

***HIV Voluntary Counselling and testing (VCT)
Guidelines for Pakistan***

National Guidelines

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Preface

HIV/AIDS has emerged as the most important new threat to world health during the last century. Few crises have affected human health and threatened national, social and economic progress in quite the way that HIV/AIDS has. The pandemic has had a devastating multi-faceted impact on lives of people living around the globe.

Voluntary Counseling and Testing (VCT) is a cornerstone for early access to both prevention and care & support services in the area of HIV/AIDS. It is a critical component of a comprehensive response to HIV/AIDS epidemic. VCT programs need to be advocated and implemented on an increasing rate as they play an essentially constructive role in addressing a range of problems and complications, faced by the community at micro and macro levels, caused by the disease at its various stages. Majority of people living with HIV/AIDS are unaware of their HIV status. High public awareness of HIV and knowledge of personal risk behaviors results in an increased level of caution and care. The protected can be empowered to remain disease-free and the infected can be given access to medical and other support services that can help them to live longer, healthier lives and prevent transmission to others.

In a world marching towards the target of achieving harmonized human rights practices it is essential to ensure the dignity and security of HIV/AIDS-affected individuals and households. Providing VCT services and support for people living with HIV/AIDS is an important part of caring at all stages of the disease.

The National AIDS Control Programme (NACP) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) jointly developed “The National Guidelines on Counselling for HIV/AIDS” in 2001. However, the need for comprehensive VCT guidelines was prompted by the decision makers and practitioners in order to attend to the more complicated behavioral, psychological and social threats and challenges associated with the disease. The development of these guidelines was also viewed as a factor complementing the initiative of establishing VCT centers nationwide under the National Response, including the Enhanced HIV/AIDS Control Programme and the Global Fund to Fight Against AIDS, Tuberculosis and Malaria.

Recognizing the sensitivity and importance of the subject, NACP and UNAIDS have again taken this responsibility with a deep and abiding belief that this matter needs attention enduring maximum possible consideration with full objectivity. It is with this responsibility firmly in mind that “*The National Guidelines on HIV/AIDS Voluntary Counselling and Testing*” are now published. These guidelines complement 2001 guidelines and contain more specific recommendations for public and private sector policy makers and service providers of VCT to the general population and the high-risk groups.

A middle path has been steered while developing these guidelines, avoiding both over-simplified description with insufficient details as well as too complex and detailed

account of the subject. With topics surrounded by controversy and debate, the currently accepted views have been drawn delicately.

Recognizing that the groups of persons living with HIV/AIDS (PLWHAs), nongovernmental organizations (NGOs) and community based organizations (CBOs) have been at the forefront of prevention and care since the world first became aware of the epidemic two decades ago, these guidelines aim to widen their participation even further by providing them local solutions that emphasize using local resources of domestic and clinical care and support and a useful collection of information and user-friendly tools. It is hoped that these guidelines will encourage groups already involved in HIV/AIDS care to extend the services they are already providing, and that it will encourage involvement by other social service groups at large.

It is profoundly hoped that these guidelines will greatly assist the users in the very intricate area of HIV/AIDS where both the fields of medicine and that of information are changing constantly. These guidelines have been designed keeping the element of change in mind and expecting that these will accommodate any practical changes identified by the users. Published as a draft presently, these guidelines would be adapted after being reviewed and revised practically during one-year of field implementation, based on the experiences, suggestions and recommendations obtained from the practitioners. It is expected that the local service providers, NGOs and other concerned entities will find this document useful in their efforts to provide effective and innovative care and support to people living with HIV/AIDS.

We share our sincere encouragement and best wishes with all those who will be utilizing these guidelines for providing VCT services.

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The diverse efforts dedicated by the former staff of UNAIDS Pakistan office to facilitate the groundwork for developing these guidelines are incomparable. Appreciation is expressed for the useful contributions made by the participants of workshops who generously shared their time and their significant inputs towards development of these guidelines. Their ideas and suggestions have indeed contributed so much to this document.

