

VCT TOOLKIT

HIV Voluntary Counseling and Testing: A Reference Guide for Counselors and Trainers

January 2004

Family Health International



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ACKNOWLEDGMENTS

Family Health International's Institute for HIV/AIDS is proud to introduce *HIV Voluntary Counseling and Testing (VCT): A Reference Guide for Counselors and Trainers*. This reference guide was developed for trainers, counselors in training, and working counselors to highlight the links between VCT and HIV/AIDS prevention, care, and support. The guide also highlights the synergies among prevention, care, and support activities. It would not have been possible without input from many people working in VCT around the world. We express sincere gratitude to our training participants, including those in the field who took time to share the fruits of their labor. They and other colleagues provided creative inspiration, technical input, practical guidance, and editorial review.

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ACRONYMS

AIDS.....	Acquired immunodeficiency syndrome
ARV.....	Antiretroviral
CDC.....	Centers for Disease Control and Prevention
CSW.....	Commercial sex worker
EIA.....	Enzyme immune assay
ELISA.....	Enzyme-linked immunosorbent assay
EUA.....	Exploration, understanding, action
GUS.....	Genital ulcer syndrome
HAART.....	Highly active antiretroviral therapy
HBC.....	Home-based care
HIV.....	Human immunodeficiency virus
HPV.....	Human papilloma virus
IEC.....	Information, education, and communication
MTCT.....	Mother-to-child transmission
NGO.....	Nongovernmental organization
NNRTI.....	Non-nucleoside reverse transcriptase inhibitor
NRTI.....	Nucleoside reverse transcriptase inhibitor
OI.....	Opportunistic infection
OVC.....	Orphans and vulnerable children
PCM.....	Protein calorie malnutrition
PCR.....	Polymerase chain reaction
PCP.....	Pneumocystis carinii pneumonia
PI.....	Protease inhibitor
PLHA.....	People living with HIV/AIDS
RIPA.....	Radio-immunoprecipitation assay
STI.....	Sexually transmitted infection
TB.....	Tuberculosis
TCEUA.....	Trust, communication, empathy, understanding, action
UNAIDS.....	Joint United Nations Programme on HIV/AIDS
VCT.....	Voluntary counseling and testing
WHO.....	World Health Organization
ZDV.....	Zidovudine

PREFACE

HIV voluntary counseling and testing (VCT) services provide a critical entry point to both HIV/AIDS prevention and care and support of infected and affected individuals. Over the past decade, the scope of VCT has evolved from a diagnostic tool for symptomatic patients to an essential component of HIV prevention efforts. With improved interventions to reduce mother-to-child transmission (MTCT), increased access to more affordable antiretroviral (ARV) drugs, and effective prophylactic treatment of opportunistic infections (OIs), providing VCT to the general public has become an urgent priority.

There is clearly a need to strengthen and expand VCT services in resource-poor countries, where 95 percent of new HIV infections occur. Though significant efforts are being made to expand the scope and scale of VCT programs worldwide, the vast majority of people are unaware of their HIV status. Knowledge of one's HIV status plays the most significant role in modifying behavior to either remain uninfected or to prevent infecting current or future partner(s). Despite its importance, there are several barriers to widespread expansion of VCT services. These include lack of government involvement, limited financial resources, and fear of stigma and discrimination. The dearth of appropriately trained counselors and health providers presents a primary obstacle to establishing and maintaining high-quality VCT services.

HIV Voluntary Counseling and Testing (VCT): A Reference Guide for Counselors and Trainers is an extremely valuable tool to address these challenges. It equips users with the competence and confidence to provide comprehensive, quality, and culturally appropriate services. Increased quality of services will lead to greater acceptance and utilization of VCT services. The reference guide includes discussion of: training and skills-building materials; sensitive HIV testing issues; basic counseling concepts; skills and coping mechanisms; standardized strategies to promote behavior change; and quality assurance systems. This diverse collection of information will benefit all involved in HIV/AIDS prevention, care, and support efforts, including health care providers, counseling professionals, community workers, and people living with HIV/AIDS.

The authors have distinguished this reference guide from others by highlighting the *interactions* among prevention, care, and support activities and emphasizing the link between VCT and the HIV/AIDS prevention-to-care continuum. This is an important step in combating the spread of the epidemic and mitigating its impact on those infected and affected by HIV. This is a valuable contribution to the future of effective HIV VCT and to enhancing prevention, care, support, and treatment efforts.

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OVERVIEW

Why is this reference guide needed?

Who will use this reference guide?

What are the objectives of the reference guide and training course?

The rate of transmission of the human immunodeficiency virus (HIV) has stabilized or decreased in some countries. But in many countries, especially in sub-Saharan Africa and parts of Asia, HIV transmission continues to increase among both adults and children. High infection rates have contributed to growing awareness of the worldwide epidemic but not to corresponding levels of behavior change. One reason for this paradox is the lack of suitable counseling and testing services in many countries.

In recent years, demand for voluntary counseling and testing (VCT) services has increased alongside understanding that seeking basic health care can extend the lives of people living with HIV/AIDS (PLHA). VCT centers can refer clients for medical care, which has encouraged community members to seek out the services. Studies have shown that once the public has accepted VCT services, more clients are likely to request VCT for social reasons, such as premarital testing and life planning, rather than solely for medical reasons.

Any attempt to prevent new infections and improve the quality of care for PLHA must begin by enabling people to learn their HIV status if they so choose. VCT is recognized as a critical entry point to prevention, care, and support services. VCT prevents new infections by helping clients assess their risk and change their behavior, and by linking clients with interventions to reduce mother-to-child transmission of HIV (MTCT). VCT services contribute to improved care and support of PLHA through early and appropriate referral for treating and preventing tuberculosis (TB), sexually transmitted infections (STIs), and opportunistic infections (OIs), as well as referral for nutritional services, legal aid, spiritual support, home-based care (HBC), and antiretroviral therapy for HIV (ART).

Given the critical role of VCT in HIV prevention, care, and support, counselors must be properly trained and supported to provide effective, high-quality services. *HIV Voluntary Counseling and Testing (VCT): A Reference Guide for Counselors and Trainers* is a handbook to aid counselors

in their work. It outlines key activities and information related to training in and provision of VCT services.

The accompanying Trainer's Manual provides teaching methodologies, including demonstrations, role-playing, supervised practice, desensitization, and negotiating skills. The Trainer's Manual contains worksheets and checklists for practical sessions, and texts for demonstrations and exercises to be conducted during the training course. The reference guide assumes that country-specific national guidelines for developing and providing VCT services will be in place. Thus, trainers from each country are encouraged to organize and facilitate training that conforms to national VCT guidelines.

HIV Voluntary Counseling and Testing (VCT): A Reference Guide for Counselors and Trainers includes content from a variety of HIV/AIDS counseling manuals and materials. It is a generic document; it should be adapted to suit specific sociocultural contexts. The reference guide should be seen as a living document to be revised as often as needed to provide up-to-date information on delivering high-quality VCT services. For training purposes, contents of this reference guide may be supplemented with other resource materials.

The reference guide is organized into 11 chapters:

- Chapter 1 presents basic information about HIV/AIDS and other STIs.
- Chapter 2 explores HIV testing issues.
- Chapter 3 outlines basic counseling concepts, features, and skills.
- Chapter 4 addresses strategies to promote behavior change.
- Chapter 5 discusses the pre- and post-test counseling framework in the context of VCT.
- Chapter 6 illustrates the physical and psychological aspects of care, coping, and social support.

- Chapter 7 addresses counseling and testing for specific groups (i.e., youth, couples, women, and children).
- Chapter 8 focuses on loss and bereavement related to HIV/AIDS.
- Chapter 9 explores counselor support, burnout, and stress management.
- Chapter 10 outlines the importance of VCT-related monitoring, supervision, and quality assurance.
- Chapter 11 reviews ethical issues related to HIV counseling and testing.

Why is this reference guide needed?

Many reference guides address training in HIV counseling, but none adequately address the interactions among prevention, care, and support activities. This reference guide is designed to highlight the link between VCT and the HIV/AIDS prevention-to-care continuum.

Who will use this reference guide?

The reference guide is intended for trainers, counselors in training, and working counselors. Users may include:

- Nurses, doctors, social workers, and other care providers;
- Counseling professionals (including psychiatrists, psychologists, and family therapists);
- Community-based workers;
- PLHA.

What are the objectives of the reference guide and training course?

The main objective of the reference guide is to provide counselors with background information and knowledge about VCT-related issues. The reference guide offers in-depth analysis of the main elements addressed in VCT training:

- Learning to know one's self;
- Understanding the basic facts about HIV/AIDS, counseling, testing, behavior-change strategies, and HIV/AIDS prevention, care, and support issues;
- Building professional and ethical relationships with clients to facilitate HIV/AIDS-related behavior change; assess the psychosocial needs of clients; and provide necessary support and/or referral.

VCT training prepares counselors to:

- Feel comfortable discussing sensitive issues, such as sexual behavior and stigma and discrimination;
- Understand the importance of ethics and human rights to VCT, particularly as they relate to confidentiality of information and HIV testing;
- Differentiate among counseling, health education, and advising;
- Provide counseling, testing services, and factual health education on HIV/AIDS and other STIs;
- Provide information on the increased risk of HIV transmission associated with other STIs and refer for STI management;
- Assess risk and develop individualized risk-reduction plans with clients; assess potential individual and social barriers to behavior change related to HIV prevention, care, and support;
- Prepare clients for HIV testing and provide them with confidential knowledge of their status;
- Facilitate disclosure of results, when appropriate, including notification of sexual partners;
- Respond to clients' immediate psychological support needs following notification of HIV test result (especially for clients with a positive result);
- For HIV-positive clients, provide appropriate preventive, psychosocial, and medical referrals for treating and preventing OIs; assess and address suicidal ideation following a positive test result; and explore issues related to living with HIV/AIDS.
- Monitor and evaluate VCT services.

BACKGROUND

The evolution of HIV counseling and testing: where are we now?

Now more than ever, the benefit of knowing one's HIV status is apparent. Increasingly, people can take advantage of a variety of prevention, treatment, care, and support options when they are aware of their HIV status. However, alarmingly few people who need to know their HIV status have access to such services. Voluntary Counseling and Testing (VCT) has been a major strategy for increasing access to knowing one's serostatus (see Box 1).

Box 1- Benefits of knowing one's HIV status

At Individual level

- Creates more realistic self-perception of client's vulnerability to HIV
- Promotes or maintains behaviors to prevent acquisition or further transmission of HIV
- Alleviates anxiety, and facilitates understanding and coping
- Facilitates entry to interventions to prevent mother to child transmission of HIV
- Helps client to plan and make informed choices for the future
- Leads to early referral to HIV specific clinical care, treatment, and support

At community level

- Creates peer educators, and mobilizes support for appropriate responses
- Reduces denial, stigma and discrimination; and normalizes HIV/AIDS.

The World Health Organization (WHO) and major international public health organizations¹ have drawn urgent attention to the need to rapidly increase access to knowing one's HIV status. They have advocated the requirement to increasingly implement innovative strategies to delivering HIV counseling and testing in more settings and on a much larger scale so that more individuals

can make use of the above benefits. All such innovations need to satisfy the minimum requirements of ensuring the voluntary nature of HIV testing, informed consent, confidentiality, and access to high quality supportive counseling (see Box 2).

This reference manual attempts to support such strategic thinking. Different outcomes (e.g. clinical care or HIV prevention goals) require different approaches to delivering HIV testing and counseling in different settings, of which counselors should be aware. However, all innovations or adaptations must satisfy those recommended and internationally required standards of care to be effective and ethically sound.

Box 2- Core Principles for HIV counseling and testing²

- HIV testing should be voluntary (mandatory testing is neither effective nor ethical)
- Informed consent should be obtained although it may vary in different context and settings. Elements to ensure true informed consent for HIV testing include: Providing pre-test information on purpose of testing and offering information on treatment and support available once results are known; ensuring understanding; and respecting individual autonomy
- Confidentiality must be protected
- Post-test support and service are crucial

¹ For further information please refer to the following two documents: 1. The article by WHO- "The right to know- New approaches to HIV counselling and testing. WHO / HIV/2003/08. 2. The revised guidelines for HIV counselling and testing and referral and recommendations for HIV screening of pregnant women from the CDC- Morbidity and Mortality weekly report (MMWR) November 9,2001/Vol.50/no. RR-19.

² Adapted from "The right to know: New approaches to HIV counselling and testing." WHO/HIV/2003/08

Evolution of HIV testing and counseling services

In the 1980s

The first ‘VCT’ model came about in developed countries in an era of high stigma and fear, when there was little or no access to HIV treatment. The approach in the 1980s emphasized being voluntary and with informed consent and placed a strong significance on its contribution to meeting HIV prevention goals. The core components—defined and endorsed by number of agencies including WHO and U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)—included pre-test counseling, HIV testing, and post-test counseling. In ‘86 CDC published VCT guidelines focusing on the need for testing and confidentiality; and in ‘87 they were revised to emphasize the need to reduce barriers to counseling and testing, especially by protecting personal information.

In the 1990s

With increased access to drugs for treatment of HIV diseases and for prevention of mother to child transmission in the ‘90s, benefits of knowing one’s serostatus increased dramatically. Studies showed that VCT could be a cost effective intervention in developing countries including low prevalence settings. As the cost per client of VCT declined, VCT was considered a basic prevention strategy, resulting in increased donor and government support. The CDC guidelines were revised in ‘93 to focus on a model of interactive personalized risk reduction, and again in ‘94 with an emphasis on linking standard VCT procedures with treatment goals.

Current thinking

There is now consensus among various agencies that VCT provides the synergy between HIV prevention and care and treatment, primarily because the most effective HIV prevention and care activities require people to know their status. VCT facilitates early referral to care and support including access to anti-retroviral therapy, and links with interventions for prevention of mother to child transmission (pMTCT), treatment of sexually transmitted infections (STI), prevention of Tuberculosis (TB) and other Opportunistic infections (OI). In addition, there is agreement that VCT still plays a critical role in prevention: studies demonstrate that VCT promotes and sustains behavior change. The current thinking around VCT is that it needs to be scaled up using innovative strategies so that more people can know their HIV status.

Recently, CDC and WHO guidelines were revised allowing for flexibility of counseling approach and to ensure that services are available: for those who want to know their HIV status, wherever medically indicated in the context of clinical care, and as part of services for preventing HIV in mothers and their infants. In addition, it is stressed that regardless of the HIV testing approach and target group being addressed, there is a need to safeguard and maintain the core principles—voluntary, pre-test information, informed consent, and post-test support and confidentiality.

Suggested approaches for VCT services delivery for these different groups

Different strategies are proposed to offer maximum coverage and ensure accessibility, acceptability and affordability of VCT services, especially for those who want to know, those who are medically indicated, and those seeking VCT services context of antenatal care.

For those wanting to know

- Traditional VCT approach is recommended with emphasis to HIV prevention goals, as the potential for behavior change is generally high. This is the most costly and difficult approach to scale up.
- The proposed target group should include-
 - › Young people- although barriers to services must be explored and removed.
 - › High risk groups regardless of sero-prevalence rates.

For those who are medically indicated in clinical care settings

- WHO recommends that HIV testing and counseling should be considered as standard of care for:
 - › Patients with signs and symptoms of HIV infection or AIDS
 - › To support clinical diagnosis and treatment
 - › For TB patients regardless of sero-prevalence rates
- Both medical and psychosocial considerations should be included in a comprehensive care package or treatment plan for these individuals.
- In sexual and reproductive health care settings, the counseling process ought to address sexual and reproductive health care needs, as well as HIV prevention.

For those seeking VCT services in the context of preventing HIV infection in mothers and their infants³

- In this situation, clients may not have considered the risk of HIV, may not be ready to undergo testing, and may have misgivings about confidentiality procedures.
- In high prevalence areas, HIV counseling and testing should be offered to all pregnant women as part of standard care and the approach could be “opt in” or “opt out.”⁴
- For primary prevention of HIV infection among pregnant women, or reduction of unintended pregnancies among HIV positive women, this can be done as part of traditional VCT services or in relationship with other services such as family planning.

³ WHO advocates a four-prong strategy to reduce the number of HIV-positive infants: 1) Prevent HIV infection among women, especially young women; 2) Reduce unwanted pregnancy in HIV-positive women; 3) Prevent the transmission of HIV from infected women to their babies (during pregnancy, labor and delivery, and breastfeeding); 4) Provide care and treatment to women and their babies and families.

⁴ Low uptake of HIV testing has been observed in many antenatal care settings that use an “opt-in” strategy for HIV testing, in which clients are offered counseling and then asked whether they wish to be tested. To increase uptake, “opt-out” strategies, are an alternative approach to HIV testing; using this strategy, all clients are offered HIV testing, though they may decline (and thus opt out) during the informed consent procedure. In some programmes, post-test counseling of HIV-negative women is not carried out, in order to save time and resources, though this may result in a missed opportunity for prevention counseling.

CHAPTER 1

BASIC INFORMATION ABOUT HIV/AIDS AND OTHER SEXUALLY TRANSMITTED INFECTIONS

Section 1: The HIV/AIDS Epidemic

Section 2: Definitions Relevant to HIV/AIDS

Section 3: The Life Cycle and Natural History of HIV Infection

Section 4: Modes of HIV Transmission and Methods of Risk Reduction

Section 5: Other Sexually Transmitted Infections

This chapter presents basic facts about HIV/AIDS and STIs that counselors need to interact effectively with clients. It reviews the state of the epidemic, provides a brief description of HIV and modes of transmission, and examines the connection between HIV and other STIs. It will be necessary to update this chapter regularly, given rapidly expanding scientific knowledge. New information can be disseminated through seminars, refresher training, the worldwide web, etc.

What are the implications of these new approaches to the counselor?

As strategies for counseling and testing continue to evolve to meet the needs of different populations, it will be important for counselors to be flexible and knowledgeable about the different strategies. Counselors should be aware of the services available in their community that will benefit both HIV positive and negative people and be able to determine the client's needs for referral. By working in variety of settings and utilizing multiple strategies, counselors are contributing to ensuring that most people who are HIV infected or at risk have access to HIV counseling and testing and are referred to other prevention, care, treatment and support services that they need.

It is our hope that as counselors go through training and continue to use this reference guide they will be better equipped to address the needs of different clients so that most clients can benefit from knowing their HIV status. Information provided in this reference manual should be seen as guidance that should be tailored to meet the needs of different clients in different settings.

Section 1: The HIV/AIDS Epidemic

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that 42 million people worldwide were living with HIV at the end of 2002 (Box 1). Of these, approximately 19.2 million (46 percent) were women aged 15-49; 3.2 million (7.6 percent) were children under age 15. There were roughly five million new HIV infections in 2002. During the same year, an estimated 3.1 million people died of AIDS. Since the beginning of the epidemic, more than 25 million people have died of the disease.

UNAIDS also estimates that at the end of 2002, approximately 14,000 new infections were occurring daily—95 percent of them in developing countries. Approximately 2,000 of these daily infections occur in children under age 15; 12,000 occur in people aged 15-49. Almost half of new infections occur in women, and half occur in people aged 15-24 year.

Sub-Saharan Africa carries the greatest burden of the disease, with approximately 70 percent of all HIV infections worldwide. In 12 African countries, at least 10 percent of the adult population is infected. In Botswana and South Africa, the figures are 38.8 percent and 19.9 percent, respectively.

While the global HIV/AIDS epidemic is hitting hardest in sub-Saharan Africa, experts posit that Eurasia (Russia and Asia) will soon reach similar proportions in devastation. India, China, and Russia are particularly at risk due to their large populations. Even if HIV rates remain far below those seen in the worst-affected African countries, the sheer numbers of PLHA will exact a devastating loss of human life and economic growth potential. UNAIDS estimates that by 2010 there will be 45 million new HIV infections worldwide, and that 40 percent of those new infections will occur in

Box 1: Adults and children estimated to be living with HIV/AIDS, end 2003



Asia and the Pacific. (Country-specific epidemiological information can be found at www.unaids.org.)

Section 2: Definitions Relevant to HIV/AIDS

What is the immune system?

The immune system is a collection of cells and substances that act as the body's defense against foreign substances, known as "antigens." The immune system can be compared to an army guarding the frontiers 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 neighbors.

The immune system functions in a similar way. It is composed of T-lymphocyte and B-lymphocyte cells, which play the role of defending army. Among the T-lymphocytes are carriers of CD4 receptors. These are T4 lymphocytes, or CD4 cells. HIV infects a person's CD4+ T-cells and uses them to replicate (make copies of itself). 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 OIs and certain cancers. Any other infection that stimulates the immune system is likely to accelerate this destruction, making the person still more vulnerable.

What are antibodies and antigens?

An antigen is a substance (such as HIV) that, when introduced into the body, stimulates the production of

an antibody (antibodies fight antigens). Antibodies form in a person's blood when HIV or other antigens enter the body. Usually antibodies defend against disease agents. But 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.

What is human immunodeficiency virus (HIV)?

HIV is the virus that causes AIDS in humans. Researchers have identified two types of HIV: HIV-1 and HIV-2. Both HIV-1 and HIV-2 have the same modes of transmission and are associated with similar opportunistic infections and AIDS, though there are differences in the efficiency of transmission and rates of disease progression. HIV-1 accounts for the majority of infections in the world and has at least 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. It is possible to be infected with both types of HIV simultaneously.

What is acquired immunodeficiency syndrome (AIDS)?

The acronym "AIDS" stands for "acquired immunodeficiency syndrome." AIDS is the disease caused by HIV, which weakens the body's immune system until it can no longer fight off the simple infections that most healthy people's immune system can resist or control (such infections are called "opportunistic infections"). Early AIDS symptoms include chronic fatigue, diarrhea, fever, weight loss, persistent cough, skin rashes, herpes and other oral infections, swelling of the lymph nodes, and memory loss

or other mental changes. As the immune system becomes further compromised by HIV, OIs such as pneumonia, meningitis, cancers, and TB easily attack the body. TB is the most common OI in AIDS patients and accounts for about one-third of AIDS deaths in sub-Saharan Africa.

Summary

- HIV is the virus that causes AIDS.
- Two types of HIV are currently known: HIV-1 and HIV-2.
- HIV infects a specific subset of white blood cells (CD4) that are fundamental to the body's immune system.
- HIV damages the immune system.

AIDS

Acquired: Neither innate nor hereditary deficiency.

Immunodeficiency: Weakening of the immune system.

Syndrome: Collection of symptoms and signs.

What is a CD4+ T-cell count?

The CD4+ T-cell count, a measurement of a person's CD4+ T-cells, is a marker of the strength of a person's immune system. As HIV destroys CD4 cells, the infected person's immune system is weakened. By measuring the CD4 cell count, it is possible to determine the stage of HIV disease and to predict the risk of complications (certain AIDS-related medical conditions occur at particular stages of HIV disease). Thus, the CD4 count can be used to identify problems for which an individual may be at risk and to determine what medications might be helpful.

What is viral load?

Viral load is the amount of HIV in a person's blood. Like CD4 counts, measuring viral load 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.

How are the CD4 cell count and viral load related?

The CD4 cell count is a marker 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 CD4 count. In general, the higher the viral load, the more quickly the CD4 cells are destroyed. Both tests are useful in guiding use of ART, staging HIV disease, and determining prognosis (predicting complications).

Section 3: The Life Cycle and Natural History of HIV Infection

The Life Cycle of HIV

HIV belongs to the retrovirus family. Retroviruses are living microorganisms containing ribonucleic acid (RNA) in their genome. They cannot reproduce in isolation; rather, an organism must act as host. HIV infects and reproduces itself mainly in so-called host cells, or CD4+ T-cells, a type of white blood cell that plays a fundamental role in the body's immune system. CD4+ T-cells are characterized by the presence of CD4 receptors on their surface, the main target of HIV.

Normally, viruses replicate by using their DNA (deoxyribonucleic acid, the carrier of genetic information) to make RNA. In turn, RNA produces proteins necessary to build all organisms. But retroviruses, such as HIV, work in reverse: their RNA creates DNA, which then combines with the DNA of the infected host cells to spread the virus.

Once contact is made between the virus and the human cell, the virus transfers its RNA to the human cell (Box 2). With the help of enzymes called "reverse transcriptase," the RNA is transformed into DNA, which is then inserted into the human cell's DNA and becomes an integral part of it, rendering the infection permanent. HIV remains latent inside the host cell for an indeterminate period. In transmitting HIV from one person to another (or one cell to another), viral particles, called "virions," move through bodily fluids to attack new CD4 host cells.

The following steps comprise the HIV life cycle:

Step 1: T-cell infection (binding)

- HIV binds to the CD4 receptor of the host cell (a co-receptor is also needed for HIV to enter the cell).
- HIV enters the cell.
- The contents of the virus are emptied into the cell.

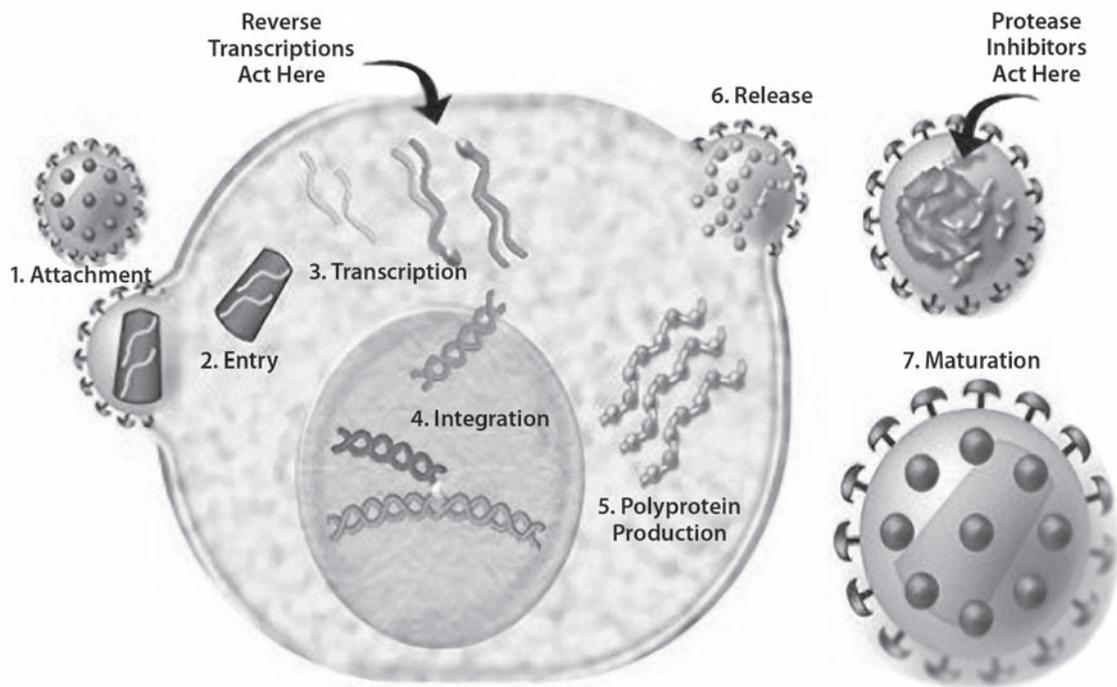
Step 2: Reverse transcription

- Single strands of viral RNA are converted into double-stranded DNA by the reverse transcriptase enzyme.

Step 3: Integration

- Viral DNA enters the cell nucleus and is combined with the cell's own DNA by the integrase enzyme.
- Once the viral DNA is integrated into the cell's genetic material, HIV can persist in the latent stage for many years.

Box 2



Step 4: Replication

- Viral DNA is transcribed into messenger RNA (mRNA).
- mRNA is translated into viral proteins.
- The new viral RNA forms the genetic material for the next generation of viruses.

Step 5: Assembly

- The viral RNA and viral proteins come together at the cell membrane.
- They form a new virus.
- Among the viral proteins is protease, which is required to process the HIV proteins (protease inhibitor drugs act by blocking this critical step).

Step 6: Budding and release

- Immature virus buds forth from the cell, taking some of the cell membrane with it.
- The protein chains in the new viral particle are cut into individual proteins that combine to make a new working virus.

Step 7: Cell death

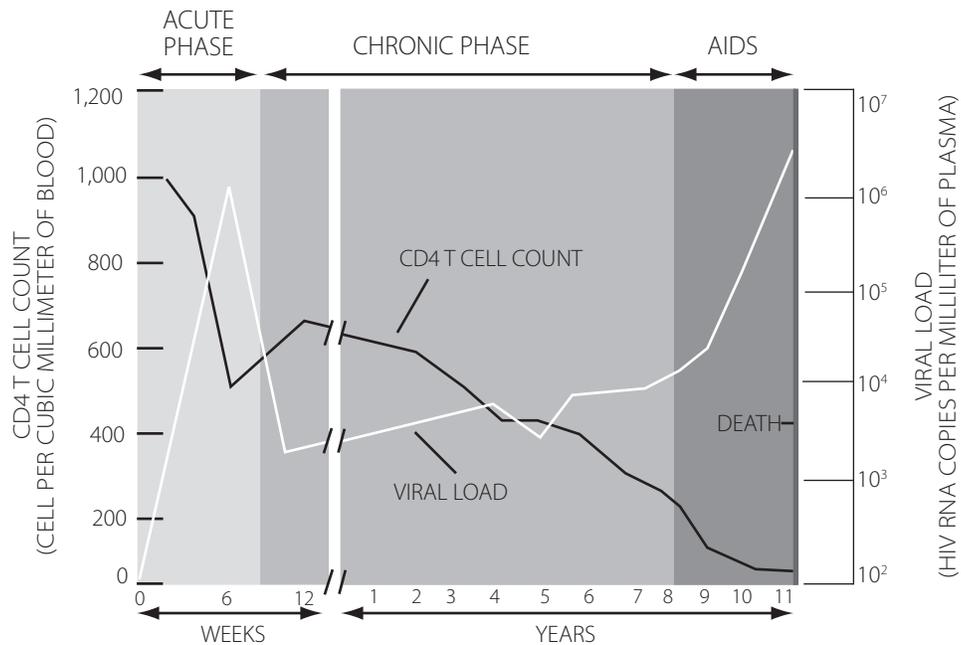
- The release of the new virus weakens the host cell and it dies (this is how HIV weakens the immune system: It kills the CD4+ T-cells).

HIV is extremely fragile outside the human body. The virus cannot withstand exposure to temperatures above 60 degrees Celsius or contact with disinfectants such as formalin, oxygenated water, alcohol, acetone, phenol, and bleach. HIV cannot penetrate unbroken skin; thus, it is not transmitted by casual physical contact such as kissing, holding hands, sneezing or coughing, sharing toilets, using the same utensils, or consuming food or beverages handled by someone with HIV.

The Natural History of HIV Infection

The term "natural history" refers to the clinical evolution of an infection. After exposure to HIV and viral replication, a person's immune system breaks down and becomes vulnerable to OIs—leading ultimately to death. Several phases occur between HIV infection and the advent of AIDS, as indicated in Box 4. Through currently available treatment, the natural progression of HIV infection can be modified considerably. In all settings, prevention and correct management of OIs have a beneficial effect on the progression of HIV infection. Where available, ART generally slows disease progression and improves the quality and length of life.

Box 3



Summary

A person does not develop AIDS as soon as he or she becomes infected with HIV. There is often a lengthy period between HIV infection and development of AIDS, averaging from five to ten years.

During most of this period people may have no symptoms; many may not even be aware that they are infected. During this “silent” phase, a person may unknowingly transmit infection to others. Viral and host factors, including presence of other infections and nutritional status, help determine the rate at which people develop AIDS.

Diagnosis and Clinical Manifestations

Diagnosis

In developing countries, 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 World Health Organization (WHO) clinical staging system, a four-stage classification system that combines signs, symptoms, and diseases, plus a physical activity framework using a performance scale (Box 5). Clients are classified according to the presence of clinical conditions and/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; he or she can only progress to a higher stage. It is important to note that some countries have modified these criteria. Though counselors are not expected to make diagnoses, they must be aware of clinical staging to facilitate referral to medical providers.

Box 4: “Natural History” or Progression of HIV Infection

- HIV enters a person’s body.
- HIV infects and replicates in the person’s cells (CD4 and macrophages).
- Significant viral replication induces the immune system to produce antibodies to HIV.
- The period between infection and production of antibodies, also called “sero-conversion,” lasts (usually) between two and 12 weeks but may continue as long as six months. This is also known as the “window period.” During this time, a person is infectious but may not test positive on common HIV antibody tests.
- At the time of infection, a small number of people may have a recognizable acute illness, with symptoms such as fever, lymphadenopathy (enlarged lymph nodes), night sweats, skin rash, headaches, and cough. These symptoms are usually ignored and/or passed off as general flu-like symptoms or as malaria in malaria-endemic areas.
- After sufficient induction of the antibody response, viral replication is kept in check. The infected person is asymptomatic (symptom-free) and may remain so for a period varying from a few weeks to 10 years or more.
- After a time that will vary from one person to another, viral replication resumes and intensifies. Other infections may play a role in facilitating viral replication.
- Viral replication leads to destruction of CD4 cells and progressive immunodeficiency.
- As immune depression progresses, the infected person becomes susceptible to OIs. Clinical syndrome at this stage depends on the level of immune depression and on previous or current exposure to ARV drugs.
- AIDS is diagnosed when an infected person presents syndromic characteristics of severe immune depression.

Clinical manifestations

AIDS is diagnosed when an HIV-positive person presents with a syndrome characteristic of severe immune depression. Multiple diseases and clinical problems are common in AIDS, and in the absence of specific therapy, death generally occurs. Progression of HIV infection to AIDS depends on the type and strain of the virus and certain

host factors. Factors that may cause faster progression include a person’s age (younger than five or older than 40), the presence of other infections, the HIV type, and, possibly, genetics (hereditary factors). As HIV infection progresses and immunity declines, people become more susceptible to OIs. These include:

- TB;
- Other STIs;
- Septicemia;
- Pneumonia (usually pneumocystis carinii);
- Recurrent fungal infections in mouth and throat;
- Meningitis;
- Other skin diseases (e.g., Kaposi’s sarcoma).

HIV wasting (chronic or intermittent fever, chronic or intermittent diarrhea, and severe weight loss) and TB are the most common problems in many sub-Saharan African countries. The higher the viral load and lower the CD4 count, the higher the chance of death. Death may be due to HIV or to OIs, particularly those that affect the brain, heart, or lungs.

The vast majority of HIV-positive children are infected perinatally—that is, during pregnancy and childbirth. The asymptomatic period is shorter in children. Some infants become ill in the first few weeks of life, and most children start to become ill before the age of two; but some remain well for several years.

Box 5: WHO Clinical Staging System for HIV Infection and Disease

- Stage 1** Asymptomatic or lymphadenopathy (enlarged lymph nodes).
- Stage 2** Weight loss < 10 percent; zoster; recurrent minor illnesses.
Activity scale: normal.
- Stage 3** Weight loss > 10 percent; fever or diarrhea longer than one month; oral candidiasis; pulmonary TB in past year; severe bacterial infections.
Activity scale: in bed less than 50 percent of days in past month.

Section 4: Modes of HIV Transmission and Methods of Risk Reduction

Modes of HIV Transmission

HIV is found in blood, semen, vaginal fluids, and breast milk.

HIV is spread in three ways:

1. Sexual contact with an infected person,
2. From infected mother to baby before or during birth or through breast-feeding after birth.
3. Through infected blood and blood products (including by sharing needles and through blood transfusions.)

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

Most clients have some knowledge of the modes of transmission and the different levels of risk that they pose. But it is important for counselors to assess each client's understanding and impart relevant information depending on the client's needs and knowledge level. It is imperative

that counselors encourage clients to make informed decisions about testing and behavior change (based on a clear understanding of modes of transmission, risk perception, and possible implications of the test results), and correct clients' misconceptions.

Sexual transmission

It is estimated that 70-80 percent of global HIV transmission occurs between infected persons and their partners through unprotected sexual intercourse. 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 become an important way people get infected if it is done often enough. Furthermore, several factors increase the risk of infection dramatically, including presence of a prior STI, sometimes manifested in genital sores or discharge, and having multiple sexual partners.

Transmission through infected blood

Transmission through infected blood accounts for an estimated 5-10 percent of all HIV infections. Transmission occurs through transfusion with contaminated blood or blood products, contaminated injecting equipment, exchange and re-use of needles or contaminated syringes, and surgical operations where equipment previously used with an HIV-positive patient has not been sterilized. Organ transplants from infected donors can transmit the infection

Risk of HIV Transmission by Type of Exposure, and the Contribution of Each Mode of Transmission to Global Infections

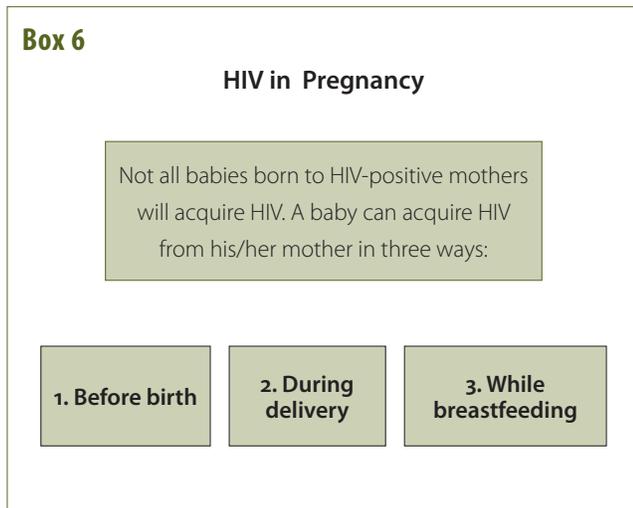
Exposure	Transmission rate/single exposure	% of global infections
Blood transfusion	> 90%	5-10%
Mother to child	25-40% in developing countries 15-25% in developed countries	2-3%
Unprotected sexual intercourse ⁵	0.1-1% ^{6,7}	70-80%
Injecting drug use	< 1% ⁷	5-10%
Needle stick and other health care setting exposures	< 0.5%	0.01%
Household contact from exposure to blood	Rare	–

⁵ Vaginal or anal sex without the use of a latex condom or similar protective barrier.

