with contempt after admitting to drug use;
- is worried that admitting to drug use during a consultation could be incriminating (may have legal consequences); or
- does not see his or her drug use as a problem or as important enough to be mentioned to a doctor.

Overcoming reluctance to disclose drug or alcohol use. To gather the information needed for a complete drug-use history it is important to overcome a client's reluctance to talk about drug use. The client must feel that the counsellor can be trusted and that it is safe to be open and honest. The counsellor should therefore:

- maintain a non-judgemental attitude;
- acknowledge to the client that drug use can be difficult to talk about;
- assure the client that the consultation is confidential; and
- obtain the client's informed consent before taking a drug-use history.

Obtaining consent to take a drug-use history. The client's right to autonomy over his or her treatment must be respected. This also applies to the client's participation in the process of assessment. It is appropriate to give the client an opportunity to decide whether or not to talk about the drug use. This will also make the assessment process more productive. Informed consent can be obtained in the following manner:

- Describe to the client the drug and alcohol treatment services that are available.
- Ask the client if he or she might be interested in these services.
- Explain that in order to provide such treatment it is necessary to assess drug use and dependence.
- Take time to explain what this assessment involves.
- Ask for the client's consent to conduct a drug-use assessment.

Identifying the drugs used. The use of some drugs or alcohol may be legal; the use of others may be illegal. People who use drugs commonly use, or have used, more than one substance. Certain substance-using behaviours may not be problematic, but the use of any drug can be problematic for most people. It is important to identify all substances, legal and illicit, injected and non-injected, that a client has used. These include substances that he or she uses currently or has used in the past. It is important to ask specifically about all the drugs listed below; otherwise, specific substances used may not be identified.

Ask: "Have you ever used [*name of drug*] before?"

- alcohol (beer, wine, spirits, etc.);
- tobacco (cigarettes, chewing tobacco, etc.);
- cannabis (marijuana, hashish, kif, etc.);
- opiates (opium, heroin, methadone, and other opioids);
- methamphetamine and amphetamines;
- other amphetamine-type substances such as ecstasy (MDMA);
- cocaine (coke, crack cocaine, etc.);
- hallucinogens (lysergic acid diethylamide [LSD], hallucinogenic mushrooms, phencyclidine [PCP], ketamine, etc.);
- inhalants (nitrous oxide, petrol, glue, etc.)
- sedatives or sleeping pills (benzodiazepines, barbiturates, etc.); or
- any other substances. *If a client has used any other substance not listed above have him or her specify what it is.*

Determining the pattern of drug use. Because people use drugs and alcohol differently over time, it is important to gain an understanding of a client's pattern of drug use. The pattern for each drug used should be determined. Use patterns can be elicited as follows:

- "How old were you when you first used [*name of drug*]?"
- "How long did you use [*name of drug*] like this?"
- "When did that change?"
- "What was the pattern after that?"
- "How long did you use [*name of drug*] like this?", etc.
- "How often and in what amounts have you used [*name of drug*] in the last three months?"
- "When did you last use [*name of drug*]?"

How do I know if the client is substance-dependent?

Counsellors must take care not to incorrectly label all substance users as being dependent. A diagnosis of dependence (see box 9.4) should be made only by a qualified physician or counsellor.

Box 9.4: Drug dependency (ICD-10 diagnostic guidelines)

A definite diagnosis of dependence syndrome is usually made only if three or more of the following were present together at some time during the previous year:

- evidence of tolerance, such that increased doses of the psychoactive substance are required to achieve effects originally produced by lower doses;
- physiological withdrawal state when substance use has ceased or has been reduced:
- strong desire or sense of compulsion to take the substance;
- difficulty controlling substance-taking behaviour – onset, termination, or levels of use;
- progressive neglect of alternative pleasures or interests because of psychoactive substance use – increased amount of time necessary to obtain or take the substance or to recover from its effects; or
- persistent substance use despite clear evidence of overtly harmful consequences – depressive mood states consequent to periods of heavy substance use or drug-related impairment of cognitive functioning.

Source: International Classification of Diseases (ICD) website: http://www.who.int/classifications/icd/en/

Ethical HIV testing and counselling of drug users

The importance of building trust between clients and providers cannot be overestimated. Many countries have adopted mandatory screening for high-risk populations such as IDUs. It is likely that, instead of reducing HIV transmission in the community, such policies will be counterproductive. Many IDUs may fail to request assistance with their substance dependency or their substance use if they know that they will be forced to test to gain access to health services. The development of good relationships between clients and health providers requires transparent procedures. Misleading clients into HIV testing will only reinforce their mistrust and ultimately their unwillingness to confide in health service providers. Ultimately a client's unwillingness to share information about exposure risk may translate into an increase in HIV transmission, and an unwillingness to share information about treatment adherence may result in transmission of HIV and the development of resistance to HIV treatments.

HIV testing and associated counselling among injecting drug users

Many substance users and in particular IDUs see little benefit in learning their HIV status. Often they are coerced into testing only to find that they are denied access not only to HIV treatments but also to other medical interventions when they test positive. From both an ethical and a public health perspective it is essential that we facilitate access to treatment and care services.

The acceptability of testing and counselling to drug users can be improved by involving current and former IDUs in service provision. They can be employed to mobilize other IDUs to attend HIV testing and counselling services. These peer ”mobilizers” can be trained to discuss the benefits of HIV testing and what to expect during HIV testing and counselling, and to offer referral to selective services that provide ethical and high-quality HIV testing and counselling. Some peer educators act as ”HIV testing buddies” and accompany individuals to testing and counselling services, help the new clients complete registration formalities, and provide companionship and emotional support to individuals while they await test results. Often these ”buddies” can facilitate attendance by newly diagnosed individuals at their first peer support session and other referral services.

In some settings peer educators have been trained to provide pre-HIV test and post-HIV test counselling under the supervision of health service providers. In many treatment and care facilities peer support clubs offer treatment adherence support to club clients receiving treatment and care for drug dependency and HIV.

Substance use and post-HIV test counselling

Many IDUs have HIV tests while still actively engaged in substance use or during early detoxification from substance dependency. Counsellors should check the client for signs of impaired cognitive function or comprehension before providing any result, positive or negative. Clients who are assessed as too impaired to comprehend the result and its implications should simply be informed that no result, whatever the status, can be provided at this time and offered a place to wait or an alternative time for getting the result. Be sure to write the time on a card as the client may not recall any information provided orally. Capacity to receive results can be assessed through observation, as well as a brief review of what was discussed at pretest and questions from the counsellor to assess capacity to understand what has been discussed.

Special considerations in providing HIV-negative results

Service providers often dismiss the importance of counselling for individuals who receive negative results; hence, results are communicated in a cursory manner that pays poor dividends, with clients failing to make behaviour changes. You must provide clients with accurate information on the reduction of risk related to their specific substance use. Tools provided in the HIV Counselling Toolkit may help you give explicit information about risk reduction for IDUs. Motivational interviewing for behaviour change is discussed in chapter 3.

During acute infection HIV transmission is significant, and many drug users presenting will have had risks within the window period. Therefore, all clients need to understand the implications of window-period transmission. Explicit and concrete information should be provided about the need to retest for HIV to cover the possibility of HIV seroconversion. Clients must understand that the window period varies for different blood-borne pathogens such as HCV. Counsellors must provide clients with a clear written schedule of dates for ”follow-up tests” that cover the different window periods for each infection.

Special considerations in providing indeterminate results

The receipt of an indeterminate result will more than likely confuse and distress the recipient. The counsellor must therefore provide emotional support. A realistic and clear explanation must be given for the lack of clarity in the results, and if there is no apparent risk of an acute HIV infection the client must be referred to a physician for further evaluation. HLA cellular antigens may cross-react and cause a false positive on an ELISA or rapid test. Individuals with certain illnesses such as rheumatoid arthritis and chronic hepatitis or who have had an influenza vaccination could also have false-positive results. In particular, chronic hepatitis co-infections may be common in IDUs. Most cases of indeterminate results will be a result of the client having either failed to disclose some transmission risk that occurred within the window period or who were tested to soon after a recent exposure. Only a small percentage will be the result of some error in the testing process.

Special considerations in providing HIV-positive results

The client’s capacity to cope with and adapt to the diagnosis should be assessed at the time the result is provided, even if this was already considered in pretest counselling. Specifically, there should be some attempt to assess whether the client has any suicidal thoughts or threatens harm to others as a result of the diagnosis. This discussion may be initiated by gently commenting, ”Some people feel they cannot live with this news and think of harming themselves or others. I am wondering if you feel this way.”

Because of the trauma associated with the result clients who are current substance users should be considered to be at high risk of either intentional or accidental overdose. For those who are not current users the possibility of relapse should be anticipated and discussed with the client. Motivational interviewing sessions may assist clients in anticipating and managing relapse triggers. Review chapter 3 for a description of these techniques.

Referrals

All newly diagnosed clients must undergo medical assessment to facilitate planning for their treatment and care needs. Health service providers must also discuss with the individual the potential benefits of allowing information regarding their health status to be shared between clinical service providers such as HIV physicians, and drug treatment and mental health professionals. The client must understand that treatments for HIV-related conditions will need to be considered in conjunction with other drug treatments and psychiatric services.

You should also offer follow-up counselling and support services or refer the client to an agency that can provide these services. In follow-up counselling sessions a variety of issues related to the diagnosis and future treatment may be discussed. The counsellor focuses on the immediate post-diagnosis needs of the client with a view to facilitating an adaptive response to the diagnosis. While all of the usual post-diagnosis strategies should be performed, some special considerations for IDUs should be highlighted.

Key counselling issues in post-diagnosis follow-up and support

Assessment of impact of the diagnosis. The ability of the client to manage the impact of the diagnosis must be regularly reviewed. The intent is not only to improve the quality of life of the client but also to facilitate adherence to transmission prevention, drug dependency, and HIV clinical treatments.

Problem solving. Clients often require more than just information to resolve their problems. Often they will need assistance in planning and rehearsing new behaviours. For some individuals diagnosed relatively late in the disease, especially those with years of chronic substance use, there may be co-morbid or HIV-related CNS complications that can impair cognitive functioning, making the client unable to initiate and adhere to a prevention and treatment programme. Such complications commonly affect these areas of cognitive functioning: planning and organization, speed of information processing, verbal fluency, short-term memory, and eye-hand coordination.

Mental health. Mental health problems are common among substance users who are HIV-positive. It has been suggested that drug use makes the brain more vulnerable to HIV and HIV dementia, perhaps by affecting the immune system. According to some estimates, 25%-50% of drug users also have co-morbid mental health problems. Some drug and alcohol users have a long history of mental illness without proper diagnosis or treatment. In a number of cases drug or alcohol use may represent the client’s attempt to manage symptoms of an undiagnosed, pre-existing mental illness. The provision of appropriate mental health support–psychiatric (antidepressant therapy) as well as psychological (e.g., cognitive behaviour therapy)–is an essential component of drug treatment services. Chapter 6 covers the conduct of a psychosocial assessment.

HIV-related neurological complications. Some studies suggest incidence of HIV encephalitis in the brains of 56% of HIV-positive drug users, compared with only 15% of HIV-positive non-users. Other studies indicate that clients with a history of injecting drug use who present with slowed psychomotor activity have a more rapid progression and show abundant macrophage activation within the CNS. But the degree to which substance use contributes to progression from minor neuro-cognitive disorders such as minor short-term memory loss to dementia remains unclear.

Decisions regarding treatment

Clients may have misconceptions about both HIV and drug dependency treatments offered, and may also need to discuss their fears and concerns. Some may need to engage the support of friends or family. Assistance may have to be provided to facilitate this.

Substance dependence (in particular to opioids) is a chronic relapsing condition, which is difficult to control because of compulsive drug use and craving, leading to drug seeking and repetitive use, even in the face of negative health and social consequences. A number of medical, psychiatric, and social problems common among substance-dependent people are important considerations in designing and delivering HIV and AIDS care.

Declining health as a result of HIV disease is a recognized risk factor for relapse into drug abuse. Physical and psychological stresses associated with HIV, such as pain, decreased functional ability, fatigue, and weakness, as well as fear, anxiety, and grief, all serve to increase an individual's risk of resuming substance use. Certain "milestones" in the progression of HIV present an increased risk of relapse and clients may need additional support at these times. Staff must review the client's treatment plan when one of these milestones is reached. Becoming symptomatic or receiving an AIDS diagnosis would be one such milestone.

Referral to specialized counselling and support services

Drug and alcohol counselling. Counsellors who are not trained in drug and alcohol counselling are advised to refer the client who needs this type of counselling to specialized services. Such services typically provide drug and alcohol use assessments, and detoxification and rehabilitation programmes.

Detoxification services. Counsellors should be aware that, while not an effective treatment for dependence, this short-term intervention has some benefit in allowing drug user to regain some control over their lives and gain insight into their dependency on the drug. Detoxification is aimed at easing the discomfort of drug withdrawal, preventing complications of self-managed withdrawal, preventing or treating destabilizing medical and psychiatric conditions, preventing polydrug overdose, intervening in social crises, interrupting a pattern of heavy and regular drug use, and finally facilitating linkage with post-withdrawal treatment options.

Post-withdrawal interventions. Drug dependency rehabilitation requires treatment beyond detoxification. Comprehensive rehabilitation should include various counselling models (supportive, behavioural, cognitive, dynamic), and a choice between residential rehabilitation and therapeutic community self-help groups (Narcotics Anonymous, Rational Recovery), on the one hand, and the use of naltrexone (an opioid antagonist that can reduce cravings and block the effects of additional heroin use; effective when taken daily but the drop-out rate is extremely high), on the other. Non-drug-related services offering employment or vocational training, education, and socialization outside the previous drug culture have been found to be beneficial as well.

Opioid substitution therapy programmes. Long-term OST attempts to reduce heroin and other drug use, mortality, the transmission of blood-borne viruses, and drug-related crime, and improve the patient's general health and well-being (psychosocial functioning). Methadone, a synthetic opioid that blocks the effects of heroin and other opioids, has been used for more than 30 years to eliminate withdrawal symptoms and relieve drug craving.

Other medications include levo-alpha acetyl methadol (LAAM), an alternative to methadone that blocks the effects of opioids for up to 72 hours, and naltrexone, a long-acting opioid blocker often used with highly motivated individuals in treatment programmes to promote complete abstinence and also to prevent relapse.

The combination of medication with psychosocial services repairs the damage to the client's psyche and socialization caused by years of illicit drug use and exclusion from the mainstream culture.

Family therapy. For many clients, "family" may need to be defined as broadly as possible. Supporting people in recovery from drug use is often a principal goal of family therapy. It may also be a useful opportunity to address issues of risk reduction for family members who are not HIV-positive and to provide emotional support to carers.

Positive peer support clubs. These may fulfil a wide range of needs: psychosocial support in modifying drug use, emotional support to members, and support for treatment adherence. Support groups may be segregated by gender, sexual orientation, and type of drug use, and also by stages of recovery from addiction or HIV infection (newly diagnosed, asymptomatic or mildly symptomatic, advanced disease).