Introduction

These guidelines aim to demonstrate the way to carry out effective VCT sessions in Pakistan, according to local needs and resources. These guidelines identify procedures to enable appropriate, confidential, and ethical counselling to all those who need them. These guidelines also outline a strategy for referral of individuals who need ongoing services or other related services. Most of the VCT centres in the country may have limited resources and may have limited potential, but these guidelines can provide a framework, which helps to achieve the main objectives of VCT. These guidelines advise the use of whatever structural elements are available, while at the same time working towards a full and supportable system of VCT.

These guidelines are designed primarily for those who are actually involved or would be involved in offering VCT services in the country: VCT counsellors and their immediate supervisors. However, they can be quite useful for all those who are involved in VCT services at policy, planning, implementing, monitoring and evaluation levels. The chapter on monitoring and evaluation is specifically designed for those who are involved in the evaluation and quality control of VCT services. To make these guidelines useful for non-medical professionals as well, the use of medical terminology has been kept at a minimum. A glossary of medical terminology has been added in the annexes.

Part I
Voluntary Counselling and Testing (VCT):
An Understanding

Voluntary Counselling and Testing (VCT): An Understanding

1.1. VCT: Introduction

VCT has become the most important cost-effective tool to prevent and control HIV/AIDS in the country. It motivates people to adopt safe sexual behaviour and safe injecting practices. It encourages people with high-risk behaviour to know their HIV status, thus helping to break the chain of transmission of the infection. VCT is also a key entry point to care and support services for people living with HIV/AIDS (PLWHA). These include access to interventions to reduce mother-to-child transmission (MTCT) of HIV; interventions to prevent opportunistic infections (e.g. tuberculosis preventive therapy and prophylaxis for other infections); as well as other medical and supportive services that can help HIV positive people to live longer and healthier lives. VCT enables PLWHA to better plan for their and their dependents' future. It helps lessen the stigma attached to the disease and the discrimination they have to face in the community. In general, VCT offers a holistic approach and addresses HIV in the broader context of people's lives, including the context of poverty and its relationship with risky practices.^{1 2 3}

1.1.1. Objectives of Voluntary counselling and testing (VCT)

Voluntary counselling and testing (VCT) is a dialogue between a counsellor and a client to achieve the following:⁴

- To provide the client with information on the HIV test, its benefits and the risks involved. The aim is to have the informed consent of the client before the test,⁵ and to help the client gain a better understanding of the test results.
- To provide the client with background information on HIV/AIDS infection, modes of transmission, preventive methods, treatment and care. To assess the risk of HIV infection in the client.
- To encourage and maintain a safe behaviour to avoid future infection and/or to prevent the further spread of HIV (e.g. through safe sex and changing drug injecting practices).
- To help the client to handle possible emotional reactions related to the HIV test results (e.g. grief, anger, fear and denial).
- To discuss courses of action adapted to each client, his family needs and circumstances.

¹ *HIV Voluntary Counselling and Testing: a gateway to prevention and care*. UNAIDS best practice collection. UNAIDS, 2002b.

² *Technical Consultation on Voluntary HIV Counselling and testing: Models for implementation and strategies for scaling of VCT services*. WHO/UNAIDS, 2001.

³ *Guidelines for counselling about HIV infection and disease*. WHO AIDS Series 8. WHO, 1990.

⁴ *HIV Voluntary Counselling and Testing: a gateway to prevention and care*. UNAIDS best practice collection. UNAIDS, 2002b.

⁵ In **Annex II** is found the *HIV Antibody Consent Form* that has to be filled as proof of informed consent.

VCT must always aim at helping clients take responsibility for their own health and the health of others.

These aims of VCT are quite achievable. However, to be successful, a sensitive, trusting and respectful relationship between the counsellor and the client needs to be formed. Further, a structured approach is necessary to ensure that the client has adequate information for problem solving and decision-making during pre- and post-test counselling.

1.1.2. Characteristics of a good VCT counsellor

VCT service is easy to learn and professionally quite rewarding. After appropriate training, any motivated doctor, nurse, community health worker, social worker, religious leader, teacher, peer leader, PLWHA, commercial sex worker or former drug user can become a VCT counsellor. VCT services are quite challenging, and therefore VCT counsellors may require continuous training, supervision and feedback to keep updating their skills and improving their services.