⁶ Risk is cumulative and increases exponentially with each exposure.

⁷ Several co-factors, such as STIs and lack of circumcision, may increase risk.

as well. HIV also can be transmitted through direct contact with materials that have been contaminated with infected blood during rituals such as circumcision and tattooing and not sterilized before re-use



Mother-to-child transmission

A mother can transmit HIV to her child during pregnancy or delivery, or through breastfeeding (Box 6). Rates of HIV-1 transmission from mother to child range from 25 to 40 percent in less developed countries, and from 15 to 25 percent in more developed countries. 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, pre-term delivery, and hemorrhage are significant predictors of the child's infection. Other factors that increase the opportunity for transmission during this period include viral, bacterial, or parasitic placental infections. Most infants who acquire HIV during delivery have been exposed to maternal blood or cervical secretions that contain HIV. Prolonged membrane rupture and invasive delivery techniques also have been associated with higher risks of MTCT during labor and delivery. The risk of MTCT increases if a woman has higher viral load, which occurs if she becomes infected or re-infected with HIV during pregnancy or if she becomes ill with AIDS.

Following delivery, breastfeeding is the most important risk factor. Without treatment, an estimated one of every seven infants breastfed by an HIV-positive mother becomes infected through breast milk. The risk of transmission is

greater when HIV-positive women do not exclusively breastfeed for the first six months, or if complications develop from poor breastfeeding techniques (e.g., with mastitis, cracked and bloody nipples).

Box 7: Summary of Modes of Transmission

HIV passes from person to person through certain bodily fluids, specifically blood, semen, vaginal fluids, and breast milk.

Research has demonstrated only three routes of HIV transmission:

- Sexual contact;
- Mother to child during pregnancy, childbirth, or breastfeeding;
- Blood-blood contact (e.g., sharing needles, blood transfusion, tattooing, sharing razor blades, traditional scarification procedures, body piercing).

HIV cannot be transmitted via toilets, swimming pools, sharing eating or drinking utensils, or insects (such as mosquitoes). HIV is not transmitted by casual contact, such as shaking hands, hugging,

The risk also increases if the mother becomes infected with HIV while breastfeeding, since viral loads are very high in the initial stage of infection.

Methods of Risk Reduction

Changing sexual behavior

The most common mode of HIV transmission is heterosexual sexual intercourse. Steps to reduce the risk of sexually acquired HIV are:

- Abstaining from sex;
- Reducing the number of sexual partners;
- Using a condom or latex barrier consistently during sexual contact;
- Avoiding sex with people who may have multiple partners or are engaging in other high-risk activity such as commercial sex or intravenous drug use;
- Getting treated for other STIs.

One barrier to condom use is that condoms also prevent pregnancy; many people, whatever their HIV status, desire children. Often, if a child is wanted, the couple has unprotected sex.

Reducing the risk of MTCT

WHO advocates a four-prong strategy to reduce the number of HIV-positive infants:

1. Prevent HIV infection among women, especially young women
2. Reduce unwanted pregnancy in HIV-positive women
3. Prevent the transmission of HIV from infected women to their babies (during pregnancy, labor and delivery, and breastfeeding)
4. Provide care and treatment to women and their babies and families.

These approaches are detailed in Chapter 7.

Safer use of injection equipment

Anyone who shares injectable needles for drugs, insulin, steroids, and/or tattooing may be at risk of HIV infection. Infected blood left in the needle contains HIV, and when needles are re-used this blood and the HIV enter the second user's bloodstream. Clients can reduce their risk of HIV from unsafe injecting practices by:

- Abstaining from injecting drugs;
- Abstaining from sharing needles, syringes, cookers, and other injecting equipment;
- Cleaning used needles and syringes three times with bleach and rinsing with water three times (a different source of water each time). The cotton or filter should not be shared.

Universal precautions to prevent HIV transmission in health care settings

The phrase "universal precautions" refers to standard protective measures for health care workers to avoid contact with bodily fluids of a patient who may or may not have a communicable disease or infection. Universal precautions for HIV are based on the simple fact that there is no way to be certain whether another person is infected; thus, it is safest to handle everyone's blood and bodily fluids as if they were infected. This pertains to most bodily fluids, such as blood, blood products, semen, and vaginal fluids (including menstrual blood). Saliva, urine, feces, and mucus may also contain blood, visible or not. Basic universal precautions include:

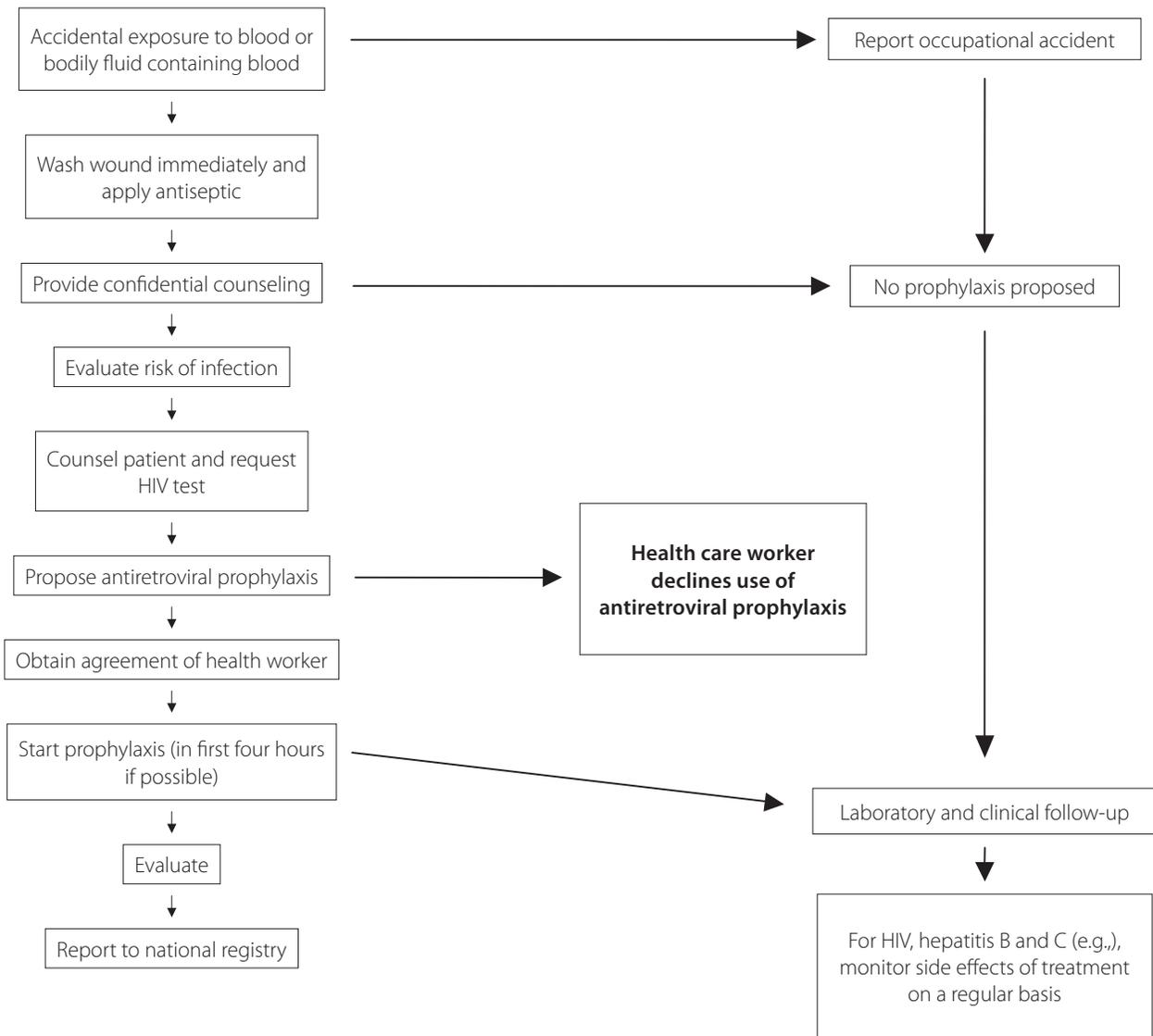
- Avoiding unprotected contact with all blood and bodily fluids;

- When avoiding contact is not possible, using barriers such as latex or plastic gloves, a towel, gauze, or a piece of clothing;
- Using a barrier when applying a bandage or gauze to a cut or scrape, or when attempting to stop bleeding after an accident or injury (nothing should touch the part of the bandage or gauze that will cover the cut);
- Discarding or decontaminating anything that has had direct contact with blood or bodily fluids, such as bloody tissues, paper towels, or gauze; washing bloody clothes first in hot water and bleach, then in detergent;
- Avoiding shared use of knives or razors used for traditional rituals that involve blood (e.g., scarification, tattooing, circumcision);
- Handling and disposing of "sharps" (e.g., used needles) carefully;
- Wearing gloves during any contact with bodily fluids, skin, or mucosal lesions, and/or contaminated or potentially contaminated materials;
- Covering all wounds;
- Washing hands immediately after contact with potentially contaminated materials and after every health care procedure;
- Wearing protective clothing when there is a risk of splashing;
- Disinfecting soiled instruments and surfaces immediately with a fresh 1:10 solution (i.e., one part bleach or other disinfectant to 10 parts water);
- Placing samples in hermetically sealed and labeled tubes, flasks, or packaging;
- Arranging to incinerate contaminated materials.

Post-exposure procedures

In the clinical setting, in the unlikely event that a VCT counselor is exposed to a client's blood or bodily fluids, the counselor should consult a trained clinician immediately. Box 8 below presents basic procedures in case of exposure to HIV-infected blood or fluids of unknown status.

Box 8: Post-Exposure Procedures



Section 5: Other Sexually Transmitted Infections

The Relationship between HIV/AIDS and Other STIs

Like HIV, STIs are contracted principally through sexual intercourse. WHO estimates the number of new cases of treatable STIs at 330 million per year. STIs are particularly prevalent in developing countries and among sexually active young people. Some of the most common are gonorrhea, 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 transmitting or acquiring HIV. The presence of STIs increases a person's vulnerability to HIV by a factor of 15-20 percent. The presence of 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 the mucous membrane. Thus, to reduce the risk of HIV infection, it is crucial to avoid contracting other STIs. If other STIs do occur,

Six Most Common STI Syndromes

STI Syndrome	Signs/Symptoms	Common Causes
Urethral discharge (in men)	Urethral discharge Urethral itching Pain on urination Frequent urination	Gonorrhea Chlamydia Trachomatis
Epididymitis: complication of untreated urethral discharge	Scrotal swelling Scrotal pain Painful inguinal Swollen lymph nodes	Gonorrhea Chlamydia Trachomatis
Genital ulcer syndrome (GUS)	Genital ulcer with or without pain Swelling of inguinal lymph nodes Abscess of fistula	Syphilis Chancroid Genital herpes Granuloma inguinale
Lower genital tract syndrome (in women)	Vaginal discharge Painful urination Dyspareunia Vaginal itching Frequent urination	Gonorrhea Chlamydia Trachomatis Anaerobic bacterial overgrowth Candidiasis Trichomoniasis
Pelvic inflammatory disease (complication of untreated endocervicitis)	Lower abdominal pain Abdominal tenderness Vaginal discharge Fever	Gonorrhea Chlamydia Anaerobic bacterial infection
Neonatal conjunctivitis	Swollen eyelids Purulent eye discharge Baby unable to open eyes	Gonorrhea Chlamydia Trachomatis

prompt and effective treatment is imperative to minimize the risk of acquiring or transmitting HIV.

There is a strong connection between the presence of another STI and HIV infection, and one STI can hide another. In fact, all STI cases should be considered possible indicators of HIV infection. Correct STI treatment contributes to control of HIV transmission, and prevention of STIs can help prevent HIV.

Modes of STI Transmission

STIs are acquired through heterosexual or homosexual relations. Another means of transmission is from mother to child during pregnancy (syphilis) or during delivery

(gonorrhea, chlamydia). The same behaviors that put individuals at risk of HIV also expose them to risk of acquiring other STIs: multiple sex partners, high-risk partners, and unprotected sex. Thus, prevention methods are the same.

Clinical Manifestations of STIs

Many STIs have similar clinical manifestations, with minor variations. Consequently, STIs can be categorized according to either signs and symptoms or causative agent. The grouping according to signs and symptoms has facilitated syndromic treatment, which does not rely on laboratory tests. This technique is useful in resource-constrained settings.

Clinical Manifestations of STIs

In Men	In Women	In Infants
Chronic infection	Chronic infection	Ophthalmia neonatorum (gonorrhea)
Epididymo-orchitis	Pelvic inflammatory disease	Conjunctivitis (chlamydia)
Urethral stricture	Tubal damage and sterility	Blindness
Cancer	Ectopic pregnancy	Congenital syphilis
	Recurring miscarriages	Congenital herpes
	Fetal wastage	Pneumonia
	Septicemia	Prematurity
	Peritonitis	Septicemia
	Cervical cancer	Death
	Death	

STI Care and Treatment

STI care and treatment should include:

- Correct early diagnosis followed by treatment with antibiotics (syndromic or etiologic);
- Counseling and education for behavior change;
- Treatment of all partners (sexual contacts).

STI management poses several challenges; four require particular attention:

- **It is difficult to change sexual behavior:**
Knowledge does not automatically lead to behavior change. STI control is difficult because sexual practices are rooted in everyday life and culture.
- **People find it embarrassing to discuss sex:**
Sometimes people are shy about asking for the information they need, slow in seeking treatment, and/or reluctant to discuss the issue with their partners. Talking about sex can make people feel uncomfortable and the subject is sometimes taboo.
- **Many people with STIs exhibit no symptoms at all:** People with STIs can spread infection without even knowing they are infected.

- **Treatment is not always available, easy, or effective.**

Recommendations for STIs

For the client:

- Avoid self-medication (encourage clients to seek medical attention);
- Inform all partners of the infection and how to get treated;
- Abstain from sexual contact during treatment, or, if this is not possible, use condoms.

For the health provider:

- Educate clients about STIs;
- Educate clients about partner medication;
- Assist in partner referral;
- Observe clients carefully;
- Inform clients of the increased risk of contracting HIV.

CHAPTER 2

HIV TESTING ISSUES

Section 1: HIV Testing Strategies and Protocols

Section 2: Types of HIV Tests

Section 3: Interpreting HIV Test Results

Section 4: Confidentiality in HIV Testing

Section 1: HIV Testing Strategies and Protocols

Selection of HIV Testing Strategies

HIV testing strategies vary from one country to the next depending on estimated HIV prevalence and available technologies. Today there are numerous high-quality HIV testing kits on the market. Ordinarily, it is the responsibility of government regulatory bodies—ministries of health, national HIV/AIDS control programs, or national reference laboratories—to formulate the most feasible testing strategies for a given country. In each country, considerations for choice of HIV testing protocols include:

- Scientific validity of the tests;
- Existing laboratory infrastructure;
- Presence and capability of reference laboratories for quality control purposes;
- Volume of HIV testing required (i.e., number of people to be tested);
- Client preferences;
- Impact of protocol on service provision (e.g., same-day results vs. return appointment);
- Costs of tests vs. available funds.

Selection of testing strategies takes into account the scientific validity (accuracy) of the test. The two measures used are *sensitivity* and *specificity*.

- **Sensitivity** is the probability that a test will be positive when infection is present (i.e., the sensitivity of a test is the percentage of those identified by the test as having the infection who actually have it). For example, if a test is 99 percent sensitive, 99 of 100 HIV-positive people will correctly test positive, and one person will falsely test negative. As the sensitivity of the test increases, so does the number of infected people correctly testing positive.

- **Specificity** is the probability that a test will be negative when infection is not present (i.e., the specificity of a test is the percentage of those identified by the test as not having the infection who are actually free of infection). In other words, if a test is 99 percent specific, 99 of 100 people who are not infected will correctly test negative, and one person will falsely test positive.

HIV Testing Protocols

Diagnosis of HIV infection usually is made based on detection of antibodies to the virus. An antibody test is rarely 100 percent sensitive (i.e., correctly able to categorize an infected person as positive) and 100 percent specific (i.e., correctly able to categorize a non-infected person as negative). Therefore, UNAIDS, WHO, and the Centers for Disease Control and Prevention (CDC) jointly recommend that all positive test results be confirmed by retesting, preferably by a different testing method.

Most VCT centers have defined testing protocols or algorithms to guide individuals administering the tests. The protocols depend on national testing guidelines, HIV prevalence, the purpose of the testing, and the number of different HIV tests available in the particular setting.

The following example of a testing strategy was adopted from the UNAIDS, WHO, and CDC HIV Testing Strategy III. It assumes presence in “Country X,” which has an adult HIV prevalence rate of approximately 15 percent. In “Country X,” the following steps might be used to determine an individual’s HIV status:

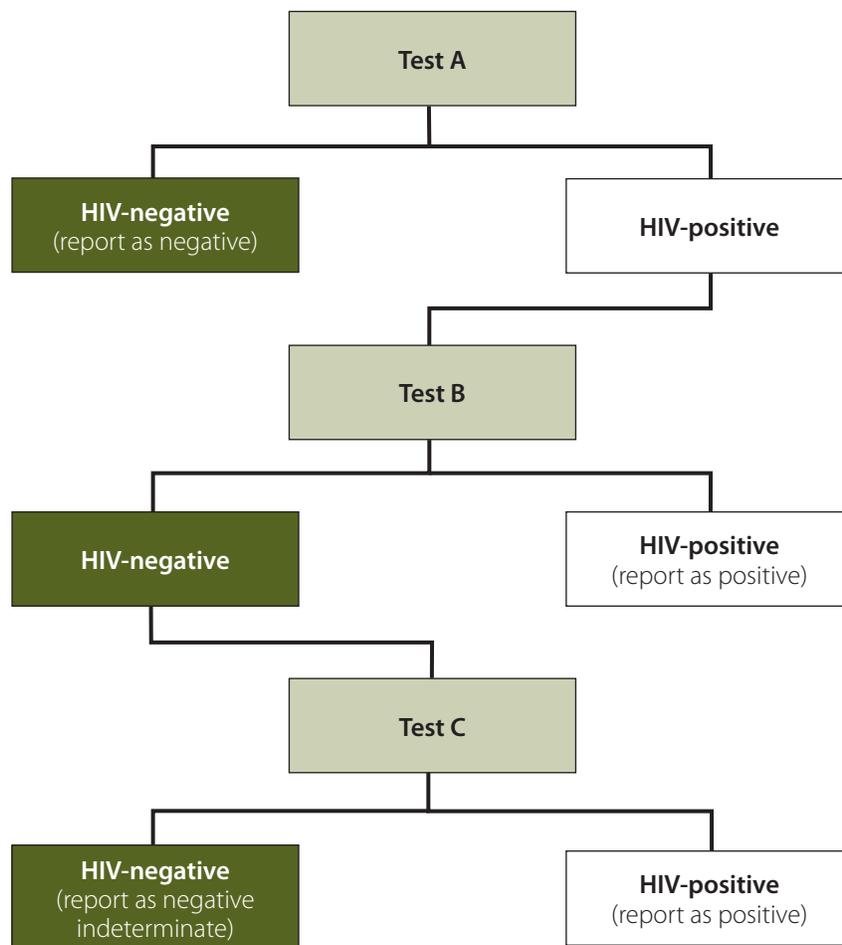
- All samples are tested for HIV antibodies using either enzyme-linked immunosorbent assay (ELISA) or a rapid test—HIV test kit A (“Test A”).
- All non-reactive (negative) samples (i.e., those testing negative) are reported as negative.

- A reactive (positive) sample will undergo a second HIV test with different principles and produced by a different manufacturer ("Test B"). If the result indicates a reactive (positive) sample, it is reported as positive.
- If the result of Test B is negative, the sample undergoes a third HIV test ("Test C"). [In settings where there are only two rapid tests, these samples are sent to a reference laboratory for ELISA testing]. If the result of Test C is also negative, the test is reported as negative. If the result of Test C is positive, the result is considered indeterminate.

For indeterminate results, it is recommended that, first, the procedure be repeated immediately. Alternatively, the client should be counseled to repeat the test after six weeks to three months, using a fresh sample.

For quality control purposes, 5-10 percent of all samples should be sent out for external quality assurance testing. This will be either a venous sample or a sample collected using a filter-paper method. For instance, one of every 10 positive samples and one of every 20 negative samples should be sent quarterly to the national reference laboratory for quality assurance, or as often as determined

Box 9: Test Strategy



by the national reference laboratory. (See Chapter 10 for more on quality assurance in HIV testing.)

Section 2: Types of HIV Tests

There are two main types of HIV tests: antibody tests (e.g., ELISA, simple/rapid, saliva and urine, and Western blot) and virologic tests (e.g., HIV antigen test, polymerase chain reaction test, and viral culture).

Antibody Tests

HIV antibody tests look for antibodies against HIV; they do not detect the virus itself. When HIV enters the body, it infects white blood cells known as T4 lymphocytes, or CD4 cells. (See Chapter 1, Section 2 for a more detailed discussion of the immune system.) The infected person's immune system responds by producing antibodies to fight the new HIV infection. Presence of the antibodies is used to determine presence of HIV infection.

The most commonly used antibody tests are the enzyme immune assay (EIA) or ELISA, including the rapid HIV test. The less commonly used Western blot antibody test is used mainly in industrialized countries to confirm a prior test. The Western blot is better than other tests at identifying HIV infection, but is more expensive than other tests. In addition, the radioimmunoassay (RIPA), a confirmatory antibody test, is used when antibody levels are very low or difficult to detect, or when results of the Western blot are uncertain. RIPA is an expensive test and requires time and expertise to perform.

Rapid HIV Testing

Rapid tests usually produce results in five to 30 minutes. Some of these tests do not require a blood sample from the client. HIV tests based on urine or oral fluid samples offer an alternative to blood-based tests.

Testing urine for HIV is not as sensitive or specific as testing blood. Available urine tests include the EIA and the Western blot, which can confirm the EIA results. These tests must be ordered by a physician. Results usually are sent back to the ordering physician or his or her assistant.

Saliva-based tests (e.g., OraSure HIV-1) collect oral fluid, which is tested for the presence of HIV antibodies. A trained specialist usually collects the sample from between the lower cheek and gum. Testing an OraSure HIV-1 specimen for HIV antibodies is accurate, but testing blood is more accurate. When both tests are available, clients may be allowed to choose.

The "window period"

In some cases, HIV tests may come back negative, even though the person is infected with HIV. This can happen during the "window period," the time between initial HIV infection and when the body builds a measurable immunologic (antibody) response to it. During the window period, HIV is not detected by most HIV tests though it is replicating in the blood and lymph nodes. The virus can be detected during this phase only by laboratory tests used to identify the virus itself. The window period can last from as little as two weeks to as long as six months. Thus, if a person tests negative to HIV antibody tests, one possible explanation is that they are still in the window period, in which their immune system has not yet begun making antibodies to the virus. A person in the window period will only test positive for HIV if a virologic test (described below) is used.

Virologic Tests

The antibody tests discussed above are the most commonly used in VCT settings. But 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, virologic tests determine HIV infection by detecting the virus itself. There are three virologic (direct) tests:

- Viral antigen detection test (also known as the P24 antigen test);
- Nucleic acid-based tests (specialized tests that look for genetic information on HIV using polymerase chain reaction or PCR);
- Virus culture, which isolates the virus.

Virologic tests are rarely used to diagnose HIV in developing countries since they require sophisticated laboratories. But they may be used to monitor progress of infection or response to therapy (e.g., by measuring viral load).

HIV tests and children

Diagnosis of HIV in infants is problematic because babies born to HIV-positive mothers test positive for antibodies acquired from their mothers for as long as 15 months after birth, due to maternal-fetal transfer of antibodies during pregnancy, delivery, or breast-feeding. A positive result on an antibody test only identifies infants who have been exposed to the mother's antibodies to 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 virologic tests, such as PCR, viral culture, and P24 antigen testing, will prove 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.

Section 3: Interpreting HIV Test Results

Explaining Test Results

A negative test result means that HIV antibodies were not detected in the person's serum sample, either because the person is not infected or because the person is still in the window period. It is imperative that the client understand that a negative result does not mean that the person is uninfected or immune to HIV infection. An HIV-negative person is still vulnerable to HIV infection if he or she engages in risky behavior. A person who tests negative but has practiced safe behaviors during the window period may be (or become) infected with HIV and infectious to others.

A positive test result means that HIV antibodies were detected in the person's serum sample. It means the person is infected with HIV and that he or she can transmit the virus to others if he or she engages in risky behaviors. It does not necessarily mean the person has AIDS. An indeterminate test result means that the presence or absence of HIV antibodies could not be confirmed. This means one of three possibilities:

- The person may be in the process of sero-converting.
- The person might have had an earlier inoculation that is cross-reacting with the HIV antibody test (cross-reactivity does not necessarily mean HIV is present).
- The person may have a prior medical condition that is affecting the test (for example, arthritis or autoimmune problems).

Box 10: The Meaning of Test Results

Negative

A negative test result indicates that no antibodies to HIV were detected in the blood. This result can have one of several meanings:

The person may not be infected with HIV.

The person may be infected with HIV, but his or her body has not had time to produce antibodies to the virus. In this case, the person is in the window period.

Positive

A positive test result indicates that antibodies to HIV were detected in the person's blood. This result indicates the person has been infected with HIV; it does not necessarily mean the person has AIDS.

Indeterminate

An indeterminate test result means one of the following:

1. The person may be infected with HIV and in the process of developing antibodies to it (acute sero-conversion).
2. The person has antibodies in his or her blood that are very similar to antibodies to HIV. These antibodies are reacting to the HIV test.

Counselors can use the information in Box 10 to explain the meaning of HIV test results to clients.

HIV tests have been developed to be especially sensitive. Consequently, a positive result may be obtained even when there are no HIV antibodies in the blood. This result is known as a "false positive." Because of this possibility, all positive results must be confirmed by another testing method. False positives have many causes, including technical errors, serologic cross-reactivity, repeated freezing and thawing of specimens, and "stickiness" of stored sera in malaria-endemic regions in Africa.

Box 11: False Positive

HLA cellular antigens may cross-react and cause a false positive on an ELISA or rapid HIV test. There is risk of false-positive results in persons with:

- Rheumatoid arthritis;
- Multiple sclerosis;
- Systemic lupus erythematosus;
- Type I diabetes mellitus;
- Addison's disease;
- Ankylosing spondylitis;
- Chronic hepatitis;
- Cancer (particularly lympho-proliferative malignancies);
- Severe kidney disease.

And in persons who have had a:

- Flu shot within the past 30 days;
- Gamma globulin injection;
- Recent transfusion or organ transplant;
- Confirmatory tests usually rule out false-positive results.

False Negative

A false negative occurs in an infected person when the blood tested 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 behavior 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.

The most frequent reason for a false-negative result is that the individual is newly infected and is not yet producing HIV antibodies. It is important to remember that someone who has tested negative correctly—that is, because he or she is not infected with HIV—can become infected at any time afterward.

Section 4: Confidentiality in HIV Testing

Given the absence of clinical symptoms in most people with HIV, a laboratory test is required to diagnose presence of the virus. Sometimes a client may request an HIV test because of his or her self-perceived risk or other reasons; other times, a health care provider recommends a test based on a patient's history and/or clinical findings, such as STIs or OIs. Regardless of the circumstances, HIV antibody testing and counseling should *always* be voluntary and confidential. Because in many societies HIV and AIDS are sensitive and emotionally charged issues, all information about the individual and his or her sexual partners must be kept strictly confidential. Confidentiality will help win a client's trust and avoid stigmatization and discrimination. Careful record management is a prerequisite for confidentiality.

There are three general methods of labeling blood samples to ensure confidentiality:

- Linked testing;
- Linked anonymous testing;
- Unlinked anonymous testing.

In "linked testing," the blood sample sent for testing has an identifier on it, such as a clinic number that links the sample to the individual client. To ensure maximum confidentiality for clients, samples sent for HIV testing should not be identified with a name, but with some other identifier, so that laboratory technicians and other people with access to laboratory records cannot identify the client. Sometimes HIV test request forms have sequential numbers printed on them whereby the laboratory gets copies of the request with a number only, and the clinic retains copies with the number and client information.

In "linked anonymous testing," no names or other client identifiers are recorded. The client receives a unique number, in no way linked to any medical record that matches the number on the blood sample sent to the laboratory. The laboratory result for the specific number is reported back to the clinic or counseling site. To learn the result, the client must come to the clinic or counseling site and present the correct number. No record is kept of clients who provided blood samples, and there is no way to find the client if he or she does not return for results.

"Unlinked anonymous testing" is often performed on blood samples obtained for reasons other than diagnosing HIV (e.g., syphilis serology in antenatal clinics or blood

donations). In this procedure, all identifiers are removed from the blood sample and the sample is tested for HIV antibodies. Unlinked anonymous testing means test results cannot be traced back to the clients who provided the blood samples, and no record is kept of those clients. Epidemiologists and ministries of health use unlinked anonymous screening to monitor HIV trends in different geographic areas and populations and to further understand the natural history of HIV infection.

CHAPTER 3

COUNSELING CONCEPTS, FEATURES, AND SKILLS

Section 1: HIV Counseling

Section 2: Counseling Concepts and Definitions

Section 3: Basic Counseling Skills

Section 4: Self-Awareness

Section 5: Counseling Models and Types

Section 6: The Counseling Process

Section 7: Counseling Recipients and Providers

Section 1: HIV Counseling

What is HIV counseling?

WHO defines HIV counseling as a “confidential dialogue between a client and a counselor aimed at enabling the client to cope with stress and make personal decisions related to HIV/AIDS. The counseling process includes evaluating the personal risk of HIV transmission and discussing how to prevent infection.”

Roles of HIV Counseling

HIV counseling plays two important roles: preventing HIV infection by promoting behavior change, and providing psychosocial support to people infected and affected by HIV. These roles are fulfilled by:

- Giving information about HIV/AIDS to clients and their partners;
- Encouraging preventive behaviors;
- Helping HIV-positive clients and those close to them cope with the diagnosis;
- Discussing decisions that need to be made, according to the client’s life circumstances;
- Referring clients to appropriate treatment and care services.

Challenges in HIV Counseling

Providing culturally sensitive interventions that are effective both as primary and secondary prevention strategies, while enhancing coping, care, and support, is an evolving and challenging task. In most countries in sub-Saharan Africa, the initial national response to the HIV epidemic was to train as many people as possible to provide hospital,

community, and home-based counseling. For instance, in Tanzania in the 1980s, the health ministry’s national AIDS control program trained 600 counselors. But a performance evaluation conducted in 1995 showed that only 16 (2.1 percent) of the counselors trained were still practicing (Nkya et al. 1996). The high attrition was attributed to poor candidate selection, inadequate training, insufficient supervision, and lack of follow-up. This pattern is common in many other countries.

Counselors’ everyday work takes place in an emotionally charged environment. Clients may release intense emotions, particularly during post-test and supportive counseling. This may be especially true for people living with or affected by HIV, who may have to face emerging issues when new symptoms develop, treatments fail, a loved one dies, or other significant life events occur. Giving test results can be emotionally challenging and stressful for counselors. Providing positive test results is particularly demanding in situations where support is inadequate and clients may be vulnerable to discrimination.

HIV counseling also requires explicit discussion of sexual practices, considered improper in many cultures. HIV counseling requires open discussion of death and dying, which is also taboo in many traditions. Counselors are likely to encounter clients who hold opinions, values, and worldviews very different from their own. In most sub-Saharan African settings, while many clients may accept the biomedical explanation of their HIV infection, they often look more for external or situational causes, all of which influence the behavior changes they are prepared to make.

Section 2: Counseling Concepts and Definitions

Counseling is ...

Counseling may be defined as an interaction in which the counselor (helper) offers another person(s) the time/attention/respect necessary to explore, discover, and clarify ways of living more resourcefully. In the context of HIV/AIDS, counseling is a confidential dialogue between a client and a counselor aimed at enabling the client to cope with stress and make personal decisions related to HIV/AIDS (WHO 1994).

Counseling is an issue-centered and goal-oriented interaction and involves carrying on a dialogue and providing options for decision-making and behavior change. Good counseling helps another person to be autonomous (i.e., able to choose, make decisions, and be responsible for his or her own actions).

Counseling is not ...

The primary difference between counseling and other forms of helping is the way in which the counselor and client communicate and relate.

- **Counseling is not giving advice:** Advice is mainly one-way. Counseling is a two-way interaction.
- **Counseling is not guidance:** The counselor avoids telling the client how to solve the problems or what decisions to make or actions to take.
- **Counseling is not health education:** Although education can be an important part of counseling, the information provided in counseling is tailored to the needs of an individual client.
- **Counseling is not ongoing therapy:** The counseling intervention focuses on an immediate problem.
- **Counseling is not a conversation:** It is not just people exchanging information and opinions.
- **Counseling is not interrogation:** The client is not being questioned to find out the truth.
- **Counseling is not preaching:** It should not be a forum to voice or promote a counselor's opinions.
- **Counseling is not confession:** The client is not being pardoned or absolved.
- **Counseling is not just information giving:** The client does not come to the counselor solely for

information, though information may be given sometimes. There is also a need for psychosocial support.

Elements of Good Counseling

Several agreed-upon elements are necessary to ensure effective counseling:

Ample Time

Providing the client with adequate time is important from the very beginning. The counseling process cannot be rushed: time is necessary to build a helping relationship.

Acceptance

Counselors should not be judgmental of clients, but rather should try to accept clients, regardless of their socioeconomic, ethnic, or religious background, occupation, or personal relationships.

Accessibility

Clients need to feel they can ask for assistance or call on a counselor at any time. Counselors 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).

Consistency and accuracy

Information provided through counseling (e.g., about HIV infection, infant-feeding options, infection risk, and risk reduction) should be consistent both in content and over time.

Confidentiality

Trust is the most important factor in the counselor-client relationship. It enhances that relationship and improves the odds that an individual will act decisively on the information provided. Given the discrimination, ostracism, and personal recrimination an individual diagnosed with HIV may face, it is all the more important to guarantee confidentiality.

Box 12: TCEUA

Effective counseling involves, trust, communication, empathy, understanding, and action (TCEUA).

Trust: Trust enhances a relationship and improves the odds that an individual or group will act decisively on the information provided. Trust can be gained by ensuring privacy and confidentiality, attending and listening, showing respect, and developing rapport.

Communication: To identify a client's needs and provide the right information, the counselor must communicate in a way that is clearly understood. Counselors should focus on two basic communication components: *content* and *feeling*, using both verbal and non-verbal techniques.

Empathy: Genuineness, unconditional positive regard, and nonjudgmental behavior are key to effective counseling. Empathy in turn leads to . . .

Understanding: It is important to understand the client's problems and related thoughts and anxieties; determine who is "in charge" in the counseling session; and assess options that will lead to taking *action*.

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

Additional Factors to Consider for Effective Counseling

Informed consent

The HIV test should always be voluntary and should take place only after a client has given informed consent. Before this can be obtained, the client needs to receive a clear explanation of the advantages and drawbacks of the HIV test and have an opportunity to ask questions. Informed clients who agree to be tested must be physically and mentally healthy to ensure they understand the relative risks, dangers, and advantages of taking or not taking the test.

Sociocultural context

Effective counseling must recognize the impact of culture on a client's perception of the world. Counselors should take a holistic view of clients and their sociocultural background, including beliefs about HIV/AIDS, sexual morals, traditional healing practices, gender inequalities, marriage practices (e.g., monogamy, polygamy), customs,

and social practices. Counselors should keep in mind that culture and tradition shape attitudes and ideas, particularly regarding illness and death. Thus, counselors should be sensitive to and respect cultural differences. Counselors should refer clients to another counselor if differences of gender, race, ethnicity, religion, sexual orientation, disability, or socioeconomic status interfere with counseling in any way.

Section 3: Basic Counseling Skills

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

Interpersonal Skills

Establishing rapport

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

- Respect and lack of judgment;
- Presence of common or complementary goals;
- Open verbal and non-verbal communication;
- Mutual trust.

One useful technique to establish rapport is "nth-degree" questions, such as, "What's the worst thing that could happen?" or "If we could only deal with 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 beginning of a session. Furthermore, through this process the counselor is able to encourage the client to be explicit in describing sensitive issues, including sexual behavior patterns. In this way, it may be possible for the counselor to determine the client's risk level accurately and develop a realistic risk-reduction plan.

Ensuring privacy and confidentiality

Contrary to previously held notions that confidentiality is a strictly Western concept, research indicates that clients everywhere need to be assured of privacy and confidentiality. The counselor can ensure privacy and confidentiality by:

- Providing adequate and appropriate space for counseling 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 counseling services;
- Being aware that notions of shared confidentiality and partner notification often raise an ethical dilemma in the context of HIV counseling. (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 on request and consent of the person undergoing testing.)

Showing respect

Counselors need to understand that people regard and cope with their 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 counselors are aware of cultural and role differences of gender, race, ethnicity, religion, sexual orientation, disability, and socio-economic status, yet eliminate personal prejudices and biases about such differences. Counselors must not participate in or condone discriminatory practices based on these differences. Counselors must also respect clients' views and beliefs and build on them.

Furthermore, counselors should be aware that their own attitudes and actions can convey respect or 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 telling them what to do);
- Keeping appointments and apologizing for lateness or failure to keep an appointment;
- Being a "guide/facilitator," not a "preacher";
- Showing concern for clients' welfare;
- Seeing each client as a unique individual;
- Seeing clients as capable of determining their own fate;

- Assuming clients' goodwill unless they demonstrate otherwise.