Partner counselling. This should focus especially on issues of sexual transmission, contraception, prevention of STI and possibly superinfections, and prevention of mother-to-child transmission (PMTCT). PMTCT does not seem to sit as well with positive peer support clubs.

PMTCT services. Counsellors need to assist all clients in preventing unplanned pregnancies especially during periods of potential exposure or suspected acute infection. It is also important to have partners of pregnant women screened and aware of the risk of transmission to unborn children. Counsellors must increase client awareness of the heightened risk of transmission during seroconversion, as well as the impact of continued substance use on the unborn or breast-fed child.

Section 7: Health workers after accidental exposure

Often VCT and PITC counsellors in HIV services are called upon to provide counselling to health workers and others who may have been exposed to HIV. These include nurses, doctors, laboratory staff, cleaners, ambulance workers, and police officers. Should these people sustain occupational exposure, they must be given information about the proper process to follow.

People with significant exposure risk should be assessed for post-exposure prophylaxis (PEP), and PEP should be administered within 24 to 36 hours (preferably within a couple of hours) of the exposure. Often health workers present ″in crisis″ for testing, and testing is given priority over counselling. Health workers are also often tested without counselling or informed consent, many are inadequately informed about the potential benefits and difficulties associated with PEP, and confidentiality is often breached.

What is the risk of infection?

The average estimated risk of HIV infection for health-care workers after percutaneous or mucous exposure is less than 0.5%. The risk of transmission from exposure to infected fluids or tissues is lower than that for exposure to infected blood. In the majority of documented exposures, nurses undergo percutaneous exposure to the blood of a patient with AIDS when placing a device in an artery or vein. Transmission through splashes, cuts, and skin contaminations is also possible, although the risk of infection in such cases is comparatively low. In addition to being assessed for the risk of exposure to HIV, health workers should be assessed for exposure to HBV and HCV as well as other blood-borne pathogens.

Your role in providing counselling and emotional support after an exposure

The first HIV test after exposure will be a baseline test. This first test will reflect only previous exposure arising from the worker's personal risks. In high-prevalence countries many people will have a seropositive HIV test result at this stage, as HIV prevalence among health workers, for example, often reflects prevalence in the general population. It is therefore important that the health worker knows this, and undergoes individual pretest counselling and personal risk assessment.

A baseline HIV test on a health worker may be carried out in a location other than the place of work, such as an anonymous testing clinic, to help maintain the confidentiality of the information. If the worker's employer should require proof later on that the worker tested negative at the time of exposure, the result can be given to the employer with the health worker's consent. The sequence of actions after a reported exposure may vary depending on local policy.

If the worker presents immediately after sustaining a potential exposure, first aid should be administered before any counselling or testing. This may include, for example, washing with cool mild soap or a dilute hypochlorite solution. An exposure risk assessment is then conducted. It should analyse in detail the nature of the exposure (wound depth, type and quantity of body fluid, etc). The source patient may, with his or her informed consent, be requested to test. Immediately after the accident exposure, the doctor or another designated health-care worker should evaluate the risk of infection according to:

- severity of the exposure;
- depth of injury;
- duration of exposure;
- type of instrument or needle involved (hollow-bore or suture needle);
- serological status of the patient;

- stage of disease (symptomatic or asymptomatic, high or low viral load or CD4 count) of the source patient; and
- zidovudine (ZDV) or other ARV resistance in the source patient, if on ART.

In general, taking all the above factors and the type of exposure into consideration, doctors should be able to assess the risk associated with the exposure and recommend the course of action to be taken. Counsellors need to discuss the level of the risk of exposure with the doctor before providing feedback to the client.

The source patient should be tested only if he or she has access to pre- and post-test counselling and gives informed consent. If the source patient is being treated for a non-HIV condition it may be useful to inquire if he or she has taken or is taking medication prescribed for HIV and, if so, which specific medication. The exposed health worker should not be asked to approach the source patient for permission to have the patient tested for HIV. If the source patient tests negative, this does not mean that he or she is uninfected. Window-period exposure should also be considered and a risk assessment should be carried out to be able to decide whether or not to initiate PEP.

PEP should be prescribed only after informed consent is obtained from the health worker. The procedure will vary across different settings. Combination therapy–preferably dual or triple drug therapy, depending on the type of exposure and the status of the source of exposure–is recommended, as it is believed to be more effective than a single agent. The therapeutic regimen will depend on the drugs taken previously by the source patient and known or possible cross-resistance to different drugs. It may also be determined by the seriousness of the exposure and the availability of the various ARVs in that particular setting. ART should be provided according to institutional protocol (and made available as a PEP "kit") or, when possible, in consultation with a medical specialist. Expert consultation is especially important when a client may have been exposed to drug-resistant HIV. Health-care workers must have ready access to a full month's supply of ARV once PEP is begun.

Pretest counselling or a pretest information session should precede any baseline blood testing. The health worker must be informed that the initial test will only reflect his or her status at the time of the injury and therefore his or her personal risk history. A confidential personal risk assessment is recommended. For privacy reasons a health worker may opt to have this baseline test done elsewhere and the results provided to the employer only if a later follow-up test shows that seroconversion has occurred.

It is important to remind workers to attend follow-up testing. This sequence should take into account the different seroconversion periods for different infections and, if the worker is to undergo PEP, the longer seroconversion period that could occur.

Psychosocial support counselling should ascertain if the worker has additional support needs. It is not uncommon for workers to experience anxiety, depression, and sleeplessness. Attitudes to caring for their clients may be influenced by their psychological response to the exposure. Many may have to consider practising safer sex even within a relationship in which they do not normally practice it.

While health workers experience many of the same issues that confront any member of the community in relationship to treatment adherence, some issues specific to health workers may include:

- fear that work colleagues may see them take medication and make assumptions about their HIV status;
- difficulties experienced at work because of the side-effects;
- possible overemphasis on the potential for seroconversion and HIV illness resulting from having to deal daily with patients who have HIV or advanced AIDS; and
- anxiety in the pregnant health worker about the impact of the regimen on the fetus.

Counsellors should review the sequence of events that preceded the exposure in a sensitive and non-judgemental way in order to advise the worker on ways to protect himself or herself from future exposure. You must address the following in addition to all of the normal issues during post-test counselling:

- how the exposed worker is coping emotionally with the waiting for follow-up test results;
- appointments for follow-up testing, where required; and
- emotional support related to the diagnosis.

Box 9.5 below summarizes the flow of HTC services in the management of occupational exposure.

Box 9.5: Summary of HTC service flow in the management of occupational exposure

- **First aid**: Was it performed? If not, advise on first aid if exposure has just occurred. For example, for needlestick exposure, bleed the wound and wash it with mild soapy water. Blood splashed into the eyes should be flushed with sterile water immediately.
- **Exposure risk assessment and feedback on risk:** Using the four principles of transmission (exit, survive, sufficient, enter), consider whether needle was hollow bore, splash was to unbroken skin, etc.
- **Prophylaxis counselling**, including informed consent for ARVs
    - evidence for intervention, avoiding unrealistic promises of altering the course of HIV
    - potential side-effects and strategies for management
    - prolonged window period (up to six months when on PEP)
    - adherence issues
- **Pretest counselling**: – all normal pretest counselling plus:
    - how to reduce future occupational exposure
    - testing procedures to cover window period
    - worker's compensation, insurance, and other formalities
    - when to present for follow-up test
- **Blood sample drawn for baseline HIV test and other serological tests**
- **Post-test counselling and scheduling of follow-up tests**

Grief, bereavement, and loss

10

Section 1: Working with grief, bereavement, and mourning in adults

Section 2: Working with grief, bereavement, and mourning in children and adolescents

Section 3: Understanding your own grief, bereavement, and mourning

Chapter 10

Grief, bereavement, and loss

Section 1: Working with grief, bereavement, and mourning in adults

Grief is an emotional response to a personal loss-of a loved one, over one's (ill) health, or a financial loss-that results in an intense feeling of sorrow or sadness. When we think of grief, we often think of death, but other losses can elicit similar reactions. For example, PLHIV may grieve over the loss of good health, or a couple undergoing divorce may grieve over the loss of the relationship. A normal grief reaction can involve a variety of feelings, physical sensations, cognitions (perceptions), and behaviours. Table 10.1 presents some of the feelings and reactions that are normal when someone experiences grief.

Table 10.1: Characteristics of a normal grief reaction

Feelings	Physical sensations	Cognitions (perceptions)	Behaviours
Sadness Anger Guilt/Self-blame Anxiety Loneliness Fatigue Helplessness Shock Yearning Emancipation Relief Numbness	Hollowness in the stomach Tightness in the chest Tightness in the throat Oversensitivity to noise Shortness of breath Weakness Lack of energy Dry mouth	Disbelief Preoccupation Hallucinations Confusion Sense of presence (e.g., perception that the deceased is around or is talking to you, or a sense of being healthy again) Depersonalization (e.g., "Nothing seems real to me, including myself")	Sleep and appetite disturbances Absent-mindedness Dreaming of the deceased /the one lost Visiting places or carrying objects that bring the deceased back to mind Treasuring objects that belonged to the deceased Avoiding reminders of the deceased Searching and calling out (not always aloud) Sighing Restlessness Crying

Because there is no cure for HIV, people often experience grief upon learning that they, their partner, or a friend is HIV-positive. People also feel grief when a loved one dies of AIDS; it may often set in long before a person experiences death. Thus, counsellors must understand grief and learn how to help clients through the grieving process. Grief is multidimensional–it is experienced emotionally, mentally, spiritually, and physically. People experiencing grief need nurturing, compassion, and patience.

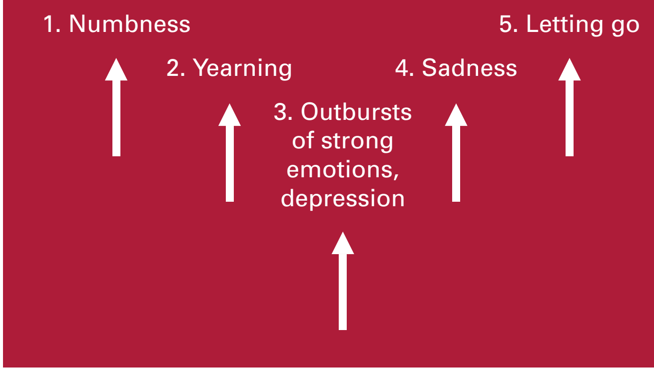
Bereavement is a term reserved specifically for the response to the death of a significant other (whereas grief can result from loss not involving death, e.g., loss of a job, limb, or status). Mourning denotes the actions and manners of expressing grief and consists of conscious, unconscious, and cultural reactions to loss. As used here, grief refers to the personal experiences associated with any loss, while mourning refers to the process that occurs after the loss. Bereavement and mourning are sometimes used interchangeably when in fact a distinct difference exists between them. Bereavement identifies the specific reactions experienced after the death of a significant other, whereas mourning speaks to the way the individual displays his or her grief.

The stages of grief

While there is no single way to grieve, adults generally experience common stages of grieving when they are bereaved. It is helpful to be aware of these stages and remember that intense emotions and swift changes in mood are normal. The stages are fluid–an individual may move in and out of them in his or her own manner and time.

- **Denial (numbness)**. Denial is usually the first reaction (e.g., ″It can't be true!″). This stage may last between a few hours and many days. While it may helpful for a client to go through some denial at first, it can be a problem if it lasts too long.
- **Anger (yearning and searching)**. Denial is usually replaced by deep yearning and searching for the person who died (or for the lost ″object″ or health). This can lead to anger, which can manifest itself in different ways, including blaming others for the loss, getting easily agitated, finding it hard to concentrate, relax, or sleep, and unleashing emotional outbursts. In addition, people often feel deep guilt about arguments they had with the deceased or about failing to express emotions and wishes.
- **Bargaining**. A bargaining stage is most likely when people themselves are dying. After the dying person or family member has vented his or her anger at friends, family, or a higher power, he or she enters the bargaining phase. This stage is seen as an attempt to enter some agreement or finish an important task to prolong life. During the bargaining stage, the affected person often makes promises to a higher power, agrees to change his or her life if allowed to live, and asks for an opportunity to do something special before he or she dies or faces a disability.
- **Depression**. Bargaining is followed by bouts of depression and sadness, set off by reminders and memories of the deceased person or of the dying person's good health (″It's all over″). People who are grieving often feel extremely tired because the process usually requires physical and emotional energy.
- **Acceptance**. The final stage of grieving is acceptance–letting go and moving on with life. This may mean resignation, not necessarily contentment. This stage helps lingering depression to clear and sleep and energy patterns to return to normal.

Box 10.1: The grieving process



Working with individual differences in grieving

Each person has a unique combination of diverse past experiences, with different personalities, attitudes, styles, and ways of coping. All these characteristics influence how people accept the circumstances around them. For some people, grief is an intense experience while for others it is milder. For some, grief begins the moment they hear of the loss; for others, grief is delayed. In some cases, grieving is relatively brief, whereas in others it seems to go on forever. The following factors affect how a person responds to a loss:

- **Past experiences.** It is important to know about prior medical history, previous or similar losses a person has faced, and how the person grieved. Questions include: ″What other losses were faced in childhood, adolescence, or adulthood?″, ″How frightening were these experiences?″, ″Did the person have good support?″, ″Were feelings allowed to be expressed in a secure environment?″, ″Has there been a chance to recover and heal from the earlier losses?″
- **Relationships with the deceased/lost object/lost health.** Grieving is affected by the relationship with the deceased or ill person and the nature of the attachment. For lost health, grieving depends on how good the person's health was previously. Questions include: ″How close was the relationship (the strength and security of the attachment/importance the person attached to his or her health)?″, ″What was the degree of ambivalence (love-hate balance) in the relationship, conflicts with the deceased, lost object, or lost health?″

- **Roles the person/object/health played in life.** The more predominant the role of a loved one or health in a client's life, the more difficult the grieving process will be. Questions to ask include: " How major was that role?", "Was the deceased/ill person the sole breadwinner, the driver, the handler of financial matters?", "Was the person the main emotional support, an only friend?", " How dependent were you on the role that person filled?", "What role did good health have in ensuring he or she could perform duties?"
- **Circumstances surrounding the death/lost object/lost health.** The cause of death, illness, or loss is also important, as is where and how the death or loss occurred. Questions to ask include: "Was it natural, accidental, suicidal, homicide, etc.?", "Near or far, sudden or expected?", "What warning was there that there would be a loss?", "Was there time to prepare, time to gradually come to terms with the inevitable?" Or, in case of illness: "How and when did the person acquire the illness?", "Do you feel that the death/loss could have been prevented?", "How much was left unsaid or undone between the deceased and yourself?", "Does the extent of unfinished business foster a feeling of guilt?"
- **Influences in the present**. The current state of a person's life, including stress level, management of feelings, social variables, ethnic and social subcultures, and religious faith, greatly affects how he or she grieves. The degree of perceived emotional and social support (inside and outside the family) is also important. Questions to ask include: "What are the secondary losses from this death or loss? Loss of income? Home? Family break-up?", "What other stresses or crises are present?", "What do friends, relatives, or others impose?", "What is in social, cultural, and ethnic backgrounds that offer strength and comfort?", "Do religious/philosophical beliefs bring comfort or add sorrow and guilt?" "What other life stresses have been present during the recent loss?", " Has there been a move to a new area?", "Were there financial difficulties, problems, or illness with another family member or with one's self?"