A counsellor must have the following qualities to conduct effective VCT sessions:

- Ability to keep counselling on the emotional and intellectual level of the client
- Capacity to create an atmosphere where the client feels safe, and to establish a supportive, non-judgmental relationship.
- Confidence to feel at ease in discussing intimate topics usually avoided in ordinary social life or during medical consultations.
- Skill to help clients talk about sensitive topics.
- Skill to focus the discussion on risk practices and behaviours.
- Understanding how one's own beliefs, feelings, attitudes and prejudices can negatively affect the counselling relationship.

It is very important for a counsellor to examine his own cultural beliefs and values, and to assess whether he is likely to be supportive of or opposed to the people he will counsel. This can be done individually, or in peer support groups where feelings and attitudes can be discussed. If cultural norms and traditions are in conflict, the counsellor must question whether he is able to rise above them in order to help his clients. For example, the counsellor should question:

- Can I openly discuss issues of heterosexuality, homosexuality, and bisexuality?
- Can I counsel a commercial sex worker without prejudice?
- Can I discuss and demonstrate condom use?
- Can I counsel transvestites and other transsexual people?
- Can I counsel injecting drug users?

In order to examine their own suitability of being a VCT counsellor, counsellors should ask themselves also the following questions:

- What are my own feelings about people with HIV/AIDS?
- What are my feelings about people whose behaviour has placed others (or themselves) at risk of infection?
- Are there kinds of people or types of behaviour, which I disapprove of so strongly that I probably could not counsel them non-judgmentally?
- Am I trying to impose my own values on my clients? How much do I want to influence and control them?
- To what extent am I willing to let clients do what they decide to do and let them take responsibility of their own lives?

In some circumstances, a counsellor may have to enquire about taboos or unusual sexual practices. He may need to explore the carefully hidden behaviour of his client. Sometimes it is necessary for a counsellor to use local or slang expressions. To be prepared, it is very important for a counsellor to learn the following about himself:

- Which sexual practices will it be most difficult to talk about, and how to overcome the difficulty?
- What everyday words will clients use, or avoid using, when explaining risk practices or behaviours? Is he prepared to use them to make the clients feel more at ease?
- How will he approach counselling clients who differ from him culturally, sexually, or in age?
- How will he explain the need to discuss intimate or taboo subjects?

Behaviour and attitudes are shaped by tradition and social background. The counsellor must respect the cultural diversity that exists within a locality, a group or a region.

If a serious conflict arises, the counsellor should not work in VCT services.

1.1.3. Characteristics of a good VCT session

Client satisfaction and consequent positive changes in behaviour are the two major outcomes that can be expected from a successful VCT session. A good VCT session can have the following characteristics: ⁶

Confidentiality

Trust is one of the most important factors in the relationship between a counsellor and a client. It improves the working relationship and increases the likelihood that the client will act on the information provided. Given the strong possibility of discrimination against a person diagnosed to have HIV, it is extremely important that confidentiality be guaranteed. The counselling relationship must be built on the understanding that discussed matters will remain a private issue until the client decides otherwise. At the

⁶ *Guidelines for counselling about HIV infection and disease.* WHO AIDS Series 8. WHO, 1990.

beginning of counselling the client should be clearly briefed about measures taken to keep his status or any linked information secret.

Time

Providing the client with time is important. Time is also necessary for the development of understanding and trust, both of which are indispensable. Some people may require a number of counselling sessions before they start to acknowledge the need to modify their behaviour and to make difficult decisions concerning their life.

Acceptance

People – irrespective of their lifestyle, sexual preferences, and socio-economic, ethnic or religious background – should feel fully accepted by the counsellor. The response to their needs should be both technically sound and sensitive to their personal circumstances, and preferably not influenced by the counsellor's own feelings. The counsellor must have self-awareness and not be judgmental during a VCT session.