Showing empathy

The ability to empathize is one of the most essential counseling skills. Empathy involves identifying with the client, understanding their thoughts and feelings, and communicating that understanding to the client. For a counselor to communicate an understanding of a client's world, he/she must get in contact with that world (i.e., understand the client so well that the counselor feels like the client). Simply stated, this means that counselors should "put themselves in their clients' shoes." Empathy requires sensitivity and a moment-by-moment awareness of fear, rage, tenderness, confusion, or whatever the client may be experiencing. To understand what the client is feeling, the counselor must be attentive to the client's verbal and non-verbal cues. The counselor needs to ask himself/herself: "What feelings is the client expressing?" "What experiences and behaviors 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 counseling. To help address difficult feelings, counselors should:

- Be aware of their own feelings;
- Acknowledge clients' feelings and realities;
- Understand that it is not the counselor's job to take feelings away or to fix them;
- Articulate and respond to non-verbal messages;
- Normalize and validate clients' feelings.

Counselors may want to resolve problems and fix feelings, but often feelings cannot be fixed; rather, they 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 counseling, it is critical that he/she feel acceptance. The counselor can facilitate this by being nonjudgmental and accepting, irrespective of socioeconomic, ethnic, or religious background, occupation, or personal relationships. Counselors should appreciate the stress caused by the fear of being infected or the need to change behavior, and accept the consequent

emotions and reactions. Even if hostility is directed toward the counselor, he/she should recognize they are not the real target and refrain from reacting. To validate acceptance, the counselor recognizes feelings such as anger, sadness, and fear in a direct, unemotional way, indicating in words and behavior, "Your feelings are very strong. I accept them, and I accept you."

Communication Skills and Techniques

A major component of a counselor's job is communicating with clients. This exchange is a two-way dialogue of both verbal and non-verbal communication methods. To identify a client's needs and provide appropriate information, counselors must have solid communication skills. It is imperative that the counselor understand the client's communication and be clear in his or her own communication with the client. The following skills are important in building effective communication.

Attending and listening

The term "attending" refers to a counselor's ability to pay close attention to the client by limiting distractions and demonstrating that he/she is giving the client full attention. Attending involves using responsive non-verbal skills such as listening, eye contact, relaxing, and using 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 counselor is engaged with the client, though clients who are annoyed, nervous, or embarrassed might try to avoid it. Maintaining eye contact will increase the client's confidence and facilitate better counselor-client communication. The counselor should distinguish between eye contact and staring, which could make the client feel uncomfortable. Attending to the client is also improved when the physical counseling space is comfortable. The space can be improved by arranging a comfortable seating plan, with a culturally appropriate distance between counselor and client. Minimizing distractions, such as noises or disruptions, can also help create a facilitative atmosphere.

The term "listening" refers to the ability of the counselor to actively listen to the client when he/she is talking. Listening signals concern for the client's problems and allows the counselor 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/AIDS because of the partner's behavior. 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 introduces condoms into the relationship.

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

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

To demonstrate listening, the counselor should reflect briefly what the client told him or her, paraphrasing the client's words. If the client gets no comments for two to three minutes, the client might conclude that the counselor has lost interest or disapproves of what the client has just said, or that the counselor does not understand the client. Counselors 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 you are able to change your behavior to remain negative").

Showing immediacy

In the context of HIV counseling, "immediacy" refers to the ability of a counselor to deal with a situation affecting the way he/she and a client are relating *at the given moment* (e.g., if the client is exhibiting hostility toward the counselor). Immediacy involves the ability to:

- Reveal how another person is affecting you;
- Explore your own behavior toward the other person;
- Share observations about the other person's behavior toward you, or point out discrepancies or distortions;

- 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 counselor's use of technical or unnecessarily complicated language. Counseling is more effective when the counselor:

- Uses simple and culturally appropriate language;
- Ensures that clients feel they are understood, and that a common communication level is employed;
- Explains important points more than once; if a counselor wants a client to leave with a particular message, the counselor should deliver the main message first, then deal with specific details, and, finally, repeat the message in summing up;
- Puts important points in writing, when appropriate, or uses visual diagrams as memory aids so clients can refer to the points after a session; printed materials, such as pamphlets or brochures, also may serve this purpose.

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 nonetheless perceived feelings. This technique is very useful to acknowledge, reflect, and normalize the client's feelings and avoid creating defensiveness. Examples of third-person statements are:

- "People can feel a lot of confusion and guilt when they hear information about HIV."
- "When I've given HIV test results to clients, sometimes they've wanted to talk about what they could do to keep themselves healthy and where they could go for help."
- "People often feel uncomfortable and guilty when you talk to them about HIV/AIDS."
- "Some of my clients want to know how they can stay in good health and where they can find help."

Counselors can also use this technique to present choices, as in the following examples: "Some people decide to abstain from sex, while others choose to remain faithful to one partner. Still others prefer to use condoms, and some

never use them. To avoid becoming infected with HIV, you must decide which of these options suits you best."

Asking open-ended questions

Open-ended questions give clients an opportunity to express themselves freely and make it easier for the counselor to identify their needs and priorities. Open-ended questions are useful in starting a dialogue, finding a direction, and/or exploring a client's concerns. But counselors should avoid long-winded, leading, or judgmental questions. Questions that can be answered with a simple "yes" or "no" are not open-ended. Following are types of open-ended questions for counseling sessions:

- **How:** "How do you think the virus is passed from one person to another?" "How much do you know about the risk factors or lifestyles of the people you are having sex with?"
- **What:** "What do you understand by the word 'confidentiality'?" "What do you know about HIV infection?" "What do you know about how HIV is transmitted?" "What do you think about using condoms?"
- **Who:** "Whom have you spoken to about taking an HIV test?"
- **Why:** "Why" questions must be chosen carefully because they can be taken to imply accusation or judgment, which can make a client defensive. The counselor should ask "why" questions of a positive nature, those that can help clients explore the dynamics of their successes, rather than their failures. An example of a positive "why" question is: "That's terrific! Why do you think you were able to use a condom that one time?"

Though it is recommended that counselors use open-ended questions as much as possible, they should recognize when closed questions are appropriate. For example, obtaining a client's consent for an HIV test or partner notification requires that the client provide only a simple "yes" or "no."

Using a non-directive approach

Exploring options rather than issuing directives minimizes the chance that a power struggle will arise between counselor and client. When discussing behavior change, counselors should avoid such directive statements as, "You have to use a condom every time you have sex!" Instead they can put responsibility in the client's hands (a "buffet" approach), giving the client control over decisions that

meet his or her needs by asking, for instance, “What do you think you could do to protect yourself?” Given such a question, some clients may decide not to have sex at all; others may decide to have sex only with one monogamous partner for their entire lives; others will find ways to be sexually active without having intercourse; and still others will opt to use condoms and other barrier methods.

The communication skills described above can be complemented with the following specific communication techniques:

Clarifying

During a counseling session there are many opportunities for either party (client or counselor) to be unclear on what has been said. Clarifying unclear points can enhance simple communication (e.g., by asking, “Do you mean . . . ?”) or supply facts (e.g., by asserting, “No, HIV is not transmitted by eating from the same dishes.”).

Paraphrasing

Active listening requires reflecting on what the client has said. Paraphrasing—restating the client’s words in the counselor’s own words—helps achieve this objective. To paraphrase effectively, the counselor must listen actively; the counselor must determine what is being said and check with the client that the paraphrase is accurate. Paraphrasing in the counseling session is meant to:

- Show that the counselor is paying attention to the client;
- Facilitate understanding;
- Validate the client’s statements;
- Encourage the client to explore his or her concerns further.

Occasionally paraphrasing can be ineffective, particularly when the counselor:

- Repeats exactly what the client said;
- Uses technical language;
- Is judgmental;
- Debates the client;
- Fails to gain the client’s acceptance of the paraphrase.

Reframing

Reframing involves responding to a client’s comments and then presenting a positive view of the issue. For example, when a client says, “You can’t feel anything when you wear

condoms!” an example of reframing might be, “You’re right, condoms can reduce sensation. And, you know, lots of men find that when they use condoms they stay erect longer, and they do not have to worry about unplanned pregnancies, STIs, and HIV.”

Reflecting feelings

Reflecting feelings is similar to paraphrasing, but it deals specifically with a client’s feelings. Counselors reflect feelings by formulating responses that:

- Demonstrate understanding;
- Identify basic feelings being expressed verbally or non-verbally;
- Recognize the level of intensity of a client’s feelings;
- Capture the association of feelings to words;
- Confirm that the client’s feelings are normal.

Below are useful phrases to reflect feelings in a counseling context, particularly when the client is primarily expressing feelings and not giving clues about the association:

- “You feel (feeling word: sad, anxious, relieved) because (paraphrase) . . .”
- “You seem (feeling word: confused, happy, excited). What’s happening to you?”
- “How are you feeling about that?”

Occasionally reflecting feelings can be ineffective, particularly when the counselor:

- Paraphrases content without naming or prompting for a feeling;
- Uses feeling words of a very different intensity from those used by the client;
- Uses psychoanalysis, a cold tone, and/or clinical jargon;
- Adds judgmental interpretations or content.

Repeating information

At times of stress and crisis, people may be in a state of denial or feel overwhelmed, so they may not always comprehend everything they are told. Counselors should repeat important information for the client if they believe he or she has not absorbed what has been said. Indeed, counselors should repeat supportive statements or facts as often as necessary to ensure the client understands risk, illness, and health management issues.

Summarizing

When clients first learn they are infected, they may respond with rapid speech, provide details to rationalize their results, or, stunned by the news, ask more questions than the counselor can absorb or comprehend. Sometimes it is helpful for the counselor to interrupt and summarize what both counselor and client have said. This is much like paraphrasing in that it helps ensure that each person understands the other correctly. Summarizing also can guide and direct clients as they try to sort out emotions, deal with practical matters, and make plans. At the end of each session, the counselor should summarize the salient points of the discussion and highlight decisions that have been made and need to be acted upon.

Probing

Probes are verbal tactics to help clients talk about themselves and define their concerns concretely in terms of specific experiences, behaviors, and feelings. Probing also helps identify themes that may emerge when exploring these elements. Probes can help clients explore their initial concerns, examine issues more fully, and/or explore different goals. They can encourage and prompt clients when the clients fail to take those steps spontaneously. Probing can take the form of statements, interjections, or questions. Counselors can use statements to help a client discuss or clarify relevant issues. For example, a client may come in looking annoyed and sit down without saying anything. The counselor might then probe with the following statement: "I can see that you are angry. I have some idea of what it's about, but maybe you could tell me more." Such probing statements are indirect invitations for clients to elaborate on their experiences, behaviors, or feelings. Counselors also can interject a word or phrase that helps focus a client's attention. For example, a client may say, "I love my fiancé, but I am hesitating in agreeing to marry him." The counselor can then probe by using the following interjection: "Hesitating in agreeing to marry him: Could you please elaborate on that?" In this instance, the counselor helps the client say more fully something she was only hinting at.

Confronting

Confronting is a communication technique used to reflect a contradiction expressed by a client. Contradictions include differences between self-perception and behavior; between verbal and non-verbal messages; or between two different verbal messages. A confrontational message should be given in a neutral tone. If the client responds with persistent

denial, the counselor must let go. Following is an example of confrontation in the context of a counseling session:

"Based on what you told me, in that you have multiple partners and you do not use condoms with all of them, I am really concerned that you could get HIV. If this is the case, are you aware that you are putting yourself at risk of acquiring the HIV infection? So I hope when you are ready to think and talk more about HIV, you will know this is the place where you can come."

Section 4: Self-Awareness

Counselor self-reflection and self-awareness are integral to counseling interaction. To be effective, counselors need to know how they themselves function emotionally. Counselors are not isolated from the fears and emotions that all people deal with when facing HIV/AIDS. Just like the clients they see on a daily basis, counselors must face their own inner feelings about HIV/AIDS. If counselors are not in touch with themselves, they cannot help others effectively. Research and experience demonstrate the importance of providing counselors-in-training with an opportunity to increase self-awareness.

Research on counselors' attitudes toward HIV/AIDS has shown that:

- Health workers with formal training and experience in HIV/AIDS counseling were adept at separating the health messages they are trained to convey from their innermost feelings and apprehensions about HIV/AIDS. Despite the fact that the majority of counselors surveyed reported having a family member or close friend who had died of AIDS, counselors usually were not able to discuss a relative's illness openly with family members, or even with that person with AIDS, due to others' collective denial.
- Most counselors were unwilling to be tested for HIV themselves, and as many as half of female counselors reported being worried about their partners' sexual behavior but being unable to discuss the risks of HIV within the relationship.
- About two-thirds of counselors reported that they were uncomfortable discussing sexual behavior with their clients.

Box 13: Interpersonal Communication Skills

Below is a checklist to help counselors evaluate their own interpersonal communication skills:

- When a client asks you a question that is not clear, do you ask the person to explain what he or she means?
- When you are trying to explain something, do other people have a tendency to put words in your mouth?
- Do you ever ask the other person to tell you how he or she feels about the point you are trying to make?
- Is it difficult for you to talk with other people?
- In conversation, do you have a tendency to do more talking than the other person?
- Do you refrain from saying things you know will only hurt others or make matters worse?
- Do you find it difficult to think clearly when you are angry with someone?
- Do you have a tendency to change the subject when your feelings enter into a discussion?
- In conversation, do you let the other person finish talking before reacting to what he or she says?
- In conversing with others, do you find yourself not paying attention?
- Do you ever try to interpret what someone is saying?
- Do you pretend you are listening to others when actually you are not?
- In conversation, can you tell the difference between what a person is saying and what he or she may be feeling?
- When speaking, are you aware of how others are reacting to what you are saying?
- Do you dwell on your experiences?

This research reflects the stigma surrounding HIV/AIDS and the disconnect that counselors and health workers are likely to experience. Many counselors face this disconnect between how they are trained to behave professionally in HIV/AIDS services and how they are socialized to feel about

HIV/AIDS within their own families and sexual partnerships. Counselors can deal with this disconnect by being aware of their own feelings and fears about HIV/AIDS. By being self-aware, counselors are better able to communicate an attitude of equality, respect, and confidence, and to empathize without projecting their own feelings and needs onto the client.

Clients may look for someone to take over for them and tell them what to do. Part of the counselor's responsibility is to encourage clients to take responsibility for themselves. Thus, it is useful for counselors to assess their own needs and feelings continually and discuss them with peers and supervisors. The following questions will aid counselors in increasing self-awareness:

- **Do I feel uncomfortable with a client or with a particular subject area?** Often, counselors are uneasy with a certain type of client, or with controversial subjects such as drugs or sex. It is important for counselors to recognize this discomfort and decide on an honest approach to deal with it. If a counselor feels he/she cannot overcome an issue, the client should be referred to another counselor.
- **Am I aware of my own avoidance strategies?** It is important for counselors to recognize when they avoid certain topics. Counselors aware of their own avoidance strategies can say to themselves, "This seems to be really bothering me. I'd better figure out what's going on so that I can really be helpful to this client." Counselors unaware of their own avoidance strategies will not be able to serve the client properly because they will skip over important topics.
- **Can I be completely honest with the client?** Counselors want to be liked and accepted like most people. Counselors who have a strong need to be liked may offer reassuring, supportive responses too often, thereby diminishing clients' ability to develop responsibility and independence. Thus, it is important that counselors are able to say things the client may not like to ensure the client has the right information. By agreeing with the client when he or she should dissent, the counselor gives the false impression that the client is on the right track.
- **Do I always need to be in control of the situation?** While counselors may prefer a degree of structure and direction *to achieve goals and objectives, it is also important to pay attention to how*

they feel when a client disagrees or wants to pursue a different topic. For example, there may be times when the counselor wants to change the approach but the client refuses. Instead of feeling angry or rebuffed, the counselor should try to accept the client's feelings and propose alternatives. Responsive listening is a safeguard against controlling. Through self-reflection, counselors must learn to distinguish clearly between themselves and their clients, between what "belongs" to the counselor and what "belongs" to the client.

- How can I develop self-awareness? **To develop self-awareness, a counselor can use the following strategies:**

Self-disclosure: sharing something about one's self the other person doesn't know;

Introspection: reflecting one's own feelings and reactions;

Accepting feedback: learning from others how one's behavior affects them.

In the training course, a set of exercises aims to increase self-awareness. These exercises help identify personal strengths and weaknesses and how they influence the counseling interaction, and increase awareness of how stereotypes and prejudices can affect counseling. They also help counselors become more comfortable communicating with others about sex, sexuality, and HIV/AIDS.

The "Johari Window" (below) assists in developing self-awareness.

The Self	
1—Known to All	2—Blind
3—Hidden	4—Unknown to All

Window 1: Known to all.

This part of ourselves can be viewed as our "open window," the aspects of ourselves we display freely and other people can see (e.g., attitudes and behavior). We can enlarge the open window through self-disclosure.

Window 2: Blind.

This refers to our "blind spots," the parts of ourselves we cannot see but others can (e.g., body language and aspects

of our behavior of which we are often unaware). Blind spots can be made "visible" by obtaining feedback from other people.

Window 3: Hidden.

This is our private self, the things about ourselves we know but choose not to share with others (e.g., secrets or things we feel ashamed about). We can work on this by taking risks and sharing ourselves with others (e.g., by disclosing secrets).

Window 4: Unknown to all.

This part of ourselves can be viewed as a "closed" window, the things about ourselves of which we and others are unaware. These may include our motivations, unconscious needs, anxieties, and undiscovered potential. The unknown parts of ourselves can be made more known by opening memories and gaining insight.

Another way to become more self-aware is through value exploration. Counselors can improve their understanding of others by understanding their own values. Counselors deal with people of all types, races, tribes, and ages. The social environment where people grow up plays a role in developing stereotypes and prejudices about other people and groups that have a major impact on social and interpersonal interactions with others. Thus, it is important to understand how stereotypes, prejudices, beliefs, values, and culture impact the counseling process.

Exercises to foster self-awareness and value exploration are presented as an addendum at the end of this chapter.

Section 5: Counseling Models and Types

Counseling Models

Counseling models are based on various philosophies and theories about human behavior and behavior change. The three counseling models discussed here are the *client-centered model*, the *behavioral model*, and the *psychosocial model*. VCT programs tend to use several counseling models that have been tested, critiqued, and used over time. One aspect of becoming an effective HIV/AIDS counselor is understanding the main focus of these approaches. No single model addresses all complexities of human behavior and how to change them, but each model sheds light on why humans behave as they do.

The counseling approach used in this manual combines elements of the three models because the core of HIV/AIDS counseling aims to facilitate behavior change and provide

psychosocial support. The challenge for counselors is to combine approaches focused on specific behavior change (e.g., a behavior risk-reduction plan) with an approach that accepts the client (and behaviors) unconditionally.

Client-centered model

The client-centered model is based on a constructive philosophy of human behavior, according to which positive behavior change is possible if certain conditions prevail in the counselor-client interaction. These conditions include the counselor's ability to:

- Be genuine with the client;
- Show non-possessive warmth;
- Show unconditional positive regard;
- Show complete acceptance of the client;
- Be nonjudgmental of the client;
- Show empathic understanding of the client.

If these conditions are present in the counselor-client relationship, the client is more likely to get to the core of his or her problem and work toward resolving it.

Behavioral model

The behavioral model is based on the premise that preventing HIV transmission requires either reinforcing safe behaviors or changing unsafe ones. Changing unsafe sexual behavior patterns may involve a significant cost to the client (e.g., a wife's decision to abstain from sex because she is concerned about her husband's risky behavior may cost her marriage). But what may be too great a cost for one person may not be too great for another.

For change to occur, the benefits must be stronger than the costs and the client must have "self-efficacy," which refers to a person's inner resources and confidence in his or her ability to effect change. Promoting self-efficacy means enabling clients to increase confidence in their ability to change their sexual behaviors and to acquire or improve behavioral skills associated with risk reduction (e.g., condom use skills or sex negotiation skills).

In addition to change at the individual level, behavior change can take place at the community level. For community-level behavior-change initiatives to be effective and sustained over time, the community must "own" them. Community members need to be active players at every point in behavior change from conception to implementation. Behavior-change initiatives need to consider the voices of those who are often denied

participation (e.g., by working with age-specific groups and ensuring that people infected and affected by HIV are actively consulted and involved). Healthy behavior change also requires a social environment that reduces or eliminates attitudes and practices of prejudice, discrimination, hostility, and violation of human rights of people affected by HIV/AIDS.

The starting point for any behavior change must be the felt needs of the individual and the community. For example, it is difficult to take action on HIV/AIDS when an individual or community's main concern is an ongoing famine, war, or any other catastrophe. While a VCT or HIV/AIDS program may have a catalytic role in drawing attention to HIV-related problems, it will only gain credibility if it is first prepared to help with other community needs or identify other resources that can help in addressing those needs.

Psychosocial model

The psychosocial counseling model holds that internal factors (e.g., personality traits) as well as external factors (e.g., social environment) influence a client's behavior. This is one reason a psychosocial perspective appears to be essential to HIV/AIDS counseling. Counseling should help a client gain perspective on his or her own reality to feel like a protagonist (i.e., in charge of his or her own destiny). Formal counseling is more likely to be effective and sustainable in the long term if innovative ways are found to integrate or apply the counseling models in a traditional social context.

For example, in some settings or cultures in sub-Saharan Africa, while many HIV-positive people may accept the biomedical explanation of their sero-status, they look more for external or situational causes, including supernatural causes (e.g., God's will). A model that does not allow for this psychic process may not reflect the worldview and core values of the society. As a result, the counseling process may assume a superficial appearance, fail to get at root problems, or lose its credibility.

Counseling Types

This section outlines several counseling types used in VCT settings. While the type of counseling used can be influenced by many factors, the method chosen is generally based on clients' needs and circumstances, including their psychological state, the type of problems they are experiencing, and the stage of the problem at which the counseling begins. Often, one client will need many different types of counseling either at the same time or over the course of a counseling relationship. For example,

a client may require psychosocial support in coping with the loss of a loved one, and at the same time need to think about his/her own risk and how to reduce it. At any time during the counseling relationship, counselors may have to refer a client to alternative or supplementary services, such as community-based or self-help groups, which can provide ongoing emotional support.

Counseling about risk

Counseling about risk comprises several elements, including giving information about the problem (in this case, HIV/AIDS), providing an opportunity for reflection on the problem's impact on daily life (client-centered approach), and working out ways to lessen or come to terms with this impact (risk assessment and risk reduction), while identifying potential social and behavioral barriers. An example is counseling on the risks of multiple sexual partners.

Counseling to relieve distress (supportive counseling)

Some counseling is designed to relieve distress among clients reacting to difficult circumstances. When this is the case, giving information is less important than listening, providing an opportunity for emotional release, and discussing ways of coping. For example, in the VCT setting, supportive counseling is used with the parents of infected children and to support people living with or affected by HIV/AIDS.

Marital/relationship counseling

Marriage counseling is intended to help couples talk constructively about problems in their relationship. This approach focuses on the need of each partner to understand the point of view and feelings of the other, and to identify positive aspects of the relationship as well as those that may be causing conflicts.

Bereavement counseling

Bereavement counseling focuses on working through the stages of grief. It combines an opportunity for emotional release (e.g., despair and anger) with an opportunity to provide information about the practical problems of living without the person who has died. This form of counseling is discussed further in Chapter 8.

Problem-solving counseling

Problem-solving counseling is particularly suitable for patients trying to cope with stress. Basic counseling techniques and skills are combined with a systematic approach to problem resolution. In problem-solving counseling the client is helped to:

- Identify and list problems or issues that are causing distress;
- Consider practical courses of action that might resolve or diminish each problem;
- Select one of those problems and try the course of action that seems most feasible and likely to succeed;
- Review the result of this attempt and then choose another problem to solve (if the first action has succeeded) or choose another course of action (if the first one has not succeeded).

In the context of HIV counseling, the problem-solving technique is used most often in combination with crisis counseling. For example, while crisis counseling focuses on the present (such as receiving an HIV-positive diagnosis), the problem-solving technique focuses on preventing transmission, coping with reactions to HIV/AIDS, and medical care. In problem-solving counseling, counselors should:

- Define all aspects of the problem, as the client sees them, including duration and effects;
- Encourage open discussion of a client's feelings and demonstrate support and reassurance that these feelings are normal;
- Assess a client's past and present problem-solving abilities;
- Break down the problem into several less-complicated and more easily solvable components;
- Establish a plan of action for each component and discuss resources available or needed to address it.

Section 6: The Counseling Process

The full counseling process comprises three main stages: relationship building, information gathering, and coping and problem solving. The counseling process and the number of sessions required for each stage of the process varies with each client; moreover, not all clients move through all stages. Additionally, some clients may come for a single session and never return, especially in this era of same-day counseling and testing using simple and rapid test kits.

Beginning stage (relationship building)

The initial interview generally influences a client's decision about whether to return for additional sessions. The

counselor should begin by ensuring confidentiality and building trust. The counselor should then take a personal history, explore the client's problem, and learn how he or she feels about it. This information helps the counselor prepare a plan of action that should include:

- Finding out how the client would like to see the problem solved;
- Determining what the client thinks should be done to manage the problem;
- Clarifying what the client expects from counseling;
- Describing the help the counselor can offer, and giving realistic hope for change or assistance;
- Stating the counselor's commitment to working with the client.

Middle stage (information gathering)

Once the client feels the counselor can be trusted and will be able to offer information, guidance, and support, counseling enters the middle stage. During this stage, the counselor should:

- Support continued expression and discussion of feelings;
- Refer to available formal and informal resources;
- Monitor progress and modify plans as necessary;
- Promote continued changes in behavior;
- Help the client move toward acceptance and control of the problem.

Concluding stage (coping and problem solving)

After the client has shown a willingness to participate in formulating and carrying out action plans, counseling enters its concluding stage. During the initial phases of this concluding stage the counselor should help the client summarize the problem (i.e., the session's main focus) or the content of the day's session or sessions, and provide the client with an agenda to work on before the next session. The counselor should end the relationship only when it is clear that the client can cope with and plan adequately for day-to-day functioning, and has a support system (family, friends, or support group) to help carry out the action plan.

End of counseling stage (final interview)

Though there is no set schedule, at some point counseling must end. Often this is very difficult for clients who have built a close relationship with their counselor. For this reason, counselors should plan the final session carefully to:

- Ensure maintenance of coping skills;
- Support maintenance of behavior changes;
- Assure the client of continuing help, if necessary;
- Review plans for illness management;
- Make sure that all needed and available resources and referrals have been identified and are being used.

Section 7: Counseling Recipients and Providers

For whom is HIV counseling intended?

HIV/AIDS is most prevalent among sexually active people between ages 15 and 49, but HIV/AIDS counseling is often aimed at even broader segments of the population. Studies indicate that VCT becomes more cost-effective if it is tailored to couples and "high-risk groups" (e.g., drug users, men who have sex with men, commercial sex workers, truck drivers, and mobile or migrant populations). HIV counseling is also particularly appropriate for people who are being tested for other STIs or TB (whether or not they are infected with HIV), people seeking help because of past or current risky behavior, and women seeking antenatal care.

Who should provide HIV counseling?

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

- Nurses, doctors, social workers, and other care providers who have been specially trained in HIV counseling;
- Full-time counselors (including psychiatrists, psychologists, and family therapists) who have been trained in HIV counseling;
- Community-based workers whose work consistently entails appropriate handling of confidential information and emotional issues;
- PLHA.

What are the qualities of a good HIV counselor?

The vital role played by counselors in the fight against HIV/AIDS is not simply a matter of preventing transmission of the virus. Counselors must also help those infected with

HIV find answers to their particular problems. Counselors may not actually be involved in treating illnesses related to HIV/AIDS, but they should be aware of the most common symptoms so they can recognize when and to whom to refer patients for appropriate medical care. A good counselor:

- Understands all aspects of HIV/AIDS (medical, behavioral, socio-cultural);
- Possesses good communication skills and is familiar with counseling techniques;
- Is accessible and available to clients and is able to deal with their reactions;
- Is able to empathize;
- Is able to express himself/herself coherently and precisely;
- Is able to recognize his/her limitations;
- Possesses a high level of self-awareness;
- Is authentic, sincere, and honest;

- Has a sense of humor;
- Lives in the present;
- Appreciates the influence of culture.

Where should counseling take place?

Counseling should take place in a quiet, distraction-free setting that is reassuring and neutral for both counselor and client. Counselors should present and carry themselves in a way that minimizes the difference between counselor and client. For example, counselors should not wear a uniform or sit in a tall chair or behind a large desk.

HIV counseling can take place in any setting where a private and confidential discussion of the issues can be held. Settings can be as varied as hospital wards, antenatal clinics, community health centers, churches, or schools. Counseling services should always be available at sites where HIV services are being provided (including testing centers, research sites, and blood donation sites where results can be “linked” to the individual).

ADDENDUM

Activities for Self-Awareness and Value Exploration

Exercise 1 for Value Exploration

In this exercise, your facilitator will ask you to rank the following categories in terms of their value to the counselor. The results, in terms of things the counselors notice about themselves (and about themselves in relation to their peers), will be shared in a plenary session.

Health _____
Pleasure _____
Freedom _____
Sexuality _____
Family _____
Control _____
Career _____

Exercise 2 for Value Exploration

You will be asked by your facilitator to describe how you feel about each of the following groups of people.

Black people are...
White people are...
Citizens of my neighboring country are...
Homosexuals are...
Men are...
Women are...
Teenagers are...
Thin people are...
Fat people are...
Rich people are...
Muslims are...
Christians are...
People in the military are...
Old people are...

Explore how these generalizations can affect your relationships with clients.

Role-Playing for Value Exploration

Scenario 1

You are a female university student and your male professor has offered to help you with your lessons. He invites you to his office after hours and starts making physical advances. You try to stop him and he threatens to fail you. Act out this scene.

Scenario 2

You are a Christian counselor and you have a client with more than one wife (a polygamist). Your client feels he is not at risk of HIV because he is faithful to all his wives. What is your attitude toward this client? Act out this scene.

Scenario 3

A couple sent by their church comes to you for counseling and testing before getting married. They love each other very much. Their church will ask them their test results. If either of them is positive, the church will not support the marriage. Act out this scene. (What are the issues? How do you feel about the church's practice? What role do you play in this situation? Is this VCT?)

After role-playing, discuss with your colleagues what happened and the implications for counselors.

Exercise for Self-Awareness: “Who Lives in Here?”

This exercise explores in greater detail who “lives in you” as a counselor. The purpose of the exercise is to help you become more aware of how what is within you might get in the way of your ability to empathize with a client (put yourself in the client’s shoes).

Name	How important is it to you?
Gender	Are you satisfied with being who you are?
Body	Are you satisfied with your physical appearance?
Abilities	What are you particularly good at?
Mind	Do you feel okay about your intellectual ability?
Age	Are you comfortable being the age you are now?
Birth	Do you have any feelings about where you were born?
Culture	Where were you brought up? If you have moved among different cultures, what influence has this had?
People	Who influenced you most while you were growing up?
Mother	What is your opinion of your mother?
Father	What is your opinion of your father? If you have no parents, how has that influenced you?
Siblings	What is your opinion of your brother/sisters? If you have no brothers or sisters, what influence has this had?
Education	What influence did your education have? What would you like to have achieved that you did not?
Employment	List the jobs you have had, the people you remember associated with those jobs, and the overall influence on you of the work and the people.
Spouse	If you are married, how has your spouse influenced you?
Children	How have your children influenced you? If you wanted children and were unable to have them, how has that influenced you?
Unmarried	If you are unmarried or have no partner, what influence does that have?
Preferences	How do your sexual preferences influence you?
Values	What are your values and what influence do they exert? Have you adopted them from other people without thought?
Beliefs	What are your fundamental beliefs? How did you acquire them?
Religion	If you are religious, what influence does that exert? If you have no religion, what influence does that exert?
Experiences	What life experiences are significant for you, and why?
Health	What illnesses or accidents influenced you?
Memories	What memories do you treasure and what memories do you try hard to forget?
Relationships	Which relationships in the past are you glad you had, and which relationships do you wish you had never had?
Circumstances	Which life circumstances, past or present, do you celebrate, and which do you regret?
Authority	Who represents authority for you, in the past and now? What influences do these figures exert on you?
Strengths	What are your major strengths and how might these influence your ability to listen to clients?
Weaknesses	What are your major weaknesses and how might these influence your ability to listen to clients?
Virtues	What do you consider to be your virtues (“good” qualities)? How do they influence your behavior?
Vices	Do you have any vices (“bad” qualities)? If so, how do they influence your relationships?

Exercise for Identifying Strengths and Weaknesses

Your facilitators will explain how they think their personal strengths and weaknesses might influence the counseling process and relationship. But you can start the process by describing your own strengths and weaknesses.

Strengths (+)

Weaknesses (-)

Next, describe what can you do to improve on your strengths and overcome your weaknesses.

Further Tools for Self-Awareness

Self-assessment checklist

Complete this list, then keep it and refer to it at the end of training to assess whether there have been changes.

Are you potentially a good counselor?

- Do you have the potential to be a good counselor?
- Why did you decide to become a counselor?
- How do you feel about being a counselor?
- With what emotions are you comfortable?
- What are your expectations of clients?
- Can you accept people as they are and not want to change them?
- Can you keep people's secrets?
- Can you let go of wanting to solve everyone's problems?
- Can you make use of your life experience without imposing it on other people?
- To what degree can you be flexible, accepting, and gentle?

Exercise for sex and sexuality

Sex is one of the strongest human drives, something that is universal and natural yet not usually taught in a formal way. Despite its universality and inevitability, and despite its essential role in procreation and HIV transmission, sex is often a subject of great embarrassment and ignorance. It is important to remember that we are all sexual beings whether or not we have sexual experience, are in relationships, or have the full physical and mental abilities to sustain sexual feelings and responses.

Brainstorm as a group and list all the sexual behaviors of which you are aware (including those about which you have heard or read), and identify those sexual behaviors considered to be "normal." Then answer the following questions:

- What was it like for you to hear and say these words?
- Were you aware of any reactions? (*either* internally or among others)
- Do you know what all these words mean?
- If you do not know what certain words mean, would you be willing to ask?
- How likely is it that each of these behaviors could transmit HIV?



CHAPTER 4

BEHAVIOR-CHANGE STRATEGIES

Section 1: Behavior-Change Strategies and HIV/AIDS

Section 2: The Process of Behavior Change

Section 1: Behavior-Change Strategies and HIV/AIDS

Individuals' lifestyles and behaviors have a major influence on physical and emotional health. Behaviors that affect health include eating, personal hygiene, sexual activity, physical activity, smoking, and substance abuse. Because these behaviors are often deeply ingrained, they are not easy to change. Yet unless harmful behaviors are changed, they can result in preventable illness and premature death.

In the context of HIV/AIDS, sexual behavior is probably the most important behavior to consider. Reducing HIV transmission in the community and helping HIV-positive clients stay in good health are essential components of the counseling process. The counselor's job is to help clients choose safe and healthy behavior patterns. This entails explaining the advantages and disadvantages of behaviors such as use of alcohol, tobacco, and other drugs; sexual activity; and eating habits.

Some actions to maintain health require a great deal of effort, while others require relatively little. For example, it takes relatively little effort, theoretically, to set up an appointment for a child's vaccination. This one-time effort can produce a substantial result. Other efforts to maintain health require a great deal more initiative over time. Eating healthy foods to prevent heart disease, for example, requires diligence, consistency, and discipline over a long period. One could place sexual behaviors in this same category. Using safer-sex barriers during sexual activity requires consistency, resources, planning, and commitment.

When an individual begins to consistently engage in unhealthy behaviors, the unhealthy behavior must be unlearned. To change behavior, the individual needs to: identify the behavior as harmful; understand available alternatives; be able to act on that knowledge; and receive the support necessary to maintain the behavior change. For example, an individual with heart disease needs to know what foods are contributing to the problem; how to replace them with healthier foods; how to prepare or acquire those

foods; and how to consistently eat them and not return to old eating habits.

Supporting behavior change is a complex interaction between the counselor and client that requires a great deal of insight into human nature and motivation. The challenge for counselors is to acknowledge the difficulty in changing one's behaviors while establishing a relationship with the client that supports the behavior change.

In behavior change, there is a considerable difference between theory and practice. In reality, it is not easy for a person to change his or her behavior. Clients can begin to change their behavior, but there is no guarantee they will be able to maintain that change. The role of the counselor is to support the client in maintaining new behavior patterns.

No single strategy for behavior change can address all human behaviors. The three strategies presented here—risk elimination, risk reduction, and harm reduction—can be thought of as tools for assessing clients and their concerns.

Risk elimination: "Abstaining from sex and 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 behaviors that lead to it are eliminated. An example of a prevention education message based on risk elimination is the "Just Say No" drug campaign developed in the United States during the Reagan Administration.

While adhering to risk elimination guarantees 100 percent safety from infection, it is often the least useful behavior-change strategy because most people find it extremely difficult to suddenly eliminate risk activities such as sex or injecting drugs. This strategy does not acknowledge that people derive pleasure from engaging in certain behaviors and does not allow for alternatives.

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

Realizing that many people cannot adhere to the risk-elimination strategy, some counselors and educators opt for risk reduction. The risk-reduction strategy acknowledges that individuals might continue to engage in sex and inject drugs. Assuming that abstinence is not a realistic alternative, the risk-reduction strategy advises that individuals engage in “safer” behaviors: using condoms during sex and, if they are going to inject drugs, not sharing needles.

The risk-reduction strategy acknowledges that, no matter what, some people will engage in risky behaviors, so realistically it is better to find ways for them to engage in those behaviors more safely than to try to influence them to give them up completely. The risk-reduction strategy cannot offer a 100 percent guarantee that a person will remain uninfected. For example, if a condom breaks during intercourse, the client will be at risk.