Counsellors should be aware of the above factors when loss occurs to someone under their care. Awareness of these factors, which affect the manner, intensity, and duration of grief, enable the counsellor to guide the grieving person to relevant support.

Grief counselling

Grief counselling helps grieving individuals go through the phases/stages of grief and can be done individually or in a group. The goals of grief counselling include:

- helping the person accept loss by talking about it;
- helping the person identify and express spoken and unspoken feelings (e.g., anger, guilt, anxiety, helplessness, and sadness);
- helping the person overcome difficulties in readjusting to life after the loss;
- encouraging the person to say goodbye (sometimes before the loss);
- allowing time for grieving, and giving permission to grieve;
- describing normal grieving and the difference in grieving among different individuals, and helping the person understand his or her coping methods; and
- providing continuous support, identifying coping problems (if applicable), and making necessary referrals for professional or ongoing grief therapy.

Counsellors can do a number of things to facilitate a client's grief process, as follows.

Listening actively. A counsellor's mere presence and desire to listen without judging are critical helping tools. In difficult times, many people need to talk about their experience, review the details, and tell the story. People feel comforted when counsellors show empathy and try to understand.

Showing compassion. Clients need permission to express their feelings without fear of criticism, and to experience hurt, sorrow, resentment, anger, fear, anxiety, or pain without concern for what is "acceptable".

Avoiding clichés. Sometimes words meant to comfort clients can be unintentionally hurtful. Among the greatest potential offenders are clichés, or comments that seem to diminish the person's loss by offering simple solutions to difficult realities. Some examples of clichés are: "You're holding up so well"; "Time heals all wounds"; "Think of all you have to be thankful for"; "Be happy he is out of pain"; "He's in a better place"; "She's at peace now"; or, "God never gives us more pain than we can handle". Such clichés fail to acknowledge the depth of the feelings of the bereaved. Moreover, these comments often are more about the person who died than the person who is grieving.

Understanding the uniqueness of grief. Counsellors should keep in mind that each client's grief, and method of handling grief, is unique. Though there are fundamental similarities in the grieving process, people do not respond to the death of a loved one or loss of health in exactly the same way. Furthermore, there is no "right" way to grieve, nor is the timetable for healing the same for everyone.

Several tools, processes, and procedures can be employed to help a grieving person deal appropriately with his or her grief.

Grief counselling processes and tools

Forceful language. Counsellors should inform their clients that it is "okay" to grieve, cry, heal, and laugh. In addition, counsellors should use appropriate words such as "AIDS", "died", and "death", and talk of the deceased in the past tense, e.g., "Your son died", instead of, "You lost your son" or "He passed away"; these substitutes can confuse the grieving person and can perpetuate denial and stigma.

Symbols. Symbols (e.g., music, photographs, and places) can be used to trigger reminders and help release grief. A client can be encouraged to look at photographs, listen to music, or visit a place as a way to tell a story about the deceased, express grief, or celebrate happy memories.

Writing and drawing. Sometimes a client can release grief by writing a letter to the deceased. This can be particularly useful if the client needs to deal with "unfinished business", if the client is having difficulty with closure ("letting go"), if the death was sudden and unexpected, or as a way of venting emotions.

Rituals. Most cultures have traditional ways of mourning that can help process grief, although in some cases these may actually hinder the process. Help your client identify rituals in his or her own culture or create meaningful "rituals" that may assist in the mourning process (e.g., lighting a candle at church, singing a song, or making a shrine in memory of the deceased). Also see box 10.2 for information on the AIDS Memorial Quilt project.

Role-playing and imagery. Help persons in mourning imagine what they would tell the deceased if the person were still alive (especially if the mourner did not have the opportunity to say these things). Imagery can also be used to create a peaceful picture that offers healing and strength (e.g., a bright warm sun, the beauty of a flower). Clients themselves should choose the imagery; it should be something with special meaning for them.

Cognitive restructuring. Help clients find alternative ways of thinking about the loss. Encourage them to consider the message the deceased might have for them, if that person were with them now. This may offer inspiration or insight.

Section 2: Working with grief, bereavement, and mourning in children and adolescents

Children express loss and grief differently from adults. They tend to move in and out of intense feelings, rather than sustaining high levels of one emotion for long periods of time. When adults see a grieving child playing or laughing, they may mistakenly believe that the child is "over it". This perception may influence how much grief support a child receives.

Box 10.2: Processing grief and loss through the AIDS Memorial Quilt project

The AIDS .Memorial Quilt is a living memory to those who have died from AIDS. It is made up of a set of eight panels, each 90 cm x 180 cm, that are sewn together to form a 4 m x 4 m patchwork square. There are many thousands of these larger squares. The quilt is an international activity coordinated by an organization, called the NAMES Project Foundation. Each quilt panel commemorates the life of someone who has died of AIDS. Panels are made by friends, lovers, and family.

Each panel includes a wide variety of materials from photographs to real life objects such as T shirts, caps, belts, and buttons. Through the panels the quilt makers spread their sincere prayers for not repeating the pain and loneliness they have experienced in losing a loved one to AIDS.

Many other countries in the Asia and Pacific regions and throughout the world have their own AIDS memorial quilts and other complementary memorial activities that facilitate grieving.

Information available: http://www.aidsquilt.org

Most-at-risk adolescents and experiences of loss

Children living on the streets may have already experienced considerable losses, including the loss of families where parents have made them leave home for work or because of behaviour problems. Children who lose a parent must cope not only with grief over their loss but possibly with significant disruptions to their home and family life such as placement in foster care or the home of another relative. This loss may be further complicated by a child's unexpressed past resentment over a deceased or surviving parent's lifestyle (e.g., a sex-worker or drug-using parent).

Children living with drug- or alcohol-using parents or close friends may experience different types of losses. The loss may be either direct, through accidental or deliberate overdose, or ambiguous. Ambiguous loss occurs when a family member is either physically or psychologically absent, as in the case of a parent with a chemical dependency. Children who are abducted or incarcerated also experience significant grief and loss issues. MARA may have lost friends to HIV or drug overdose or other illnesses common to those living on the streets. The impact of loss of street peers should not be underestimated. For many children living on the streets they regard their peer network as alternate families. Frequently street children have experienced multiple losses and exhibit signs and symptoms of disordered mourning.

Social support and increased age have been associated with improved grief outcomes, but paediatric HIV and AIDS patients may be lacking on both counts.

Often counsellors have to work with the family members of MARA. Families dealing with HIV and AIDS are faced with concerns of separation and grief. Grief and mourning may be complicated by feelings of guilt, or anger over the lifestyle of the child or adolescent. In the event of a parent's death, a grandmother or other extended family members may be called upon to raise the children. Grandmothers experience grief regarding the loss of their own children, as well as the stress of assuming parenting responsibilities at a late age. Additionally, some families are now experiencing multiple losses. HIV and AIDS are unique in their ability to strike multiple members of the immediate family as well as the larger community, thus severely compromising traditional social support systems. Paediatric HIV and AIDS patients who die may leave behind not only grieving parents, but also grieving siblings. The topic of children's reactions to sibling death is one that does not receive widespread attention, but there is evidence that the sibling relationship is one of the most important social relationships people have. Better family adjustment after the death of a child has been shown in the oncology literature to be related to open communication and social support. Siblings and parents of deceased paediatric HIV and AIDS patients may be at risk because of the social isolation associated with HIV.

Talking about death and dying with children and adolescents

Children and adolescents go through stages of awareness of death as they develop. The interventions we use should be guided by these stages. The stage of death conceptualisation should always be assessed. Adults are often reluctant to talk about death and dying with children. However, children are aware of death through fairy tales, games, television, overheard adult conversations, religious instruction, and attendance at funerals. If we permit children to talk about death we can prepare them for crisis, and help them when upset, and address any fears.

Some points to remember regarding children and death:

- We can make it easier for them if we are honest and open.
- What children sense or overhear may be worse than the truth.

At each developmental stage, a child's perceptions and concepts of death change because he or she reaches a different level of cognitive development, possesses a greater storehouse of experience, and has new ideas about the world.

Assessing death conceptualization in children and adolescents

Before either grief or loss counselling starts, or a child is told about impending death, the counsellor must assess the child's conceptualization of death.

Key questions to ask:

- "What does 'dead' mean?"
- "Can dead people come back to life?"
- "Tell me what you know about dying or dead people."
- "Can dead people get hungry?"
- "Can dead people feel things like pain?"

Additional questions to ask children:

- "Have you heard adults talking about death? What did they say about it?"
- "Have you ever had someone close to you or a pet die? What happened?"
- "Does everybody and do animals die?"
- "Why do things die?"

Summary of developmental stages and death conceptualization

Infant death conceptualization. Up to age two, there is no formal concept of death. Key points:

- Infants' awareness of the world is narrow. This includes their awareness of mother, physical being, and separation.
- Infants need warmth, physical contact, and consistency.

Infants will grieve over the loss of a loved one they were used to being with. Before children can talk, they communicate with sounds of crying and cooing, body language, and physical symptoms such as colic and fretfulness. Grieving babies can be difficult to console. If a surviving parent or family members are grieving too, chances are that the baby will sense their distress. It may also be difficult for the grieving family member to remember all the needs of an infant. Counsellors can help in these circumstances by looking for support for families. Ask friends, groups, religious organizations, or NGO community groups to help with a toddler's or baby's care while the family is in crisis.

Death conceptualization: Preschool age (2-4 years). Among this age group, common issues include:

- fear of abandonment;
- preoccupation with physical function;
- "How does he play now that he is dead?", "He will get hungry if Mummy can't feed him";
- death as impermanent and reversible; and
- death confused with sleeping (or fear development).

As children learn to use our symbolic language of words, they can begin to share feelings with words. They learn what ″sad″, ″mad″, and ″scared″ mean. They communicate about the concrete world-what they can see, touch, hear, taste, and smell. The future and the idea of ″never″ are outside their understanding. They fully expect their loved one to return. They will believe, for example, that if they are ″good″ the dead mother or father will return (″If I am a good boy, my Mummy will come back″). Children will seek out the dead people; they will continually ask where that person has gone and may even look for them.

Death conceptualization: 5-9 years. At this age:

- 15% of children at this age think about death at night and believe people die at night.
- Death comes from an external source-a monster, ghost, or angel that takes people away.
- Death is something that can be ″outwitted″ or escaped,
- Often the child's exposure to death has been through TV or the sight of a dead animal.
- Death is associated with ″mutilation″ and horrible images.
- Children will often shock adults with detailed questions about decayed bodies and mutilation of bodies.
- Death is seen as punishment.
- Children will try to make bargains with death: ″If I do a certain thing Mummy will not die or I will not die;″
- Key fears around death:
  - fear of losing another parent or family member;
  - fear of dying at same age as the deceased;
  - fear of going to sleep;
  - fear of separation; and
  - fear of loss of protection.

Around the age of six, children begin to understand that the loved one is not returning. This can bring about a multitude of feelings at a time of other significant changes in a child's life, including entering first grade. Children who do not remember their parent may feel an acute sense of loss as they see peers with their parents and hear their family stories. Children at this age are increasingly interested in biological processes about what happened to their loved one. Questions about disease processes and what happens to the body are of keen interest. When asked questions, it is important to clarify what it is the child wants to know.

Children's worlds are sometimes messy and have a high level of energy. Sometimes, grief is also messy. It does not always take a form that makes adults comfortable. Parents and caregivers should be informed that allowing your child to express feelings through creative play can be helpful (finger painting, making mud pies and throwing them, etc). The counsellor or parents may want to join in the creative play.

Death conceptualization: 9-12 years. Among this age group:

- Majority of children realize death is the end of life and is permanent.
- Death is increasingly seen as a biological process.
- More conscious of the consequences of death, for example, they may wonder: ″Will my brother be lonely?″, ″Will I have to move when Mum and Dad die?″

Children 10 years of age show an interest in burial and ceremonies associated with death.

Death conceptualization: Adolescents. For adolescents, death is understood as an abstract concept:

- death as a distant prospect;
- fear of death; and
- tests of mortality (″driving fast″, etc.).

Adolescents are more likely to engage in high-risk behaviour, especially after a death. One young person said that her friend was always careful and followed all the safety rules, but died anyway. She asked, " Why should I be careful?" Teenagers are usually growing in independence. Teenagers living on the streets for many years will often have a veneer of adult toughness. They may feel a need to hide their feelings of grief to show their control of themselves and their environment. Teens often prefer to talk with peers rather than adults when they are grieving.

Telling a child about a death: Basic principles

- Keep it simple. Use "died", not "He is sleeping." For example: "Tanveer, there was an accident on the street today. Your best friend was walking on the street and was hit by a car, and he fell down to the ground. The fall was so far and so hard that he died."
- Allow the child/adolescent to express raw feelings freely or ask questions.
- Answer questions honestly and simply. Do not go into details unless asked. Offer only as much detailed information as is requested.
- If the death was due to a violent crime, explain how the child/adolescent can remain safe.
- If the body is suitable for viewing, allow the child/adolescent to see the deceased loved one, if he or she asks to. Prepare the child/adolescent for what he or she will see.
- Tell the child/adolescent what will be happening in the few days after a death.
- Give the child/adolescent choices in what to do. Some children want to go to school or continue to work or engage in their normal social activities the day of the death. Familiar routines are comforting. Inform the school or NGO that the child/adolescent attends about the death before the child returns.
- Reassure the child that he or she will be cared for and explain the plan.

Counselling tasks and interventions

There are four key tasks that children work through as they mourn a loss. These are: understanding, grieving, commemorating, and moving on. One of the first questions asked when a person has experienced a loss is "Why?" During the task of understanding, a child or adolescent seeks to determine what caused the loss and why it happened. The task of grieving means allowing children and adolescents to experience the painful feelings associated with a loss. In commemorating a loss, children and adolescents are encouraged to develop a personally meaningful way to affirm and remember the lost person or object. The last task in the process of mourning is the task of moving on. During this task children and adolescents discover new ways to "maintain an inner connection with and representation of the deceased as they develop other friendships, attend school, play, and perform all the things that shape their daily lives".

Several interventions have been found to be useful in helping children and adolescents tackle the tasks of mourning that they are faced with. Some interventions we have found to be effective with this population are the use of loss genograms; play therapy; narrative therapy, such as a "Letter to Loss"; art therapy, such as drawing a picture to show "what happens when someone dies"; or commemoration of the loved one or object through a CD, tape, journal, or scrapbook.