Accessibility

VCT services must be easily accessible. They must be based in health or other premises that are easy to get to in terms of physical accessibility and easy to use. People who need VCT should feel that they can ask for a meeting when need arises. This means that the counsellor should be available on a regular basis. It may also mean having to call on other helpers who, with some basic training, can provide additional counselling support. On the other hand, excessive dependency on the counsellor is not always advisable.

<p><i>The location and opening hours of the VCT service should reflect the needs of the particular community.</i></p>

Consistency and accuracy

Any information provided through counselling and HIV voluntary testing should be consistent. The counsellor therefore needs to have a clear understanding of the facts concerning HIV tests, infection and disease, and maintain close and confidential links with the other health workers who provide care to the client. All counsellors should have access to up-to-date information about HIV infection and its management, so that questions from clients can be answered as accurately as possible. Any uncertainties in knowledge should be acknowledged so that new information can be introduced in a consistent framework.

Sensitivity and tact

Although it is essential to raise issues related to sexuality and drug use, especially during pre-test sessions, such discussions should be sensitive to the client's concerns. These delicate topics should be used to help the client explore emotional issues, solve important concerns, and make healthy decisions.

The following features are essential to all counselling activities:

- *Acceptance of the client and respect for his specific concerns.*
- *Maintenance of client confidentiality at all times and in all settings.*
- *Accessible counsellors and facilities when needed.*
- *Provision of consistent and accurate information to the clients.*
- *Enough time for counselling.*

1.1.4. Clients of VCT services

VCT services should be available to the following people:

- People who want to know their HIV status, including the relatives of PLWHA.
- Patients who are referred by their physicians for clinical diagnosis.
- Blood and body organ donors.
- People who need a HIV test for visa, insurance or other purposes.

Who needs HIV testing?

Not everybody needs to be tested for HIV. HIV testing can be considered, if a person who asks the following questions from himself answers yes to one or more?

Have you ever had unsafe sex outside a marital relationship?

Have you or your regular sexual partner ever had a sexually transmitted infection?

Have you ever received an unscreened blood transfusion?

Have you ever injected illegal drugs?

Have you ever been injured with a needle contaminated with HIV infected blood?

1.1.5. VCT sites

VCT services can be offered at any place that is accessible and that ensures the confidentiality of the clients. The following settings can be appropriate places for offering VCT services:⁷

- Freestanding sites.
- Sites integrated into primary health care services (ANC, MCH, TB, STI, RH, primary health care settings).
- Sites integrated into hospital-based governmental services (clinics and hospitals).
- Sites integrated into hospital-based non-governmental services (clinics and hospitals).
- Workplace clinics.
- School health services.
- Blood transfusion services.

⁷ *Technical Consultation on Voluntary HIV Counselling and testing: Models for implementation and strategies for scaling of VCT services.* WHO/UNAIDS, 2001.

*The existence of good VCT services is directly related to the existence of a good referral system. A referral system should be developed in consultation with NGOs, community based organizations, hospital managements, as well as with networks of PLWHA. An efficient referral system will enable VCT centres to refer clients requiring medical care to hospitals and clinics. VCT centres should also refer clients for ongoing HIV/AIDS counselling, food and nutrition guidance, home care, and social support.*⁸

1.1.6. The basic physical requirements for a VCT centre

It is generally recommended that a VCT centre should have at least the following facilities and resources:

- A well functioning laboratory.
- A separate room for counselling.
- A waiting area.
- A trained laboratory technician.
- A trained counsellor.
- Good infection control and waste disposal practices.

1.1.7. Characteristics of an ideal VCT centre

Counsellors:

- Must be trained on National VCT guidelines, have good know-how of VCT services and be motivated.
- Must be accessible, available and reliable to their respective clients.
- Should have knowledge of psychosomatic and hypochondriac issues.
- Must have basic communication skills.
- Should be intelligent, and with an empathic character.
- Both male and female counsellors should exist at each VCT centre.

VCT sites:

- Must be easily accessible to target clients.
- Must ensure privacy and confidentiality.
- Must have a reliable HIV testing facility.

VCT sessions:

- Must be well organized and structured, and appropriate checklists should be used.
- Must be flexible in order to meet the requirements of individual clients
- Must have a goal-based strategy for each session.