Many educators feel that focusing so much attention on condoms and how to use them does not allow sufficient discussion of why a client might be engaging in behaviors that put him or her at risk in the first place. For this reason, many educators believe that the risk-reduction strategy lacks the humanistic and individualistic approach necessary for behavior change.

Harm reduction: “Follow a step-by-step process of change”

The harm-reduction strategy recognizes that risky behaviors do not only occur, they also have meaning. This strategy assumes 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 behavior change; instead, change is incremental and takes place over time. Any positive change brings the individual one step closer to healthy behavior. The counselor works with the client to identify risky behaviors, understand the reasons why he or she may continue engaging in them, and identify what the client can do to move toward healthier behaviors. An example is needle-exchange programs, which acknowledge that some clients engage in risky behavior. In this strategy, eliminating the behavior that puts them at risk might not be an immediate goal, but, for some, a long-term one.

Unlike the risk-elimination and risk-reduction strategies, which leave no room to acknowledge the difficulty of

giving up certain behaviors such as substance use, the harm-reduction strategy acknowledges that the risky behavior may continue, but reduces the harm by, for example, making clean needles available. Providers who use the harm-reduction strategy must have the cultural competence, sensitivity, resources, and skills to work effectively with clients. Some counselors and educators may feel uncomfortable ethically because this strategy does not protect the client from immediate infection.

Conclusion

Each of the three strategies (and others) is available to HIV counselors and educators. Elements of different strategies may be appropriate at different times for the same client. Most importantly, HIV educators and counselors must be familiar with these strategies and know how to use them, not as absolutes but as tools to interact with clients. Educators and counselors also should keep in mind that they can adapt these strategies to their own style.

Section 2: The Process of Behavior Change

Behavior change is a process that takes place in stages, from acknowledging the need to change behavior through actually adopting and sustaining behavior change. Understanding these stages can strengthen the counseling process. While it is important to understand these stages, it is equally important to recognize that no behavior change follows an absolutely predictable pattern. A client can conceivably go through the stages of behavior change many times before a successful change is achieved. The stages of behavior change are presented here not as an absolute, but as a tool for the counselor when assessing the client and determining where the client is on the behavior-change continuum. It is important to stress that behavior change takes place in the context of the client's life and the social, societal, economic, and emotional challenges that he or she is facing.

The primary tool for stemming HIV transmission is education that promotes healthy behavior. But experience has demonstrated that simply providing facts or advocating abstinence is not enough. Human beings tend to be resistant to behavior changes of all sorts, particularly to changing sexual and drug-related behaviors.

An important first step toward understanding and supporting healthy behavior change is reexamining perceptions of client behaviors. A client's perception of his/her behaviors may be vastly different from the

counselor's perception. The client and counselor often have a different understanding of what behaviors present risk. Ironically, some of the behavior changes counselors encourage their clients to adopt often feel riskier to them than their current risk-taking behaviors. For example, when counselors suggest introducing condoms into a client's relationship with a sexual partner, the client may fear losing the relationship. The client therefore may reject the recommendation.

In many communities, condoms have social and cultural connotations that can make their use problematic or even unacceptable. Condom use can be considered a sign of promiscuity, interference with fertility, or a threat to the assumption of trust in the relationship. For women and adolescents, in particular, suggesting condom use may ignore an important reality: they often lack power in sexual decision-making. When sexual behaviors and drugs are linked, a client's attempts to control or change the situation can entail risks that he or she feels overshadow any warnings about potential infection.

If a client feels the costs of behavior change exceed the benefits, he or she may ignore suggestions to adopt the change. Thus, such encouragement actually may be irresponsible if not given with explicit recognition of the client's perception, and pragmatic support for managing the hoped-for change in the context of the client's daily life and personal and social needs. Counselors must understand the conditions and strategies that will maximize the possibility of change.

In counseling for behavior change, counselors can:

- Ask clients what they can do to avoid HIV infection;
- Ask about the specifics of how they will accomplish this;
- Identify potential barriers to implementation;
- Practice strategies to deal with these barriers;
- Identify and assist with other resources for support;
- Document the plan.

Determinants of the ability to change behavior

Research on behavior change has repeatedly identified four characteristics that seem to influence people's ability to change:

- **Self-efficacy:** the degree to which a person feels in control of his or her own life and destiny;

- **Assertiveness:** the ability to communicate clearly what a person wants or needs;
- **Rationality:** the ability to make decisions about one's own life and behavior in a fully considered way;
- **Social affiliation:** how and to what degree a person feels part of a larger group, and how important that connection is.

Counselors can support behavior change by:

- Recognizing, supporting, rewarding, and affirming all changes and efforts to change;
- Assisting clients with problem solving rather than chastising them for their failures;
- Being available for ongoing support and/or identifying and assisting with other sources of support;
- Focusing on the benefits of the changes made while allowing for regret of past behavior.

Behavior change is most likely to occur when:

- Clients gain new awareness or insight and perceive its significance in their lives;
- Clients have the opportunity to examine not just the benefits of behavior change but the costs of making the change as well;
- Clients have access to necessary tools and services, the opportunity to develop needed skills, and ongoing support for behavior change;
- Clients can rehearse behavior changes with role-playing and other practices (for example, if a client wants to inform a partner of his or her HIV status but is afraid to do so, the counselor can suggest the person act out the imagined exchange);
- Clients make an initial attempt to introduce change and perceive this attempt as more positive than negative.

Many models identify the stages of behavior change.

The one presented here is an adaptation of the CDC's *HIV Prevention and Counseling Guidelines* (1993). The stages are Knowledge/Awareness; Significance to Self; Cost/Benefits Analysis; Capacity Building; Provisional Try (initial attempts at behavior change); and Maintaining Behavior Change. For effective counseling, the counselor must know the client's current stage. Each of these stages is described below.

Stages of Behavior Change

Knowledge/awareness

Counselors need to assess clients' HIV/AIDS knowledge and awareness and the risks posed by their behavior. Clients must know that they are at risk before behavior change can occur. Open-ended questions are a good tool for assessing a client's knowledge and/or awareness.

Possible questions for assessing knowledge:

- "What have you heard about HIV?" (Alternatively, "What do you know about HIV?" Be aware that the latter may sound more like interrogation than inquiry.)
- "What have you heard about how people get HIV?"
- "What have you heard about what people can do to avoid HIV infection?"
- "What are you doing that might put you at risk of HIV infection?"
- "Why do you think we talk about HIV here in an STI clinic?"

Significance to self

Once the client is aware of the problem, he or she then must acknowledge the significance of the problem in his/her own life. Significance to self is the ability of the client to connect the information that he or she has to his/her own behavior. Often, clients will know how HIV infection occurs but not see how they are placing themselves at risk of infection. Counselors can help clients recognize risk behavior.

Clients respond to their risk of HIV infection by:

- Recognizing that their behavior places them at risk of HIV infection;
- Being unwilling or unable to accept that their behavior can result in HIV infection; or
- Recognizing their risk and feeling helpless, hopeless, and unable to change their behavior.

Cost/benefits analysis ("pro" and "con" analysis)

The cost/benefits analysis acknowledges that there are both gains and losses for the client in changing behavior. Cost/benefits analysis examines the "pros" and "cons" of both the current behavior and the desired change, and assists the client in expressing the losses they might feel for giving up the old behavior.

Questions/strategies for initiating a cost/benefits analysis include:

- "What's working for you about what you are doing now?"
- "What are you doing now that you'd like to change?"
- "What's the hardest (scariest/worst/most difficult) part about changing this behavior?"
- "What might be good about changing?"

Capacity building

After the client is aware of the problem and how it relates to his/her own life, and has decided that the benefits associated with the behavior change outweigh the costs, he or she is ready to start making changes. But often, the client does not have the personal resources to make and sustain the behavior change. Capacity building prepares for behavior change. For example, counselors should not only give a condom demonstration, but should also identify factors that prevent the client from using condoms. Then the counselor can help the client develop the skills he or she needs to start using condoms regularly. During capacity building, the counselor provides the client with specific, practical, and achievable skills. One method to build capacity for behavior change is to conduct reverse role-plays and affirmations.

Questions/strategies for capacity building include:

- "What do you expect will be the most difficult part of this for you?"
- "How have you handled similar situations in the past?"
- "What will you have to do differently?"
- "When you do this, what words will you use?"

Provisional try (initial attempt at behavior change)

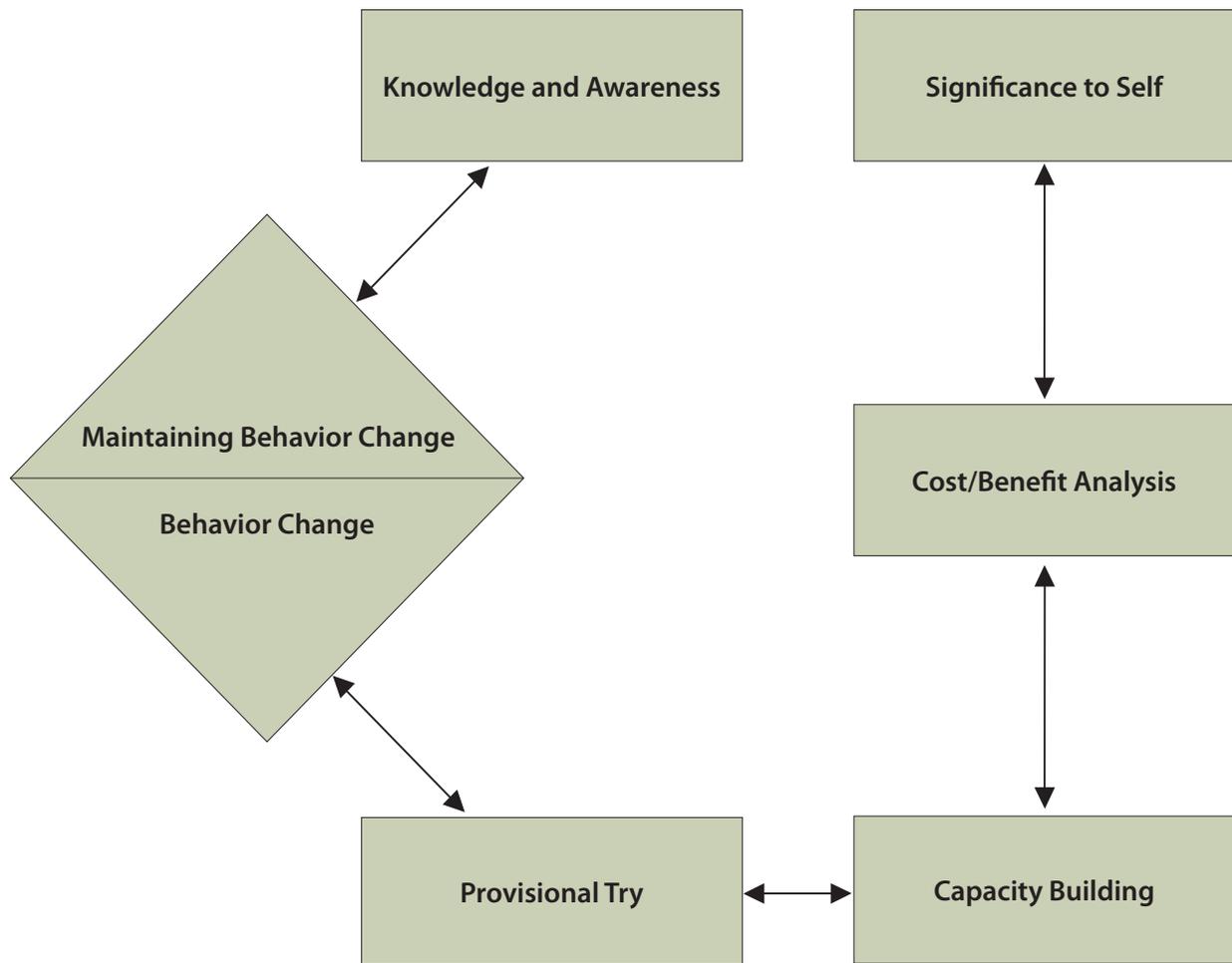
The provisional try takes place when a client leaves the counseling session and attempts a step toward changing behavior. Though provisional tries may not always be successful, the minimal attempt at behavior change can be considered a success and must be supported by counselors. Counseling strategies during the provisional try stage include:

- Reinterpreting the concept of "failure";
- Asking "why" in a positive way;
- Providing closure.

Maintaining behavior change

Maintaining safer sexual behaviors over time depends on continuous and repetitive interventions. It is expected that some behavior will change as an individual's life changes. For example, condom use may no longer be necessary

Box 14



when an uninfected person enters a monogamous relationship with someone who is HIV-negative. But relapses to less safe behavior may invalidate the previous safe behavior and lead to HIV infection. Rates of high-risk behavior and new HIV infections will increase if interventions are withdrawn; thus, continued risk reduction depends on continued behavior-change programs and continued encouragement and support from counselors.



CHAPTER 5

PRE- AND POST-TEST COUNSELING FRAMEWORKS IN VCT

Section 1: Counseling Overview

Section 2: Pre-Test Counseling

Section 3: Post-Test Counseling

Section 4: Helpful Hints for Promoting Care and Support Options

Section 1: Counseling Overview

The pre- and post-test counseling procedures outlined in this chapter can be modified according to circumstances in various settings. Nonetheless, some elements are essential for every pre- and post-test counseling encounter:

- Each individual should be provided with information that allows him/her to decide for himself/ herself whether to be tested (informed decision with informed consent).
- The HIV testing procedure should be organized to maximize confidentiality.
- HIV antibody testing should be linked with information and recommendations regarding HIV prevention, care, and support.
- Adequate pre- and post-test counseling should be provided to all individuals seeking a test.
- Disclosing HIV status should be discussed with all clients. If a client is found to be HIV-positive, he or she should be encouraged to disclose the result to sex partner(s). The need for additional and appropriate referrals should be addressed where possible.

The following steps, covered more explicitly in Sections 2 and 3 of this chapter, comprise pre- and post-test counseling:

- Determining a client's knowledge;
- Giving information;
- Conducting a personalized risk assessment;
- Developing a personalized risk-reduction plan;
- Demonstrating appropriate condom use;
- Explaining the HIV test and discussing implications of the test result;

- Obtaining informed consent;
- Assessing a client's ability to cope;
- Notifying the client of test results;
- Providing psychological and emotional support and referrals, as appropriate.

Section 2: Pre-Test Counseling

Pre-test counseling, which occurs before a client's blood is tested for HIV antibodies, is conducted to:

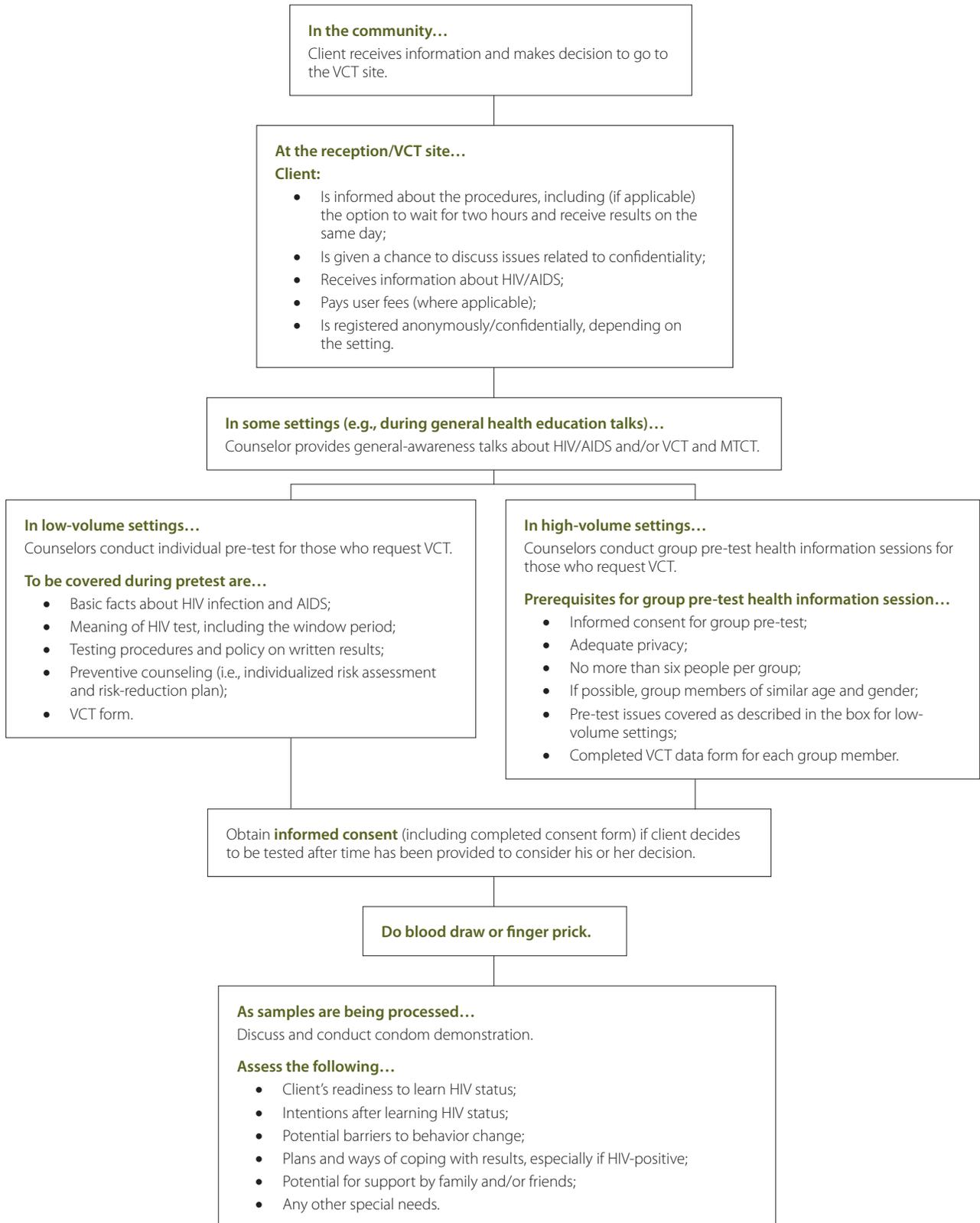
- Review a client's risk of infection;
- Explain the test and clarify its meaning;
- Explain the limitations of test results and caution the client about potential misuse of results (e.g., to understand that a negative result remains negative only as long as no new exposure to risk occurs);
- Help the client think about possible reactions to the test result and whom to inform;
- Help the client understand why the test is needed and make a decision about the test.

The first step in pre-test counseling is for the counselor to establish a relationship with the client. During this phase, the counselor identifies himself/herself and clarifies his/her role. In addition, the client should be told how much time is available for counseling. It is critical that the counselor emphasize confidentiality at this time.

Once the counselor and client have become acquainted, the counseling session begins. First, the counselor obtains the client's basic biographical information, including his/her name or code name (if a code name is used, no address is recorded), age, sex, address, telephone number, occupation, education, tribe, religion, and marital and economic status. (The information collected will vary among settings.)

Box 15

Client Flow for Pre-Test Session



The next step is for the counselor to obtain background on reasons the client is seeking testing and on his/her behaviors and perceived risk. It is important to obtain relevant medical history (past and present), including serious illnesses, blood transfusions, cough, diarrhea, STIs, etc. If the client is female, the counselor should determine how many pregnancies she has had. Additional information needed includes the client's personal habits (smoking, drinking, drug use, etc.), his/her sexual history (whether the client has a steady partner, husband/wife, boyfriend/girlfriend, or other partners, condom use, etc.), and any risky behaviors.

After this phase, the counselor needs to ascertain the client's level of knowledge about HIV/AIDS and the HIV test. It is important to identify misconceptions and misunderstandings so they can be corrected. The counselor should assess the client's understanding of what the test entails and explain positive and negative results, including the window period (see Chapter 1). It is important to explain how the test is administered and how long it will take for results to be available. The client needs to be informed about where the testing will be done and how to go through the testing "system" in the specific clinic setting.

This is a good time to explore the personal implications of taking the test, including what a positive or negative result will mean to the client, the client's family, and/or significant others. Psychosocial reactions and support mechanisms should be discussed, including the client's plans regarding whom to tell about the test result. If same-day testing is not used, the client should be encouraged to determine whom to contact for support while awaiting the result.

In the absence of HIV-related services, learning that one is HIV-positive may be perceived as a "death sentence." Nevertheless, it is important that clients recognize the

benefits of knowing their HIV status. One of the most beneficial outcomes of knowing one's status is the ability to be referred to related medical and social services.

The next phase of pre-test counseling is to provide information about safer-sex practices and healthy lifestyle practices. If the client is practicing risky behavior, it is important to discuss what may be required of the client in terms of behavior change. A condom demonstration can be given while discussing safer-sex strategies. It is critical that the client have an opportunity to ask questions.

The final stage in pre-test counseling is for the client to determine whether he/she wants to be tested for HIV antibodies. At this point, the client should have a good understanding of the test, its meaning, the implications of taking the test, and his/her personal reasons for doing so. If the client decides to take the test, the counselor must obtain informed consent. The counselor should explain the consent form and, when feasible, allow the client time to read a leaflet on the testing procedure. After the client has taken the HIV test, he/she will need to obtain the results and post-test counseling. Where same-day results are not provided, the counselor should arrange a date and time for a follow-up interview or post-test counseling.

The Exploration-Understanding-Action Model of Counseling

The "Exploration-Understanding-Action" (EUA) counseling model provides a simple framework for moving through pre-test counseling in an orderly manner in keeping with the client's state of mind. It is an effective framework for using the most appropriate skills at each stage.

In the EUA model, counselors first explore clients' concerns or reasons for seeking counseling. The next step is to develop a shared understanding of the situation as the

Box 16: EUA Model



client sees it, which may take one or a number of sessions. Only after the counselor and client arrive jointly at this level of understanding can they embark on the third step: action. In the context of the EUA model, “action” means developing a plan and set of strategies to achieve the desired outcome. A common mistake made by inexperienced counselors is to rush to this stage without allowing sufficient time to truly explore and understand a client’s needs and concerns.

Box 17: Steps for Developing an Individualized Risk-Reduction Plan

- The counselor asks the client to propose some ideas about how to reduce his or her risk of HIV exposure.
- The counselor may initiate a discussion of risk reduction by listing several alternative risk-reduction strategies for the client to consider.
- For each risk-reduction behavior, the counselor assesses internal and external obstacles to change, perceived efficacy in enacting the new behavior, readiness to change, and availability of resources to support change.
- In supporting a client to enact his or her personalized risk-reduction plan, the counselor acknowledges and supports the client’s strengths (e.g., social support, self-efficacy, previous success in changing behavior) and assists problem solving in areas of concern or expected difficulty.
- If condom use is part of the risk-reduction plan, the counselor asks the client to tell what he or she knows about condoms and invites the client to practice putting a condom on a penis/vagina model before the counselor conducts the condom demonstration.
- If the client does not mention condoms, the counselor may introduce the subject, whether or not the client is planning to use them.
- The counselor elicits a commitment from the client to try to implement specific behavioral changes before the next counseling session.

Risk Assessment

After the counselor has begun exploring HIV/AIDS issues with the client (and, therefore, after the client has become more familiar with the subject), the counselor needs to

assess the client’s risk of infection. As this involves the client sharing very personal information, which the client may never have shared with anyone else before, the counselor must show a great deal of sensitivity. To assess a client’s personal risk, the counselor should explore the following:

- Current and past sexual behavior (number of partners, type of partners, frequency of partner change, unprotected vaginal and/or anal intercourse);
- Current and past sexual behavior of the client’s sexual partner(s), if known;
- Current and past drug and/or alcohol abuse by the client and the client’s partner(s), if known;
- Client’s history of blood transfusion (i.e., date and location, whether the blood was screened for HIV);
- Current and past exposure to non-sterile invasive procedures (injections, scarification, non-medical circumcision, tattooing).

In addition to listening actively and showing empathy and acceptance, counselors can use such techniques as probing, repeating, paraphrasing, and reframing to elicit accurate information (see Chapter 3). Open-ended questions (e.g., “What can you tell me about your current sexual relationships?”) are generally more productive than “yes or no” questions (e.g., “Are you currently in a sexual relationship?”) for eliciting detailed information and showing interest without judgment. Based on the information elicited, counselors can help clients identify and recognize the connection between the modes of transmission discussed earlier and their own particular behaviors or practices that may put them at risk of acquiring or transmitting HIV.

Individualized Risk Reduction

A personalized risk-reduction plan is a key element of behavior change-oriented HIV counseling. The process is interactive and respectful of clients’ circumstances and readiness to change. Rather than *telling* clients how to change their risky behaviors, counselors can develop an individualized risk profile for each client and, through discussion, *assist* the client in developing a specific risk-reduction plan. Counselors must allow sufficient time to complete each step of the process and not appear rushed or hurried. At this stage within the EUA model framework, clients have explored and understood their level of risk and are contemplating action.

The risk-reduction plan should be challenging, but not so much so that clients will fail to follow it or become frustrated. The plan can be useful in defining several goals, some of which may be easy to attain while others may be more difficult. It also can be useful to divide the new behavior into steps and encourage clients to take these steps one at a time. Some clients may find it useful to have a written risk-reduction plan so they can take it home.

Assessing a Client's Psychological Status

In addition to assessing a client's interpersonal and social situation, it is important for counselors to appraise the client's psychological/emotional state. Factors affecting a client's psychological state may include:

- The person's physical health at the time;
- How well prepared the person is for the results of the HIV test;
- How well supported the person is in the community and how readily he or she can call on friends for assistance;
- Cultural and spiritual values attached to HIV/AIDS, to illness in general, and to death.

The counselor can get a good idea of the client's emotional state by exploring:

- Any client anxiety;
- Any client depression;
- Any client history of tendency to harm self (suicide attempts or suicidal ideation);
- Client's history of coping; current coping mechanism;
- Family situation;
- Existing social network (friends, support groups in the community, clubs, etc.).

Demonstrating Condom Use

Because using a condom correctly is one of the most effective means of preventing HIV transmission, counselors often need to demonstrate proper use during pre-test counseling.

The male condom

The male condom is the best-known and most commonly used means of protection against HIV transmission. It is made of latex and looks like a long balloon that can fit over a penis. (In cases where users are allergic to latex, alternatives can be sought.) The condom is often lubricated

and needs to be stored and used properly to be effective. The decision about whether to use a condom usually rests with the man; many women have a great deal of difficulty getting their sexual partners to agree to it.

With the aid of a diagram, counselors can use the following text to demonstrate male condom use:

1. "Pinch the end of the condom and then place it on the erect penis."
2. "Still pinching the end, unroll the condom right to the base of the penis."
3. "If you want to use a lubricant, choose one that is water-based. Oil-based lubricants cause condoms to tear."
4. "After ejaculation, hold the condom and withdraw the penis before it becomes soft. Never re-use a condom."
5. "Wrap and dispose of the condom in a bin, not in a toilet."

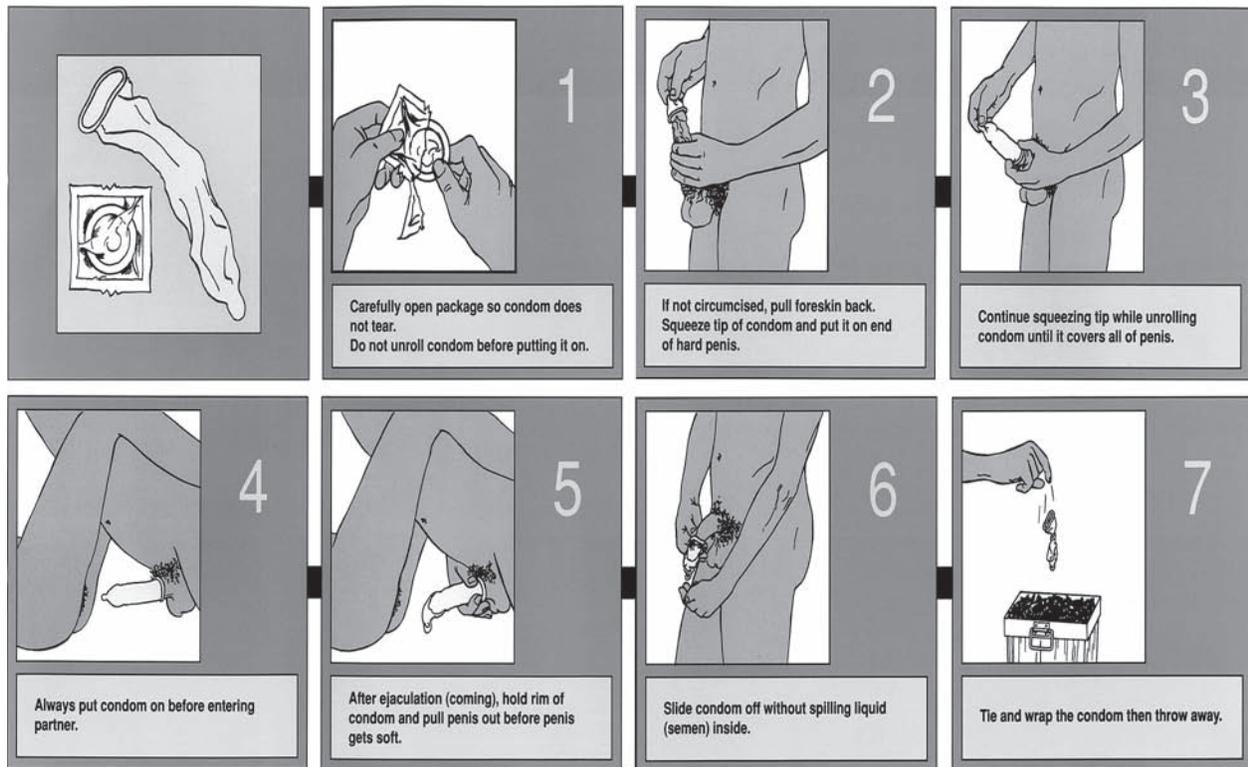
The female condom

The female condom is a sheath made of polyurethane, which is stronger and more supple than the latex used in male condoms. At the closed end of the sheath is a ring used for inserting the condom. At the open end of the condom is an outer ring, which lies outside the vagina and covers the vaginal opening and the base of the man's penis. The woman should guide her partner to make penetration easier. The female condom is pre-lubricated and should only be used once.

With the aid of a diagram, counselors can use the following text to demonstrate female condom use:

1. "The condom has two rings: the inner ring, which allows the condom to be inserted into the vagina, and the outer ring, which is larger and covers the exterior of the vagina."
2. "Squeeze the inner ring between the thumb and forefinger."
3. "Insert the folded ring into the vagina and push it in as far as it will go."
4. "The inner ring should stay in position, and the outer ring should cover the opening of the vagina."
5. "After ejaculation, remove the condom before getting up. Pinch and turn the outer ring, then pull the condom out gently. Dispose of in a bin, not a toilet."

Box 18: How to Use a Male Condom



Salim Khalaf/Family Health International

Explaining the Meaning of Test Results

Clients considering an HIV test must be provided the information they need to make an informed decision. The counselor should initiate the conversation by asking the client what he or she knows about the HIV test. The counselor can then provide information about HIV testing as needed, describe the laboratory procedures used at the VCT center, reiterate that the test is anonymous, and correct any misconceptions.

Given that clients often have concerns about the accuracy of the test and pose specific questions about the laboratory procedures used, it is important that counselors be knowledgeable about the testing procedures and demonstrate this knowledge. The counselor should tell the client how long it will be before the test results are available. If the test requires a fee, the client needs to be informed about the cost and acceptable methods of payment.

Obtaining Informed Consent for Testing

Counselors must never assume that because a client has come to the counseling center, he or she is willing and

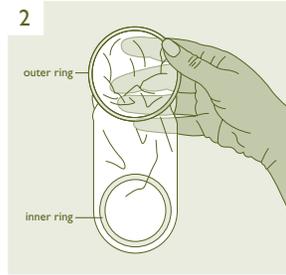
ready to take an HIV test. Some people may come to be tested but change their mind or become hesitant after learning more about HIV.

When giving informed consent, clients must evaluate the information they receive without any pressure from the counselor. If the counselor has provided all necessary information and the client decides to take the test, the counselor makes arrangements for the client's blood to be drawn. The counselor must support clients by acknowledging their possible anxiety about returning for the results, and they should help clients develop a plan to cope with this anxiety. It is also crucial that the client is reassured that the test results will be held in the strictest confidence. This is also a good time to reinforce reasons why the client may benefit from knowing his or her HIV status, and to set up an appointment to return for the results (if the center does not offer same-day results). When scheduling the post-test counseling appointment, the counselor should solicit the client's commitment to return. If a rapid test with same-day results is used, the counselor must make arrangements to accommodate the client during the time he or she waits for the results.

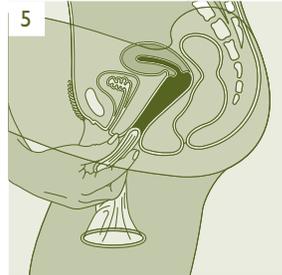
Box 19: How to Use a Female Condom



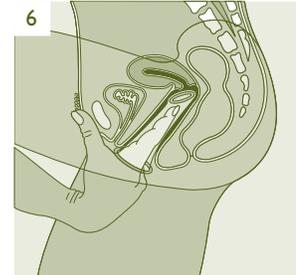
1 Open the package carefully; tear at the notch on the top right of the package. Do not use scissors or a knife to open.



2 The outer ring covers the area around the opening of the vagina. The inner ring is used for insertion and to help hold the sheath in place during intercourse.



5 Gently insert the inner ring into the vagina. Feel the inner ring go up and move into place.



6 Place, the index finger on the inside of the condom, and push the inner ring up as far as it will go. Be sure the sheath is not twisted. The outer ring should remain on the outside of the vagina.



3 While holding the sheath at the closed end, grasp the flexible inner ring and squeeze it with the thumb and second or middle finger so it becomes long and narrow.



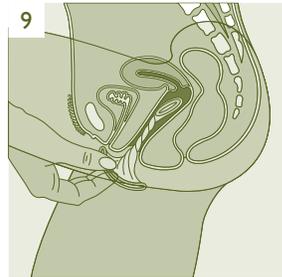
7 The female condom is now in place and ready for use with your partner.



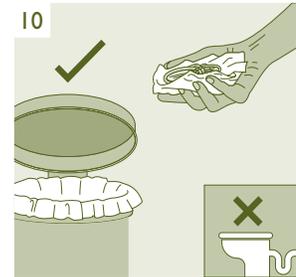
8 When you are ready, gently guide your partner's penis into the sheath's opening with your hand to make sure that it enters properly – be sure that the penis is not entering on the side, between the sheath and the vaginal wall.



4 Choose a position that is comfortable for insertion – squat, raise one leg, sit or lie down.



9 To remove the condom, twist the outer ring and gently pull the condom out.



10 Wrap the condom in the package or in tissue, and throw it in the garbage. Do not put it into the toilet.

Courtesy of The Female Health Company

Preparing for Test Results

The following steps can help prepare clients for their test results:

- Talk to the client about getting support during the testing process;
- Ask the client whether anyone else knows he or she is taking the test;
- Find out whether the client has anyone to talk to while waiting for results;

- Encourage the client to use his or her existing support systems;
- Ask the client to consider bringing another person for support when coming in for results;
- Ask clients what it would mean to them to receive a negative or a positive result, and make plans with them to outline what they would do in each case.

Counselors should assure clients that results are given in a private and confidential setting.

It is important to remind clients that their last possible exposure to HIV and the subsequent six-month window

Box 19: Client Flow for Post-Test Session

Giving test results

Give results calmly in a quiet and private setting.

Give results as soon as possible.

Allow client to express his or her feelings about the test and other concerns.

Offer time for client to ask questions.

Offer one-on-one or couples counseling, depending on the client's preference.

At the client's request, allow a family member, friend, or other supportive person to be in the room when the results are given.

For HIV-positive

Counsel about "positive living," which includes:

Maintaining positive attitude;

Avoiding additional exposure to the virus and other STIs;

Providing early referrals for medical services, even for minor illnesses;

Avoiding re-exposure to the virus and other STIs;

Maintaining weight through good diet and avoiding diarrheal diseases;

Joining PLHA organizations and/or other social support organizations.

For HIV-negative

Encourage those who have exhibited recent risky behavior or had known exposure to return for confirmation after three months, since they may now be in the window period.

Encourage clients in the window period to practice risk-reduction behaviors.

Those who are HIV-negative and have no recent possible exposure do not need *confirmatory testing*.

For both HIV-positive and HIV-negative

Encourage partner notification (learning results together is the best way).

Provide education and counseling on family planning.

Offer condom education and demonstration and provide condoms for those who are willing to use them. (Do not coerce unwilling clients.)

Provide additional supportive and informational counseling.

Refer according to clients' needs.

period have a bearing on the test result, and that they can choose to re-test. Finally, counselors can ask clients whether they know anyone who is HIV-positive. It may be helpful for the counselor and the client to understand the significance of HIV in the client's life as well as the kind of role models the client may have for living with HIV. Counselors should offer additional pre-test counseling if the client feels unsure or has more questions about testing.

Section 3: Post-Test Counseling

One aim of post-test counseling is to help clients understand and accept their test results. Post-test counseling is also a chance for counselors to help clients *make choices* based on their results. Messages will be different for those who test positive and those who test negative. Below is a flowchart for post-test counseling.

Giving HIV Test Results

Counselors should give clients their test results only when they feel the clients have received adequate counseling. For counselors, telling someone that his or her test is positive can be difficult and uncomfortable. Some of the most common fears among counselors are that clients will harm themselves or others, or that they will leave and not return. Although these fears are valid, they often diminish as counselors gain experience in giving clients their test results. Following are suggested steps for giving results:

- Begin the post-test session by asking how the client has been feeling since he or she had the blood drawn, and congratulate the client on returning or waiting for the results.
- Ask whether the client has any questions, while understanding that most clients will want the test results as soon as possible.
- When the client is ready, give the test results in a neutral tone of voice and wait for the client to respond before proceeding. For a positive test result, say, "Your test result was positive. That means you are infected with HIV." For a negative result, 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 results and integrated the information cognitively and emotionally.