Some counselling tools to assist with counselling children can be found in the toolkit.

Appropriate communications

Offering support to a grieving child or adolescent can begin with a simple statement or open-ended question. Here are some conversation starters:

- "I'm sorry your Mom/Dad/sister/boyfriend/girlfriend/husband/wife has died."
- "What was your Mom/Dad/sister/boyfriend/girlfriend/husband/wife like?"
- "Tell me about your __________."
- "What was his/her favourite food?"
- "What do you miss the most?"
- "What is the hardest part for you?"

- "What is the hardest time of day for you?"
- "I cannot know how you feel, but I remember how I felt when my _________ died."
- "I care about you."
- "I care about how you are feeling."
- "Would you like to talk about it?"
- "I'm available at this time, if you would like to come by to talk."
- "Whenever you want to talk about it, I'm here for you."
- "I'm thinking about you especially today because I'm aware that today is your friend's birthday (anniversary of the death, your birthday, etc.)."
- "I'm here to listen if you want to talk, or just spend time together if you don't want to talk."

Avoiding words that can hurt

The following are a few of the potentially harmful comments that are often offered to children and adolescents grieving the loss of someone who is important to them.

- "I know just how you feel."
- "I know just how you feel… My dog died last year."
- "Lick your wounds and move on."
- "You'll get over it."
- "It will be okay."
- "Don't think about it."
- "You are better off without him."
- "Don't cry."
- "It's your fault."
- "You drove your father to drink."
- "If only you had _________________ ."
- "Tears won't bring her back."
- "Be strong."
- "Forget about it."
- "You are the man/woman of the house now."
- "You should feel… (proud, relieved, happy, sad, etc.)."

Memory books/boxes: A tool for disclosure and grief counselling with children

Memory is a key component of identity, but as HIV and AIDS leave many children without parents, they lose this fundamental link to their roots. For children affected by HIV and AIDS, metaphorical and literal memory boxes can create strong links in a chain of familial history while easing the grief of losing a loved one. A memory book is a similar tool to preserve memories.

> *When I am sad, I take out the things left to me by my mom and it makes me feel better… I know she loved me, and I do not feel so alone.*
>
> – Response of a 10-year-old orphan when asked about the memory box her mother left her on her death.

History of the memory book and memory box

The memory book/box was inspired by a group of HIV-positive women in some countries to help them disclose their HIV serostatus to their children, plan their funeral, sort out the will, begin the process of grieving, and plan for the future with their children. This concept has been adopted and revised in various settings to include memory books, memory boxes, narrative therapy (telling the story), and art therapy.

What is a memory book/box?

A memory book is a written account of a family's history. In Uganda, pages with appropriate headings help HIV-positive women work though different aspects of their history, lifestyle, culture, and beliefs. The pages are then inserted into the memory book. Examples of headings are:

- "Our family came from…";
- "Your grandparents' names were…";
- "These are some of the jobs our family did…"; and
- "You walked when you were…"

Since a memory book is written, and some people have trouble writing, a memory box is sometimes easier to create. Memory boxes can be as simple or as ornate as one chooses and may contain mementos, letters, diaries, photographs, documents, certificates, tapes, transcribed family history, and personal treasures, objects of sentimental value, and favourite faith or spiritual passages.

Why make a memory project?

Memory projects create space to discuss sickness and death and to cope with the loss of a loved one or news of HIV infection. These reminders can provide children with a sense of comfort and belonging for the rest of their lives. Developing a memory project can gently encourage parent(s) to write a will and discuss issues relating to disclosure of HIV status.

Memory projects help HIV-positive parents develop their communication skills. The projects become a joint activity between parent and child where they sit together to tell the story of the child(ren) from birth to the present. Similarly, parents tell their own life stories. It becomes easier for parents to disclose their HIV status to children as they gradually recount special family memories and cultural history. This process also provides an opportunity for children to ask questions of parents and get clarifications. Sharing personal memories, recording those memories, and storing them in a memory box helps family members break the silence surrounding HIV and AIDS. In addition to helping family members communicate with and understand each other, memory projects allow helpers (e.g., caretakers).

Other tools and strategies are located in HIV Counselling Tools.

Most-at-risk children and adolescents and special cautions

Counsellors need to work carefully to address the grief and bereavement counselling needs of MARA. Too often adults take street toughness as a sign of a child's or adolescent's adjustment to a death. Disordered mourning results from a lack of psychological processing of normal grief reactions. Disordered mourning has been associated with suicide, increased HIV transmission risk behaviour, increased drug or alcohol use, and accidental overdose. Disordered mourning has also led to increased vulnerability to physical, emotional, and sexual abuse among children or adolescents.

Section 3: Understanding your own grief, bereavement, and mourning

The loss of a loved one is among the most intensely painful experiences a human being can suffer. Such a loss is painful not only for the mourner but for the counsellor as well, especially if he or she feels unable to make a difference. Moreover, being with the bereaved may make counsellors aware of losses in their own lives. If counsellors have not dealt adequately with their own losses, they may find it hard to help and relate to a client in mourning.

In addition to being reminded of their own past losses, many who work with the dying and the bereaved may be haunted by the fear of losses yet to come–for example, of their own children, parents, or spouses. Counsellors are often unaware of their own fears of losing loved ones. However, if the loss experienced by the bereaved client is similar to the one the counsellor fears most, then that fear can affect his or her ability to help the grieving client.

The counsellor's ability to help clients is affected not only by past loss and fear of future loss, but by his or her own personal death awareness. By hearing of others' losses every day, counsellors may be made aware of the inevitability of their own death. The situation can be especially difficult when the bereaved person is of similar age, sex, or professional status. Thus, people who work with the bereaved should explore the history of their own losses first. Counsellors should try to identify their own ways of coping and, if they have been successful, use those experiences to help clients. Similarly, it is beneficial for counsellors to recall how other people were helpful, and what kinds of things failed to help, or even hurt.

It can be helpful for counsellors to examine the personal losses that have affected them most, including the deaths of clients with whom they had a special bond. Counsellors may also have to go through a grieving process after a client's death. By looking at their own experiences of loss and grief, counsellors can become more aware of their own inherent limitations. From this they may learn to ask colleagues for assistance. It is important that counsellors share their own more recent losses with their counselling team, know where to get emotional support, know how to reach out when they need it, and understand their own limitations.

11

Counsellor self-care

Section 1: The potential impact of your work

Section 2: Occupational stress and burnout

Chapter 11

Counsellor self-care

Section 1: The potential impact of your work

In the Asia and Pacific regions HIV counsellors are faced with the challenge of working with highly marginalized clients, often with limited resources. Many counsellors have received only limited training and work in contexts where counselling is a new concept. Frequently within health services counsellors fail to encounter professional recognition and reward. Many newly trained counsellors, often idealistic and enthusiastic, promise themselves that they will never become like some of the more experienced counsellors they have known – tired, cynical, frustrated individuals who no longer seem to care about what they do and who have lost their compassion. It is difficult for these new counsellors to imagine that the burned-out counsellors were once idealistic as well.

Counsellors never start out in this profession planning for the days when work no longer seems vibrant and exciting. It is therefore important to discuss burnout during training. Anticipating the predictable stresses and strains of HTC and the toll it can take on one's physical and emotional health allows counsellors to take steps to minimize these negative effects.

What is stress? What is burnout?

Stress can be defined as anything that stimulates an individual and increases his or her level of alertness. Life without stress would be incredibly dull and boring; on the other hand, life with too much stress becomes unpleasant and tiring, and may ultimately damage health and well-being. Too much stress interferes with work performance. Stress often originates from an external event or circumstance that places a demand on an individual's inner or external resources. How stressful an event is experienced depends partly upon the individual's resources. If the demands on the person (e.g., disclosing an HIV-positive test result) exceed his or her ability to cope with them, the person experiences stress.

Burnout generally refers to a state of mental/physical exhaustion caused by excessive and prolonged stress. It is a gradual process by which a person, in response to prolonged stress and physical, mental, and emotional strain, detaches from work and other meaningful relationships. The result is lowered productivity, cynicism, confusion, and a feeling of being drained, or having nothing more to give. Burnout has been described as a ″physical, emotional, psychological, and spiritual phenomenon; an experience of personal fatigue, alienation, and failure″. It has also been described, with respect to those in the helping and care professions, as a ″progressive loss of idealism, energy, and purpose″. The term burnout evokes an image of a fire going out or the ashes left over.

Stages of burnout

The physical and emotional exhaustion associated with burnout causes individuals to cut corners in their work (when they used to pride themselves on doing a thorough job). This may result in guilt or shame. Other common warning signs are: physical inability to shake off a lingering cold or fever, frequent headaches, or sleeplessness. Another telltale sign of burnout is when the thought of going to work in the morning loses its appeal.

As burnout progresses, many experience changes in their outlook. This might involve developing an attitude that pushes others away or being bitter towards one's job. Emotional and behavioural signs such as angry outbursts, obvious impatience or irritability, or treating others with apparent contempt are common. These often lead people to experience severely negative feelings towards themselves, others, or, in extreme cases, all of humanity. Intense loneliness and alienation are characteristics of the end stages of burnout, as one's coping structure and psychological defences wear down. A slight emotional bump can set off an overly sensitive and personal reaction. Frequent mood swings with short highs and long lows might also occur.

Thinking about burnout as the culmination of a series of stages may make it easier to recognize. Symptoms associated with the three stages of burnout – stress arousal, energy conservation, and exhaustion – are listed below.

Stage 1: Stress arousal (includes any two of the following symptoms)

- persistent irritability;
- persistent anxiety;
- periods of high blood pressure;
- teeth grinding at night;
- insomnia;
- forgetfulness;
- heart palpitations;
- unusual heart rhythms (skipped beats);
- inability to concentrate; and
- headaches.

If any two of these symptoms are present, you may be experiencing stage 1 of the burnout cycle.

Stage 2: Energy conservation (includes any two of the following symptoms)

- lateness for work;
- procrastination;
- needed three-day weekends;
- decreased sexual desire;
- persistent tiredness in the mornings;
- habit of turning in work late;
- social withdrawal (from friends or family);
- cynical attitudes;
- resentfulness;
- increased coffee/tea/cola consumption;
- increased alcohol consumption; and
- apathy.

Any two of the above symptoms may signal stage 2 of the burnout cycle.

Stage 3: Exhaustion (includes any two of the following symptoms)

- chronic sadness or depression;
- chronic stomach or bowel problems;
- chronic mental fatigue;
- chronic physical fatigue;
- chronic headaches;
- desire to ”drop out” of society;
- desire to move away from friends, work, and perhaps even family; and
- perhaps the desire to commit suicide.

Any two of these symptoms may signal stage 3 of the burnout cycle.

Recognizing that you are not immune

Almost anyone can experience burnout. Burnout cuts across demographic characteristics, affecting people regardless of age, length of time on the job, marital status, number of dependents, or the number of hours worked each week. However, some people may be more likely to experience burnout than others. For example:

- highly committed individuals who hold high expectations of themselves;
- frontline workers (more than those "behind the scenes") – for example, nurses are more likely to suffer from burnout that physicians; and
- counsellors dealing with difficult issues such as HIV.

People suffering from burnout may progressively feel a lack of personal accomplishment in their work. There is also evidence that clients can identify a counsellor suffering from burnout. It has been documented that clients become dissatisfied and tend to be more critical of the "burned out" counsellor's actions and interventions.

Are you at risk of burnout? Take some time to complete the questionnaire in annex 4 of this handbook.

Causes, or the stresses and strains, of counsellor burnout

Counsellor burnout can be caused by a number of factors. These stresses and strains are enumerated below, not to alarm, but to create awareness of the realistic stresses and strains that a counsellor might face. These include:

- a strong sense of commitment;
- job stress;
- lack of adequate support;
- isolation and alienation;
- fear of HIV infection;
- ostracism and stigma;
- excessive work;
- increasing responsibilities;
- diminishing resources;
- political pressures;
- client-related issues (e.g., how to inform clients or their partners of test results, especially if they are HIV-positive or a discordant couple or a couple refusing to be separated; conflict between counselling and giving advice; conflict between encouraging a client and giving false hope; the counsellor's own emotions surrounding HIV); and
- boredom—day after day and year after year clients enter a counsellor's office and tell their stories, ask similar questions, and expect the counsellor to do essentially the same thing;

Recognizing burnout

Counsellors can recognize burnout by its physical, behavioural, and/or cognitive symptoms, including those listed in the table below.

The visible effects of burnout in HIV counselling are high turnover, absenteeism, declining quality of service, decreasing communication, disorganization, declining enthusiasm, and increasing client complaints.

Symptoms of burnout

Physical	Behavioural	Cognitive
Exhaustion	Irritability or frustration	Exasperation: ”I’ve had enough” or ”I can’t take this anymore”
Lingering minor illness	Quickness to anger or irritability	Rumination
Frequent headaches and backaches	Tendency toward prejudice	Emotional numbness, indifference, impoverishment
Sleeplessness	Alcohol or drug abuse	Emotional hypersensitivity
Gastrointestinal disturbances	Marital or relationship problems	Over-identification
Chronic and vague physical pains	Rigidity (inflexibility) in problem solving	Pessimism, helplessness, hopelessness
General malaise	Impulsiveness or acting out	Grief and sadness

Section 2: Occupational stress and burnout

General strategies

- Ensure that there is an opportunity for individual, peer, or group supervision or counselling for counsellors (if available).
- Be associated with committed, concerned colleagues who can help identify risk of burnout, analyze the situation, and decide on corrective actions.
- Draw support from a partner, work team, or the work culture (environment).
- Engage in self-assessment.
- Retain an attitude of hope.
- Keep changing the way of working (e.g., alter the counselling style, get different supervision, take on new challenges).

Responding to some unique workplace stressors

Ethical dilemmas. Counsellors may encounter a number of ethical challenges when they attempt to balance their ”duty of care” to individual clients with their duty to the ”broader community”. Ethical guidelines offer not only protection to our clients but also serve to protect us, and reduce uncertainty about the way we should respond to certain situations that we encounter in work. You are referred to the Ethical Guidelines for counsellors that have been included in annex 1 of this handbook.

Managing challenging client situations appropriately. In our work we will encounter clients who are intoxicated or in the process of withdrawal and clients who are experiencing significant psychological disturbance and may behave in a challenging and threatening way. An important part of burnout prevention, and stress management is recognizing these situations and learning how to respond to them.

Containing threats of violence in our workplace

Pay attention to the warning signs:

- loud, clipped, angry speech;
- demeaning or hostile verbal behaviour;
- intense staring/angry facial expression;
- affective lability/irritability;
- refusal to cooperate with clinic or hospital routine;

- refusal to communicate;
- purposeless movements, pacing, restlessness/psychomotor agitation;
- intimidating behaviour/threats or gestures;
- attacks on property; and
- direct threats/reports of violent/homicidal ideation or impulses.