⁸ *Counselling and HIV/AIDS*. UNAIDS technical update. UNAIDS best practice collection. UNAIDS, 1997a.

VCT services:

- Should meet the needs of each specific group of clients, such as personalized interactive counselling for injecting drug users, and group counselling for the families of PLWHA.
- Preferably should have support services available, such as condoms and free syringes.
- Must have an appropriate and effective referral system.

Monitoring and evaluation:

- There should be regular training and continuous education programmes for the counsellors.
- There should be regular supervision of counselling sessions.
- There should be periodic evaluations of: counsellors; training; support; quality and content of counselling; physical space; client flow; and client satisfaction.

1.2. Basic communication skills of a VCT counsellor

1.2.1. Understanding the client's emotions

Understanding the clients' emotions is fundamental in meeting their psychological needs, and thus helping them in coping with their situation. Clients may express one of the following emotions when they either suspect or are diagnosed with HIV/AIDS.^{9 10}

Fear of having HIV/AIDS

Clients are anxious and under considerable stress when they suspect that they have HIV/AIDS or are referred for that reason. Before diagnosis it is the uncertainty of the disease, and after diagnosis it is the uncertainty of life that kills most patients. The clients should be let explore their fear, openly and frankly. Active listening and empathizing often relieve the anxiety to a considerable extent.

Shock

Shock is the most common response to diagnosis of HIV/AIDS. Clients can express it through:

- Numbness, silence, disbelief or being stunned.
- Confusion, distractibility or uncertainty about present and future circumstances.
- Despair.
- Emotional instability (e.g. moving quickly and unpredictably from tears to laughter and vice versa).
- Withdrawal, distancing themselves from present issues and circumstances, reluctance of becoming involved in conversation, counselling, or activities and plans for treatment or for the future.

⁹ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

¹⁰ *Guidelines for counselling about HIV infection and disease*. WHO AIDS Series 8. WHO, 1990.

Shock is a normal response to hearing the news of a life threatening illness. Discuss the shock-related feelings of the client. As these feelings are aired, it is more likely that the effects of shock will diminish.

Denial

Denial of the disease is also quite common among people living with HIV/AIDS, particularly in the initial phase of their illness. It commonly occurs among Pakistanis who have been tested without counselling and informed consent, such as overseas workers who have been deported after a positive result. This is one of the reasons that VCT is being recommended for HIV testing. While initial denial can reduce stress, if it persists, it can prevent the appropriate changes in behaviour and adjustments in life, which are necessary to cope with HIV and to prevent transmission. If denial is not challenged, people may not accept the social responsibilities that go with being infected.

Guilt

In Pakistan, most of the PLWHAs pass through shock and denial into the stage of guilt. The feeling of guilt grows deeper if also loved ones are infected with the virus. A counsellor must help the client fully explore the feelings of guilt. If these feelings are not examined in depth, there is a tendency for them to magnify as the illness progresses. One way of exploring guilt is to ask, "Many people feel guilty when they realize they are HIV-infected, is this something you are feeling?" In this way, the subject can be approached, but the client is given the opportunity to explore this feeling by himself. A supportive and sensitive counsellor can help the client make the choice towards responsible behaviour and a positive attitude towards life. During this state, clients are more responsive to partner notification and couple counselling.

Depression

Sometimes clients, following diagnosis, become depressive. Depression often results in a feeling of powerlessness and usually arises from the realization that the disease is lifelong and that healing is not yet possible. Knowing others, who have died from AIDS, can also be depressing. Depression can manifest itself in different ways. The person may become:

- Quiet or withdrawn.
- Angry or irritable.
- Lethargic, insomniac or constipated.

The client may also verbalize his feelings of depression. If the counsellor suspects that the client is depressed, it is important to share the suspicion with the client so that his feelings can be fully explored. As the feelings of depression are verbalized, they become more accessible to the client, helping him to cope and to manage his feelings.

Acceptance

Most of the clients, after passing through the different emotional states, reach the stage of acceptance. Counselling quite effectively helps clients accept their situation at an early

stage. Once clients accept that they have HIV/AIDS, they often find themselves with more energy and a new will to live their lives to the fullest. This can bring about a sense of peace.