- Assess cognitive understanding by asking the client to tell you what the test result means. Check for misperceptions or misinformation.
- Assess emotional understanding by asking the client how he or she is feeling at that moment, and allowing the client to express his or her emotions.
- Proceed to behavioral integration only when the client is ready to talk about what he or she plans to do next. Behavioral integration requires the client to make an immediate plan, including partner notification and modifying the risk-reduction strategy (or other behavior changes), depending on the test results and the client's situation.

Possible Client Reactions

Clients can react to a positive test result in a variety of ways, from resignation to severe shock and disbelief. Some clients assume they will become ill immediately and die. It is important to remind them of the difference between HIV and AIDS, and to point out that, with HIV, it is possible to remain healthy for a long time. Counselors should ask clients what they are planning to do when they leave the session and, if necessary, remind them of the plan they made during the pre-test session. Counselors need to assess clients' social support systems and their plans for partner notification. Although clients who receive a positive test result are not likely to be concerned about safer sex during the first post-test counseling session, it is important to remind them of their risk-reduction plan and the necessity of protecting their partners from infection and themselves from re-infection.

There is also a wide range of potential client responses to a negative test result. Counselors must not assume that clients will react with relief and happiness to such a result. Clients who receive negative results often tell counselors they will stay safe by no longer having sex. While acknowledging clients' intention not to have sex, counselors must be sure that clients have sufficient skills and a plan to protect themselves in the event they do have sex. Counselors should ask clients who test negative whether they intend to tell their partner(s) they were tested, and should engage clients in planning how to discuss risk reduction with their partner(s).

After a client's HIV status is known, the counselor may want to work with the client to revise his or her risk-reduction plan. The counselor should remind the client of the need to retest if he or she received a negative test

result but has engaged in high-risk behavior over the previous three months. The counselor should encourage all clients who receive a negative result to consider the possibility they could be infected but not yet showing HIV antibodies. At this stage, the counselor should ask specific questions to ascertain the client's ability to cope, assess whether he or she has a history of threatening suicide or harming others, and learn whether the client has had any recent unfortunate experiences. The counselor also must determine whether the client has a specific plan to inflict harm on himself or herself or others, and whether he or she has the means to pursue such a plan. If the answer to any of these questions is "yes," the counselor must contact a trained clinician to evaluate the client and assess possible interventions. If clients need services that are not available at the VCT center, they should be informed of other available counseling services and/or be referred to community resources

Emotional Coping

VCT counselors quickly learn that HIV/AIDS is complex and touches on many different aspects of a person's life. For this reason, counselors must give their clients the opportunity to integrate information about their HIV status and/or risk of infection emotionally as well as cognitively and behaviorally. This can be achieved by allowing clients to express their reactions to counseling and testing, listening in a nonjudgmental manner, and giving relevant information. Even after expressing and integrating emotional reactions, some clients may be unable to cope and will require some sort of intervention. Clients may express their inability to cope verbally (e.g., saying they do not know what to do, describing feelings of hopelessness, or expressing a desire to hurt themselves or others) or behaviorally (e.g., isolating themselves socially or refusing to continue with the activities of daily living). In such cases, counselors should become more active and engage the client's support network more directly (subject to client's consent).

Counselors can take the following steps when clients are unable to cope with their emotional reactions:

- Identify, explore, and validate the client's ability to cope with past crises and the techniques he or she used to address them. It is reassuring to clients to be reminded that they have coped with and solved personal problems in the past. Discussion of past crises may provide counselors with clues to help clients cope with the present crisis.

- Encourage the client to make a specific short-term coping plan. The counselor should elicit a personal commitment from the client to follow this plan and report back to the counselor. For example, the counselor might ask the client what he or she is planning to do after leaving the session and arrange a return appointment to discuss it.
- If appropriate, engage the client's partner(s) to ensure that the plan is enacted and that the client returns for follow-up.
- During the counseling session, encourage the client to express his or her feelings about the current situation and redirect the client's attention to taking action and solving problems.
- Encourage the client to take advantage of existing social support systems.
- Refer the client to appropriate community resources.

If the client does not respond to these techniques or refuses to engage the counselor, the counselor may need to request psychiatric consultation or consider hospitalization for the client. In such cases, the counselor should request assistance from a peer or a counseling supervisor.

Additional Discussion about Risk Reduction

Once a client's HIV status is known, the counselor must work with him or her to revise the risk-reduction plan discussed during pre-test counseling. If the client engages in risky behaviors, the counselor should discuss practical and specific actions for behavior change. Counselors should address the following when discussing a client's risk-reduction plan:

- How will the client revise the risk-reduction plan that was discussed during pre-test counseling, given his or her situation and HIV status?
- Is the risk-reduction plan adequate and appropriate?
- What immediate actions must the client take to protect himself/herself and others?
- What skills and means does the client need to carry out the risk-reduction plan?
- What are the barriers to needed behavior changes?
- What type of assistance does the client need from the counselor to initiate the actions identified in the risk-reduction plan?
- What are the client's additional counseling needs?

Counselors should encourage clients to tell their partners they were tested and assist the clients in planning how they will discuss risk reduction with their partners. If the client is not psychologically ready to discuss these issues, the counselor should negotiate a commitment from the client to return as soon as possible for follow-up counseling or to follow up on a referral made to an appropriate service.

Actions for counselors during post-test counseling: negative test result

- Discuss the challenges of remaining negative (“Everybody is positive except you”);
- Reinforce the “ABC” message (A = abstinence, B = be faithful to one uninfected partner, and C = correct condom use consistently);
- Encourage the client to negotiate with partner(s) to go for VCT;
- Discuss safer-sex negotiation skills (extremely important for youth);
- Promote the female condom, if appropriate;
- Stress the importance of being tested periodically;
- Convey safer-sex guidelines:
 - › Slow down and enjoy the sensation of another person (holding, caressing, hugging).
 - › Spend more time getting to know your partner(s). Reduce the number of partners.
 - › Talk about sex first; this clears the air and reduces tension so that both of you will have a better time.
 - › Vaginal and anal sex is the primary means of transmitting HIV, but it can also be transmitted by oral sex.
 - › Limit or desist from alcohol and/or other drug intake, since it may impair judgment needed to make decisions about protection and may also weaken the immune system.

Actions for counselors during post-test counseling: positive test result

- To help clients remain healthy, recommend that they:
 - › Attend referral services for follow-up care and support;
 - › See a doctor immediately when sick, even with minor illnesses;

- › Maintain their weight and reduce stress by eating a nutritious diet, preventing diarrheal diseases, exercising regularly, and resting;
 - › Talk to family and/or friends whom they can trust;
 - › Avoid alcohol or smoking, which can weaken the immune system.
- To help prevent sero-positive clients from transmitting the virus to others, suggest they:
 - › Tell their partner(s) they have tested positive;
 - › Practice safer sex with all partners or abstain from intercourse;
 - › Protect their unborn child: If the client or client’s partner is considering pregnancy, or is currently pregnant, discuss options and/or refer the client to a health care provider.
 - Recommend that the client does not donate blood, plasma, or serum;
 - Recommend that the client does not donate organs (e.g., eyes, kidneys) for transplant.

Actions for counselors during post-test counseling: indeterminate test result

- Convey that because the result is indeterminate, the client may be capable of passing the virus to others if he or she has the infection, or get infected if he or she does not take protective measures. Recommend that clients:
 - › Practice safer sex with all partners;
 - › Prevent transmission of HIV through blood by not sharing personal items such as toothbrushes, razors, etc.;
 - › Tell their partner(s) they have tested indeterminate and that they are awaiting results of another test;
 - › Discuss pregnancy or plans for pregnancy with the counselor and/or a health care provider.
- Do not donate blood, plasma, or serum;
- Do not donate organs (e.g., eyes, kidneys) for transplant.

Section 4: Helpful Hints for Promoting Care and Support Options

One important function of VCT for HIV is linking people who test positive with related services, such as care and support options, skills training, and income-generating

mechanisms. Counselors should encourage HIV-positive clients to explore ART where available, affordable, and feasible. While ART cannot cure HIV infection, it can significantly reduce the viral load (amount of virus in the body). 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 pneumocystis carinii pneumonia (PCP). Counselors should encourage HIV-positive clients to seek early treatment if they become ill with any ailment, particularly STIs. In addition to referring clients to care and support services, counselors can:

- Clarify that while traditional herbs and medicines may play a role in boosting the immune system, there is no evidence that they can cure AIDS.
- Remind clients that prayer may provide some comfort or hope, if this is desirable and requested by the client. But there is no evidence that prayer can eliminate HIV from a person's body.
- Encourage involvement of family and/or friends, where possible.

- Encourage clients who have tested positive to contact other HIV-positive individuals (through a network/support group or on an individual basis).
- Explore the issue of disclosure with clients and, where appropriate, assist them in disclosing their status to relevant parties. Clients must consider the impact of disclosure and consider who would provide them with unconditional support if their status were revealed.
- Encourage clients to document and/or share their experiences in a supportive environment. For example, clients can write their story on paper, tell their story in a support group, or speak before groups of health professionals.
- Assist clients to explore creative means of remaining self-sufficient, such as undertaking income-generating activities.

CHAPTER 6

PHYSICAL AND PSYCHOLOGICAL CARE, COPING AND SUPPORT

Section 1: Psychological Issues and Emotional Reactions Surrounding HIV/AIDS

Section 2: Crisis Counseling

Section 3: VCT as an Entry Point to Prevention, Care, and Support

Section 4: Care and Support Issues

Section 5: Prevention and Treatment of Opportunistic Infections and Other HIV-Related Illnesses

Section 6: Treatment for HIV/AIDS

Section 7: Follow-Up and Referral Plans

Section 8: Living Positively with HIV/AIDS

Section 1: Psychological Issues and Emotional Reactions Surrounding HIV/AIDS

HIV testing creates considerable psychological pressure, especially for those who test positive. Most people who test positive feel uncertainty and question their ability to cope with the situation. HIV infection raises questions about all aspects of a person's life, including quality of life, length of life, effect of treatment, and response of society. In response to such uncertainty, persons with HIV make a variety of adjustments. An apparent absence of response may itself be an adjustment, through denial.

There is no way to predict reactions to a positive test result. Following are possible reactions:

- **Shock:** Common responses include numbness, disbelief, despair, and withdrawal.
- **Denial:** Initial denial may help reduce stress, but persistent denial may prevent appropriate changes in behavior and life adjustments necessary to cope with HIV and prevent its transmission.
- **Anger:** Anger may manifest itself outwardly, through irritability, and/or inwardly, toward the self, in the form of self-blame or suicidal thoughts or behaviors.
- **Suicidal thoughts or actions:** People who learn they are HIV-positive have significantly increased risk of suicide, which may be a way of avoiding their own pain or lessening that of relatives.
- **Fear:** PLHA may have many fears. Fear of death, or of dying alone and in pain, is very common. Other common fears include fear of isolation, rejection,

leaving children or family uncared for, loss of bodily functions, and loss of confidentiality.

- **Loss:** PLHA may experience feelings of loss about their ambitions, physical attractiveness and potency, sexual relationships, status in the community, financial security, and independence.
- **Grief:** PLHA often have deep feelings of grief over the losses they have experienced or anticipate experiencing. They also may sense grief of family members or others who care for them or witness their declining health.
- **Guilt:** When HIV infection is diagnosed, people often feel guilty about the possibility of having infected others, or about the behavior(s) that resulted in their own infection (e.g., unsafe sexual behaviors).
- **Depression:** Depression may arise for a number of reasons, including the realization that a virus has taken over one's body, absence of a cure, and a resulting sense of powerlessness.
- **Anxiety:** Anxiety can become chronic for PLHA, reflecting the uncertainty associated with the infection.
- **Loss of self-esteem:** Rejection by neighbors, co-workers, acquaintances, or loved ones can result in loss of confidence and feelings of reduced self-worth. The physical impact of HIV-related diseases can compound this problem.
- **Hypochondria:** A person with HIV/AIDS may become excessively preoccupied with his or her health and even the smallest physical changes. This

may be temporary following diagnosis or persist when adjustment to the disease is difficult.

Because of these possible reactions, it is important that the counselor:

- Pay attention to clients' emotional reactions when they learn their test results, particularly when the results are positive (see also Chapter 5, Section 3);
- Be aware that most of the time, when clients learn they are HIV-positive, they may respond with denial, followed by depression, anger, and/or bargaining, followed finally by acceptance;
- Recognize that receiving a positive diagnosis makes people highly emotionally sensitive;
- Realize that multiple life stresses can further complicate a person's psychosocial health;
- Acknowledge that depression can be brought on by many additional issues, such as development of new symptoms, changes in intimacy, changes in physical appearance, new medications, loss of relationships, loss of job and/or health insurance, and financial problems.

Counselors can play a crucial role in helping clients develop a supportive and nurturing environment, experience autonomy, and gain a sense of control over their health in general. (For details, see Chapter 5, Section 2)

Section 2: Crisis Counseling

The term "crisis" characterizes a person's response to a rapid disruption of personal affairs, such as the breakup of a relationship or unexpected bereavement. In the case of HIV/AIDS, the trigger that leads to crisis might be death of another person living with HIV/AIDS, diagnosis with HIV, emergence of a new symptom, or failure of a treatment.

A crisis situation is one in which a person is unable to make use of his or her normal problem-solving techniques. The situation is experienced as emotionally and cognitively overwhelming.

A crisis may manifest itself as an emotional reaction or as disturbed behavior, such as deliberate self-harm, and has the potential to cause psychosocial deterioration. Crisis is a subjective experience; what one person perceives as a crisis, another person may not.

A crisis is made up of the following elements:

- **Blow:** The blow is the shock of fearing or realizing that something is wrong. For example, clients may learn that they are at risk of HIV, that they have put themselves at risk, and/or that a test result is positive.
- **Recoil:** The recoil occurs as the person struggles emotionally to come to grips with the full implications of the information. For example, after the blow of a positive HIV test result, the person may deny and recoil from this new reality and demand a new series of tests in a different clinic.
- **Withdrawal:** Some people can come to terms with and adapt to their predicament quickly. But many withdraw to be alone with their sorrow, anger, depression, or anxiety.
- **Acceptance:** In this last stage, individuals generally use their own psychological resources (or draw on help from counseling) to come through the crisis without a permanent loss of self-esteem and with a restored sense of control. This is called acceptance.

In a crisis, the counselor should move quickly to define the problem and restore the client's sense of control. The counselor should "begin where the client is." The counselor should also:

- Be reassuring and supportive as the client discusses the crisis;
- Remain calm and listen carefully;
- Comment on the strength of the client's feelings, fears, and efforts to deal with the problem;
- Accept the client's fears as genuine.

It is important that the counselor not:

- Play down the seriousness of the client's challenge (e.g., by saying, "You're overreacting");
- Panic;
- Offer false assurances;
- Give advice;
- Take offense.

These goals can be accomplished by observing the following principles and techniques:

Guided (structured) questioning. Example: "It seems to me that you may feel angry at yourself, at me, and at everyone else. I accept those feelings. However, I would like you to explain me what in your opinion is making you to feel so angry?"

Emotional support. Example: “You may feel frightened, and you may need some extra time to talk. I am here for you.”

In using such techniques, the counselor should:

- Focus on the client’s expression of current feelings and anxieties, and affirm his or her feelings;
- Assess whether the client shows decision-making ability or seems to be feeling helpless and out of control;
- Clarify what the client regards as the crisis and agree on a course of action to resolve or ease it;
- Start working on one aspect of the crisis that can be addressed easily, thereby building the client’s confidence that he or she can deal with future problems;
- Repeat some information if the client is in denial or too distressed to understand what is being said;
- Refer the client elsewhere, depending on a needs assessment.

Box 21: Guidelines for Crisis Counseling

- Remain calm and show confidence;
- Listen;
- Be accepting and nonjudgmental;
- Provide empathy and reflect the client’s feelings;
- Provide a relaxing atmosphere;
- Allow the client to speak freely, with minimal interruption;
- Allow the client to vent his or her feelings;
- Explore the immediate crisis rather than underlying causes;
- Do not minimize the crisis;
- Agree on a plan of action, but do not prescribe;
- Prioritize; agree on aspects of the problem that can be dealt with most readily;
- Assess suicide risk; ask whether the client has had suicidal thoughts. (Note that asking about suicidal ideation does not make suicidal behavior more likely. On the contrary, if the client has already thought about suicide, he or she may feel better understood if the counselor raises the issue; it may actually reduce the risk of suicide.) The most obvious sign of risk is a direct statement of intent to commit suicide. Two-thirds of people who die by suicide have told someone of their intentions. So, if the client makes such a statement, refer him or her immediately for psychiatric services. If there is a real risk of suicide, have local resources available to help take all necessary precautions.

Section 3: VCT as an Entry Point to Prevention, Care, and Support

VCT is not an end point but rather an entry point to the prevention-to-care continuum. VCT supports *prevention* by offering individuals and couples risk-reduction counseling. VCT promotes and sustains behavior change and links with prevention of MTCT, prevention and treatment of STIs, and other interventions. In *care and support*, VCT facilitates early referral to comprehensive clinical and community-based services, including provision of ART, where available, and treatment of OIs.

Box 22



Adapted from UNAIDS, "Report on the Global HIV/AIDS Epidemic" July 2002

Section 4: Care and Support Issues

An individual's care and support needs vary at different stages of HIV infection and disease. Box 23 depicts this continuum.

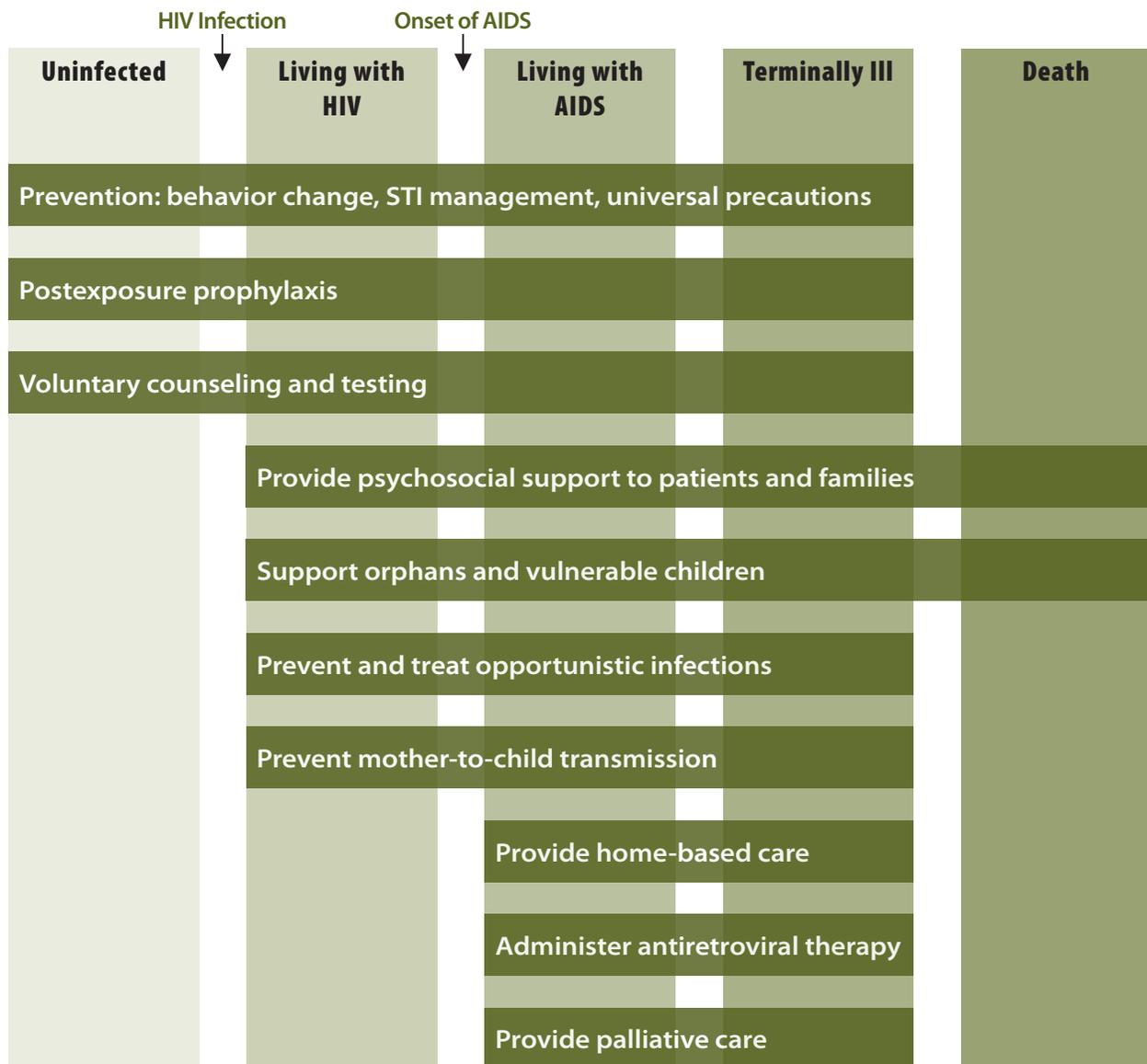
- Following are examples of needed care and support interventions:
- Case management and development of an individual action plan;
- Psychosocial support;
- Economic support;
- Emotional and spiritual support;
- Home-based care;
- Assistance to orphans and other vulnerable children;

- Support groups and networks, including post-test clubs;
- Befriending or "buddying";
- Nutritional support.

Case Management and Development of an Individual Action Plan

PLHA 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, social worker, or counselor who can provide ongoing care and support and assist the client in negotiating complicated medical and social service systems. Counselors should know that:

Box 23: Continuum of Care in the Management of HIV/AIDS



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

Psychosocial Support

Psychosocial support is indispensable for PLHA and their families. HIV-positive clients need to accept their status and learn to live with HIV while facing discrimination, stigmatization, long periods of illness, financial insecurity, and numerous psychological issues.

Psychosocial support is necessary for caregivers as well and can come from various sources.

Psychosocial support should be made available to members of the community at large.

Counselors need to conduct psychosocial support assessments and be aware of community interventions that can address the social and psychological needs of PLHA and their family members and caregivers.

Economic Support

PLHA can experience tremendous financial burdens during the course of their illness. Loss of income, increased medical expenses, and loss of productivity compromise the person's financial stability and indirectly affect the family and/or caregiver(s). Moreover, in developing countries (particularly in Africa), health insurance is not available to PLHA.

Poor families are especially vulnerable to the financial consequences of HIV/AIDS. Families may have to sell everything they own to pay for ARV drugs and treat OIs. It is critical that families' earning power at least be maintained.

For economic support services, the counselor should:

- Assess the client's needs (e.g., food, clothing, medicine, housing, care, work, spirituality, befriending);

- Help the client identify organizations that offer material support;
- Understand what services exist in the community to address these needs;
- Refer clients to appropriate groups.

Emotional and Spiritual Support

Most PLHA—and their caregivers—seek spiritual support at some point. This is particularly the case toward the end of a person's life. Consequently, religious institutions and leaders should be encouraged to offer programs that improve the general well-being of PLHA and help them cope with the fear of dying and feelings of frustration.

For spiritual and emotional support, counselors should:

- Respect the client's desires and religious beliefs;
- Be aware that spiritual and emotional support can supplement counseling services and, in many cases, are more readily accessible than counseling;
- Understand that pastoral care can comfort people who have questions and fears about death and dying.

Home-Based Care

Home-based care (HBC) is any form of care given to sick people in their homes, and can include physical, psychosocial, palliative, and spiritual care. Overcrowding of hospitals and exorbitant costs for intensive in-patient care, coupled with the risk of acquiring non-HIV related infectious diseases from other patients, make HBC a preferable and appropriate option in many cases.

Appropriate, high-quality HBC can help clients and their families maintain their independence and maximize quality of life within the limits of HIV/AIDS. HBC may include palliative care and follow-up and monitoring by medical professionals or hospital staff. It can include psychosocial support, such as HIV/AIDS counseling, and death and dying/bereavement services.

HBC is an opportunity for care providers to get to know the patient, family, and family dynamics, and to build a special trusting relationship with the family. This relationship facilitates ongoing counseling, promotes shared confidentiality, and creates opportunities for family counseling. The client and family can obtain much-needed information and skills related to self-care, care giving, and prevention, and learn about other care and support

services available in the community for the client, spouse, and children.

There are various HBC models, including health facility-initiated and community-based HBC. Health facility-initiated programs typically offer a team comprising a nurse, counselor, and social worker, all of whom conduct home visits at regular intervals. Community-based initiatives tend to rely on volunteers. While these volunteers may not have a professional background, they can be trained to provide nursing, basic counseling, pastoral, and other kinds of care, including administering and monitoring medications and recording basic patient data. For each model, the involvement of health facilities *and* communities is critical to providing a continuum of care.

For counselors involved in HBC, the following procedures are suggested:

- Introduce yourself and state the purpose of your visit. (For example, "I'm here to pay a visit to . . ." or "This is a courtesy call to . . .")
- Request permission to see the client alone.
- Once alone with the client, introduce yourself and give details related to your visit. For example, explain what you do and who arranged for you to come. Ask whether this arrangement is acceptable to the client.
- Obtain consent from the client.
- Tell the client you have to ask a few questions to understand his or her state of health more clearly.
- Take a detailed socio-demographic profile, medical history, list of current symptoms and concerns, drug history (ask to see the drugs, including non-allopathic), family and social history, and nutrition history. If the client is very sick, you may have to limit your questions. In addition, get a sense of the family dynamics.
- Use a "problem-based" approach and discuss your findings with the client.
- Prioritize the problems based on what is most important to the client.
- Agree on a plan of action, emphasizing what clients can do for themselves and how family members can help.
- Involve family members as appropriate (with client's consent).

- Thank family members for the job they are doing, and discuss with the client and family how they can do even better.
- If you provide supplies, such as dressings or medications, advise on their use.
- Make appropriate referrals, verbally and in writing.
- Tell the family the proposed date of your next visit and ask whether it is acceptable.
- Make a record of your visit and findings.
- If appropriate, arrange for a nurse, doctor, or medical assistant to examine the client, with client consent.

Some HBC programs use a "home-care kit," which typically contains soap, gloves, dressing materials, pain and fever medications, a plastic sheet, and, in some cases, dry food rations. Not all families will need all of these supplies, and some families may need more than one kit. The HBC provider will know each family well enough to determine its needs.

Counselors involved in HBC should take note of the following:

- To interact with family members, you need consent from the client, who is your entry point to the family (unless a family member rather than the client initiated contact).
- As much as possible, speak with the primary caregiver and family members in the client's presence. This promotes openness and allays client anxiety about "closed-door" discussions.
- Support the client in sharing confidentiality, giving him or her a chance to break the news to the family. (In some instances, the client may ask the counselor to be present when this is done.)
- Maintain neutrality; do not take sides.
- When confronted with direct questions, such as, "Does my wife have AIDS?" or "Am I going to die?" do not lie. Ask, "What did she tell you?" or "What makes you think she might?" or "What do you think?" Encourage the husband and wife to talk. (Use probing and challenging skills, which are described in Chapter 3.)
- Pay attention to the unique needs of children and young people who have taken on a caring role.
- Be sensitive to the sexual and reproductive health of clients, who are still sexual beings. Unless the client is

terminally ill, it is appropriate to discuss condom use and contraception.

- Be aware of your own attitudes and feelings about HIV/AIDS and encourage family members to overcome any negative attitudes they may harbor toward the client.
- Be familiar with other AIDS support programs in the area to help make appropriate referrals and establish two-way communication.
- Make follow-up plans and carry them out.
- After HBC visits, record data that may be useful for planning, monitoring, and evaluation purposes.
- Continue to educate community members about HIV and their role in caring for infected persons.
- Involve PLHA in these community education and care activities.

Caring for caregivers

Counselors should realize that the burden of caring for clients in their homes usually falls on women. In the case of HIV/AIDS, this burden falls increasingly on children and the elderly.

Thus, counselors should ask:

- Who is the primary caregiver?
- Who else is helping?
- What are their concerns?
- What resources do they need to give good care?
- What support do they need?

Counselors should discuss any concerns with the caregiver(s) and client; together, they should draw up an action plan.

Assisting Orphans and Other Vulnerable Children

Increasing numbers of orphans and children are living in families affected by HIV, particularly in sub-Saharan Africa. In many developing countries, orphans have been cared for by their extended family. But because of the overwhelming number of orphans and the burden of HIV on other household members, many of these children find themselves in already-strained households. Other orphans seek to survive on the streets or find marginal shelter in child-headed households.

Orphans are less likely than other children to receive adequate nutrition or education. They often have to leave

school because the household can no longer afford related fees. They may be taken out of school while their parents are still alive to provide household labor, help care for sick family members, or generate income. When parents die, children often have limited capacity to return to school. Orphans face not only the trauma of losing their parents, but also the stigma of losing them to AIDS. Without parents to protect them, orphans—especially girls—are more likely than other children to face sexual abuse and exploitation (and, hence, HIV infection themselves).

Counseling and emotional support services for orphans and children in families affected by HIV are still poorly developed in most high-prevalence developing countries. Psychological and material support for orphans and children living in HIV-affected households remains an important challenge.

Counselors should facilitate effective age-appropriate counseling services that build on indigenous structures and existing care models. Because most counselors do not have the skills to deal with children, it is important they identify local facilities capable of providing these services. Note that even with limited skills, counselors should facilitate communication with and support to children. For example, counselors might:

- Talk with children about illness and/or impending death (for ill parents and children);
- Talk with children about plans for their future, involving them as much as possible in the decision-making process; address the range of questions, concerns, and fears a child may have (e.g., regarding future schooling, housing, who might become their guardian) in an open and supportive manner;
- Talk about HIV/AIDS in clear, simple language; be specific about individual circumstances;
- Talk with children about their involvement in funerals and helpful ways for them to grieve;
- Affirm children's emotions and provide them with opportunities to express these emotions in therapeutic settings;
- Provide older children with information on self-care, safe sex, and HIV prevention;
- Link children with services that would develop their skills (e.g., life skills, caring for others, vocational training, income generation, and food-security skills).

Support Groups and Networks, Including Post-Test Clubs

Due to misconceptions and myths surrounding HIV/AIDS, PLHA often experience feelings of isolation, stigmatization, and abandonment. In many settings, they fear rejection by friends and family, restrictions on travel, and exclusion from employment, housing, and educational opportunities. These fears often lead individuals to hide their HIV status from loved ones and the community at large. In many countries, extreme isolation has led PLHA to form self-help groups, which give members support and strength.

Peer support groups and networks of PLHA provide individuals with a sense of solidarity and understanding that they might not gain with trained counselors or medical professionals. These groups offer opportunities for members to share experiences and discuss problems openly, which counteracts feelings of isolation, fear, and despair. The groups often have role models for “living positively” with hope and purpose despite the unknown future. These groups also assist individuals to cope with HIV and empower them to engage in safer behaviors.

Because there is relatively little start-up funding involved and because they contribute to the overall well-being and security of communities, support groups are extremely cost-effective. Formation of support groups—including groups with counselors who themselves may be infected with HIV—should be encouraged. When counselors living with HIV are involved, clients/members have a role model with whom they can identify.

It is now widely accepted that once clients know their HIV status, they can benefit from the support of other clients with similar concerns. To provide a context in which clients can continue to make positive life choices, it is recommended that counselors help establish post-test clubs that include both negative and positive clients. Post-test clubs foster “healthy living” attitudes and help members avoid sexual risk. They also help members maintain focus and motivation.

Note that counselors might not play the main supportive role. Self-help support groups, whether made up of PLHA and/or their relatives, may be the primary source of support. There is some evidence that the benefits of support groups are occasionally greater than those of individual supportive counseling. There are support programs for infected individuals, their families, and orphans.

Befriending or “Buddying”

Befriending is a way for a counselor to help a client at the end of life. A befriending counselor is different from an HIV counselor or family members. The role of the befriending counselor is not to change anything but to offer comfort and allow clients to express their feelings, which they may be unable to do in front of family or other friends. The befriending counselor should maintain a positive demeanor and present death as a kind of “leave-taking.”

Nutrition and HIV/AIDS

Because nutrition can affect the morbidity and mortality of PLHA, nutritional intervention is fundamental at all stages of illness. Weight loss, nutrient deficiencies, and malnutrition (particularly protein calorie malnutrition, or PCM) are common among PLHA. As HIV disease progresses, there is a simultaneous decrease in lean body tissue and an increase in intracellular and extra-cellular water. Malabsorption, diarrhea, oral/esophageal complications, nausea/vomiting, and fever can compromise nutritional status. The severe malnutrition that frequently accompanies AIDS can exacerbate the effects of the illness and compromise quality of life.

Several factors may contribute to HIV-related weight loss (wasting), including inadequate dietary intake, malabsorption of nutrients, abnormalities in metabolism and energy expenditure, and OIs. Reduced intake often results from loss of appetite (due to nausea), diarrhea, and oral, pharyngeal, and esophageal sores. Other factors associated with weight loss include depression, dementia, anorexia, and adverse drug reactions or interactions.

Comprehensive nutritional intervention requires an experienced nutritionist or dietitian. It is important that the counselor identify appropriate referrals for individualized long-term professional nutritional support and follow-up. However, before referring, the counselor must discuss nutrition with his or her clients. Please see the Appendix for a full discussion of nutritional support for PLHA.

Section 5: Prevention and Treatment of Opportunistic Infections and Other HIV-Related Illnesses

Though incidence and distribution of OIs varies from country to country, OIs frequently encountered in Africa include TB, bacterial pneumonia, non-typhoid bacterial salmonella, candidiasis, cerebral toxoplasmosis, genital herpes, herpes zoster, pneumocystis, pneumococcal

meningitis, and atypical mycobacteria. In an immunosuppressed client, clinical manifestations are often atypical and disseminated (i.e., symptoms are not typical; two or more infections can be present simultaneously).

Methods of preventing and treating OIs also vary from country to country, depending on the availability of resources and technology. Prevention methods include avoiding exposure to pathogens responsible for such infections, as well as chemoprophylaxis and vaccination (against either initial or recurrent infection). To offer effective options, a counselor must be familiar with the sources of pathogens in a client's environment. It may be unrealistic to ask clients to avoid pathogens that are essentially an unavoidable part of their everyday life. But counselors can encourage clients to avoid drinking unpasteurized milk, eating uncooked foods that could harbor salmonella or cerebral toxoplasmosis, both of which have a very poor prognosis, and being with people who have TB (among other suggestions).

Many infections can be managed successfully if appropriate drugs are available and patients are treated promptly. Below are vital and practical recommendations to help HIV-positive clients live longer, more productive and enjoyable lives, even in the most resource-poor countries.

The Hand Model

The Hand Model can guide counselors in advising HIV-positive clients about caring for their health. For each part of the hand, the counselor has a message to convey to the client. These messages, essential for clients to make informed decisions, can be provided in just a few minutes, even at the busiest VCT sites. The messages can make a tremendous difference in the quality of a client's life.

Wrist: Make the decision to take an HIV test. People who know their HIV status are likely to live longer and healthier lives than people who do not. If people know their HIV status, they are able to make informed choices about their future health and well-being. Counselors should encourage partner(s) and children of PLHA to be tested for HIV. They have a right to know their own HIV status so they can receive necessary information and services.

Thumb: Cotrimoxazole prophylaxis. Daily use of Cotrimoxazole can help protect against OIs in both HIV-positive adults and children. WHO and UNAIDS recommended in an April 2000 consensus paper that adults and children in Africa take Cotrimoxazole. This recommendation is based on studies carried out in

Africa demonstrating that people with HIV who take Cotrimoxazole have fewer episodes of OIs and require fewer hospital admissions.

WHO recommends that adults begin treatment with Cotrimoxazole if they have symptomatic HIV or an AIDS-defining diagnosis (including fungal skin or nail infections, herpes zoster, recurrent upper or lower respiratory infections, fevers, excessive sweating, weight loss, chronic diarrhea, oral thrush, recurrent genital herpes, TB, or Kaposi's sarcoma). Pregnant women can begin treatment with Cotrimoxazole after the first trimester. The dose for adults is two 480-milligram tablets per day (960 mg daily).

Children with symptomatic HIV infection should take Cotrimoxazole as well. In addition, children born to HIV-infected mothers should undergo Cotrimoxazole treatment until repeated tests show they do not have HIV. The recommended dosage for children is prescribed according to body surface area, at 150 mg of trimethoprim per square meter and 750 mg of sulphamethoxazole per square meter.