Managing verbal de-escalation and distraction

- Clients will often settle down if time is spent calmly discussing their concerns and if offered suitable support.
- If the client is standing and yelling at you, calmly ask the client to sit and do not respond until the client sits with you. Offer the client time to state his or her concerns.
- If the client remains standing up then stand slightly to his or her side, calmly asking the client to sit with you. Keep repeating this request and do not respond to any aggressive verbalization.
- Focus on the here and now, and do not delve into long-term grievances or issues, or to irrelevant complaints. React in a non-judgemental way, in a lowered voice, and with relaxed body posture, explaining your desire to help sort out the client's current difficulties.
- Attempt to ascertain the cause of the violent behaviour. Try to calm the client by responding calmly and evenly. Do not become aggressive or threatening in response.
- Courtesies, such as offering a cup of tea (lukewarm!), a sandwich, or access to a phone, attending to physical needs, providing an opportunity to rest, can be very helpful, as is regular orientation to place/person/situation.
- Getting relatives or trusted staff to talk with the client may help.
- Encourage the client to choose help such as agreeing to talk to a mental health professional or, where necessary, accepting medication voluntarily if you have a prescribing medical practitioner available (e.g., "It seems to me things are a bit out of control. Will you let us help you? This medication will help calm things down").
- If aggression escalates and violence seems imminent, withdraw from the patient and mobilize help. If trapped, a submissive posture with eyes averted, hands down and palms towards patient may help. If all else fails, lift arms to protect head and neck, shout "NO" very loudly, and try to escape.

If further intervention (such as medication) is required, having a number of staff backing up the nominated clinician speaking to the patient (sometimes known as a *show of force*) may facilitate the client's cooperation. One person should lead the staff and negotiate with the client.

Stress management and preventing burnout

Stress management refers to efforts to control or reduce the tension felt when a situation is perceived to be especially difficult or beyond one's resources. Heavy demand and high performance is expected of HTC. There are several strategies for coping with stress and burnout. The techniques selected by counsellors will depend on the cause of the stress and burnout and the situation in which stress occurs. Thus, counsellors should ask themselves where the stress is coming from. For example, if important events and relationship difficulties are causing stress, a positive-thinking or imagery-based technique (changing the way we think) may be useful. Where stress and fatigue are long-term, lifestyle and organizational changes (adopting a healthy lifestyle and time management) may be appropriate. If feelings of stress come from within (caused by anxiety, worries about client results, issues beyond their control, or anxiety based on their own behaviour), relaxation techniques might be more appropriate.

Adopting a healthy lifestyle

Counsellors can care for themselves by talking to others (friends, family members, colleagues, supervisors) about their stress and asking for help when needed. They can try physical exercise or recreation, avoid smoking, drink alcohol only in moderate quantities, adopt an adequate sleep routine, and eat balanced and regular meals. They can either withdraw or confront the stressful situation, directly targeting a mood change and shifting the focus from counselling exclusively (by broadening their focus, interests, and activities). Counsellors should try to get plenty of rest. A common stress reaction is for people to bury themselves in work or activity. This can be self-defeating physically and mentally. If sleep is interrupted, the counsellor should get up and replenish himself or herself by having a glass of orange juice or milk, eating, reading, talking, or writing about pressing feelings. After a while the counsellor should return to bed.

Managing time

Counsellors can better manage their time by working more efficiently, rather than harder. A range of skills might help in time management: assessing value and use of time; setting goals and routines; creating more time; managing and avoiding distractions; increasing productivity and personal effectiveness; and choosing priorities. For effective time management, it is important to learn to say no, plan projects or duties so they are done properly with adequate resources, do one thing at a time, and break down large tasks into manageable components.

Changing the way one thinks

Sources of stress can sometimes be recast or neutralized by transforming negatives into positives. For example, if counsellors experience significant stress from other people, or realize they are not in control of their life, they can eliminate negative feelings by having a more positive outlook, keeping things in perspective, setting personal goals, welcoming changes, or recognizing and changing irrational beliefs. It is important to avoid generalizing, focusing on unimportant details, jumping to conclusions, ”making mountains out of molehills”, and taking things too personally. In addition to positive thinking, counsellors can employ an imagery method. With imagery, a person substitutes actual experience with scenes from his or her imagination. The body will react to the imagined scenes almost as if they were real. Imagining pleasant scenes can reduce stress.

Employing relaxation techniques

Relaxation techniques are often effective in managing stress when stress appears to be coming from within. Meditation helps one feel peaceful, relaxing the body and clearing the mind of stressful thoughts. Concentrating on one thing for an extended period (possibly 20-30 minutes) helps achieve the desired effect. The focus of one’s concentration might be breathing, an object, a sound, or an imagined scene. Progressive muscular relaxation and deep breathing are purely physical techniques for relaxing tense muscles and calming stress. They can be used in conjunction with mental techniques such as imagery or meditation.

Setting boundaries between personal and professional lives

It is critical that counsellors maintain boundaries between their professional and home lives. Counsellors should regulate the balance between their work life and personal life so that work does not consume all of their time. Some counsellors may find it easier to maintain the boundaries by avoiding work-oriented social networks. It is also helpful to develop a decompression routine, a ritual that signals one part of life is ending and another part is beginning (the work day is ending and the personal life is beginning). These routines help counsellors diffuse emotional energy from work and enter their personal lives in a relaxed manner.

Finally…

HIV counselling will expose you to many situations that are hard to deal with. It is important that you know yourself, and are able to respond to some of the situations or events that you will face as a counsellor. This may mean identifying issues that you have trouble dealing with yourself. No counsellor is perfect and each has his or her own personal experiences and beliefs, which result in specific reactions to certain situations and issues. Some of these may involve past experiences with sexual assault, domestic violence, or even beliefs about sexuality. Even with extensive training and the use of the techniques outlined in this handbook and other publications, it is not uncommon to find that some issues still make us react in an uncontrollable manner. This can evoke feelings of vulnerability, anger, or fear.

When you find yourself with a client who needs to discuss such issues, it is important for you to be honest and ask yourself, Can I provide this client with the advice and services that he or she needs? If the situation allows it (if another counsellor is available), then you should not feel guilty telling the client that you would like him or her to speak with another counsellor. Do not do this in a manner that will make the client feel uneasy or embarrassed; rather, you may want to be honest and say that you have personal reasons for not being able to discuss these issues with him or her. You are not confident that you would be able to focus on them, and their needs. If the situation does not allow for another counsellor to come in, then you may want to ask the client to wait for you, and you can step outside and try to organize your thoughts before going back in. It is not a sign of a bad counsellor to acknowledge limitations. Rather, it will help you minimize undue stress and do a better job.

Annex 1

Counselling code of ethics

The purpose of *the counselling code of ethics* is to:

- establish and maintain standards for counsellors; and
- inform and protect members of the public who seek and use their services.

The code of ethics outlines the fundamental values of counselling, namely, integrity, impartiality, and respect. A number of general principles arise from these. They address such issues as client safety, clear contracting, and competence. *Counselling is a non-exploitative activity* and counsellors should have the same ethical values in both voluntary and paid counselling positions.

Your responsibilities to the client

Client safety

- Counsellors should take all reasonable steps to ensure that the client suffers neither physical nor psychological harm during counselling.

Client autonomy

- Counsellors must not exploit their clients financially, sexually, emotionally, or in any other way. Engaging in sexual activity with the client is unethical.
- Counsellors are responsible for working in ways that promote the client's control over his or her own life, and respects the client's ability to make decisions and change in the light of his or her own beliefs and values.
- Counsellors do not normally act on behalf of their clients, unless at their express request or in certain exceptional circumstances.
- Counsellors are responsible for setting and monitoring boundaries between the counselling relationship and any other kind of relationship, and making these boundaries explicit to the client.
- Clients should be offered privacy during counselling. The client should not be observed by anyone other than their counsellor or counsellors unless they give informed consent. This also applies to photos/audiotaping/videotaping of counselling sessions.

Contracting

- Counsellors are responsible for communicating the terms on which counselling is being offered, including availability, the degree of confidentiality offered, and their expectations of clients.
- It is the client's choice whether or not to participate in counselling. Reasonable steps should be taken in the course of the counselling relationship to ensure that the client is given an opportunity to review the terms on which counselling is being offered and the methods of counselling being used.
- If records of counselling sessions are kept, clients should be made aware of this. At the client's request, information should be given about access to these records, their availability to other people, and the degree of security with which they are kept.
- Counsellors should gain the client's permission before conferring with other professional workers.

Counsellor competence

- Counsellors should monitor actively the limitations of their own competence through counselling supervision or consultative support, and by seeking the views of their clients and other counsellors.
- Counsellors should not counsel when their functioning is impaired by personal or emotional difficulties, illness, disability, alcohol, or drugs, or for any other reason.
- It is an indication of the competence of counsellors when they recognize their inability to counsel a client and make appropriate referrals.

Responsibility to self as a counsellor

- Counsellors have a responsibility to themselves and their clients to maintain their own effectiveness, resilience, and ability to help clients. They are expected to monitor their own functioning and to seek help or withdraw from counselling, whether temporarily or permanently, when their personal resources are sufficiently depleted to require this.
- Counsellors should receive basic counselling training before starting counselling, and should maintain ongoing professional development.
- Counsellors should take all reasonable steps to ensure their own physical safety.

Responsibility to other counsellors

- A counsellor who suspects misconduct by another counsellor that cannot be resolved or remedied after discussion with the counsellor concerned should implement a complaints procedure (if there is any) without unnecessary breaches of confidentiality.

Responsibility to colleagues, members of the caring professions, and the community

- Counsellors should be accountable for their services to colleagues, employers, and funding bodies as appropriate. This should be achieved with respect for the client’s needs.
- No colleague or member of the caring professions should be led to believe that a service is being offered by the counsellor when it is not, as this may deprive the client of the offer of such a service from elsewhere.
- Counsellors should work within the law and should take all reasonable steps to be aware of all current laws affecting their work.

Counselling supervision/Consultative support

- It is a breach of ethical requirement for counsellors to practice without counselling supervision or consultative support.
- Counselling supervision/Consultative support refers to a formal arrangement that enables counsellors to discuss their counselling regularly with one or more people who have an understanding of counselling and counselling supervision/consultative support. It is a confidential relationship whose purpose is to ensure the efficacy of the counsellor-client relationship.
- Counsellors who have line managers owe them appropriate managerial accountability for their work. The counsellor supervisor role should be independent of the line manager role. However, where the counselling supervisor role is also the line manager, the counsellor should also have access to independent consultative support.
- The volume of supervision should be in proportion to the volume of counselling work undertaken and the experience of the counsellor.
- Whenever possible, the discussion of cases within supervision/consultative support should take place without revealing the personal identity of the client.

Research

- The use of personally identifiable material gained from clients or by the observation of counselling should be used only after the client has given consent, usually in writing, and care has been taken to ensure that consent was given freely.

Confidentiality issues

Confidentiality with respect to clients, colleagues, and others

- Confidentiality is a means of providing the client with safety and privacy.
- Counsellors treat with confidence personal information about clients, whether obtained directly or indirectly or by inference.
- Counsellors should work within the current agreement with their client about confidentiality.
- Exceptional circumstances may arise which give the counsellor good grounds to believe that the client will cause physical harm to him or her. In such circumstances the client's consent to a change in the agreement about confidentiality should be sought whenever possible unless there are also good grounds for believing the client is no longer able to take responsibility for his or her own actions. Whenever possible, the decision to break confidentiality agreed on by a counsellor and client should be made only after consultation with a counselling supervisor or experienced counsellor.
- Any breach of confidentiality should be minimized both by restricting the information conveyed to that which is pertinent to the immediate situation and to those persons who can provide the help required by the client. The ethical considerations involve balancing between acting in the best interests of the client and in ways that enable clients to resume taking responsibility for their actions, and the counsellor's responsibilities to the wider community.
- Counsellors should take all reasonable steps to communicate clearly the extent of the confidentiality they are offering to clients. This should normally be made clear in the pre-counselling or initial contracting.
- If counsellors include consultations with colleagues and others within the confidential relationship, this should be stated to the client at the start of counselling.
- Care should be taken to ensure that personally identifiable information is not transmitted through overlapping networks of confidential relationships.
- It is therefore good practice to avoid identifying specific clients during counselling supervision/consultative support and other consultations, unless there are sound reasons for doing so.
- Any agreement between the counsellor and the client about confidentiality may be reviewed and changed by joint negotiations.
- Agreements about confidentiality continue after the client's death unless there are overriding legal or ethical considerations.
- Any discussion between the counsellor and others should be purposeful and not trivial.

Annex 2

Adherence calculation tool

Adherence calculation tool from pill counts

$$\% \text{ Adherence} = \frac{\text{Total \# of pills patient should have taken} - \text{\# of pills missed}}{\text{Total \# of pills patient should have taken}} \times 100$$

Name of medication	Number of pills dispensed	Number of pills patient is expected to have taken (A) (take into account whether patient has come early, on time, or after the refill due date)	Number of pills patient actually took (take into account remaining pills and whether patient has come early, on time, or after the refill due date)	Number of pills missed (B)	% Adherence $\frac{A - B}{A} \times 100$
Example: D4T one tablet taken twice daily	60 (for 30 days)	54 (patient came in 3 days early)	50 (10 pills remaining when there should have been only 6)	4	$\frac{54 - 4}{54} \times 100$ = 92.5%

Adherence could be <100% when patients have taken fewer pills than required or >100% when they have taken extra pills by mistake.

Adherence from self-report

Adherence measured using a self-report will only reflect the adherence over the period of recall; e.g. 3 days in the table below.

Patients should be asked about missed doses: how many doses of d4T did you miss – yesterday, the day before that and the day before that (3 days ago)?

$$\text{Adherence} = \frac{\text{\# of doses patient should have taken - \#of doses missed}}{\text{\# of doses patient should have taken}} \times 100$$

Names of medications	Yesterday (missed dose)	Day before yesterday (missed dose)	The day before that (3 days back) (missed dose)	% Adherence
Example: d4T one tablet taken twice daily	0	1	1	$\frac{6 - 2}{6} \times 100 = 67\%$

Source: Population Council/Family Health International. Adherence to antiretroviral therapy in adults: A guide for trainers. Population Council India, 2004. p.102.

Annex 3

Psychiatric conditions

People with HIV psychiatric conditions

There are two main groups of people who develop psychiatric illness and HIV infection:

- those with pre-existing mental illnesses who become secondarily infected with HIV; and
- those who are HIV-positive and present with or develop psychiatric disorders (either directly or indirectly).

Mental disorders in patients who are HIV-positive are always diagnosed through a process of exclusion. For example, many conditions such as opportunistic infections, metabolic changes, and drug or alcohol abuse produce symptoms similar to AIDS dementia complex (ADC) and other psychiatric conditions. These conditions need to be ruled out.

There are four major groups of psychiatric conditions:

- organic disorders (delirium and ADC);
- mood disorders (depression and mania);
- anxiety disorders;
- psychotic disorders; and
- HIV-related dementia (also known as AIDS dementia).