1.2.2. Learning effective communication

Counsellors need to communicate effectively in order to explore the clients' issues and concerns. Following are the principles of effective communication that can improve counselling skills, but regular practice and feedback is required to master them.¹¹

Active listening

The counsellor has to listen actively what the client is saying with words, expressions and gestures. Such skills as nodding and reflecting back what the client has said are important.

Encouraging

Some people do not express their feelings openly, even though they may feel them deeply. The counsellor should encourage the expression of feelings. It is only when people work through their feelings that they can begin constructive change. Words like "Yes, please continue" can be very encouraging.

Recognizing

The counsellor should be skilled in recognizing and distinguishing various emotions the client is experiencing. Statements such as "that must be very difficult to accept" demonstrate the counsellor's ability to recognize particularly difficult issues.

Acknowledging

The counsellor should acknowledge feelings such as anger, sadness and fear in a direct, unemotional way. Statements such as "I understand that this is not easy for you" are helpful.

Effective questioning

Questions are very critical in counselling. Only through an honest and open dialogue can the counsellor elicit information about risk, check the understanding or misunderstanding of facts, and assist the client in deciding about his course of action. Such questions might address relationships, the type of sexual practices the client engages in, and the client's knowledge about HIV/AIDS, including the modes of transmission.

Counsellors use questions to help clients express their feelings and problems. These questions should be open-ended, aimed at promoting further exploration. Therefore, closed questions that require only a "yes" or "no" as an answer rarely are helpful. Open questions also enable the client to give a variety of answers. "Please tell me what you

¹¹ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

know about...?” or “How do you think your wife will respond to this information?” are exploratory open-ended questions.

Empathizing

Empathy is more than sympathy; it involves trying to place oneself in another person’s situation. This is a difficult skill to fully master as it requires that the counsellor suspends his own feelings and judgments and enters the experiences of the client. The counsellor does not lose himself in the process, but places himself into the “shoes” of another, and reflects on the client’s experience, emotions, and concerns. A statement such as “I can see you are feeling very anxious about...” is an effective empathic response. The response captures the feeling of the client while being specific about the reason the feeling has occurred.

Responding

The counsellor should respect the client’s views and beliefs. This respect can be shown by asking the client to explain unfamiliar aspects of his beliefs and values. These beliefs and values might be cultural, traditional, or based on personal experience. Statements such as, “I am not familiar with this, can you tell me more?” are helpful. Another way of showing respect is to listen attentively and paraphrase what was said.

Clarifying

The counsellor can clarify what the client has said by repeating the question in his answer. For example, he can answer, “No, HIV is not transmitted by touching the infected person”. The counsellor can also clarify the client’s question with a second question. For example, he can say “Do you mean...?”, and then give factual information.

Paraphrasing

Clients can tell that they are being understood if the counsellor repeats what the client has said, using his own words with statements like, “So you are saying that you are pregnant and want to continue pregnancy“. In this way, the client can either agree with the paraphrase, or clarify his/her statement.

Challenging

The counsellor should confront the client if he/she appears to be avoiding important issues or when the client has not followed an agreed action plan. An effective challenge might be, “Last week you said that you were going to talk to your wife about your illness, what has got in the way of you doing this?”

Repeating

At times of stress and crisis people may not understand everything they are told because they are in a state of denial or feel overwhelmed. The counsellor should not hesitate to repeat important information. In fact, most people need to be told more than once, in order for certain information to be fully understood and retained.

Emphasizing

Often people avoid focusing on the real problem. The counsellor should highlight the most critical issues. For example “Of all the things we have covered today, the point that stands out for me is...” or, “Can I just emphasize the following points?” In this way, the client has an opportunity to focus on some important issues that have been raised during the counselling session.

Structuring

Structuring determines which problems or issues need immediate attention, and which can be postponed to a later session. Planning is essential and helps to structure the ongoing counselling process. However, it is important to note that the structure of one session might not be appropriate for another. Structuring provides the counsellor and the client with a sense of progress. Such statements as, “There are three main issues we are facing” help focus and structure the sessions.