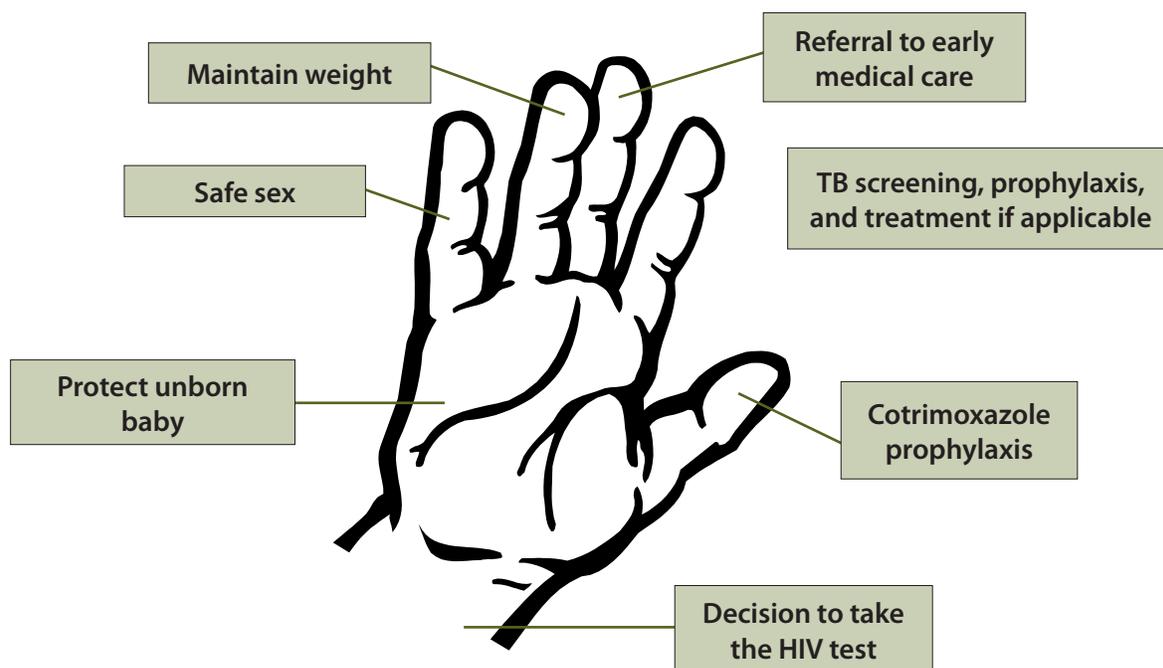
There is concern in some countries that widespread use of Cotrimoxazole could lead to bacterial resistance. Before recommending this drug to clients, counselors should check the country's related policy; based on the standard of care in that country, counselors should refer clients to a physician to discuss Cotrimoxazole.

Index finger: TB screening, prophylaxis, and treatment.

All HIV-positive clients should be screened for TB. If results indicate they have TB, counselors should advise clients to go for treatment and consider prophylaxis for OIs. Clients who do not have active TB should consider preventive therapy, which can reduce the risk of TB in PLHA. Based on several studies examining the efficacy, feasibility, and cost-effectiveness of preventive therapy in HIV-positive individuals in countries with high TB prevalence, WHO and UNAIDS recommend that:

- People with HIV receive counseling on TB;
- People with HIV be screened for active TB;
- Preventive therapy be directed at those who are most likely to benefit from it;
- Preventive therapy be provided to those without active TB;
- People with HIV be monitored for adherence to a preventive regime;
- People with HIV who are receiving preventive therapy be monitored for toxicity;

Box 24: The Hand Model



- Health care providers bear in mind that preventive therapy protects against latent infection but not new infection.

Middle finger: Referral to early medical care. It is critical that clients are educated about the importance of seeking early medical attention, even for minor illnesses. Beginning antibiotic treatment as soon as symptoms of an infection occur may prolong the life of PLHA. People with HIV need to know their immune system is weakened and therefore less able to fight pathogens. Delaying treatment can allow an infection to spread rapidly.

High-cost interventions, such as ART, can be recommended to people who can afford them. It is outside the scope of this manual to discuss the use of ART; clients who want to begin ART and can afford it can be referred to a health professional with appropriate knowledge and experience. Alternatively, the client's physician can seek this information on the client's behalf.

Ring finger: Maintain weight. Counselors should advise HIV-positive clients to maintain their weight by eating a balanced diet and avoiding diarrheal diseases. Maintaining proper nutrition and body weight enhances quality of life

and may prolong life. Because people with HIV often have diminished appetites, frequent small meals are often the best strategy. Meals should be high in calories and consist of approximately 50 percent carbohydrates, 30 percent proteins, 15 percent vegetables, and 5 percent fruits. (See the Appendix for more information about nutrition for HIV-positive persons).

Preventing diarrheal diseases in PLHA enhances quality of life. Once people with HIV get chronic diarrhea, their quality of life and life expectancy drop significantly. They lose weight and generally feel weak. Little can be done for HIV-positive people with chronic diarrhea, since treatment of most of the common pathogens causing diarrheal diseases is at best partially effective and, for most people, prohibitively expensive. To prevent diarrheal diseases, the best recommendations are to boil drinking water and water used to brush teeth, wash and/or peel all fruit, and make sure meats and vegetables are well cooked.

Little finger: Safe sex. Advise clients to practice safe sex to prevent transmission or re-infection.

Palm: Protect the unborn. HIV-positive women who are pregnant and HIV-positive men whose wives or partner(s)

are pregnant need information to help protect the unborn. Counselors should provide relevant information and refer or link clients to services geared toward preventing MTCT. Strategies to protect the unborn from HIV infection are discussed in Chapter 7.

Section 6: Treatment for HIV/AIDS

Note: *The following section was prepared using the most recent information available at the time of writing. But in the rapidly changing field of HIV treatment, information can become dated quickly. Course directors and participants are encouraged to compare information here with the most recent guidelines from other sources.*

Because treating HIV is a complex process, counselors should refer clients to an HIV/AIDS expert. It is important to help clients choose a physician with whom they feel comfortable, since physicians and clients need to work together closely to make decisions about treatment.

What is HIV treatment?

HIV treatment is the use of ARV drugs to decrease viral load in people with HIV infection and slow progression to AIDS. In most people who undergo ART, the viral load drops to undetectable levels (below 500 copies/ml within 12 to 16 weeks). But ART is complex, and different people may experience different results.

When should treatment begin?

ART has been shown to benefit HIV-positive persons with advanced HIV disease and weakened immune systems. Many experts believe treatment also benefits people in earlier stages of HIV disease, though there are different views regarding when to start treatment. Physicians generally consider the following factors:

- Whether the client has advanced disease or symptoms;
- Results of viral load test and CD4 cell count;
- Client's willingness to begin therapy;
- Likelihood of client adhering to treatment (adherence is critical to success);
- Potential benefits of the therapy versus potential risks (risks include development of drug resistance, side effects, interactions with other drugs, and negative effects on lifestyle).

Which tests are needed before treatment begins?

Before starting treatment, physicians should take a client's complete medical history and perform a physical examination and several blood tests. The tests measure blood count, CD4 count, and viral load. Physicians also screen for other STIs, TB, and other OIs. There may be additional tests, depending on a client's symptoms.

Which medications are used in HIV treatment?

The three classes of ARV drugs (drugs that inhibit viral replication) commonly used today are summarized below.

Box 25: Classes of ARV Drugs

Nucleoside reverse transcriptase inhibitors (NRTIs):

These include Zidovudine (AZT), Didanosine (ddI), Zalcitabine (ddC), Stavudine (d4T), Lamivudine (3TC), CombivirTM (AZT+3TC), and Abacavir (ZiagenTM).

Non-nucleoside reverse transcriptase inhibitors (NNRTIs):

These include Nevirapine (Viramune), Delaviridine (Rescriptor), and Efavirez (SustivaTM).

Protease inhibitors (PIs):

These include Saquinavir (InviraseTM + FortovaseTM), Ritonavir (NorvirTM), Indinavir (Crixivan), and Nelfinar (Viracept).

The preferred HIV treatment is a triple-drug combination referred to as "highly active antiretroviral therapy," or HAART. The recommended first-line HAART regimens are two NRTIs and one PI, or two NRTIs plus Efavirez, or two NRTIs plus Ritonavir and Saquinavir. A recommended alternative HAART regimen is two NRTIs plus Nevirapine or Delaviridine, though this regimen is less likely to keep the viral load suppressed. It is generally not recommended that clients take two NRTIs without anything else; in most people, it has been found that the initial decrease in viral load will not be sustained. Similarly, taking a single ARV drug is not recommended, except for pregnant women, who may take Zidovudine or Nevirapine to reduce the risk of MTCT.

How can clients know whether their treatment is working?

The viral load and CD4 cell count of a person living with HIV are two important measures of the effectiveness of ART. How much and how quickly the viral load decreases depends not only on the drugs used but also on factors such as baseline viral load and CD4 count (i.e., before

treatment has begun), previous use of ARVs, the presence of other AIDS-related illnesses, and how closely the client is adhering to therapy. During treatment, viral load should be tested every three or four months to ensure the drugs are still working. Note that this might not be realistic or a standard of care in most resource-poor settings.

How can clients maximize their likelihood of adhering to a treatment plan?

Counselors should encourage clients to play an active role in their treatment plan. Counselors should encourage clients to ask their physician about all treatment options, including potential benefits and risks. Counselors should also encourage clients to talk to their physician about any personal issues that might affect adherence to the plan. Studies have shown that adherence is difficult for many people—especially those who are abusing alcohol or other substances, those with unstable housing situations, those with mental illness, major life crises, and advanced HIV disease, and those who have had problems taking medications in the past.

Clients should be encouraged to consider a “dry run” (i.e., practice their treatment regimen using jellybeans, mints, or corn kernels). This can help determine which doses might present difficulties.

Most important, clients should ask their physician to tailor the treatment plan to their particular lifestyle. Studies have shown that clients who arrange their medication schedule around their daily routine tend to adhere more successfully than clients who do not. Once a physician and client decide on a treatment plan, the client should ask for a written copy.

What makes adherence to HIV treatment difficult for some people?

HIV treatment is extremely complicated. Studies indicate that many people have difficulty adhering even to simple treatments for diseases such as malaria. By contrast, HIV treatment may involve taking 25 pills or more each day. Some HIV medications must be taken on an empty stomach, some must be taken with meals, and some may cause unpleasant side effects, such as nausea. Some people may sleep through a treatment time or scheduled dose time, may be away from home often or otherwise busy, may feel too sick or depressed to take their medication, or may simply forget. Among the most difficult factors in long-term adherence to treatment is that ART must be continued indefinitely.

How can clients maximize treatment success?

Clients should find the strategy that works best for them. Clients should keep medications where they will notice and take them (e.g., for morning pills, next to the alarm clock or coffeepot). Counselors can suggest their clients use daily or weekly pillboxes or egg cartons to organize their medications. Timers, alarm clocks, or pagers can be helpful reminders to take medication. It may be helpful to develop a support network of family members, friends, or co-workers who can give reminders about taking medication. Clients should keep a medication diary and plan ahead for weekends, holidays, changes of routine, etc.

People being treated for HIV should ensure their drug supply does not run out. Clients undergoing ART should talk to their physician about any problems related to side effects, skipped doses, difficulty in taking medications as prescribed, or interference of treatment with their lifestyle.

Section 7: Follow-Up and Referral Plans

In the context of VCT, referral is the process by which immediate client needs for prevention, care, and support services are assessed and prioritized, and clients are assisted to access these services (e.g., setting up appointments, 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 (see Section 4 of this chapter). Counselors cannot fulfill all client needs, but they can mobilize additional resources to reinforce the care and support offered. This requires involvement of the family, community, religious groups, self-help groups, nongovernmental organizations (NGOs), development partners, health care facilities, etc. Counselors 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.

Counselors 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 counselor makes a referral. Counselors can refer clients during the pre-test or post-test session, or at any other time. Counselors need to know how to make an appropriate referral and have a clear plan for discharging clients.

Reasons for Referrals

Clients may have complex needs that affect their ability to adopt and sustain behaviors that will reduce their risk of transmitting or acquiring HIV. They may need referral for medical evaluation, care, and treatment for OIs and communicable diseases (e.g., TB, hepatitis, and STIs). Clients and their families or partners may also need referral in cases of:

- HIV-positive pregnant women;
- People who are addicted to drugs and/or alcohol;
- People with mental illness, developmental disabilities, or difficulties coping with an HIV diagnosis or HIV-related illnesses;
- Clients who need legal services to prevent discrimination in employment, housing, or public accommodation;
- People who require individual counseling;
- People who require relationship counseling;
- Clients who need family counseling;
- Clients who need spiritual counseling;
- People who require access to social services;
- Clients in need of home-based care;
- Clients in need of family planning services;
- Families with orphans and vulnerable children.

Clients may also need assistance with housing, food, employment, transportation, childcare, or domestic violence issues. Addressing these needs can help them access and accept medical services, and adopt and maintain behaviors that reduce the risk of transmitting or acquiring HIV.

Assessing Clients' Referral Needs

Counselors should identify key factors likely to influence the client's ability to adopt or sustain behaviors that: reduce the risk of transmitting or acquiring HIV; promote health; and prevent progression of the disease. Assessment should include examination of the client's willingness and ability to accept and complete a referral.

Service referrals that match the client's self-identified priority needs are most likely to be completed successfully. Counselors may refer a client to either clinical or community support groups, depending on the client's needs and responsiveness to counseling.

How to Make a Successful Referral

- Work with clients to decide what their immediate referral needs may be.
- Outline the health and social service options available and help the client choose the most suitable (in terms of distance, cost, client's culture, language, gender, sexual orientation, age, and developmental level).
- In consultation with the client, examine factors that may make it difficult for the client to complete the referral (e.g., lack of transportation or child care, work schedule, cost) and address them.
- Inform the client of the possible need to move from anonymity to confidentiality, depending on the type of referral indicated.
- Make a note of the referral in the client's file. Ensure 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 located near the counseling site, services offered, hours of operation, and contact persons.

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

Box 26: Basic Elements of a Good Referral

- Clear, specific, and up-to-date information;
- Confidentiality;
- Safe and easy accessibility;
- A multi-sectoral/multi-disciplinary approach;
- Several referral options;
- A system for clear communication between the VCT center and the services to which the client has been referred;
- Absence of discriminatory practices by service providers;
- Documentation of referral and follow-up.

Section 8: Living Positively with HIV/AIDS

“No one has ever said ‘yes’ to AIDS. No one has asked for it. Most of us who have it now had never even heard of it when we caught it. You cannot attach blame or assign guilt to anyone. It doesn’t matter who was responsible—the husband or the wife or the blood transfusion. The important thing is to think and live positively.”

This quote from a Ugandan counselor sums up the positive attitude counselors should encourage in their clients. Promoting positive living begins with the counselors and the attitude and language they use. To promote positive living from the start, counselors should:

- Accept the client;
- Avoid blame;
- Avoid negative ideas, such as describing AIDS as a “catastrophe” or a “plague”;
- Refer to people who are HIV-positive as “clients” or “people living with HIV,” never as “AIDS victims” or “AIDS sufferers.”

Only use the term “patient” if a person has been admitted to a hospital.

There is substantial evidence that even in the absence of ART, people living with HIV can do many things to maintain a healthy and fulfilling life. Counselors can communicate the following elements of living positively with HIV to their clients.

- **Gather information:** With HIV/AIDS, ignorance is not bliss. Learn what you can about HIV infection to reduce unnecessary worries and problems. Keep expanding your knowledge.
- **Be accepting:** For peace of mind, accept your situation and try to make the best of it. This implies a positive realization of your situation, one that does not assign blame or guilt. Acceptance is not the same as inertia or resignation.
- **Value affection:** Give and receive physical and emotional affection.
- **Avoid isolation:** The more friends you have and keep, the more likely you are to seek and receive support.
- **Continue working:** Staying mentally and physically active helps prevent depression and anxiety. You should continue working as long as you feel strong enough to do so. Abandoning work or your daily routine may actually be detrimental to your health;

boredom, depression, and loss of self-esteem may rush in to fill the gap. Your health may be affected as a result, making it easier for HIV to impair your immune system further.

- **Get involved in prevention and care activities:** Remain or become involved in HIV prevention and care activities in the community.
- **Focus on nutrition:** Eat healthy foods. Even if you have inadequate resources, you can eat ordinary, less-expensive foods that contain carbohydrates, proteins, and the necessary nutrients.
- **Focus on prevention:** Prevent infections such as TB, STIs, and pneumonia. Adopt a high standard of hygiene.
- **Avoid alcohol, cigarettes, and other drugs:** Stop or reduce consumption of alcohol, cigarettes, and other drugs. These substances impair immunity and may quicken progression to AIDS.
- **Use caution:** Try to detect symptoms of illness early and seek medical attention. Comply with medical advice about exposure to other infections and use of non-prescribed drugs.
- **Exercise:** Exercise, if possible, to improve blood circulation and maintain well-being, but avoid straining yourself. Get plenty of rest.
- **Make informed decisions:** Think carefully about your sex life, including childbearing. Practice safer sex or consider abstaining at times.
- **Understand the world you live in:** Try to observe and understand your own health and disposition; similarly, try to take note of and understand how other people feel about interacting with those living with HIV. This will reduce unnecessary mental stress and facilitate your interaction with others.
- **Enjoy life:** Laugh and be cheerful whenever you can. Following the popular East African phrase and attitude, *Hakuna Matata: Enjoy yourself!*



CHAPTER 7

COUNSELING AND TESTING FOR SPECIFIC GROUPS

Section 1: Child Counseling and Counseling Parents of HIV-Infected and -Affected Children

Section 2: Counseling Youth

Section 3: Counseling Women

Section 4: Antenatal Counseling for Preventing Mother-to-Child Transmission of HIV

Section 5: Counseling Couples

Section 6: Group Counseling

Section 7: Family Counseling

Section 1: Child Counseling and Counseling Parents of HIV-Infected and -Affected Children

Counseling Children

The impact of HIV/AIDS on children begins long before they actually lose a parent: children are affected as soon as a parent is diagnosed as HIV-positive. Parents, families, and children need support in coping effectively with HIV/AIDS in two ways: programs to help parents communicate and facilitate disclosure to children, and programs to help children (and other caregivers, such as grandparents) with such issues as managing the household, caring for an ill parent, planning for the parent's death, and taking care of siblings.

Testing Infants and Children for HIV

In most parts of sub-Saharan Africa, infants are not tested, given the limited accuracy of antibody tests for children under age 15-18 months (Chapter 2, Section 2). For infants under 15-18 months, testing is done only where polymerase chain reaction (PCR) technology is available; in most instances, PCR testing is used for serological surveillance purposes (i.e., epidemiological surveys). Where available, PCR testing is conducted mostly at major referral hospitals or private health facilities. In both cases, the cost is prohibitive for most clients. In circumstances where infant testing is available, counselors should be aware that:

- The inherent difficulty in identifying HIV-positive infants poses serious problems for the families of these infants;
- These children require careful monitoring of their growth, development, and health status; hence,

parents should be alert to any changes that might indicate HIV infection;

- Even though most infants turn out to be uninfected, families of these infants often experience emotional trauma and need support in dealing with this uncertainty.

It is important for a counselor to understand the motivation behind bringing a particular child in for testing. Issues to consider include: Who has requested or suggested the testing? What is the rationale? What are the perceived benefits to and/or possible adverse consequences for children if they are tested?

Testing a child can be considered if:

- The child is sexually active;
- The child has been sexually abused;
- The child is symptomatic;
- The child has been exposed to other risks (e.g., perinatally or otherwise through contaminated blood).

Questions counselors should ask themselves when testing infants and children include:

- Under what circumstances is testing of infants and children advantageous, and to whom?
- What is the role of health care providers in guiding parents or guardians to make decisions about whether to test an infant or child?
- Once results are known, how, in what manner, and with whom is the information shared?

- How will knowledge of HIV-positive sero-status be used to ensure access to care and support for the infant or child?

Consent

Each country will have different policies regarding testing of children, including age restrictions on testing and rules governing whom is authorized to give informed consent, and under what conditions. Counselors should be aware that “age of consent” is a contentious issue that often confounds provision of VCT and care and support to children and young adults.

Policy frameworks

Counselors should be aware of the policy frameworks governing testing and psychosocial support of children. National policies are required to guide counselors and other service providers on child- and infant-related issues; until such guidelines are in place, site-specific protocols are needed. But few countries have incorporated sections in their national HIV/AIDS policy to address the needs of infants, children, and young adults. Box 27 provides examples (Kenya and Zimbabwe) of approaches to testing children and young adults.

Disclosure: Should the child be told his or her HIV sero-status?

There are no guidelines for the best age or most appropriate method for telling a child his or her sero-status, or the best person to do it. Several disclosure studies have been conducted in the United States. In a small survey of U.S. caretakers—biological and non-biological (foster, kinship, or adoptive) parents of children age 5 and older—all caregivers said the best time to tell a child his or her HIV sero-status is around 10 or 11 years, especially if the child has been asking questions about medicines and clinic visits. Regarding where to make such a disclosure, 65 percent of caregivers indicated the best place is in the home. More than 90 percent wanted to be primarily involved in making the decision to disclose, though one-third of the non-biological caretakers felt the decision should be made along with clinic providers. Among biological parents, 70 percent said they wanted to disclose diagnosis to the child themselves; among non-biological caretakers, only 40 percent preferred to assume that responsibility. In cases where caretakers preferred not to disclose at all, the most common reason given was they felt the child might not be “ready.”

Box 27: Zimbabwe National HIV/AIDS Policy (1999)

The Zimbabwe National HIV/AIDS Policy is confusing and somewhat contradictory. The policy stipulates that children and young people below age 16 who have concerns about and/or have an STI have the right to appropriate counseling and care services and advice on means to prevent HIV/STIs. But the policy also states that persons under age 18 are considered minors according to the Legal Age of Majority Act (1982). In addition, guiding principle 17 of the policy states that “under the legal age of consent a child is considered a minor, and consent (for testing) is obtained from parents or a legal guardian.” On the other hand, Section 6.5 of the same policy provides the following guidance to providers: “If children and young people have HIV/AIDS, they must:

- Have the right to freedom from discrimination in all spheres of life and the right to full access to health care, education, and welfare support;
- Receive support and be counseled to help them cope with HIV infection and/or living in a family with someone infected with HIV.”

The policy states that parents and guardians should be supported so they can inform and educate their children about HIV/AIDS/STIs and unwanted pregnancy.

Kenya National Guidelines for Voluntary Counseling and Testing (2001)

The Kenya guidelines indicate that adolescents (under age 18) can be encouraged to go for VCT if they are “mature minors.” In this context “mature minors”:

- Are already sexually active or pregnant;
- Have a child;
- Are about to be married or enter into a relationship;
- Have another STI or TB;
- Have been a victim of rape or sexual exploitation.

The American Academy of Pediatrics recommends disclosing HIV infection to children of school age. But health care providers vary widely in their actual disclosure practices. Concrete guidance for disclosure is not currently available. Parents, with the guidance of a counselor, must decide for themselves if, when, and how they will disclose. Counselors may share with caretakers the potential

advantages and disadvantages of disclosing a child's status. Potential advantages of disclosure include the following:

- It can help children cope with their illness (i.e., to address fears, concerns, and suspicions in an honest and supportive manner).
- It can facilitate involvement in planning their care, including medical (preventive therapies and ARVs, where accessible), educational, and psychosocial needs.
- Nondisclosure may carry a variety of problems, such as anxiety, phobias, and depression.
- Nondisclosure deprives the child of support from support groups and medical camps.

Potential disadvantages of telling a child his or her sero-status include possible discrimination and harm by others.

There is no evidence that a supportive parent, guardian, or provider telling children their HIV sero-status causes long-term psychological harm. To the contrary, there is some evidence that certain kinds of psychological harm may be associated with nondisclosure.

Disclosure: Should children be told if their parent(s) are HIV-positive?

Evidence from some sub-Saharan African countries (South Africa, Tanzania, Uganda, Zambia, Zimbabwe, and others) suggests that older children want parents to tell them the truth if they (parents) are HIV-positive.

In most instances, it is beneficial for older children to learn the HIV status of their parent(s) directly from the parent(s) and before there is evidence of illness. At present, many children learn the sero-status of their parent(s) much later in life, through a caregiver, guardian, or other individual, or even remain unclear about the cause of their parent(s)' death, which can have a negative psychological impact. Helping parents disclose their HIV status to their children (as well as to their children's potential guardians) should be a priority for programs that aim to address children's psychosocial needs.

When to disclose HIV status to a child can be based on a number of factors, such as child's age or maturity, but inevitably it is the choice of the individual parent or caretaker. Few programs address this issue successfully. One tool to aid in disclosure to children is the memory book (described in Chapter 8).

Counseling Parents of HIV-Infected and -Affected children

Most babies with HIV infection (acquired from the mother) will show clinical features within six months of birth. Counselors should discuss the following issues with parents of such infants. Some of these topics may be covered during post-test counseling; others are more appropriate during follow-up counseling. The individual client's circumstances should determine when and how these issues are covered:

- Information on ARV drugs and access to them (as available and appropriate);
- Information on infant-feeding options and the benefits and risks of breastfeeding;
- Parent(s)' coping capacity, concerns, and fears;
- Options for referral;
- Parent(s)' support system and potential for shared confidentiality within the extended family and/or friendship circle;
- Information on family planning;
- Information about available treatment, care, and support services, and appropriate referral for mother, partner (where present), and baby;
- Information about and exploration of infant HIV testing and how to ensure the infant's well-being, including advice on nutrition and the importance of seeking early treatment of illness;
- Disclosure issues for the mother (to the spouse and/or potential support persons);
- Potential for couples counseling (if counseling is not already taking place in a couples context);
- Information about safer sex, including condom use to prevent transmission of HIV and STIs;
- Discussion of sero-discordance and HIV testing for partner(s), as appropriate;
- Planning for the future (including emotional, spiritual, and legal matters).

Many of these elements are complex and may require significant investment, and most cannot be addressed adequately in a single session. Some can be addressed through referral to peer support groups or "peer buddy systems," where available.

Organizations that have developed child counseling and related training materials include:

- Chikankata Health Services (Zambia);
- CHIN (Zambia);
- Connect (Zimbabwe);
- Humuliza (Tanzania);
- Kara Counseling and Training Trust (Zambia);
- Salvation Army Masiye Camp (Zimbabwe);
- Save the Children (United Kingdom);
- Sinosizo (South Africa).

Training materials include *Starting from Strengths: Community Care for Orphaned Children*, an informative manual relating to grief and loss, as well as care and support for OVC. The manual was developed at the University of Victoria, Malawi, in collaboration with a range of Malawi-based governmental bodies and NGOs. It provides practical materials and exercises easily adapted to a variety of African settings.

Section 2: Counseling Youth

Adolescents who visit counseling and testing centers may come by themselves or be accompanied by parents or guardians. They may have a broad range of HIV-related needs, some of which may be best met by counseling. Other needs may be met adequately through access to comprehensive health education and life-skills training.

The HIV-related needs of young people might present opportunities to discuss:

- VCT;
- Peer pressure, assertiveness, and negotiation skills;
- Self-esteem and sexual identity;
- Risk taking and experimentation, as related to developing safer behaviors;
- Limit and boundary setting;
- Alcohol and other drug use and abuse;
- STIs, including HIV;
- Contraception;
- Condoms and overcoming obstacles to their safe and effective use;
- Sexual, intimate, and family relationships;

- Abuse (sexual, physical, or emotional), domestic violence, and rape;
- Pregnancy and fertility;
- Safe abortion;
- HIV/STI disclosure;
- HIV treatment (e.g., adherence to ART, coping with adverse effects, treatment failure).

Research has shown that young people value counseling and that more than one counseling session is needed to be efficacious. Counseling youth requires specific counseling skills, patience, and understanding of young people's special needs.

Additional support for youth during pre-test counseling:

- Exploring reasons the young person presented for testing and providing unconditional support;
- Affirming the young person: lauding his or her courage to present for the service and encouraging attempts to adopt healthy practices;
- Exploring risk, perceptions, and factors relating to vulnerability;
- Supporting the young person when he or she is deciding whether to test (e.g., outlining test procedures and practice, what a positive or negative result would mean to them, to whom they would disclose their status);
- Exploring existing support systems;
- Providing health education and/or information, as required (including modes of transmission and prevention, and condom demonstration and distribution);
- Exploring personal risk reduction, as appropriate (including opportunity for role-playing);
- Providing opportunities for the young person to ask questions and discuss concerns;
- Referring, as appropriate (for generic or specialized counseling, drug and alcohol services, abuse and domestic violence services, medical services, support groups, peer support, personal, legal, and financial services, religious support, etc.);
- Distributing information, education, and communication (IEC) materials, as appropriate;
- Facilitating or mediating for familial and spousal support, as desired and appropriate.

Additional support for youth during post-test counseling:

- Exploring readiness to receive test results;
- (If not on the same day as the pre-test) Exploring how things have been and what, if anything, has changed since last meeting;
- Revisiting risk assessment and risk-reduction planning, as required.
- Offering opportunities to role-play and/or practice behavior modification;
- Providing additional health education and/or information, as required (including modes of transmission and prevention, and condom demonstration and distribution);
- Providing opportunities for the young person to ask questions and discuss concerns;
- Revisiting issues related to support systems, disclosure, and coping capacity (especially with a positive test result);
- Referring, as appropriate (for generic or specialized counseling, drug and alcohol services, abuse and domestic violence services, medical services, support groups, peer support, personal, legal, and financial services, religious support, etc.);
- Distributing additional IEC materials, as appropriate;
- Facilitating or mediating familial and spousal support, as desired and appropriate;
- Planning for additional or ongoing support, as possible and desired.

What should counselors address when counseling young people?

Assess maturity, including a young person's or, in some cases, adolescent's (i.e., over age 12) capacity to consent for VCT (without parental consent);

- Assess their own (counselor's) capacity to undertake VCT for young people who request it, without fear of retribution;
- Discuss issues related to disclosure to parents; this can be encouraged where young people have supportive relationships with their parent(s);
- When young people are deemed to be at high risk, ascertain whether there would be adequate support systems in case test results are positive (this should be done during pre-test counseling);

- Be aware of national policy frameworks that support access to VCT by young people without parental consent (though parental support is encouraged, where appropriate; in the absence of a supportive parent, support by a trusted relative or friend is encouraged).

An example of a national policy related to VCT and youth is provided in Box 28.

Box 28: Consent and Youth

In Kenya, the legal age of consent is 18 years; that is, anyone 18 years of age or older who requests VCT is deemed capable of providing full and informed consent. (Rwanda has formulated similar guidelines.) For young people between ages 15 and 18, however, VCT may be provided if the counselor determines the young person has sufficient maturity to understand the testing procedure and results. Young people between 15 and 18 who are married and/or pregnant are also considered "mature minors" who can give consent for VCT, though the counselor makes an independent assessment of the minor's maturity to receive VCT services.

Children 14 and under are given counseling if requested, but they are not tested unless it is for medical reasons. The counselor determines VCT has potential benefit for the minor and this is explained clearly. When children are brought to a VCT site for testing, the counselor meets with the parents or guardians to determine the reasons for testing. VCT services are provided only if there is a clear potential benefit for the child and the counselor determines there is no potential for neglect or abuse of an HIV-positive child.

Disclosing Test Results

As with consent to testing, there may be a legal obligation to inform a parent or guardian of the HIV test result in some instances. Consequences should be explored with the young person during pre-test counseling. There are great benefits to sharing test results with someone. But some young people's relationships with their parent(s) or guardian(s) are such that they may suffer (or at least fear suffering) physical, sexual, or emotional abuse as a result of disclosure. In these circumstances, another trusted adult family member or close friend might be identified who can provide post-test support.

Box 29: Ethical Issues Surrounding VCT for Youth—Questions for Counselors

Disclosure (to parent, guardian, family members, sexual partner/partners):

Are you adequately trained and competent to explore disclosure issues in counseling? What service (and/or countrywide) policies are in place regarding disclosure? Are you familiar with them?

Consent (legal and ethical considerations):

Who can validly provide consent for a young person to have VCT and/or medical care? Can a young person give consent without parent/guardian permission? Under what conditions? Are you aware of the legal and ethical framework in which “age of consent” operates? Do you know how to ensure and facilitate procedures relating to informed consent?

Confidentiality (anonymous vs. confidential VCT):

Does your service offer anonymous or confidential services? What is the service’s experience regarding access by young people? Would it be feasible to consider modifying services to increase access by youth (which might entail having to revisit confidentiality practices)?

Availability (of ongoing emotional and support services):

Are you aware of local support services available for young people? Provision of VCT for young people should be linked with development of support services following testing. These may include linkages with youth support groups; involvement of and support by religious groups that advocate a holistic approach to AIDS prevention and care; ongoing support for vulnerable young people, including sex workers and those who inject drugs; and adequate support for orphans, homeless children, and child-headed households.

Coercion

HIV testing should take place within an ethical framework, one that ensures testing is voluntary with informed consent. Some young people may be unable to give informed consent. In other instances, an adolescent may be ambivalent about HIV testing but may be brought in by a parent or guardian. HIV testing in such circumstances should be carried out only if the counselor deems it to be of benefit to the young person (after a thorough assessment with the young person alone, in the absence of the parent or guardian). In the case of minors, consent to meet with the young person privately requires permission from the parent or guardian.

Section 3: Counseling Women

In many parts of the world, women contract HIV at higher rates than men. (See Box 30). Studies conducted in Africa and elsewhere have shown that marriage can be an HIV risk factor for women. HIV/AIDS prevention campaigns often fail married women by assuming they are at low risk of HIV infection, or by urging prevention methods that women have little power to implement, such as condom use, abstinence, and mutual fidelity. Women who seek VCT services may reveal a variety of related problems.

Some aspects requiring special attention for women who undertake VCT are discussed in the following sections.

Psychological and Social Support

To provide or identify needed psychological and social support, counselors must recognize the special conditions that pertain to female clients at each phase of the counseling process. Following are some reasons women need psychological support:

- From the very beginning of the pre-test phase of counseling, a woman may have severe anxiety and/or feelings of anger, grief, or guilt as a result of the conditions under which she decided to come for an HIV test.
- Women who become aware of the possibility of being infected because their husband, partner, or child has been diagnosed as HIV-positive are often already symptomatic.
- During negotiation and development of the individualized risk-reduction plan, women may express feelings of powerlessness vis-à-vis their husband or partners.
- Women who avail themselves of HIV counseling and testing services may experience negative psychological and social ramifications, either for

Box 30: Women's Vulnerability to HIV

Biological, cultural, and socio-economic conditions contribute to women's greater vulnerability to HIV/AIDS. During unprotected vaginal intercourse, a woman's risk of becoming infected is up to four times higher than a man's. The vagina's greater area of susceptible tissue (compared with the male urethra) and micro-trauma during intercourse make women more physiologically vulnerable to HIV. Younger and adolescent women are at even greater risk because their immature cervix and scant vaginal secretions put up less of a barrier to HIV. Tearing and bleeding during intercourse, whether from rough sex, drying of the vagina with herbs, rape, or prior genital mutilation, increase the risk of HIV infection. Women run a similar risk from unprotected anal intercourse, which is also likely to cause tearing.

In addition, HIV-infected semen typically contains a higher viral concentration than do vaginal secretions. This makes male-to-female transmission more likely than female-to-male. A final biological factor that makes women more vulnerable to HIV involves the synergy between HIV and other STIs. Research shows that an untreated STI in either partner can increase the risk of HIV transmission as much as 10-fold. This is especially significant for women because most STI cases in women are untreated. Women's symptoms are often latent or difficult to detect, and many women who have been diagnosed with STIs have no access to medical treatment. In addition, monogamous women often do not suspect they are at risk.

Socio-economic factors, including women's lack of access to education or personal income perpetuate women's lower status and create even greater vulnerability to HIV infection. Failure to respect the rights of girls and women to schooling, training, and employment reinforces their economic dependence on men, whether a single "sugar daddy," a husband, a stable partner, several steady male partners who have fathered the women's children, or (for women in commercial sex work) a succession of clients. For many girls and women, sex is the currency with which they are expected to pay for life's opportunities, from a passing grade in school to a trading license or permission to cross a border. A woman who is economically dependent on her partner cannot afford to jeopardize his support, even when she suspects he may have HIV. If she refuses him sex or asks him to use condoms, she is implying that she suspects him of having extramarital sex or, worse, she is implying that he or she has been unfaithful. While some men agree to use condoms, many others react with anger, violence, or abandonment.

Cultural traditions such as forced marriage, older men's preference for young women, and female genital mutilation contribute to women's lack of power. Throughout the world, prevailing views about masculinity encourage men to undertake risky sexual behaviors—multiple sex partners, alcohol consumption prior to intercourse, and sexual violence—that make women more vulnerable to HIV and other STIs. Young girls are at even greater risk of sexual coercion because of their social vulnerability, and because some men assume that young girls are virgins and free of infection.

simply having sought the services or because of their HIV status.

- Women need special support to facilitate behavior change in their partners.

Referral to women's self-help groups or other community organizations for women may empower female clients by exposing them to the experiences of women who have been in similar situations. Counselors should assess the appropriateness of such referrals with their clients and arrange for contact between client and group.

Women of Childbearing Age

Ideally, all women should receive counseling before deciding to become pregnant. If HIV test results are negative, counselors should help women remain

uninfected. If a woman tests HIV-positive, counselors should discuss the following:

- The risk of being re-infected and of infecting someone else in attempting to become pregnant;
- The risk of MTCT;
- The negative impact of pregnancy on the progression of illness, especially if the woman is already showing symptoms

Counselors should encourage HIV-positive women to consider all these factors before deciding to become pregnant. Pregnancy in HIV-positive women is considered a medical risk for both mother and baby. Consequently, termination of pregnancy on medical grounds should be

explored with the woman, within the terms of laws in the given country.

Box 31: Messages for Women of Childbearing Age

Counselors can communicate the following information in very simple terms to all women of childbearing age and repeat this information to HIV-positive women during post-test counseling:

HIV-positive mothers in developing countries face a 25-40 percent risk of giving birth to an HIV-positive child. Beyond the risk of transmission during pregnancy and childbirth, breastfeeding adds a risk of 15 percent or more, depending on duration of breastfeeding and other factors currently under study.

Contraception

Contraception is a very sensitive issue, particularly in cultures where having many children is a source of status. In addition, many women want to have children. Counselors should provide all necessary information and help each client make an informed decision about becoming pregnant. Counselors should remind female clients that behaviors leading to pregnancy carry the risk of exposure to HIV and other STIs. If a woman opts for contraception, the counselor should encourage her to bring in her partner for additional counseling.

Section 4: Antenatal Counseling for Preventing Mother-to-Child Transmission of HIV

Note: The following section was prepared using the most recent information available at the time of writing. But in this rapidly changing field, information on HIV treatment, care, and management becomes dated quickly. Course directors and participants are encouraged to compare the information here with the most recent guidelines from other sources.