Organic disorders

People with delirium or ADC can present with psychiatric symptoms. Although confusion and disorientation are both signs of delirium and dementia, they are different. Delirium is an acute *confused state* that is potentially reversible.

Delirium usually occurs over a period of days to months. Dementia is much slower and thus develops over a period of time. Common causes of delirium include medication side-effects, metabolic and cardiopulmonary problems, and acute systemic illness (including some opportunistic infections). Organic disorders are assessed through history gathering, assessment of opportunistic infections, magnetic resonance imaging (MRI) scans, and perhaps lumbar puncture.

Treatment

Treatment includes specific sedation measures for agitated delirium, a stable environment, maximum support, minimal sleep disruption, and the discontinuation of any suspected toxic medications. HIV-positive new mothers may present with postpartum (postnatal) depression. AIDS dementia complex may present with some apparent psychiatric symptoms such as agitation, hallucinations, or paranoid thoughts.

Mood disorders

Depression

Studies show that depressive disorders are very common but under-diagnosed and under-treated in HIV infection. Depressive symptoms may increase over the course of HIV illness, especially after the onset of AIDS. Major depression is never a ”normal” response to a particular situation. It should be approached with the same rigour as any other medical illness.

Presenting symptoms. Can be of a physical nature (low energy, loss of appetite, insomnia, early-morning wakening, constipation). Cognitive changes may include loss of memory and poor concentration and affective changes that may include low mood, hopelessness, worthlessness, nihilism, suicidal ideation, guilt, and anhedonia (lack of enjoyment or pleasure).

Treatment

Medical treatment of depressive disorders is dependent on the severity of the depression. The more severe the depression, the more likely antidepressants need to be administered. Clinically depressed clients with HIV have been shown to benefit from a therapeutic relationship and medications to alleviate depressive symptoms. Generally, a selective serotonin retake inhibitor (SSRI) or tricyclic antidepressant (available on the WHO essential drugs list) is the treatment of first choice. To start with, antidepressants are prescribed at a low dose and are gradually increased while the client is carefully monitored for side-effects.

For mild to moderate depression, or as an adjunct to pharmacological therapy, therapeutic interventions such as cognitive behavioural therapy have proven effective.

Mania

As with major depression, mania can occur early or late in the course of HIV infection. Clients with mania usually fit into two categories: clients with pre-existing bipolar disorder (manic depressive disorder) and clients with mania as a consequence of HIV involvement. In addition, mania in advanced disease can be associated with cognitive changes or AIDS dementia complex.

Common symptoms of HIV-related mania include the following:

- decreased sleep, increased activity (although often replaced by psychomotor slowing);
- elevated mood (sustained for days or weeks and client is usually irritable);
- over-talkativeness (cannot be interrupted);
- invention of ″grand schemes″;
- attention to unimportant or irrelevant activities;
- sometimes a grandiose belief that he or she has been ″cured″;
- ″racing″ thoughts; and
- cognitive slowing despite elevated mood.

HIV-related mania can differ clinically from the true mania of bipolar disorder in that irritability, rather than true grandiose euphoria, is the core symptom. Clients with late-onset mania (where the first manic episode comes in the late stages of HIV infection) are less likely to have a personal or family history of mania. They are also more likely to have cognitive impairment. Clients with a pre-existing bipolar disorder can develop mania at any time in the course of their HIV infection. Prescribed (including acyclovir and dapsone) and non-prescribed drugs and steroids can cloud and exacerbate the condition.

Treatment. In early-stage HIV infection (seroconversion), the treatment of mania is the standard treatment (benzodiazepines and low doses of neuroleptic drugs). In the ″middle″ stages of HIV progression the treatment is the same as that for manic clients without HIV infection (mood stabilizers, neuroleptic drugs, and benzodiazepines). In the late stages of HIV infection, treatment has to be closely monitored owing to the client’s physiological vulnerability (usually a single neuroleptic is most effective). At this stage of the infection, clients are extremely sensitive to the side-effects of neuroleptic medication. Doses much lower than customary are sufficient. Mania responds well to treatment in HIV clients including those clients with advanced AIDS; however, the treatment period may well be longer than it is for people without HIV.

Anxiety disorders

These disorders are:

- fairly common, up to 20%-40% prevalence; and
- often co-exist with depression and drug or alcohol abuse

Anxiety disorders may be related to HIV-related stressors including highly active antiretroviral therapy (HAART). Diagnosis of anxiety is important as it can affect the capacity of the client to take in information, plan ahead, or adhere to a treatment plan. Anxiety responds well to relaxation, cognitive behavioural treatment, and supportive counselling.

Treatment

Treatment infrequently requires the use of medication-sometimes small doses of sedating antidepressants (tricyclic antidepressants) or short-acting benzodiazepines may be prescribed (there is some risk here of abuse and dependence).

Psychotic disorders

Presenting symptoms include delusions (paranoid, grandiose, and somatic) and auditory hallucinations. Individuals who present with psychosis are unlikely to adhere to treatment or HIV transmission risk reduction.

Psychotic disorders can sometimes be misdiagnosed by health workers with limited mental health training especially in the context of a client presenting with co-morbid drug or alcohol use histories. Often symptoms are wrongly attributed to drug or alcohol use.

Treatment

Antipsychotics such as olanzapine, risperidone, and quintapine are used in the treatment of HIV and psychotic disorders. Small doses initially should assist in reducing the high risk of side-effects, especially Parkinsonian-type symptoms. Benzodiazepines are used for sedation in combination with antipsychotics.

AIDS dementia complex

ADC is a complication of HIV disease that occurs in some patients, usually those with advanced disease. HIV affects the functioning of the normal brain, possibly leading to difficulty with concentration, memory, and speed of thought. A change in personality can also occur, usually manifesting as a lack of interest in previously pleasurable activities. In addition, patients note a degree of clumsiness of the arms and legs. Most patients first notice poor concentration ability. For example, they may find it difficult to read or watch a movie because they cannot follow the plot, or they lose track of the conversation when speaking with people. Memory for day-to-day events also becomes a problem so that patients have to use a diary or rely on someone else to prompt them to do things. Their personality changes, so that they may become apathetic and not care to keep up with friends or perform their hobbies or interests. Motor function also becomes impaired, leading to clumsiness so that patients bump into objects and drop things more easily. These complaints usually develop slowly over several weeks to months. Some patients continue to worsen slowly but most patients remain relatively stable for several more months before they notice any worsening. Sometimes other infections can cause these same symptoms and sometimes depression can lead to very similar complaints.

Once these complaints become obvious it is important to seek medical attention so that other causes can be addressed and treated as required. To address these alternatives, a brain scan as well as blood tests and a lumbar puncture should be performed, and a neuropsychological assessment is often useful. If there is no other cause for the complaints, then it is likely that HIV is disturbing the brain and consideration should be given to changing the anti-HIV drugs so that medications that are better able to attack HIV in the brain can be chosen. There is a good chance that with appropriate treatment the complaints can be improved and in some patients reversed completely. It is important, however, to realize that these treatments can take several weeks and sometimes 2-3 months to work. Thus, the person may require assistance with taking these medications, as decreased motivation and memory problems can be part of their ADC presentation.

ADC in resource-poor settings

As it is unlikely that individuals with ADC in resource-poor settings will get adequate treatment it is important that counsellors learn to recognize symptoms and raise their concerns with HIV medical staff. Significant counselling support can be offered to staff of health facilities, families, and other carers to assist them in managing the many challenging patient behaviours.

Understanding the causes of difficult behaviour

Difficult behaviour can be due to the following:

- stress caused by the excessive demands of a situation;
- frustration caused by miscommunication;
- another underlying illness, such as an opportunistic infection; or
- interactions of alcohol and other drugs.

Supporting people who are caring for somebody with ADC

Somebody who is caring for a person with ADC may begin to notice behaviours that are uncharacteristic or inappropriate to the situation. For example, people may appear to regress in their behaviour or act childishly. At times, coping with such behaviours can be difficult and stressful. However, it is important to remind the carer that the behaviour is usually not deliberate. The person may be having difficulty controlling his or her behaviour and is probably quite frightened. The carer should be informed that the individual often needs reassurance, even though it may not appear that way. Trying to make sense of the environment can become increasingly difficult and as the ADC progresses simple tasks such as bathing, dressing, and eating can become major hurdles to overcome.

People with ADC are often confronted with failure, so maintaining their dignity is most important. While there are common features in the progression of ADC, each individual's response is unique. General guidelines outlining useful strategies for a range of common experiences are given in the box below. If you find that you need more specific assistance then it is recommended that you contact your HIV medical specialist. Carers should be informed that consistency is one of the most important aspects of dealing with people with cognitive impairment and challenging behaviour.

Simple strategies for carers of individuals with ADC

Try to minimize stress

- A calm, unstressed environment where there is a clear, familiar routine can help avoid excessive reactions.
- Speak clearly and use simple sentences, allowing time for response. Do not interrupt the response.
- Give limited choices in order to avoid confusion.
- Try to talk in a place free from distractions (e.g., turn off TV when discussing daily activities).
- Try to focus on familiar skills within the person's capabilities.
- Break a task down into simple steps that are not overwhelming. If possible, encourage the person to help break the task down into steps. This helps to maximize their input and independence.

Modify the environment

- Be aware of situations that lead to difficult behaviours such as aggression and try to avoid them.
- Try to do difficult and frustrating tasks when the person is at his or her best and not tired.
- Use a diary to help monitor when good and difficult times are likely to occur.
- Use pictures or labels on objects that will assist in their identification and location. These are useful as prompts, too, especially in the bathroom during the performance of activities of daily living.
- Try to avoid frustration by adapting the environment to cope with the difficult behaviour. Simplify the environment (e.g., reduce excess "clutter").
- Try to remember that a difficult behaviour may intensify when there is a major change in lifestyle.

Distraction strategies

If there are a few moments before an outburst when you notice the person appears agitated you may be able to prevent the over reaction by calming the person down early.

- First try to respond to the feelings of anger by soothing, comforting, and reassuring the person gently. Then try to defuse the situation by distracting them, and, finally, praise success.
- Alternatively, you could try calmly ignoring the outburst and busying yourself with something else.
- Try to distract a person who is sobbing excessively or laughing uncontrollably because this is not a sign of true emotion and may be very exhausting.

Deal with violence and aggression

Remember that you are dealing with an illness rather than the person. Sometimes the person with dementia may become very violent for a short time. He or she may become verbally abusive, cause damage to property, or become physically violent.

- Try to stay calm and not show fear or alarm. Try not to raise your voice.
- Try to understand that even if the aggression is directed at you, it is not a personal attack.
- Never put your own safety at risk. If the behaviour escalates out of control, remove yourself from the situation, call your doctor or the police, and contact your local mental health crisis team.
- Never try to restrain the person. Try not to argue with the person when he or she becomes upset because at times it may be difficult for him or her to rationalize or be logical. There is no point in trying to reason with the individual. Save your energy and concentrate on trying to remain calm.
- Try not to engage in a way that escalates the behaviour (e.g., arguing or reasoning with the person).
- Try not to be punitive towards the person.

Source: Adapted from materials provided by ADAPTS South Eastern Sydney Area Health Service (South East Health) and Central Sydney Area Health Service (CSAHS) Australia, a service specifically for people with HIV and complex needs, such as may stem from AIDS dementia or a psychiatric illness. http://www.health.nsw.gov.au/adahps/factsheets.html

Annex 4

Burnout risk survey

The questions in the survey do not predict burnout, but might help identify individuals at risk of burnout. For example, answering ”yes” to three of the questions indicates risk; answering ”yes” to more than four questions suggests high risk. The same items can be used to identify corrective actions and hence prevent burnout.

Questions	Yes	No
Do you derive your self-esteem from achievements?		
Is your personal identity tied to your work role or professional identity?		
Do you tend to withdraw from offers of support?		
Do you hesitate to ask for or accept help?		
Do you always make excuses, like ”it is faster to do it myself than to show or tell someone”?		
Do you always prefer to work alone?		
Do you lack a close confidant with whom you feel safe discussing problems?		
Do you ”externalize” blame (obsessively seek to place blame away from yourself)?		
Are your work relationships asymmetrical? Are you always giving?		
Do you have more difficulty making a commitment to yourself to exercise or relax than making a commitment to others?		
Do you overload yourself or have difficulty saying no?		
Do you have few opportunities for positive and timely feedback outside your work role?		

Annex 5

What are psychoactive drugs and substances?[2]

A psychoactive drug is any substance that, when taken by a person modifies perception, mood, thinking (cognition), behaviour, or motor functions. This definition is broad; it includes both licit (legal) and illicit (illegal) substances, those that can lead to dependence (of the individual).

What substances do young people commonly use?

Students may provide a variety of names of different drugs. The facilitator should try to have the students determine which names actually refer to the same drug. It is common to find that a substance has a generic name, a trade name, and at least one street name. The names are not so important. What is important is to be able to recognize the local substances. The following table is for the teacher's reference.

Name	Examples
Alcohol	
Nicotine	Cigarettes, cigars, pipe tobacco, chewed tobacco, snuff
Cannabis	Marijuana, ganja, hashish, bhang
Stimulants	Cocaine, crack, khat, and ”designer” substances such as amphetamines and methamphetamines, ecstasy
Opioids	Codeine, heroin, morphine, opium, buprenorphine, spasmo proxyvon, pentazocine, methadone, oxycodone, fentanyl, pethidine
Depressants	Sleeping pills, benzodiazepines, methaqualone, barbiturates, chloral hydrate
Hallucinogens	Lysergic acid diethylamide (LSD), mescaline, psilocybin, peyote, ayahuasca
Over-the-counter pharmaceutical preparations	Antihistamines, cough syrups, antidiarrhoeal drugs, anti-anxiety drugs
Volatile inhalants solvents, nitrites	Aerosol sprays, butane gas, petrol/gasoline, glue, paint thinners,

What are the different methods of use?

Substances can be taken into the body by many different means. The methods by which substances are taken influence *how quickly* the substance can produce its *effects* and also the different health consequences that the individual may experience. It is important to note that the same type of substance may produce the effect faster or more slowly depending on where, specifically, the substance is introduced. For example, injecting the substance into the muscle will not produce the effect as quickly as injecting it into the veins. Absorption through the mucous membrane of the nose is faster than absorption through other mucous membranes. Below are common ways that people take substances:

- injected with a needle under the skin, into a vein or muscle;
- smoked or inhaled through the mouth or nose;
- placed on a mucous membrane (the nose or under the eyelid);

---

[2] Source: World Health Organization and United Nations International Drug Control Programme. *Primary prevention of substance abuse: A workbook for project operators.*, WHO and UNIDCP, 2003. pp. 17-19.

- chewed, swallowed or dissolved in the mouth; or
- rubbed into the skin.

Effects of drug or alcohol use:[3]

Here it is important to stress the fact that while drug or alcohol use has many desired effects, these effects are outweighed by the negative consequences. The effects of these substances can be short- or long-term. Short-term effects occur shortly after the substance is taken into the body, and these are influenced by the dose, the method of administration, and whether or not the substance is used in combination with other substances. The long-term effects are usually due to damage to the body organs. Other important factors that influence the effects are the individual, the substance, and the setting in which the substance is used. For the individual, this includes the person's physical condition and state of mental health, their expectations about the substance, and their past experiences with the substance. Substance-related factors that influence effect include the dose and method of administration. Lastly, factors involved in the setting can include expectations of others and the nature of materials used to take the substance into the body. Consider the example of a group of young people at a party or an environment where the sharing of needs takes place.

The following two boxes summarize what is known about the effects of the common substances.

Substance	Short-term effects	Long-term effects
Alcohol	Short-term effects include doing things that normally one would stop oneself from doing, possible loss of physical coordination, unclear vision, slurred speech, poor decisions, and impaired memory. Excessive drinking over a short period of time can cause headache, nausea, vomiting, deep unconsciousness, and death.	Drinking large amounts of alcohol regularly over a lengthy period of time can cause loss of appetite, vitamin deficiency, skin problems, depression, loss of sexual drive and memory, and liver and brain damage. Alcohol consumption during pregnancy can lead to fetal alcohol syndrome. Tolerance and dependence also develop.
Nicotine	Some short-term effects are: a feeling of alertness just after using tobacco and then relaxation afterwards, increase in heart rate, and a temporary rise in blood pressure. Dizziness, nausea, and reduced appetite also occur.	Long-term nicotine use can cause heart and lung disease, blockage of arteries (peripheral vascular disease), hypertension, bronchitis, cancer of the lungs, and cancers of the mouth (with pipe smoking and tobacco chewing).
Cannabis	Cannabis may make the individual feel euphoric at first and then relaxed and calm. There are feelings of well-being and relaxation, loss of inhibitions, muscle coordination, and concentration. There may also be increased heart rate, redness of the eyes, and increased appetite. Large quantities can cause panic, hallucinations, restlessness, and confusion. Large doses can also change physical perceptions, in the same way as hallucinogens.	Regular use over a long period of time increases the chance of dependence, causes impairment of cognitive functions, and may worsen existing mental problems.
Opioids	These produce detached and dreamy sensations, sleepiness, and constriction of the pupils of the eyes, nausea, vomiting, and constipation. Overdose leads to unconsciousness, inability to breathe, and death.	Tolerance and physical and mental dependence can develop quickly. Stopping use results in withdrawal syndrome.

---

[3] From World Health Organization and United Nations International Drug Control Programme. *Primary prevention of substance Abuse: A facilitator guide*. WHO and UNIDCP, 2003. pp. 23-25.

Substance	Short-term effects	Long-term effects
Stimulants	Short-term effects include enhanced or increased central nervous system activity, a brief intense feeling of intoxication, and exaggerated feelings of confidence. Soon the mood quickly changes to a low feeling, prompting the person to repeat the dose. Overdose is more common with crack than with other forms of cocaine.	Long-term effects include inability to sleep, irritability, mental health problems, and suspiciousness and mistrust of others (paranoia).
Depressants	Effects are similar to those of alcohol. They slow down a person's thinking and movements and decrease the ability to concentrate. They cause effects such as slurred speech, sleepiness, and problems with coordination, and cause "hangovers". Low doses reduce feelings of anxiety, while higher doses cause sleepiness. Consumption of alcohol (at the same time) increases their effect, and repeated doses cause toxicity because the substance cannot be broken down (metabolized) quickly. Accidents and suicide are common.	Substances in this category can lead to dependence, inability to learn, and problems with coordination. Convulsions can occur when the substance is withdrawn.
Hallucinogens	Hallucinogens can alter a person's mood, the way the person perceives his or her surroundings, and the way the person experiences his or her own body. Things may look, smell, sound, taste, or feel different, and one may see, smell, taste, hear, or feel things that do not exist. For example, the individual may see colours, lights, or images, or have an altered awareness of things happening inside or outside the body. Other short-term effects are feelings of panic, fear, or anxiety. A "bad trip" usually refers to an unpleasant and disturbing mental/emotional state caused by hallucinogens. Accidents and suicide are common.	Tolerance can develop. Many individuals who have used hallucinogens report feeling effects produced by the substance days or even months after last taking the substance. These replays of past effects are often called "flashbacks". Regular use of hallucinogens can decrease memory and concentration. The flashbacks can also result in disorientation, anxiety, and distress.
Volatile inhalants	The individual feels uninhibited at first and drowsy later. With continued inhalation, hallucinations may occur. Other effects include feelings of happiness, relaxation, sleepiness, poor muscle coordination, slurred speech, irritability, and anxiety. The most immediate danger to the individual is "sudden sniffing death".	Although little is known about volatile substances, regular long-term use may lead to nose bleeds, skin rashes around the mouth and nose, loss of appetite, and lack of motivation. Some of the solvents are toxic to the liver, kidney, or heart, and some may cause brain damage. Little is known about the long-term effects of regular inhalant use.

Annex 6

Counselling strategies for reducing disclosure-related violence

Fear of violence is a major barrier to disclosure of HIV status by women to male partners. However, men are also subject to partner, familial, or community-related violence related to disclosure.

Social marketing of HIV testing and counselling (HTC) in communities could target couples and encourage joint HIV testing, as studies demonstrate that where couples test together, or at least discuss the decision to test with each other, the risk of disclosure-related violence is reduced. Counsellors should create opportunities for sexual histories of couples to be undertaken separately. This not only ensures accurate risk assessment but also offers the counsellor an opportunity to foresee potential relationship difficulties that may arise from the disclosure of an HIV-positive result.

Assessment. In addition to engaging in the standard process of disclosure counselling it is important to assess the couple's history and potential for violence, preferably at both pre- and post-test counselling sessions. This should be done with the women in an interview separate from that with her partner and reassuring about confidentiality. The table below shows suggested questions for use in assessing for potential disclosure-related violence. Where the threat is less tangible and there is little to suggest a real threat but the client is anxious, encourage couple disclosure of results with the counsellor. Develop a ″disclosure plan″ with the client and include planning for an aggressive response. It is important that counsellors maintain a referral directory of welfare agencies offering support to women (e.g., shelter from domestic violence).

Suggested questions to use to assess for potential disclosure related violence

"There are some routine questions that I ask all of my clients because some are in relationships where they are afraid their partners or families may hurt them"

"What response would you anticipate from your partner if your test comes back HIV-positive?"

↓

If the client indicates that he or she is fearful or concerned, then proceed as follows:

↓

"Have you ever felt afraid of your partner or family?"

"Has your partner or anybody in your family ever…

- "…pushed, grabbed, slapped, choked, or kicked you?"
- "…threatened to hurt you, your children, or someone close to you?"
- "…stalked or followed you or monitored your movements?"

↓

If the client responds affirmatively to any of these points, add:

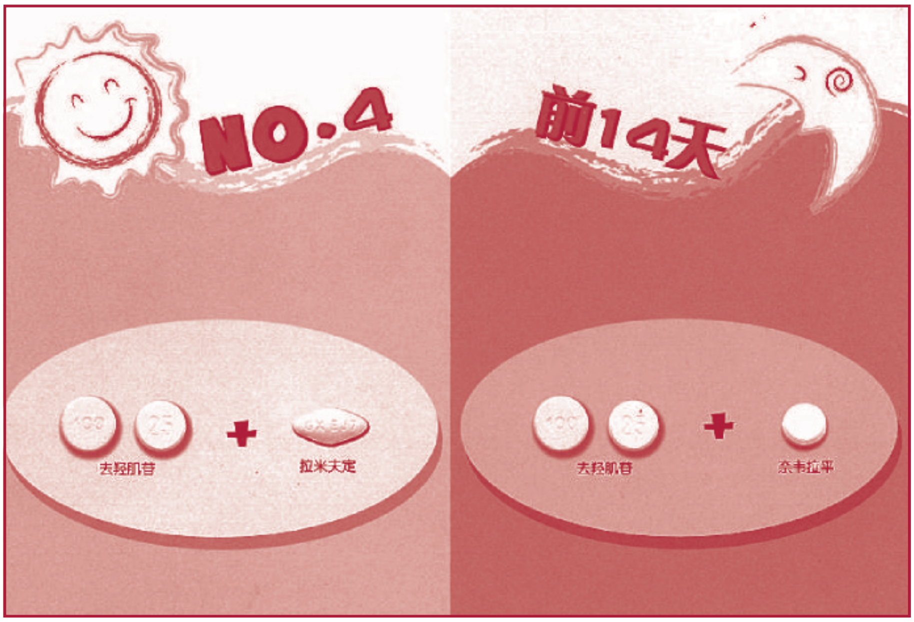
"From what you have told me, do you think telling your partner about your result will result in risk to you or your children's safety?"

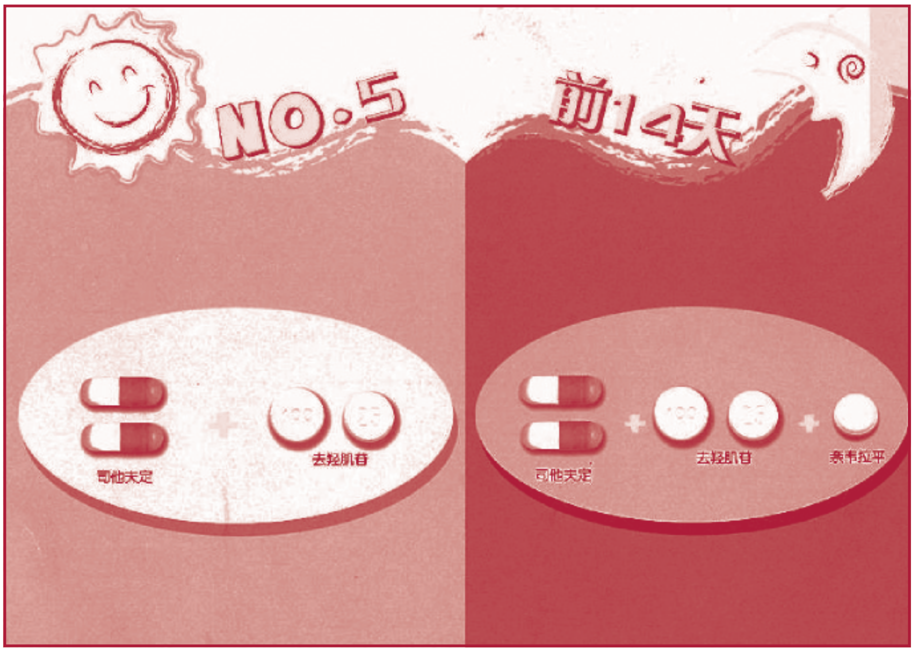
↓

The client should make the decision to disclose on the basis of a realistic appraisal of the threat.

Annex 7

Sample ART patient treatment cue cards





Additional online resources

Additional reading and resources on HIV testing and counselling may be found at a number of sources. A broad selection of tools and guidance for training for and implementing HIV testing and counselling are available on the Internet. For more information, you may also refer to the articles and documents listed in the reference section of this handbook.

Disclaimer: Websites listed here are for information purposes only and their inclusion does not constitute an endorsement by WHO, UNICEF, or FHI.

Antiretroviral[MEA1] therapy and clinical care

WHO. Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: Towards universal access. Recommendations for a public health approach, 2006.
http://www.who.int/hiv/pub/guidelines/pmtctguidelines2.pdf

WHO. Antiretroviral therapy for HIV infection in adults and adolescents: towards universal access. Recommendations for a public health approach, 2006.
http://www.who.int/entity/hiv/pub/guidelines/artadultguidelines.pdf

WHO. Antiretroviral therapy of HIV infection in infants and children: Towards universal access. Recommendations for a public health approach, 2006.
http://www.who.int/hiv/pub/guidelines/paediatric020907.pdf

WHO. ARV Toolkit. http://who.arvkit.net/arv/en/index.jsp, PDF version:
http://whqlibdoc.who.int/hq/2003/9241591161.pdf

WHO. Integrated management of adolescent and adult illness (IMAI) and integrated management of childhood illness (IMCI). Various documents. http://www.who.int/hiv/pub/imai/en/

WHO Regional Office for South-East Asia. Management of HIV infection and antiretroviral therapy in infants and children: A clinical manual, 2006.
http://www.searo.who.int/LinkFiles/AIDS_Management_of_HIV_infection.pdf

WHO Regional Office for South-East Asia. Management of HIV infection and antiretroviral therapy in adults and adolescents: A clinical manual, 2007.
http://www.searo.who.int/LinkFiles/Publications_Management_HIV_infection_antiretroviral_therapy_adults_adolescents.pdf

HIV and STIs

Sydney, Australia Health Services. STI information website. http://www.whytest.org

University of California San Francisco. HIV InSite. What are STDs and how do they relate to HIV infection? http://hivinsite.ucsf.edu/hiv?page=basics-00-15

US Centers for Disease Control. STD site. http://cdc.gov/std/

WHO. Guidelines for the management of sexually transmitted infections, 2004.
http://www.who.int/entity/hiv/pub/sti/en/STIGuidelines2003.pdf

WHO. HIV and STI site. http://www.who.int/hiv/pub/sti/en/

HIV and TB

US Centers for Disease Control. HIV-TB webpage.
http://www.cdc.gov/hiv/resources/factsheets/hivtb.htm

US Centers for Disease Control and WHO. Testing and counselling in TB clinical settings: Tools, 2007.
http://www.cdc.gov/nchstp/od/gap/pa_hiv_tools.htm

Module one: Introduction, background, and rationale
http://www.cdc.gov/nchstp/od/gap/docs/tb_tools/TB%20Module%201_12.6.06.pdf

Module two: Understanding the provider-initiated and -delivered HIV testing and counselling process in the context of TB clinical settings
http://www.cdc.gov/nchstp/od/gap/docs/tb_tools/TB%20Module%202_12.7.06.pdf

Module three: Preparing the provider to perform PTC
http://www.cdc.gov/nchstp/od/gap/docs/tb_tools/TB%20Module%203_12.12.06.pdf

Module four: Administrative, implementation, and standard operating procedures
http://www.cdc.gov/nchstp/od/gap/docs/tb_tools/TB%20Module%204_12.13.06.pdf

Module five: Clinical considerations
http://www.cdc.gov/nchstp/od/gap/docs/tb_tools/TB%20Module%205_12.6.06.pdf

Module six: Demonstration clinic
http://www.cdc.gov/nchstp/od/gap/docs/tb_tools/TB%20Module%206%20Demo_12.1.06.pdf

WHO. TB and HIV Site. http://www.who.int/hiv/pub/tb/en/

Counselling practices (ethics and effectiveness)

FHI. VCT Toolkit for voluntary counselling and testing for HIV: A strategic framework, 2003.
http://www.fhi.org/en/HIVAIDS/pub/guide/VCT_HIV_Strategic_Frame.htm