HIV Counseling and Testing for Women in the Antenatal Setting

Counselors should encourage pregnant women who do not know their HIV status to undergo early testing, and should discuss the risk of MTCT with every woman in the antenatal setting. It is important to note that women do not always see the connection between their own infection status and the infection status of their future children.

Counselors must explain that HIV can be transmitted from mother to child during pregnancy, delivery, or breastfeeding. Women need to know that without treatment to reduce the risk of transmission, an HIV-positive woman has an estimated 70 percent chance of giving birth to an uninfected child. But this means that almost one-third of children born to HIV-positive women will be infected with HIV.

Box 32: Advantages and Disadvantages of Testing Pregnant Women

Advantages:

- Knowledge of HIV status facilitates early referral for care.
- Knowledge of HIV status allows appropriate treatment and follow-up of the child.
- Knowledge of HIV status provides an opportunity to implement strategies to prevent transmission to the child.
- Knowledge of HIV status enables women to take precautions to help prevent transmission to sexual partners.
- Knowledge of HIV status facilitates and promotes VCT to their sexual partners.
- For HIV-negative women, knowledge of HIV status can lead to appropriate HIV prevention measures and risk-reduction behavior.

Disadvantages:

- Testing can increase the risk of violence against women.
- Testing can increase the possibility that women will be stigmatized by community members and health care workers.
- Testing can increase levels of anxiety and have psychological implications.

Three primary approaches to HIV testing in pregnant women

Most people agree on the goals of testing pregnant women in the context of reducing HIV transmission from mother to child. There is also agreement that HIV testing of pregnant women should be accompanied by individual, culturally competent counseling that covers the benefits of determining HIV status and its implications for a woman's

life, pregnancy, and, potentially, her unborn child. But there is still wide debate over related policies. There are three primary HIV testing policies for pregnant women.

The traditional approach consists of *counseling and voluntary testing* (also referred to as the “opt-in” approach). This approach means that all clients receive information about HIV/AIDS in the context of MTCT, and those who are willing opt to receive pre-test counseling. Using this approach, pregnant women are advised and counseled about HIV testing and its implications. They are also offered the test. It is up to the woman to say she would like to be tested; the default is that she will not be tested.

Another approach is *universal or routine* (also referred to as the “opt-out” approach). This approach includes an HIV test in the standard battery of tests that all women receive when they are pregnant (i.e., the HIV test becomes a standard test; the pregnant woman is informed that she will have an HIV test but has the right to refuse testing). In opt-out testing settings, it is up to the woman to refuse the test; the default is that she will be tested.

The third approach is *mandatory testing*. In this approach, all pregnant women/newborns get tested for HIV. This generally means there are sanctions or penalties for those who refuse to test, including criminal penalties. Recent

discussions about and recommendations for mandatory testing of pregnant women have led to concerns about the autonomy and rights of women.

The table below summarizes the definition, advantages, and disadvantages of the “opt-in” and “opt-out” approaches.

Practical considerations for HIV counseling and testing during pregnancy

Various models of VCT in antenatal settings have been used, including: group counseling; video education; incorporating HIV information into the first interview by midwives; integrating HIV information into general health talks; and using lay counselors based on prevalence rates, service utilization patterns, level of community awareness, and availability of staff at the antenatal setting. Information about HIV testing has occasionally been incorporated into the health education and promotion activities of antenatal clinics to minimize time spent by clients at the facility. The following sections offer practical considerations for counselors involved in antenatal VCT.

Should the counseling be individual or shared?

Usually pre-test, post-test, and follow-up counseling are conducted on a one-to-one basis. But in the context of MTCT, partners should be encouraged to take part and go through the whole counseling process, if the woman

“Opt-in” and “Opt-out” Approaches

	Opt In (Counseling and Voluntary Testing)	Opt Out (Universal or Routine)
Definition	HIV testing is carried out only if specifically prescribed by the treating physician or for those women who make a decision and consent to test (i.e., the HIV test is not part of routine testing). Testing is only carried out after counseling and consent.	HIV testing is carried out on all women, unless they specifically refuse and the treating physician records this on the requisition (i.e., the HIV test becomes a standard test). The physician/counselor provides counseling; if a woman does not provide consent, HIV testing is not done.
Advantages	<ul style="list-style-type: none"> • Greater assurance that women will be tested only with knowledge and consent. 	<ul style="list-style-type: none"> • High level of HIV testing achieved (95+ percent); • Preventable HIV transmission reduced; • Testing seen as routine and, therefore, less threatening; • Increased access to other benefits of HIV diagnosis (e.g., ART, secondary prevention).
Disadvantages	<ul style="list-style-type: none"> • Lower level of HIV testing (60-80 percent); • Greater number of preventable HIV transmissions; • Reduced access to other benefits of HIV diagnosis (e.g., ART, secondary prevention). 	<ul style="list-style-type: none"> • Probability is greater that women will be tested without knowledge and consent.

feels this is appropriate. This may be impractical in some antenatal settings, so couples may be referred to a designated VCT site for testing (if one is available). When women do not have a partner, if the partner does not wish to attend, or if the woman does not wish to involve the partner, the support of a friend or relative can be valuable. But counselors should be aware that risk assessments usually should be conducted individually, followed by joint counseling with the partner or support person. Sometimes women prefer to receive their HIV test results alone and need time to “process” the information before sharing it. Counseling associated with MTCT should be flexible and may vary depending on setting and the woman’s preferences.

How many counseling sessions are required?

Communicating test results and post-test counseling must be done individually (or as a couple, if two partners are tested together). For women who test sero-negative, post-test counseling may be relatively short (e.g., involving a single session) and should be seen as an opportunity to discuss protecting against future HIV infection. Further sessions should be offered if the woman’s partner has not been tested or if the woman anticipates difficulties protecting herself from future infection.

Women who test HIV-positive may require longer sessions, and follow-up support and counseling should always be offered. In many cases it may not be feasible for VCT/MTCT projects to provide longer-term counseling to large numbers of sero-positive women. But some of these projects can establish linkages with other counseling services to provide longer-term supportive counseling.

Essential elements of counseling sessions for women receiving VCT as part of antenatal care

Essential elements of HIV counseling for antenatal care:

1. Understanding and accepting HIV status (for those testing positive);
2. Remaining HIV-negative (for those testing negative);
3. Sharing HIV status with partner and/or family or “significant other”;
4. Sharing HIV status with health care workers;
5. Avoiding blame through family counseling;
6. Referring for related health care and social support;
7. Understanding proposed MTCT interventions;
8. Counseling about infant feeding;

9. Counseling about safer sex and condom provision (male and female);
10. Counseling about STIs;
11. Family planning counseling;
12. Planning for the future.

1. Understanding and accepting HIV status (for those testing positive)

Women who test sero-positive during the antenatal period need support to come to terms with the implications, and referral for further counseling and medical and psychosocial care (including MTCT interventions where available). Referral to local support groups also can be helpful. Anger, depression, and denial are common initial reactions to a positive result. These feelings may be even stronger when a woman is tested during the antenatal period, since she is already adjusting to being pregnant, with its associated worries about the pregnancy itself, the future health of the baby, and the well-being of other children.

2. Remaining HIV-negative (for those testing negative)

Helping HIV-negative people remain negative is one of the most important functions of VCT. In antenatal care, it is extremely important to counsel women who test sero-negative about the implications of acquiring HIV during pregnancy and breastfeeding. This is critical given recent research indicating that becoming infected during this period carries an especially high risk of MTCT.

3. Sharing HIV status with partner and/or family or “significant other”

It is easier to make decisions about sexual behavior and act on those decisions when both partners are informed about their HIV sero-status. In some settings, testing and counseling as a couple (as opposed to individually) has been found to help reduce HIV transmission from one partner to the other. In fact, it has been reported that when people test as individuals they often find it difficult to share the result with their sexual partner, especially immediately after receiving the result. (It has been shown that over time people are able to tell their partners more easily.)

But there are settings where couples are very reluctant to be tested together. If men feel awkward about attending VCT with their partner, it may be appropriate for them to receive the service elsewhere. If a woman feels confident that she can tell her partner about a positive test result without fear of negative consequences (e.g., abandonment, rejection, violence), the partner may be able to go for VCT himself.

Some women may wish to involve family members in the VCT process, in addition to the partner. Mothers, sisters, or “aunties” can take on important supportive roles, which can be particularly valuable in ensuring the success of follow-up care (including MTCT interventions). In some MTCT projects, pregnant women have been more likely to confide in a female relative than in their partner or husband. Pregnant adolescents who are not in a stable relationship especially should be encouraged to share their HIV status with a close family member.

The decision to tell a partner about one’s HIV status depends on individual and societal factors. In many countries women risk negative consequences, such as abuse and/or abandonment, when they disclose their HIV-positive status. But MTCT interventions, which involve ARV drugs and/or breast milk substitutes, make it almost impossible for women to keep their positive status confidential. Thus, protection mechanisms for sero-positive women need to be considered, a referral network for vulnerable women established, and the advantages and disadvantages of disclosure weighed carefully and on a case-by-case basis. If a woman feels uncomfortable or undecided about sharing her HIV test result, the counselor can help with role-playing and other counseling techniques.

4. Sharing HIV status with health care workers

For a sero-positive pregnant woman to benefit from many MTCT interventions (e.g., intrapartum zidovudine [AZT], nevirapine, or counseling on infant-feeding choices), it is important that health workers are aware of her HIV status. This may involve several people, and the potential exists for the woman’s sero-status to be leaked. A woman should be counseled about the benefits of sharing her HIV status with her counselors and health workers and assured that being sero-positive will not mean discrimination against her. She also should be assured that systems are in place to prevent test results from being divulged to anyone other than those directly involved in her care. If this cannot be guaranteed, a pregnant woman may decline testing or move to another clinic for antenatal care. Systems for maintaining confidentiality should be developed.

5. Avoiding blame through family counseling

A sero-positive woman is often blamed as the person who brought HIV infection into a family, even though in the majority of cases the husband or partner has infected the woman. As a result, the woman is not only blamed but also abused and/or abandoned. Involvement of other

family members, in addition to the husband or partner, in the VCT process may help to diminish such problems. Family counseling can also be beneficial in future planning, especially if the pregnant woman has other children or symptomatic family members. Family counseling requires special skills that are often beyond the capability of the VCT/MTCT counselor. In those cases, referral to other counseling services should be provided; thus, knowledge of other locally available counseling resources is essential.

6. Referring for related health care and social support

Counselors must consider a woman’s ongoing health and support needs. Care of the HIV-positive pregnant woman needs to be comprehensive and long-term. Her immediate needs relating to her pregnancy cannot be addressed in isolation from her overall health, her other children, her responsibilities, her means of support, or the assistance she is likely to get from family and her community. Referral to local services and support groups is a crucial part of the counselor’s role.

7. Understanding proposed MTCT interventions

For a woman to make informed decisions about her pregnancy, counselors must present available options for treatment and care. If ART to prevent MTCT is offered, detailed explanations, monitoring, and follow-up are particularly important, since the treatment procedure is complex and involves a number of different services, including family planning and infant-feeding support.

Adherence to the treatment program, which is essential, can be enhanced if both the health worker and the woman clearly understand the regimen and its benefits. Many VCT/MTCT projects with pregnant women report very low rates of adherence to or completion of the regimen. Counselors must be trained to assess constraints on a woman’s potential adherence to the program and ways to overcome them, rather than just provide information about the ARV regimen. Counselors also may need to address certain health beliefs of the client’s particular culture.

Counselors need to explain that ARV intervention is not always successful. With ART, the number of infants who contract HIV is greatly reduced. But a proportion (approximately 10 percent) of infants of mothers receiving short-course ZDV treatment (the regimen currently recommended in many developing countries) will be infected anyway. These infants will need continuing medical care, and their mothers and families will need social and emotional support.

8. Counseling about infant feeding

Counselors must be able to discuss the risks and benefits of breastfeeding when the mother is HIV-positive and counsel the woman on all infant-feeding options. WHO recommends the following:

- Exclusive breastfeeding by women who are known to be uninfected with HIV, and by women whose infection status is unknown, should be protected, promoted, and supported for six months.
- With women who are known to be HIV-positive, replacement feeding is recommended where acceptable, feasible, affordable, sustainable, and safe; otherwise, exclusive breastfeeding is recommended during the first six months of life.

To minimize the risk of HIV transmission, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation, and the risks of replacement feeding (including malnutrition and infections other than HIV).

If a pregnant woman is considering ART to prevent MTCT, the implications of infant-feeding options must be explained thoroughly. Assessing the feasibility and safety of alternative feeding in her particular circumstances may affect her decision about the intervention used. Counselors must help women weigh the options for themselves and their babies and be supportive of their choices, whatever they may be. Women may face particular difficulties if they choose not to breastfeed in communities where breastfeeding is the norm, or where not breastfeeding is considered tantamount to declaring oneself HIV-positive. A detailed training course on counseling HIV-positive women about infant feeding is available.

9. Counseling about safer sex and condom provision (male and female)

Pregnant women must be given safer-sex counseling. If women who test sero-negative become HIV-infected during pregnancy or breastfeeding, they run a higher risk of MTCT, since the viral load is particularly high at the time of HIV infection. If women are unaware of their partner's HIV status or feel they may be at risk of HIV infection, they should encourage their partners to use condoms. When appropriate, partners should be involved in decisions about safer sex, and couples should be encouraged to get tested together. Many women say they have difficulty discussing safer sex and other sensitive issues with their husbands or partners. Therefore, counseling about safer sex should involve more than just offering information about safer

sexual practices; it also should explore beliefs about and constraints on practicing safer sex.

Sero-positive women must be provided with information, counseling, and condoms to prevent sexual transmission of HIV. This is particularly important for women whose partners are sero-negative or have not been tested.

10. Counseling about STIs

Pregnant women usually have blood drawn to test for syphilis and other STIs, so counselors should be able to discuss STI diagnosis, treatment, partner notification, and other issues.

11. Counseling about family planning

For women who decide to continue their pregnancy, family planning should be discussed and made available in the postnatal period. This is especially important if women choose not to breastfeed, since they may have planned to rely on prolonged breastfeeding for infant spacing and will lose this benefit. Women in early pregnancy who have a confirmed positive HIV test result should be counseled on whether to continue the pregnancy and be referred to appropriate services accordingly.

Counseling about family planning may need to include exploration of sexual practices. For example, in some cultures, couples engage in anal sex as a means of pregnancy prevention. Couples should be informed that this might heighten the risk of HIV transmission.

12. Planning for the future

Women with HIV often worry about what will happen to their children if they become sick or die. Counselors must be open to discussing this subject with them. Women may need help planning for their children's future or advice to prevent property grabbing. They may be anxious or depressed about what the future holds, especially if they have seen what happened when friends or relatives died. Counselors should be able to refer for spiritual and legal support (e.g., for preparing wills) where those types of support are available. Such planning issues are addressed most appropriately in ongoing counseling sessions. Helping the woman cope with the test result and deal with her immediate reactions and needs generally take priority in immediate post-test counseling.

Reducing the Risk of MTCT in HIV-Positive Pregnant Women

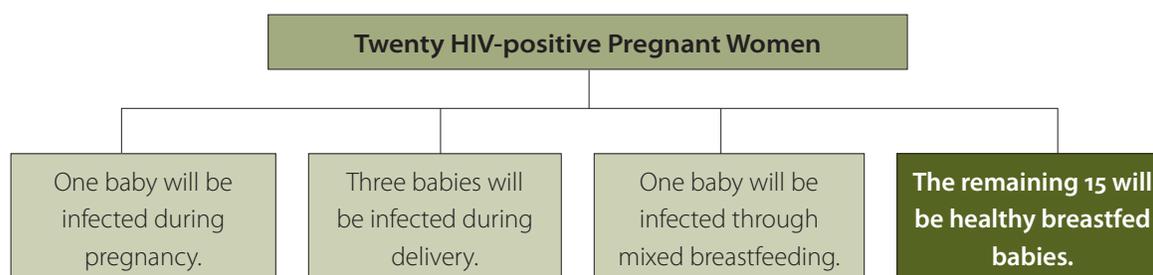
HIV-positive women of childbearing age need advice about healthy reproduction and reducing the risk of MTCT.

Box 33: MTCT Messages

Counselors may use the following simple information to explain MTCT to their clients.

Out of 20 babies born to HIV-infected mothers:

- 1) One baby will be infected during pregnancy.
- 2) Three babies will be infected during delivery.
- 3) One baby will be infected through mixed breastfeeding.
- 4) The remaining 15 will be healthy breastfed babies.



Women do not always recognize the relationship between being infected with HIV and having children. Some find the idea of not having more children (or not having children at all) unacceptable or unfeasible. Counselors must explain that HIV can be transmitted from mother to child in three ways: during pregnancy, during delivery, or through breastfeeding.

Counselors should explain that based on currently available figures, an HIV-positive woman has an estimated 70 percent chance of giving birth to a healthy child without taking steps to reduce the risk of transmission. This means that approximately one-third of children born to HIV-positive women are infected with HIV. Counselors should encourage women to make their decisions about bearing children based on this information.

Many pregnant women who learn they are HIV-positive women choose to continue their pregnancy. When this is the case, the role of the counselor is to help the future mother work out how best to avoid transmission of the virus to the child. Whenever possible, the woman's

partner should attend counseling sessions as well and should be present when decisions are made. The partner's involvement facilitates the medical and psychosocial support pregnant HIV-positive women need.

Reducing risk during pregnancy

The risk of HIV transmission during pregnancy is reduced by quality prenatal care; treatment of malaria, TB, and STIs; provision of information on how preventing HIV infection and re-infection affects MTCT; and provision of ART. Because of higher viral loads, the risk of MTCT increases if a woman becomes infected or re-infected during pregnancy, or if she becomes ill with AIDS. Other factors that increase the risk of transmission during this period include viral, bacterial, and parasitic placental infections.

Reducing risk during labor and delivery

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 labor and delivery. Strategies to reduce transmission during labor 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 hemorrhage 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;
- Providing a short course of an ARV drug, if available and acceptable.

Many women in developing countries give birth at home. Counselors, birth attendants, family members, and pregnant women themselves can help reduce the chance of HIV transmission during home delivery by using sterile instruments and following good hygiene practices. Counselors, birth attendants, and families should acquire a "clean-birth kit," which are packed in a sturdy plastic bag, are disposable after use, and are usually available from public health services or pharmacies. If a kit is not available, counselors should encourage families to collect the materials that would have been provided in it: a one-square-meter plastic sheet (about 0.05 millimeters thick); a bar of soap; two wooden sticks to clean finger nails; two lengths of clean but non-sterile tape (one half-meter in length) for tying the umbilical cord; and a pack of five double-edge razor blades. Birth attendants should use gloves (when gloves are not available, plastic bags may be used), particularly for postnatal handling.

Reducing risk during breastfeeding

All women considering pregnancy or already pregnant or breastfeeding should know that breastfeeding carries a risk of HIV transmission to the child. Women with HIV infection have the virus in both their blood and breast milk. Counselors should provide full facts about the risks of breastfeeding and about alternative infant-feeding options. If facilities for special counseling on infant-feeding options are available, they should be offered. This special counseling can help a woman make an informed decision about how to feed her infant.

If HIV-positive women have access to breastfeeding 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 breastfeed their infants. If breastfeeding alternatives are not available, the health risk to infants who are not breastfed 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 breastfeed for the first six months, or if complications develop (e.g., mastitis, cracked and bloody nipples) from poor breastfeeding techniques. Risk of transmission also increases if the mother becomes infected with HIV while breastfeeding. Duration of breastfeeding is also associated with the level of transmission risk; after six months, the risk of HIV transmission may be greater than the benefits of breastfeeding. Counselors should inform HIV-positive women of the alternative options listed in Box 34. If none of these options is possible, women should continue breastfeeding, seek prompt treatment for any breast problems, and treat any case of thrush in the infant.

Box 34: Alternatives to Breastfeeding

- Commercial infant formula;
- Home-prepared formula (modified animal milk or dried milk powder and evaporated milk);
- Non-modified cow's milk;
- Modified breast milk (mother expresses milk, boils it briefly to kill the virus, then cup-feeds);
- Breast milk banks, functioning according to established standards;
- Wet nursing.

Section 5: Counseling Couples

Couples of different types attend counseling centers for a variety of reasons. The couples may be married, planning to marry, of the same sex, or simply sexual partners. They may come together on their first visit, or one partner may receive services first and subsequently decide to bring the other along. In other cases, partners may be brought in at a counselor's request or suggestion. In any of these situations, it is important to ensure that each person voluntarily

consents to HIV counseling and testing. The counseling process is generally the same for couples as for individuals, with the following additions:

- Individuals should be encouraged to disclose their test results to their partner.
- The risk-assessment component may be conducted separately to give partners an opportunity to assess their risk behaviors honestly.
- Test results should be given individually first. Then counselors should help the couples share their results with each other at the counseling center.
- After disclosure of test results, post-test counseling may proceed with both partners present.
- Individuals reluctant to disclose their test results to their partners should be encouraged to do so with the counselor's assistance. Counselors should be aware, however, that they may not disclose an individual's test result without his or her permission.
- A couple's joint test results may be positive, negative, or discordant.
- Couples who are concordant (have the same HIV status) are often reluctant to use condoms.

Counseling Concordant Couples

When both partners have the same HIV test result, they are said to be a sero-concordant couple.

Concordant negative couples (neither partner is HIV-positive)

Counselors should review the risk-reduction plan developed in pre-test sessions and encourage concordant negative couples to discuss ways of maintaining their negative status. Counselors should explain the window period (the possibility of sero-conversion) as well and ask couples to repeat the test in three to six months.

Concordant positive couples (both partners are HIV-positive)

It is important to counsel both partners together; the counselor should be able to deal with the psychological reactions and emotional problems of both partners. But the counselor may begin just with the partner who is most ready to discuss his or her challenges. Next, the counselor can try talking with the other partner. Ideally, an arrangement is then made to see both partners together.

Counseling for concordant positive couples can help dispel misunderstandings and reduce the threat of violence

toward the female partner. Following a positive test result, counselors should help clients develop a positive living plan and maintain a healthy relationship. Counselors should encourage safer-sex practices and explain re-infection. In general, concordant positive couples need help in the following areas:

- Communication with one another;
- Communication with the extended family;
- Communication with their children;
- Reconciliation;
- Anger management;
- Forgiveness;
- Personal hygiene;
- Ways to ensure the welfare of their children.

Counseling Sero-Discordant Couples

When sexual partners are found to have differing HIV status (i.e., one is HIV-positive and the other is HIV-negative) the couple is "sero-discordant." Various studies from sub-Saharan Africa have shown that 16-20 percent of couples who are counseled and tested for HIV are sero-discordant. It is important that couples hear this figure during pre-test counseling; it may help reduce their distress or lack of understanding when they first learn their own results are discordant.

Counselors need to help discordant couples develop a long-term plan, not only to protect the HIV-negative partner from infection but also to help the infected partner live "positively" with infection. It is also important to raise the possibility that the HIV-negative partner may still be in the window period, and that he or she should undergo a second test in three to six months.

In sero-discordant couples, it is common for the uninfected partner to blame the partner who is infected for behavior that may have resulted in infection. Counselors must help prevent partners from verbally or physically abusing each other and refocus them on developing a plan for living positively with their reality, whatever it may be.

The counselor's role in discussing sero-discordance includes:

- During pre-test counseling, explaining the possibility of discordant results to couples and to any individual who is in a sexual relationship;

- Exploring the implications of discordant results (including preventive measures to protect the negative partner).

Pregnancy for sero-discordant couples is a complicated issue that demands consideration of each partner's health status, resources, family circumstances, and spiritual beliefs. Couples who receive counseling together should be encouraged to discuss their plans for pregnancy and family planning. The counselor must provide relevant information and options, but should leave the ultimate decision to the couple. The counselor can refer sero-discordant couples for family planning services and medical evaluation.

In any event, the counselor must remember at all times to avoid becoming emotionally involved with the couple. The counselor's role is to provide couples with appropriate information and to initiate and facilitate discussion.

Section 6: Group Counseling

Group counseling operates under the premise that because behavior is socially determined, it can best be changed in a social context. A counseling group is more than a collection of individuals; it is a collection of experiences, positions, and roles. Change occurs when group members share experiences with each other, when individual problems become group problems, and when these problems progress toward a solution in an open and trustful atmosphere. The role of group counselors and facilitators is to help identify and modify problems using an evolving, dynamic group structure and the processes associated with it.

Therapeutic effects of group counseling:

- Group experience tends to resemble everyday interactions, so opinions and experiences expressed in-group may be close to members' everyday reality. Entrenched beliefs and behaviors dissipate more easily through social consensus, which is reached in a group.
- Group counseling can help reduce social isolation. By listening to others, clients learn they are not alone.
- Group work encourages people to share emotions, both negative and positive.
- Group counseling can be an opportunity for role modeling, and members can learn to imitate successful coping styles and skills.

Box 35: Couples Counseling, Summary of Main Points

- Couples counseling can facilitate disclosure of sero-status and contribute to behavior change through risk-reduction planning.
- Special promotions/communication campaigns can target couples. For example, Valentine's Day promotions and "free days" for couples are effective in increasing couples' attendance at freestanding VCT sites.
- As reported by women, a major barrier to initiating VCT is their inability to obtain (or even seek) consent from their husband or partner.
- Not all women (pregnant or otherwise) are part of a couple. Service providers should keep this in mind before suggesting that women bring their partners. This caveat applies particularly to young pregnant women who may not have or want active involvement of the father of the unborn child.
- Couples counseling must uphold voluntary, consensual practice.
- Coercion to attend VCT by one partner and/or an organization (e.g., some forms of faith-based premarital testing) may result in adverse consequences for parties (particularly women) who test positive.
- Couples-based VCT can be effective when offered on weekends. Weekend duty (e.g., if paid at overtime rates) can be an incentive to staff as well.
- Couples counseling may play a role in reducing gender-based violence, discrimination, isolation, and abandonment experienced by women who test positive.
- Sero-discordant couples may be able to implement risk-reduction planning more effectively when VCT is targeted at both partners.
- Involving men in decision-making may help women adhere to MTCT interventions (e.g., ARV drugs, infant-feeding options, nutritional plans).

- Group experiences can lead to increased self-esteem. Mutual support is offered and group members offer sympathy and acceptance.

In initiating group counseling, the counselor needs to:

- Define the goals of the group;
- Determine the size of the group;
- Outline the criteria for membership;

- Establish group rules and regulations;
- Safeguard the group's survival and ensure it is functioning according to its goals;
- Create a facilitative atmosphere that encourages openness and trust;
- Facilitate the direction of communication (i.e., guide or manage the direction);
- Listen continuously and help group members express themselves;
- Translate individual problems into a group context.

Types of Group Counseling

Small-group therapy

This form of counseling usually is undertaken with six to eight clients who are concerned with a similar problem and are of similar age and socioeconomic background. The goal of small-group therapy can be to bring a substantial change to problems, to promote behavior change, or to provide supportive counseling.

Large groups

Membership in large groups can range from 20 to 50 and may involve both clients and service providers. In their simplest form, large groups allow clients to discuss their challenges living with HIV. At a more ambitious level, large groups can help modify their members' behavior through social learning. The group initiates change by presenting individual members with an example of their risky behavior or irrational response to their HIV diagnosis. At the same time, other members who share similar problems and opportunities for social learning provide support. Because large groups can evoke anxiety in both clients and counselors, care should be taken to prepare new members for the experience. It is also important to protect vulnerable people from attacks by other group members, and to decide when a member may be too angry or disruptive to participate.

Supportive groups

Supportive groups are led by professional therapists to support people living with HIV.

Self-help groups

Self-help groups are organized and led by people who are living with or are affected by HIV and who have learned ways of overcoming or adjusting to their difficulties. Group members benefit from hearing each other's experiences and can discuss their problems with people who have

overcome similar obstacles. Some groups have professional advisers.

Post-test clubs are a good example of an HIV self-help group. It is recognized that knowledge of one's HIV status does not automatically reduce risky behavior. Once clients know their HIV status, they can benefit from the support of other clients who share similar concerns. Thus, to provide a context in which clients can continue to make positive life choices, counselors are encouraged to establish a post-test club. The post-test club caters to both negative and positive clients. The criteria for membership is having received counseling and testing at a VCT center. The working assumption is that post-test clubs, where avoiding sexual risk is reinforced and "healthy living" attitudes are fostered, help clients maintain focus and motivation.

Section 7: Family Counseling

Family counseling can take a variety of forms. One example is counseling minors on how to behave toward family members who are living with HIV, and what precautions they should take in the home when caring for those individuals. Another is helping family members understand that people living with HIV need affection and should be treated as normally as possible. Family members who are old enough to understand the implications of HIV infection may need psychosocial support to help them cope with the stigma and discrimination they may encounter in the neighborhood, at school, at work, or elsewhere.

In many cases, families have misgivings about living with someone who is infected with HIV. Counselors should reassure family members that HIV is not transmitted through day-to-day social contact. Family members need to know they can play and eat with a person who is HIV-positive without running any risk of infection. But the counselor also should explain that if members of the family come into contact with the infected person's blood, a very slight risk of infection exists. Box 36 contains guidelines for avoiding infection from the blood of a person living with HIV.

Box 36: Guidelines for Avoiding Infection from HIV-Infected Blood

- If an HIV-positive person is wounded, try to avoid contact with the blood.
- If it is necessary to stop the flow of blood, try to use a barrier (such as gloves).
- Clean the wound with a piece of absorbent cloth, to be used only once, and a disinfectant, such as bleach.
- The material used to wipe up the blood should be discarded or stored where no one else will come in contact with it.
- After cleaning contaminated surfaces, wash your hands with soap and water.

Any items that come in contact with the blood and are to be used again (e.g., clothes, towels, kitchen utensils) should be handled with care and boiled for at least 25 minutes in water at least 61°C.

CHAPTER 8

GRIEF AND BEREAVEMENT

Section 1: Understanding Grief, Bereavement, and Mourning

Section 2: Helping Clients Deal with Loss and Bereavement

Section 1: Understanding Grief, Bereavement, and Mourning

Even as the counseling field explodes with new and sophisticated research on AIDS bereavement, there is still lack of agreement about basic terminology. For example, the terms “grief,” “bereavement,” and “mourning” are often used interchangeably, even though they have different meanings.

This reference guide has adopted the following definitions:

Grief is an intense feeling of sorrow or sadness people feel when they experience a personal loss, such as loss of a loved one, one’s health, or a financial loss. In other words, grief is an emotional response to one’s loss (i.e., the normal process). When we think of grief, we often think only of death, but other losses can elicit similar reactions. For example, PLHA 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 behaviors (table below).

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

Bereavement is 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 following the

Characteristics of a Normal Grief Reaction

Feelings	Physical Sensations	Cognitions (Perceptions)	Behaviors
Sadness	Hollowness in the stomach	Disbelief	Sleep and appetite disturbances
Anger	Tightness in the chest	Preoccupation	Absentmindedness
Guilt/self-blame	Tightness in the throat	Hallucinations	Dreaming of the deceased/ lost
Anxiety	Over-sensitivity to noise	Confusion	Visiting places or carrying objects that recall the deceased/lost
Loneliness	Shortness of breath	Sense of presence (e.g., perception that the deceased is around or is talking to you, or a sense of being healthy again)	Treasuring objects that belonged to the deceased
Fatigue	Weakness	Depersonalization (e.g., “Nothing seems real to me, including myself”)	Avoiding reminders of the deceased/ lost
Helplessness	Lack of energy		Searching and calling out (not always vocal)
Shock	Dry mouth		Sighing
Yearning			Restlessness
Emancipation			Crying
Relief			
Numbness			

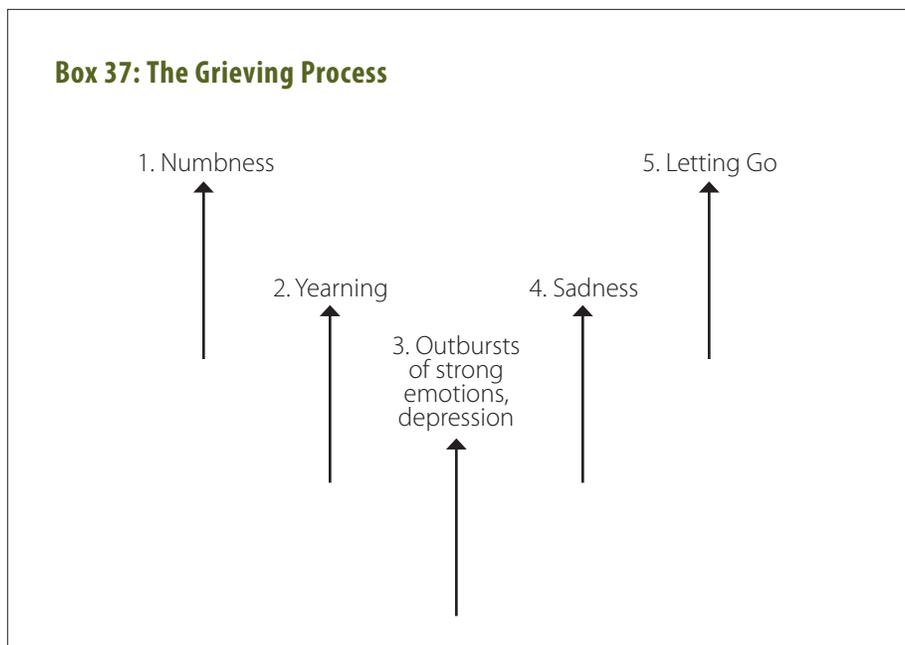
death of a significant other, whereas mourning speaks to the way the individual displays his/her grief.

The Stages of Grief

While there is no single way to grieve, people generally experience common stages of grief 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 of grief are fluid; an individual may move in and out of them in his or her own manner and time.

- 1. 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 be helpful for a client to go through some denial at first, it can be a problem if it lasts too long.
- 2. 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.

- 3. 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, and/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 they die or face a disability.
- 4. Depression:** Bargaining is followed by bouts of depression and sadness, set off by reminders and memories of the dead 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.
- 5. 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.



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?”
- **Relationship 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 (i.e., the strength and security of the attachment/importance the person attached to his/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 predominantly a person’s loved one or own health played in his/her life, the more difficult the grieving process will be. Questions include, “How major was that role?” “Was the deceased/ill person the sole breadwinner, the driver, the handler of financial matters?” “The only one who could fix a decent dinner?” “Was the person the main emotional support, an only friend?” “How dependent was the client on the role that person filled?” “What role did good health have in ensuring he/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/loss occurred. Questions include, “Was it

natural, accidental, suicidal, homicide, etc.?” “Near or far, sudden or expected, etc.?” “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 or lose an object? “Do we feel that the death/loss could have been prevented?” “How much was left unsaid or undone between the deceased and ourselves?” “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 include, “What are the secondary losses of this death or loss? Loss of income? Home? Family breakup?” “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?”

Counselors 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, should enable the counselor to guide the grieving person to relevant support.

Counselors Understanding Their Own Grief

The loss of a loved one is among the most intensely painful experiences a human being can suffer. Such a loss is not only painful for the mourner; it can be painful for the counselor, especially if he or she feels unable to make a difference. Moreover, being with the bereaved may make counselors aware of losses in their own lives. If counselors have not dealt with their own losses adequately, 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. Counselors are often unaware of their own fears of losing loved ones. However, if the loss the bereaved client is experiencing is similar to the one the counselor fears most, then that fear can affect the counselor's ability to help the grieving client.

The counselor'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, counselors 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. Counselors 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 counselors to recall how other people were helpful—and what kinds of things failed to help, or even hurt.

It can be helpful for counselors to examine the personal losses that have affected them most, including the deaths of clients with whom they had a special bond. Counselors may also have to go through a grieving process after a client's death. By looking at one's own experiences of loss and grief, counselors can become more aware of their own inherent limitations. From this they may learn to ask colleagues for assistance. It is important that counselors share their own more recent losses with their counseling team, know where to get emotional support, know how to reach out when they need it, and understand their own limitations.

Section 2: Helping Clients Deal with Loss and Bereavement

Grief is a normal response to loss. Recognizing and dealing with grief can help people move toward a healthy response to a significant loss. Counselors may play a large part in helping the client address and manage grief.

Grief Counseling

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

- Helping the person accept the loss by assisting him/her to talk 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 and giving permission to grieve;
- Describing normal grieving, the difference in grieving among different individuals, and helping the person understand his/her coping methods;
- Providing continuous support, identifying coping problems (if applicable), and making necessary referrals for professional or ongoing grief therapy.

Counselors can do a number of things to facilitate a client's grief process, including:

Active listening: A counselor'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 counselors 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—trite comments that seem to diminish the person's loss by offering simple solutions to difficult realities. Clichés (e.g., "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"; "God never gives us more pain than we can handle") fail to acknowledge the depth of feeling of the bereaved. Moreover, such comments often are more about the person who died than the person who is grieving.

Understanding the uniqueness of grief: Counselors 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 can be employed to help a grieving person deal appropriately with his/her grief:

Box 38: Select Tools for Grief Counseling

Forceful language: Counselors should inform their clients that it is “okay” to grieve, cry, heal, and laugh. In addition, counselors should use “proper 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/or stigma.

Symbols: Symbols (music, photographs, 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 (i.e., “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 (though some 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).

Role-playing and/or 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 also can 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.

Talking with Children about Death and Dying

In the past, children were thought to be miniature adults and were expected to behave as adults. It is now understood that children and adults mourn differently. Unlike adults, bereaved children do not experience continual and intense emotional and behavioral reactions. The needs of mourning children may have to be addressed again and again, as they will think about the loss repeatedly as they grow, especially during important events such as birthdays, graduations, marriage, etc. This longer grief period is due to children’s limited ability to experience intense emotions. A child’s grief may be influenced by age, personality, earlier death experiences, ongoing care needs, opportunities to share his or her feelings or memories, and the caretakers’ ability to cope with stress.