FHI. VCT Toolkit for HIV voluntary counselling and testing: Skills training curriculum participant's manual, 2005. http://www.fhi.org/en/HIVAIDS/pub/guide/vcttrain2.htm

FHI. VCT Toolkit trainer's manual: Counselling supervision and training, 2005.
http://www.fhi.org/en/HIVAIDS/pub/guide/VCTToolkitCounseling.htm

FHI. VCT reference guide, 2004. http://www.fhi.org/en/HIVAIDS/pub/guide/vcttoolkitref.htm

Behaviour change

Change Project. (from 2005). http://www.changeproject.org/

EngenderHealth. Behaviour Change. http://www.engenderhealth.org/res/onc/hiv/preventing/hiv6p3.html

Motivational interviewing: Resources for clinicians, researchers and trainers.
http://www.motivationalinterview.org/

Population Services International. Social marketing approach to VCT, 2004.
http://www.aidsmark.org/resources/pdfs/vct-brochure.pdf

HIV counselling and testing

FHI. Counselling and Testing for Youth.
http://www.fhi.org/en/Youth/YouthNet/rhtrainmat/vctmanual.htm

FHI. Counselling and Testing, VCT webpage.
http://www.fhi.org/en/Topics/Voluntary+Counseling+and+Testing+topic+page.htm

FHI. Current issues in HIV counselling and testing in South and Southeast Asia, 2003.
http://www.fhi.org/en/HIVAIDS/pub/survreports/Current+Issues+In+South+and+Southeast+Asia.htm

PEPFAR. VCT page. http://www.pepfar.gov/pepfar/press/76382.htm

UNAIDS. Testing and Counselling web page.
http://www.unaids.org/en/PolicyAndPractice/CounsellingAndTesting/default.asp

WHO. Guidance on provider initiated testing and counselling in health settings, 2007.
http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf

WHO. Testing and Counselling Toolkit. http://www.who.int/hiv/topics/vct/toolkit/en/index.html

WHO Regional Office for South-East Asia. *Voluntary Counselling and Testing: Manual for Training of Trainers*, New Delhi, 2004.
http://www.searo.who.int/en/Section10/Section18/Section1562.htm

Suicide

Suicide Awareness. Voices of Education. http://www.save.org/

US Dept of Health. Suicide prevention resource center. http://www.sprc.org/

US National Institute of Mental Health.
http://www.nimh.nih.gov/health/topics/suicide-prevention/index.shtml

WHO. Dept. of Mental Health: suicide prevention.
http://www.who.int/mental_health/prevention/suicide/suicideprevent/en/index.html

HIV care counselling

The Body HIV and AIDS Resource. Mental Health.
http://www.thebody.com/Forums/AIDS/Mental/index.html

NSW Australia. AIDS Dementia & HIV Psychiatry Service, http://www.health.nsw.gov.au/adahps/

WHO. HIV Psychosocial support. http://www.who.int/hiv/topics/psychosocial/support/en/

UNAIDS. Access to Care and Support.
http://www.unaids.org/en/PolicyAndPractice/CareAndSupport/default.asp

UNAIDS. Psychological Help.
http://www.unaids.org/en/PolicyAndPractice/CareAndSupport/PsychoSupport/

US Dept of Health. Mental Health Information: HIV/AIDS
http://mentalhealth.samhsa.gov/cmhs/HIVAIDS/

Disclosure

STIGMA. Disclosure e-postcards. http://www.whytest.org/postcards/index.php

UNAIDS. Opening up the HIV/AIDS epidemic, 2000. http://data.unaids.org/Publications/IRC-pub05/JC488-OpenUp_en.pdf and http://whqlibdoc.who.int/unaids/2000/UNAIDS_00.42E.pdf

WHO. Gender Dimensions of. HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes, 2004. http://www.who.int/gender/documents/en/genderdimensions.pdf

ART adherence

FHI. Adherence Support Worker Training Materials, 2007.
http://www.fhi.org/en/HIVAIDS/pub/res_ASW_CD.htm

Synergy Project. www.synergyaids.org/documents/mombasaarvtrainingguide.pdf

University of California San Francisco. HIV InSite, ARV Management: Knowledge Base Chapters and Related Resources. http://hivinsite.ucsf.edu/insite?page=ar-00-00-01

WHO. Medicines Publications and Documentation, www.who.int/medicinedocs/index.fcgi

Special needs

The Body HIV and AIDS Resource. http://www.thebody.com/sitemap.html

FHI. Current Issues in HIV Counselling and Testing in South and Southeast Asia, 2003.
http://www.fhi.org/en/HIVAIDS/pub/survreports/Current+Issues+In+South+and+Southeast+Asia.htm

Transgender Care. What is Gender and Who is Transgendered?
http://www.transgendercare.com/guidance/what_is_gender.htm

WHO. Mother-to-child transmission of HIV. http://www.who.int/hiv/mtct/en/index.html

WHO. Prevention, treatment and care for injecting drug use (IDU) and prisons.
http://www.who.int/hiv/idu/en/index.html

WHO. Post-exposure prophylaxis to prevent HIV infection, 2008,
http://whqlibdoc.who.int/publications/2007/9789241596374_eng.pdf

Children and adolescents

FHI. Testing and counselling for youth, 2007.
http://www.fhi.org/en/Youth/YouthNet/rhtrainmat/vctmanual.htm

UN. Convention on the Rights of the Child, 1989.
http://whqlibdoc.who.int/publications/1998/9211541301.pdf

UN. Convention on the Rights of the Child General Comment No 3: HIV/AIDS and the rights of the child, 2003. http://whqlibdoc.who.int/publications/2002/9291730254.pdf

WHO. Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings, 2008. http://www.who.int/entity/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf

WHO, UNICEF, UNAIDS, UNFPA. HIV and infant feeding update, October 2006.
http://whqlibdoc.who.int/publications/2007/9789241595964_eng.pdf

Most-at-risk populations

UNAIDS. Strategies for involvement of civil society in HIV testing within context of ”3 by 5”: Focus on marginalized communities, 2004. http://data.unaids.org/Topics/Human-Rights/hr_refgroup3_06_en.pdf

WHO. Online sex work toolkit (Web site: http://who.arvkit.net/sw/en/index.jsp; PDF version: http://www.who.int/entity/hiv/pub/prev_care/sexworktoolkit.pdf)

WHO. Prevention, treatment and care for injecting drug use (IDU) and prisons. http://www.who.int/hiv/idu/en/index.html

Women and girls

The Body – HIV Resource. Ask the experts about women and HIV. http://www.thebody.com/Forums/AIDS/Women/

CDC, WHO, UNICEF, USAID and PMTCT implementing partners. Testing and Counselling for Prevention of Mother-to-Child Transmission of HIV (TC for PMTCT) Support T ools. http://www.who.int/hiv/pub/vct/tc/en/index.html

WHO. Nutrition counselling, care and support for HIV-infected women, 2004. http://whqlibdoc.who.int/publications/2004/9241592125.pdf

WHO. Addressing violence against women in the context of HIV testing and counselling – a meeting report, 2006. http://www.who.int/gender/documents/VCT_addressing_violence.pdf

WHO. Briefing Note - HIV and Infant Feeding. Conference on Retroviruses and opportunistic infections. Los Angeles, 25-28 Feb 2007. http://www.who.int/hiv/mediacentre/Infantfeedingbriefingnote.pdf

WHO and CDC. Prevention of mother-to-child transmission of HIV: generic training package, 2004. http://www.cdc.gov/nchstp/od/gap/PMTCT/

WHO and UNFPA. Sexual and reproductive health of women living with HIV/AIDS, 2006. http://whqlibdoc.who.int/publications/2006/924159425X_eng.pdf

Women, Children and HIV. Testing and counselling page. http://www.womenchildrenhiv.org/wchiv?page=wx-t2&root=top&cat=01&subcat=vc

Grief and bereavement

HelpGuide.org. Coping with grief and loss. http://www.helpguide.org/mental/grief_loss.htm

MentalHelp.net. http://www.mentalhelp.net/poc/center_index.php?id=58

UNAIDS. Psychological support webpage. http://www.unaids.org/en/PolicyAndPractice/CareAndSupport/PsychoSupport/

UNAIDS. The Positive Partnerships Program in Thailand: Empowering People Living with HIV, 2007. http://data.unaids.org/pub/Report/2007/jc1362-pppthailand_en.pdf

Counsellor self care

UNAIDS. Caring for the carers, 2000.
http://data.unaids.org/Publications/IRC-pub02/JC717-CaringCarers_en.pdf

UNAIDS. Preventing carer burnout: Inter-Mission Care and Rehabilitation Society (IMCARES), 2008.
http://data.unaids.org/pub/Report/2008/jc1384_imcares_full_en.pdf

HIV rapid testing

CDC and WHO. Guidelines for assuring the accuracy and reliability of HIV rapid testing: applying a quality system approach, 2005.
http://www.who.int/diagnostics_laboratory/publications/HIVRapidsGuide.pdf

CDC and WHO. Training package for HIV rapid testing, 2006.
http://www.phppo.cdc.gov/dls/ila/hivtraining/default.aspx

WHO. HIV diagnostics webpage. http://www.who.int/hiv/amds/diagnostics/en/index.html

UNAIDS/WHO. Revised recommendations for the selection and use of HIV antibody tests, 1997.
http://www.who.int/docstore/wer/pdf/1997/wer7212.pdf

WHO/UNAIDS. The importance of simple/rapid assays in HIV testing, 1998.
http://www.who.int/docstore/wer/pdf/1998/wer7342.pdf

Legal and policy issues in testing and counselling

UNAIDS and IPU. Handbook for legislators on HIV/AIDS, law and human rights, 1999.
http://whqlibdoc.who.int/unaids/1999/UNAIDS_99.48E.pdf

UNAIDS and OHCHR. HIV/AIDS and human rights - international guidelines, 1996.
http://whqlibdoc.who.int/publications/1998/9211541301.pdf

UNAIDS and OHCHR. International guidelines on HIV/AIDS and human rights (consolidated version), 2006. http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

UNAIDS and WHO. Policy statement on HIV testing, 2004.
http://data.unaids.org/unadocs/hivtestingpolicy_en.pdf

References

Baker, A., Dawe, S. (2005). Amphetamine use and co-occurring psychological problems: Review of the literature and implications for treatment. *Australian Psychologist*, 40(2), 87-94.

Beyer, J.L., Taylor, L., Gersing, K.R. and Krishnan, K.R. (2007). Prevalence of HIV infection in a general psychiatric outpatient population. *Psychosomatics*, 48(1), 31-37.

Brew, B.J. and Gonzales-Scarano, F. (2007). HIV-associated dementia: an inconvenient truth. *Neurology*, 68(5), 324-325.

Carvalhal, A.S., Rourke, S.B., Belmonte-Abreu, P., Correa, J. and Goldani, L.Z. (2006) Evaluation of neuropsychological performance of HIV-infected patients with minor motor cognitive dysfunction treated with highly active antiretroviral therapy. *Infection*, 34(6), 357-360.

Chader, G., Himelhoch, S., and Moore, R.D. (2006). Substance abuse and psychiatric disorders in HIV-positive patients: epidemiology and impact on antiretroviral therapy. *Drugs*, 66(6), 769-789.

Forsyth, B.W. (2003). Psychological aspects of HIV infection in children. *Child Adolesc. Psychiatr. Clin. N. Am (United States)*, 12(3), 423-437.

Huba, G.H., Panter, A.T., Melchior, L.A., Anderson, D., Colgrove, J., Driscoll, M., et al. (2000). Effects of HIV/AIDS education and training on patient care and provider practices: a cross-cutting evaluation. *AIDS Educ Prev*, 12(2), 93-112.

ITECH. (2006). *Working with MSM: A Training for Health Care Providers*. Retrieved 10 April, 2007, from http://www.go2itech.org/itech

Kelly, B., Raphael, B., Burrows, G., Judd, F., Kernutt, G., Burnet, P., et al. (2000). Measuring psychological adjustment to HIV infection. *Int J Psychiatry Med*, 30(1), 41-59.

Panter, A.T., Huba, G.J., Melchior, L.A., Anderson, D., Driscoll, M., German, V.F., et al. (2000). Trainee characteristics and perceptions of HIV/AIDS training quality. *Eval Health Prof*, 23(2), 149-171.

Scharko, A.M. (2006) DSM psychiatric disorders in the context of pediatric HIV/AIDS. *AIDS Care*, 18(5), 441-445.

Trotta M.P., Ammassari, A., Murri, R., Monforte, A., and Antinori, A. (2007). Sexual dysfunction in HIV infection. *Lancet*, 369(9565), 905-906.

Turton, C.G., C.K.B., Cairns D.P., Kaewduangjai, P. (2004) *HIV voluntary counselling and testing (VCT): Implementation of a training-of-trainers (TOT) program in Thailand*. Paper presented at the XV International AIDS Conference, Bangkok.

UNAIDS (2000). *Opening up the HIV/AIDS epidemic: Guidance n encouraging beneficial disclosure, ethical partner counselling and appropriate use of HIV case reporting*. (Vol. UNAIDS/00.42E (English original)). Geneva: UNAIDS/WHO.

UNAIDS (2000). *Preventing the transmission of HIV among drug abusers- position paper of the United Nations System*. Geneva: Joint United Nations Programme on AIDS.

UNAIDS (2000). *Technical update: Voluntary counselling and testing (VCT)*. Geneva: Joint United Nations Programme on AIDS.

WHO (2004). *Testing and counselling toolkit*. Retrieved 6 December, 2004, from http://who.arvkit.net/tc/en/index.jsp

WHO (2006). *WHO case definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-Related Diseases in Adults and Children*. Geneva: World Health Organization.

WHO (2007) *Guidance on provider-initiated HIV testing and counselling in health facilities*. Retrieved July, 2007 from http://www.who.int/hiv/topics/vct/PITCguidelines.pdf

WHO (2007) *Management of HIV infection and antiretroviral therapy in adults and adolescents – a clinical manual*. WHO Technical Publication No. 58.

WHO (2008) *Post-exposure prophylaxis to prevent HIV infection*

WHO Regional Office for South-East Asia (2007) *Management of HIV infection and antiretroviral therapy in adults and adolescents – a clinical manual*

WHO Regional Office for South-East Asia (2007) *Management of HIV infection and antiretroviral therapy in infants and children – a clinical manual*

WHO, UNICEF, UNAIDS, UNFPA (2006) *HIV and infant feeding update*

Wong V., Macleod I, Gilks C. Higgins D., Crowley S. (2006) The lost children of universal access – issues in scaling-up HIV testing and counselling. *Vulnerable children and youth studies*, 1(1); 44-55

UNICEF East Asia and Pacific Regional Office
19 Phra Atit Road
Bangkok 10200, Thailand
Tel: (66 2) 356-9499
Fax: (66 2) 280-7056
E-mail: eapro@unicef.org
www.unicef.org/eapro