Evidence suggests that talking about death and dying can be a positive experience for both children and parents. It gives children the opportunity to say goodbye and start the healing process; it gives parents the satisfaction that the child will be prepared to live without them. Grieving children often express three issues: 1) Did I cause the death/illness to happen? 2) Is it going to happen to me? 3) Who is going to take care of me? It is important to discuss these issues and whatever other questions/concerns the child may have. Counselors should be aware that parents might need counseling to help them talk with their children about dying. A memory book or memory box is a useful tool to facilitate this process.

Memory Books/Boxes: A Tool for Disclosure and Grief Counseling with Children

Memory is a key component of identity. But as HIV/AIDS leaves many children without parents, they lose this fundamental link to their roots. For children affected by HIV/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 in Uganda when asked about the memory box her mother left her on her death.

History of the memory book/box

The memory book/box was inspired by a group of HIV-positive women in Uganda to help them disclose their HIV sero-status 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 a memory book, memory box, 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 the positive women work through different aspects of their history, lifestyle, culture, and beliefs. The pages are then inserted into the memory book. Examples of headings include the following:

Our family came from...

Your grandparents' names were...

These are some of the jobs our family did...

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 are as simple or as ornate as one chooses and may contain mementos, letters, diaries, photographs, documents, certificates, tapes, transcribed family history, personal treasures, objects of sentimental value, and favorite Bible 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/AIDS. In addition to helping family members communicate with and understand each other, memory projects allow helpers (e.g., caretakers,

counselors) to gain appreciation of the intense emotions felt by their clients.

Memory Project Training Sessions

The following information can guide fieldworkers (i.e., home and community caregivers, counselors, peer support people) in creating and using memory books/boxes.

Supplies and personnel required for a memory box activity:

- Empty box;
- Private space with enough room for everyone to sit in a circle;
- Experienced facilitator;
- Reporter.

Roles

Facilitator: The role of the facilitator is to introduce the exercise and facilitate (not take over) the discussion. The facilitator should be careful not to dictate the items to be put in the box and not to impose judgments on them. The facilitator also should be sensitive to people's emotions; participants must feel safe and able to express themselves.

Reporter: The role of the reporter is to take notes on the discussion, which will form a written report that summarizes the experience (including quotations) for participants and program records. The reporter should not specify who said what.

Group size: The exercise can be conducted with up to 20 participants.

Duration: The duration should be one to two hours, depending on the size and makeup of the group.

Steps

- Organize the group in a circle around an empty box, with everyone facing the center of the circle.
- Provide brief background on the nature of the memory box and its uses.
- Hand out small pieces of paper (up to five for each participant).
- Explain that people should imagine they are preparing to leave things behind for their children (or other significant person, if they do not have children) in the event of their own death, or if they have to leave home for an extended period. (The latter scenario is for people who are terminally ill but choose not to be open about their condition to the group.)

- Ask group members how they think counselors can help bereaved clients deal with their losses. Give them time to reflect and do not allow cross talk.
- Ask each person to write or draw his or her chosen items on a separate piece of paper. Group members can write or draw as few or as many items as they wish. Let them know they will not have to tell the group everything they have written. They should feel free to write what they want.
- Allow enough time for each group member to finish. Some people will need more time than others. Encourage the group to be patient and quiet while waiting for others to finish.
- Once all group members have written or drawn all of their items, ask them (one by one, and when they are ready) to put their items in the memory box without speaking and to close the lid.
- Ask for volunteers who are willing to share with the group one or two things they put in the box. Where appropriate, ask selected participants why they chose the items they did.
- Upon completion of the exercise, hold a discussion as explained in the box.

Discussion points

Why did people choose the things they put in the memory box?

What emotions and thoughts did people experience while going through the exercise? (Where appropriate, ask why they felt or thought the things they did.)

What are the uses of the memory box, and how can it help both parent and child? If not brought up previously, discuss

the memory box process as an entry point to disclosure, the writing of wills, etc.

If group members were to receive a memory box, would they want it before the person who made it died or left? Why or why not?

Ask group members how they would feel when opening a memory box made for them.

Challenge participants to create their own memory boxes and discuss briefly how this exercise can help fieldworkers understand, have compassion for, and feel some of what we are asking of those we work with (i.e., clients).

Cautionary note

This exercise may evoke a range of emotions and have longer-term emotional implications for some group members. Thus, the facilitator should be particularly skilled in responding to the personal experiences of trainees who participate in it. The facilitator should have completed the exercise earlier. Participants should be clear about why they are involved in the exercise, and adequately debriefed upon its completion (both in terms of their individual experiences and how they think the memory box might be applied with their own clients, families, and/or communities). This is particularly important when participants themselves are living with HIV/AIDS. Group members can be encouraged to support each other if they notice the exercise has had a strong impact on one of their peers.

CHAPTER 9

COUNSELOR BURNOUT AND STRESS MANAGEMENT

Section 1: Understanding Stress and Burnout

Section 2: Stress Management

Section 1: Understanding Stress and Burnout

Many newly trained counselors—often idealistic and enthusiastic—promise themselves that they will never become like some of the more experienced counselors 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 counselors to imagine that the burned out counselors were once idealistic as well.

Nobody starts out in the profession planning for the days when work no longer seems vibrant and exciting. This is why it is important to discuss counselor burnout during training. Anticipating the predictable stresses and strains of VCT counseling and the toll it might have on one's physical and emotional health allows counselors to take steps to minimize these negative effects.

What is Stress? Burnout?

"Stress" can be defined as anything that stimulates an individual and increases their level of alertness. Life without stress would be incredibly dull and boring; 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 felt to be depends partly on 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 also has been

described, in regard to people in the helping 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.

The 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 cause guilt or shame. Other features are often-physical warning signs, such as an inability to shake off a lingering cold or fever, frequent headaches, and/or sleeplessness. Another 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 toward the job. Emotional and behavioral signs such as angry outbursts, obvious impatience or irritability, and/or treating people with apparent contempt are common. This often leads people to experience severely negative feelings toward themselves, others, or, possibly, all humanity. Intense loneliness and alienation are common characteristics of the end stages of burnout, as one's coping structure and psychological defenses wear down. A slight emotional bump can set off an overly sensitive and personal reaction. Mood swings might be common with short highs and long lows.

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;
- Grinding one's teeth at night;
- Insomnia;

- Forgetfulness;
- Heart palpitations;
- Unusual heart rhythms (skipped beats);
- Inability to concentrate;
- 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)

- Lateness for work;
- Procrastination;
- Needed three-day weekends;
- Decreased sexual desire;
- Persistent tiredness in the mornings;
- Turning work in late;
- Social withdrawal (from friends and/or family);
- Cynical attitudes;
- Resentfulness;
- Increased coffee/tea/cola consumption;
- Increased alcohol consumption;
- Apathy.

Any two of the above symptoms may signal Stage 2 of the burnout cycle.

Stage 3: Exhaustion (includes any two of the following)

- Chronic sadness or depression;
- Chronic stomach or bowel problems;
- Chronic mental fatigue;
- Chronic physical fatigue;
- Chronic headaches;
- The desire to “drop out” of society;
- The desire to move away from friends, work, and perhaps even family;
- Perhaps the desire to commit suicide.

Any two of these symptoms may signal Stage 3 of the burnout cycle.

Who Burns Out?

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, and number of hours worked per week. But 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 behind the scenes); for example, nurses are more likely to suffer from burnout than physicians;
- Counselors dealing with difficult issues such as HIV.

People suffering from burnout seem to progressively feel a lack of personal accomplishment in their work. There is also evidence that clients can identify a counselor with burnout. It is documented that clients become dissatisfied and tend to be more critical of the “burned out” counselor’s actions and interventions.

Causes (Stresses and Strains) of Counselor Burnout

Counselor 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 counselor might face.

- A strong sense of commitment;
- Job stress;
- Lack of adequate support;
- Isolation and alienation;
- Fear of HIV infection;
- Ostracism and stigma;
- Excessive identification with clients;
- Involvement of family and loved ones in the counseling session;
- 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; a couple refusing to be separated; conflict between counseling and giving advice; conflict between encouraging a client and giving false hope; the counselor’s own emotions surrounding HIV);
- Boredom—hour after hour, day after day, year after year clients enter a counselor’s office, tell their stories,

Burnout Symptoms

Physical	Behavioral	Cognitive
Exhaustion	Quickly irritated or frustrated	Exasperation: "I've had enough" or "I can't take this anymore"
Lingering minor illness	Quickness to anger and/or irritability	Ruminating
Frequent headaches and backaches	Prone to prejudice	Emotional numbness, indifference, impoverishment
Sleeplessness	Alcohol and/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	Impulsivity or acting out	Grief and sadness

ask similar questions, and expect the counselor to do essentially the same thing.

Recognizing Burnout

Counselors can recognize burnout by its physical, behavioral, and/or cognitive symptoms, including those listed in the table below.

The visible effects of burnout in HIV counseling are high turnover, absenteeism, declining quality of service, decreasing communication, disorganization, declining enthusiasm, and increasing client complaints.

Section 2: Stress Management

"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 expected of VCT counselors make them continue to work hard in the face of high sustained stress. Thus, it is essential that counselors learn to pay attention to their own needs and feelings. This means knowing when to relax, get more sleep, or implement stress management strategies. If counselors do not take feeling tired, upset, or discontent seriously, they may face failure, burnout, or breakdown. Counselors ought to:

- Take care of the single most important instrument: *themselves*;
- Be aware of the causes of burnout;
- Know how to recognize and remedy burnout;
- Know how to prevent burnout.

To recognize burnout in themselves, counselors can ask the following questions:

- If I were "burning out" . . . what signs do you think my clients would see first?
- Who would be the first person to notice that I was burning out? . . . Me, my clients, my family, a friend, a colleague, or a supervisor?
- Have I ever noticed that someone I work with is burning out? What did I notice and how did I respond?

A burnout risk survey has been used to help counselors recognize burnout. 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 suggests high risk. The same items can be used to identify corrective actions and hence prevent burnout.

What can counselors do to prevent burnout?

- Ensure that there is an opportunity for individual, peer, or group supervision or counseling for counselors (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 counseling style, get different supervision, take on new challenges);

Burnout Risk Survey

	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?		
Will you ask for/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 have 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 value commitment to yourself to exercise/relax as much as you value those of others?		
Do you often overload yourself or have difficulty saying "no"?		
Do you have few opportunities for positive and timely feedback outside your work role?		

- Learn to accept what one can and cannot control.

Counseling for the counselor

If possible, VCT counselors themselves should go for counseling. Evidence suggests that "... counselors cannot hope to open doors for clients that they have not opened for themselves." Counseling for counselors can have several benefits. By experiencing counseling from the client perspective, counselors can:

- Consider their motivation for wanting to be a counselor;
- Find support as they struggle to be a professional;
- Receive help dealing with personal issues that surface through interactions with clients.

Coping Strategies for Stress and Burnout

There are several strategies to cope with stress and burnout. The techniques selected by counselors will depend on the cause of the stress and burnout and the situation in which stress occurs. Thus, counselors 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 behavior), relaxation techniques might be more appropriate.

Adopting a healthy lifestyle

Counselors 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 and/or recreation, avoid smoking, drink alcohol only in moderate quantities, adopt an adequate sleep routine, and eat balanced and regular meals. They can withdraw or confront the stressful situation, directly targeting a mood change and shifting the focus from counseling exclusively (i.e., by broadening their focus, interests, and activities). Counselors 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 counselor should get up and replenish himself/herself by having a glass of orange juice or milk, eating, reading, talking, or writing about pressing feelings. After awhile the counselor should return to bed.

Managing time

Counselors 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 sometimes can be recast or neutralized by transforming negatives into positives. For example, if counselors 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, counselors can employ an imagery method. With imagery, a person substitutes actual experience with scenes from his/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.

Developing boundaries between personal and professional lives

It is critical that counselors maintain boundaries between their professional and home lives. Counselors should regulate the balance between their work life and personal life so that work does not consume all of their time. Some counselors 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 (i.e., the work day is ending and the personal life is beginning). These routines help counselors diffuse emotional energy from work and enter their personal lives in a relaxed manner.

CHAPTER 10

MONITORING, SUPERVISION, AND QUALITY ASSURANCE

Section 1: Definition of Key Terms

Section 2: Supervision and Support of VCT Counselors

Section 3: Practical Requirements for Supervising Counselors

Section 1: Definition of Key Terms

Monitoring

Monitoring, in the context of VCT, comprises day-to-day record-keeping, built-in system(s) of checks and balances, and reporting of daily activities to ensure each staff member is performing his or her job correctly. Monitoring is essentially an ongoing effort to track and report on activities being implemented and ensure that activities are conducted as planned. Monitoring takes place throughout the entire process of setting up and executing VCT services (i.e., through planning, assessment, design, and implementation). Different methods have been used to monitor VCT services, including: reviewing VCT service records; reporting regularly on activities; and conducting key informant interviews. These monitoring methods are carried out with “monitoring tools”—logbooks, registers, and patient management forms. The goals of monitoring in the context of VCT are to:

- Ensure that activities are being implemented as planned;
- Show how VCT service delivery systems and linkages are working;
- Serve as a preliminary indicator of behavior change.

Evaluation

Evaluation refers to structured and periodic assessment of counselors’ personal skills, a quality assurance system, assessment of clinical settings, program activities (or program components), or training activities (using pre- and post-test assessments) to determine if expected results (e.g., counselors’ skills, behavior change) are being achieved. The purpose of evaluation is to inform action and enhance decision-making.

Supervision

Counseling supervision is a working alliance between a supervisor and counselor in which the counselor gives

an account or record of his/her work, reflects on it, and receives feedback and guidance. This helps the counselor develop ethical competence, confidence, and creativity, which enhances the quality of services offered to clients. Counseling supervision is neither a privilege nor a reward; it is a necessity. It is part of a legal and ethical duty of care to protect clients, and is both supportive and educational. By tracking each counselor’s work and providing constructive feedback, supervisors play an integral role in maintaining the quality of client care. Supervision is also important in preventing burnout. Supervisors use the following tools to supervise and support counselors:

- Checklists;
- Formal and informal observation of day-to-day activities and counseling sessions, and staff-client interactions;
- Individual/peer/mentor support meetings;
- Feedback from peers and clients.

Counseling supervision provides an opportunity for counselors to:

- Explore the way they work;
- View their work with greater objectivity and gain different perspectives on clients;
- Become more aware of the way they affect and are affected by clients;
- Discharge emotions and recharge energy and ideals;
- Feel supported as professionals;
- Receive feedback and challenge the quality of their practice;
- Monitor and develop ethical decision-making.

Supervision and support help maintain staff morale and positive attitudes and ensure the environment (including supplies, client-flow logistics, etc.) is conducive to meeting

program goals. Counseling supervision also helps increase counselors' knowledge and skills, which in turn:

- Ensures that correct and complete information is conveyed to the client at the appropriate time;
- Ensures that staff members use their counseling skills appropriately and completely;
- Fosters professional development of counselors and provides an appropriate balance of support and challenge of counselors' skills.

Quality assurance

Quality assurance is a planned and systematic approach to monitoring, assessing, and improving the quality of services on a continuous basis with existing resources. "Quality of care" has different meanings to different stakeholders (e.g., counselors and clients). All quality assurance systems should encompass three perspectives on quality: clinical standards; performance management; and client satisfaction. There are usually several elements of a quality assurance system, including clinical audit, quality control of laboratory services, standards setting, and client satisfaction surveys.

Quality assurance measures/tools for VCT are designed to assess staff performance, client satisfaction, and adequacy of counseling and testing protocols. Quality assurance tools play a role in supervision and provide a mechanism for monitoring and mentor/peer/self-evaluation. Several VCT quality assurance tools and strategies have been developed and field-tested by Family Health International (FHI) and other agencies, including the UNAIDS and CDC. These tools, which can be adapted to a range of contexts and settings, address two main strategies. The first is aimed at the HIV counseling process; the second is aimed at HIV testing protocols.

Quality assurance strategies for HIV counseling include:

- High-quality counselor training (e.g., trainee selection, methodology);
- Counselor reflection form;
- Exit survey;
- Mystery clients;
- Regular individual, peer, and group supervision and monitoring sessions;
- Counselor quality assurance tools used by independent observers;

- Follow-up training, stress management, exchange visits, and formation of a counselor support network.

Quality assurance strategies for HIV testing include:

- Training and refresher training for laboratory technicians;
- Testing a percentage of samples in a reference laboratory.

Section 2: Supervision and Support of VCT Counselors

Effective supervision of VCT services requires a good working relationship between the supervisor and counselor. The counselor offers a reflective account or record of his/her work and receives feedback and/or guidance from their supervisor. The objective of this relationship is to help the counselor gain ethical competence to provide clients with the best service possible. Effective supervision simultaneously protects clients and sustains accountability and professional development of the counselor. It also helps to prevent burnout.

Supervisors can only work with the information that counselors reveal. Thus, it is essential that counselors feel free to represent their work honestly. The supervisor must be both challenging and supportive of counselors, helping them discover their individual resources. The supervisor-counselor relationship contains many elements of the counselor-client relationship, though supervision is not equivalent to counseling. For example, supervisors should help counselors become more autonomous in their choices, decisions, responsibilities, and actions. The relationship should also ensure trust, honesty, acceptance, empathy, and communication.

Counseling supervision should be formalized and contracted in regularity, roles, responsibilities, reporting, and expectations of both supervisor and supervisees. Methods to enhance the supervision process include:

- Case studies and case presentations;
- Written transcripts (verbatim) of counseling sessions;
- Audio- and videotaped sessions (with client consent);
- Direct observation of counseling sessions (with client consent);
- Role-play;
- Application of written reference materials;

Counselor Reflection Form

Counselor Code or Name:

Client Code:

Counselor Code or Name:

Client Code (optional):

Date: _____

	Yes	No	N/A
Did I conduct a client-centered session that responded to the client's needs and concerns?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I provide appropriate technical information?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did the client speak as much or more than I did?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I perform a risk assessment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I work with the client to develop a risk-reduction plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did the client understand the meaning of the test results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I assess and address the availability of the client's social support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I discuss relevant referral options with the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I discuss disclosure of test results with the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did the client determine an immediate plan of action?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did I deal with the client's and my own emotional reactions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What did I do well? _____

What could I have improved on? _____

Professional issues to follow up: _____

Models of Counseling Supervision and Support, Advantages and Disadvantages

Model	Advantages	Disadvantages
Individual supervision (can be peer or mentor based)	<ul style="list-style-type: none"> • Quality one-on-one support • Depth of intervention • Can tailor to individual needs 	<ul style="list-style-type: none"> • Requires time • Requires skilled supervisors • Has cost implications
Group supervision (group, pairs or triads, led or peer facilitated)	<ul style="list-style-type: none"> • Time efficient • Learning through shared experiences 	<ul style="list-style-type: none"> • Limited attention to individual needs • May be limited in enhancing competency
Counselor network (can be national, regional, or district based, or a counselor support group)	<ul style="list-style-type: none"> • Networking capacity • Additional opportunity to address counselors' needs and emotional well-being 	<ul style="list-style-type: none"> • Cost investment to address logistics and administration • Hard to sustain in some contexts • Requires effective leadership, endorsement, and commitment
Counselor council/association	<ul style="list-style-type: none"> • Regulation and accreditation capacity • Leadership role in promoting standards and norms for professional practice • Networking and training 	<ul style="list-style-type: none"> • Requires human resource capacity and support facilities • Requires buy-in from national bodies and constituents to be sustained
Training, mentoring, exchange visits, attachment, etc.	<ul style="list-style-type: none"> • Motivation for counselors • Exposure to new/innovative practices • Enhanced teamwork 	<ul style="list-style-type: none"> • Time, costs • Requires substantial workplace buy-in • May be "one off" versus ongoing

- Homework tasks;
- Identification of in-service skills training.

Group supervision

Group supervision is a working alliance between a supervisor and several counselors, in which each counselor regularly offers an account or record of his/her work, reflects on it, and receives feedback and guidance from the supervisor *and colleagues*. Like individual supervision, group supervision enables counselors to gain ethical competence, confidence, and creativity, which enhances the services offered to clients.

The following table summarizes the advantages and disadvantages of various models of counseling supervision and support.

Section 3: Practical Requirements for Supervising Counselors

Counselors can take steps to assist in effective supervision. They should:

- Attend periodic training to update their knowledge and skills;
- Attend monthly individual and group supervision sessions;

- Maintain client confidentiality during all discussions with supervisors by disclosing details relevant to supervisory issues only;
- Attend stress-management workshops to guard against burnout (in addition to the monthly individual and group supervision sessions);
- Attend ongoing in-service training at least once or twice a year.

Counseling supervisors should conduct periodic evaluations of their own work in the following ways:

- Allow counselors to evaluate each supervisory session, in turn;
- Include a reflection period; to discern possible patterns in counseling style over time, supervisors should retain completed “reflection forms”;
- Use reflection forms to compare counselors’ subjective evaluation with the supervisor’s quality assurance inventory;
- Encourage counselors to discuss identified problem areas in greater detail.

CHAPTER 11

ETHICS IN COUNSELING AND TESTING

Section 1: Introduction

Section 2: Ethical Code of Conduct for HIV Counselors, General Principles

Section 3: Other Ethical Considerations

Section 1: Introduction

The fundamental values of counseling are set forth in an ethical code of conduct. Counselors should understand these universal values so they can maintain a professional relationship with their clients. The values are: benefit others; do no harm; respect others' autonomy; and be just, fair, and faithful. Ethical codes educate about responsibilities, provide a basis for accountability, protect clients, and offer guidance to improve professional practice and make ethical decisions. The standards followed by counselors and clients safeguard the integrity, impartiality, and respect of both parties.

The following section outlines the main generic and universal values of an ethical code of conduct for counselors, social workers, clinical psychologists, and other helping professionals engaged in VCT for HIV. For use in a given country, this chapter should be tailored to conform to country-specific policies. It is helpful to have details of a country-specific ethical code from relevant governing bodies. Since each country might adapt these codes differently, it is important that counselors identify problems, review relevant codes, seek consultation, brainstorm, list consequences, and make decisions.

Section 2: Ethical Code of Conduct for HIV Counselors—General Principles

Competence

- Counselors are responsible for their own competence, effectiveness, conduct, and physical safety, and should avoid any compromise of the counseling profession.
- Counselors are expected to have received requisite training in counseling skills and techniques.
- Counselor performance should be monitored regularly through supervision or consultative support, and by seeking the views of clients and other counselors.

- Counselors should recognize their boundaries and limitations; they should provide only those services and use only those skills and techniques for which they are qualified through training and practice.
- Counselors should not claim to have qualifications or expertise they do not have.
- Counselors should make appropriate referrals to others with expertise they themselves do not have.
- Counselors should not make exaggerated claims about the effectiveness of HIV prevention and care interventions offered by their facility.

Consent

- Counselors must obtain their clients' consent to engage in counseling and testing.
- Unless sanctioned by legal authorities on criminal or mental health grounds, counseling is undertaken voluntarily and deliberately by counselors and clients, and should take place in a private and confidential setting.
- Counselors must explain to clients the nature of the counseling offered and any attendant contractual obligations, such as timing, duration, confidentiality, and cost/fees for services, if applicable.
- Counselors should ensure that clients understand all issues involved in VCT before giving informed consent for HIV testing.
- Counselors must obtain (or be provided with) informed consent before clients are tested for HIV.
- Counselors must recognize the rights of individuals whose ability to give valid consent to HIV testing may be diminished because of age, learning disabilities, or mental illness.
- Counselors must recognize the right of clients to withdraw their consent at any time, even after their blood has been taken for HIV testing.

- Nonconsensual HIV testing cannot be justified in any circumstances, including medical emergencies where health workers contend they must know a patient's HIV status to protect themselves. The risk of occupational transmission of HIV is extremely low, and basic precautions can eliminate it.

Confidentiality

- Counselors must maintain adequate records of their work with clients and take all reasonable steps to preserve the confidentiality of information obtained through client contact. Counselors also should protect the identity of individuals, groups, or others, unless a client gives express permission to reveal it.
- No information concerning the client, including HIV test results, should be given without the permission of the client. But "shared confidentiality" is encouraged. This term refers to confidentiality that is shared with a limited number of people (e.g., family members, loved ones, caregivers, and trusted friends). This is provided only on request and consent of the person undergoing testing.
- Counselors should be aware that, although HIV test results must be kept confidential, other professionals involved in a given case (e.g., other counselors and health workers) might need to know a person's HIV status to provide appropriate care. But even to such personnel, this information should be shared only with the permission of the person tested.
- Counselors must take all reasonable steps to communicate clearly the extent of confidentiality they are offering to clients. Normally, this should be made clear in pre-test counseling.
- Any agreement between counselor and client about confidentiality may be reviewed and changed by joint negotiation, but the counselor must work within the guidelines of the current agreement.
- Counselors must maintain confidentiality in storing and disposing of client records.
- Counselors must not disclose any information about a client to colleagues or third parties without first seeking the client's consent (except as noted below.)
- Counselors may break the confidentiality agreement only under the following circumstances:
 - › The counselor believes a client might cause serious physical harm to himself or herself, or

to another person or persons, or be harmed by another person or persons;

- › The counselor believes a client is no longer able to take responsibility for his or her decisions and actions;
- › A court has ordered disclosure of such information;
- › The person infected with HIV continues to behave in a way that presents a clear threat to identifiable individuals' lives;
- › The client requests a release of record.
- If a decision to break confidentiality is agreed to by a counselor and client, it should be done only after thorough consultation with a counseling supervisor or other experienced counselor.

A counselor's confidentiality oath specifically states that they should:

- Keep strictly confidential any identifying information about a client, unless the client gives written permission to act otherwise;
- Take reasonable steps to ensure a client's record is identifiable only to that client;
- Destroy records no longer required for services being offered;
- Ensure security of records and prevent access to them by anyone not involved in the services being offered;
- Ensure that colleagues, staff, and trainees understand and respect the need for confidentiality in the counseling services.

Personal conduct and integrity

- Counselors must conduct their counseling activities in a way that does not damage the interests of their clients or undermine public confidence in either the service or their colleagues.
- Counselors must maintain respect for clients in the counseling relationship by: not engaging in activities that seek to meet counselors' personal needs at the expense of clients; and not attempting to secure financial or other benefits, other than those contractually provided for or awarded by salary.
- Counselors should not exploit any counseling relationship for the gratification of personal desires. They must avoid sexual harassment, unfairness,

discrimination, stigmatization, and derogatory remarks.

- Counselors should refrain from counseling when their physical or psychological condition is impaired by the use of alcohol or drugs, or when their professional judgment and abilities are impaired for any other reason.
- Counselors should appear professional and presentable in dress and manner and be clearly identifiable by a badge with their name, professional position, and facility.
- Because counselors are responsible to the community, they should be aware of laws governing counseling in the community and be careful to work only within those laws.
- Counselors must promote honesty, fairness, and respect for others, and avoid improper and potentially harmful dual relationships with clients.
- Counselors should not accept clients with whom they have engaged in sexual relations or with whom they have a current personal relationship.
- Counselors should not engage in any relationship (including counseling) with a client in another service facility.
- Counselors must not engage in personal or sexual relationships with current clients (i.e., “dual relationship” (see box below).

Box 39: Some Helpful Questions about “Dual Relationships”

Will my dual relationship keep me from confronting and challenging the client?

- Will my needs for the relationship become more important than therapeutic activities?
- Can my client manage the dual relationship?
- Whose needs are being met—my client’s or my own?
- Can I **recognize** and manage professionally my attraction to clients?

Respect for human rights

- Counselors must recognize the fundamental rights, dignity, and worth of all people.

- Like any other health professionals, counselors are expected to provide services to people irrespective of race, culture, religion, values, or belief system.
- Counseling is not about forcing people to conform to certain “acceptable” standards by which they must live. Rather, it is a process in which clients are challenged to assess their own values and behaviors honestly, and decide for themselves how they might change.

Disciplinary measures

- Counselors have a responsibility to other counselors to point out wrongdoing if they observe it.
- Counselors have a responsibility to maintain high standards of professional conduct toward clients and the institution where counseling services are performed.
- All personnel involved in HIV counseling should sign an oath of confidentiality. Corrective measures should be taken upon breach of this oath. Further disciplinary actions may be taken, depending on the ethical code addressing termination of services, justification for termination, and the mechanisms for doing so.

Section 3: Other Ethical Considerations

Counselors may encounter ethical dilemmas not covered in this manual. When facing an unfamiliar situation, counselors should remain calm, use their best judgment, and use the counseling techniques they have learned. If counselors are unsure how to respond in a given situation, they should seek help according to the rules and procedures of their counseling center. Knowing when to ask for help, and being able to accept it, are essential qualities for a counselor. When a client’s problem is beyond a counselor’s capabilities, it is far more effective and useful, from the client’s point of view, for the counselor to refer the problem to an appropriate agency, rather than to attempt to solve it by himself or herself.

HIV counselors might face a number of ethical issues, including:

- Client dependence;
- Disclosure of test results to partners;
- Provision of services to minors;
- Appropriateness of gifts received or offered.

APPENDIX: NUTRITIONAL SUPPORT FOR PLHA

Much of the following information comes from a booklet on nutrition for PLHA prepared by the Mutare City Health Department in Zimbabwe.

Food and HIV/AIDS

Food can neither cure AIDS nor treat HIV, but it can improve fitness and quality of life for PLHA. Eating an adequate and balanced diet can help maintain body weight and muscle mass and improve immune function. To understand what constitutes healthy food, it is important to learn about nutrient composition. Food can be divided into four groups, according to its dominant nutrient content: carbohydrates, fats, proteins, and vitamins and minerals.

Foods rich in carbohydrates

Grains (e.g., corn, wheat, millet, sorghum, rice, barley), potatoes, sweet potatoes, cassava, yam, and legumes (beans and peas) are rich in carbohydrates (starches and sugars). Carbohydrate-rich foods provide the body with energy, and they are usually inexpensive and easy to digest.

Foods rich in fats

Oils, butter, margarine, fatty meats and poultry, fatty fishes, peanut butter, nuts, and seeds are rich in fats. Like carbohydrates, fats provide the body with energy, but they can be harder to digest than carbohydrates.

Foods rich in proteins

Meat, chicken, liver, fish, ants, caterpillars, dairy products, eggs, beans (soy and others), lentils, nuts, peanuts, peas, and seeds are all rich in proteins. Proteins, which are made up of amino acids, help build and repair the body and play an important role in immune function. Consuming animal proteins provides the range of amino acids the human

body needs; individual vegetable proteins do not. Thus, vegetable sources of protein should be varied or combined with other sources. An example of a good combination is legumes and grains.

Foods rich in vitamins and minerals

Green leafy vegetables (including cabbage, green beans and peas, tomatoes, pumpkin and other squash, carrots, and avocados) and many fruits (pear, mango, orange, guava, banana, mulberry, baobab, peach, pineapple, apple, paw-paw, plum, passion fruit, and lemon) provide the body with vitamins and minerals. There are at least 17 vitamins and 14 minerals, each with a special use in the body; the body cannot work properly if any of these are missing. Each vegetable or fruit is rich only in a few vitamins or minerals, so it is important to eat a variety (varied in color, shape, and botanical function—leaves, fruits, and roots). Generally, dark green and orange or red vegetables and fruits are best.

Balanced Diet

Good nutrition requires a balance of proteins, fats, carbohydrates, and vitamins and minerals. No single food contains every nutrient. A healthy meal is made up of at least one food item from each of the four food groups.

Food Safety

It is important to avoid ingesting food-borne bacteria and parasites, especially because PLHA are 20 times more likely to contract illnesses from these pathogens than are people without HIV. Comprehensive care programs should encourage food safety and, when possible, offer guidelines for action. Following are guidelines for safe food handling (adapted from Food for People with HIV/AIDS)

Balanced Eating

Examples of what healthy foods provide		
Carbohydrates (energy)	Protein, fats	Vitamins, minerals
Maize (corn) Bread Sweet potato Rice	Milk Eggs Meats Beans Peanut butter	Mango Oranges Paw-paw Pumpkin Green leafy vegetables
Examples of incomplete meals	Incomplete because	To improve the meal
Bread and jam Chips and chicken	Energy only Mostly protein and fats	Add tea with milk; mash fresh fruits on bread Add vegetables and/or fruits

Guidelines for safe food handling

General:

- Always wash hands with soap and water before and after touching food.
- Keep hot foods hot and cold foods cold.
- Do not eat food after the “best before” date has passed.
- Be especially careful with leftovers; do not eat them unless they were refrigerated immediately after initial serving.
- Store cooked foods for no more than a day, and boil them or heat thoroughly before eating.

Animal products:

- Cook all animal products (e.g., meat, fish, eggs) at high temperature until well done. Cooking destroys harmful bacteria. Do not eat soft-boiled eggs.
- Use only plastic or Formica cutting boards when cutting raw or cooked animal products. Wooden cutting boards cannot be cleaned adequately.
- Wash utensils and surfaces where animal products have been before handling other foods.
- Put meat, poultry, and fish into plastic bags before placing them in your shopping basket. Put them at the bottom of the basket so they will not drip onto other foods.

Fruits and vegetables:

- Thoroughly wash fruits and vegetables that are to be eaten raw to remove bacteria from the skin. Cut off bruised parts. If washing is not possible, peel skin.

Food and Diarrhea in People Living with HIV/AIDS

PLHA, especially those who are in advanced stages of HIV/AIDS, often experience diarrhea. The main causes are infection (viral or bacterial), poor nutrition, and malabsorption (improper absorption of food in the digestive tract). Proper nutrition can play an important role in both minimizing the causes of diarrhea and treating it.

Selecting foods carefully and following the foregoing guidelines for food handling can reduce the risk of infection-related and malabsorption-related diarrhea significantly.

If diarrhea does occur, practical steps can be taken to prevent dehydration (the biggest danger of severe diarrhea) and/or malnutrition (the biggest danger of long-

lasting diarrhea). Counselors should provide the following guidelines to clients with HIV/AIDS:

- Drink lots of fluids (non-alcoholic) to prevent dehydration.
- Eat soft, mashed, liquid foods that are easy to eat and swallow, such as porridge and soup.
- Eat small meals five or more times a day.
- Eat food low in fat. Do not add cooking oil and margarine. Boil food rather than fry it. Cut away visible fat in meat and skin on chicken.
- Eat food high in carbohydrates to provide energy (e.g., rice, potatoes, maize, bread).
- Eat soft fruits and vegetables, such as banana, paw-paw, watermelon, pumpkin, squash, and potatoes.
- Avoid milk and milk products.
- Avoid acidic fruits and vegetables, including onions, tomatoes, and pineapple. Do not use “hot” spices like curry or piri-piri.
- Prepare vegetable soups and stews using a refined meal of rice, barley, or potatoes and soft vegetables such as squash, pumpkin, or carrot.
- Be creative in preparing soups and meals, starting with food you like.
- Prepare fresh food from fresh ingredients. Do not store prepared food and risk food poisoning.

Nutritional Supplements

When there is insufficient caloric or protein intake (difficulty maintaining or gaining weight), nutritional supplements may be used. These may include blended food products, commercial formulas, intravenous solutions, vitamins, and micronutrients.

Recent studies examining the relationship between micronutrient status and HIV progression suggest that vitamins A, B-complex, C, E, and niacin, and the mineral selenium, may be helpful in replenishing absent nutrients in PLHA. The role of other micronutrients, such as iron and zinc, and of vitamin A and other antioxidants, appears to be more complex; in fact, high intake of these may be harmful. Although some studies support micronutrient supplementation, there are still no specific guidelines or policies in most settings concerning them. Until such a time, multivitamin and mineral supplements are recommended only if an individual is unable to obtain an adequate balance of nutrients through diet.

Summary

Depending on client volume at the counseling center, a counselor may not always have time to discuss nutrition in detail. In such cases, the counselor must at least provide the information below, along with an appropriate referral.

Box 40: Nutrition, the “Take-Home Message”

Food is not a cure, but can be used as “co-therapy.” Stay as healthy as possible by developing healthy eating habits.

The golden rules for this are:

- Eat whole (unrefined) foods.
- Eat natural (unprocessed) foods.
- Eat indigenous (not imported) and in-season foods.
- Drink clean water; boil for 10 minutes or filter it.
- Eat small but frequent meals—five or more daily.

What to eat:

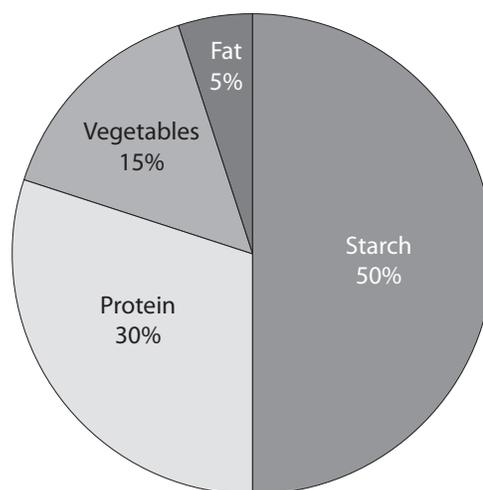
- 50 percent whole grains;
- 30 percent vegetables;
- 15 percent proteins;
- 5 percent other (e.g., fruits and dairy products).

Foods to avoid:

Avoid sugar and all foods containing sugar; fats, especially in the presence of diarrhea; strong tea or coffee; alcohol and tobacco; and tinned, processed, and/or refined foods.

Seek professional help for nutritional questions and/or persistent diarrhea.

Box 41: Balanced food plate for HIV-positive individual



Source: Marlou Bijlsma, *Nutrition guide for people with HIV*, Mutare City Health Department, Zimbabwe

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