Motivating

The counsellor should try to motivate the client by offering positive encouragement for a new behaviour. For example, the counsellor might explain how the changed behaviour will help protect the client’s loved ones. This may be a critical source of motivation. Another source of motivation is to explore what might happen if the client does not change his risk-behaviour. Anticipating potential problems can be another source of motivation. For example, “What do you think might happen if you continue to have sex with commercial sex workers?”

Summarizing

This is very much like paraphrasing in that it helps to ensure that the client and the counsellor understand each other correctly. Either the client or the counsellor can do the summarizing. At the end of the session, it might be important to summarize the important points that have been covered during the session. Such statements as, “To summarize, these are the issues...” help focus and highlight the major issues of the counselling session.

1.2.3. Being conscious of common errors

Followings are the most common errors that affect the quality of counselling and voluntary HIV testing, and that counsellors must avoid.¹²

Controlling the session rather than encouraging the client’s spontaneous expression of feelings and needs.

Judging, by showing non-verbal disapproval, or by making statements that indicate that the client does not meet the counsellor’s standards.

¹² *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

Moralizing, preaching, and patronizing the client, by telling people how they ought to behave or lead their lives.

Labelling, rather than trying to find out the person's motivation, fears, and anxieties.

Unwanted reassuring, trying to induce undue optimism by making light of the client's version of the problem.

Not accepting the client's feelings, saying he should feel differently.

Advising before the client has enough information or enough time to arrive at a personal solution.

Interrogating, using questions in an accusatory way. "Why"-questions often sound accusatory.

Encouraging dependence, increasing the client's need for the counsellor's continuing presence and guidance.

Persuading the client to accept new behaviour by flattery or deceit.

1.2.4. Case studies

Case study 1

An eighteen-year-old national junior hockey player donated blood to his friend. His blood was routinely tested for HIV/AIDS, without offering any pre-test counselling. Some time later he overheard that his blood could not be used for transfusions as it was HIV-infected. Shocked and embarrassed, he immediately started thinking how to end his life that he thought had become meaningless. He told one of his friends that he had donated blood and how he had heard of his HIV infection. He expressed his desire to commit suicide and begged the friend to help him. His friend promised help provided he would agree to consult another doctor to confirm the diagnosis. The two boys visited one of the VCT centres in Karachi, and there it was discovered that the player did not have HIV/AIDS and that the earlier result had been a false positive result.

Case study 2

A 52-year-old Pakistani driver was deported from a Middle Eastern country on account of having “bad blood” at the time of the renewal of his working visa. The driver, who was in financial disagreement with his employer, accused the employer of arranging his deportation. He came to Pakistan, resumed a normal relationship with his wife, and started working. After some years he started losing weight and having a persistent fever. He consulted several doctors, but in vain. Only some time later he recalled that he had been diagnosed with “bad blood” and told a doctor the story of his deportation. The doctor immediately referred him to diagnostic centre where he was diagnosed to have HIV/AIDS. Later, his wife and one of his children were also found to be HIV-infected. During post-test counselling the patient realized how he could have saved his wife and child from the disease if he had been properly counselled about the disease when he was first diagnosed.

Case study 3

An entertainer, who had lived in the West for a long time, and who was aware of HIV/AIDS and its modes of transmission, realized that he was engaged in high-risk behaviour. He went to a laboratory to know his HIV status, but was afraid of the possible consequences. Even after several sessions of pre-test counselling he was hesitant about taking the test. Only after starting to lose weight, which further strengthened his fear of having the disease, he accepted to take the HIV test at one of the counselling centres. Soon the result proved his worse fears to be true, but relieved him of the anxiety of uncertainty. He continued his post-test and follow-up counselling, and within weeks his appetite was back to normal and after some time his weight as well. Since the diagnosis, eight years have passed and he is leading a very active and competitive life. He often says that the fear of the disease is worse than the disease itself. He believes that confidential counselling can have an effect that no pills can offer.

Part II
Stages and Processes of VCT

Stages and Processes of VCT

2.1. Successful VCT

Once a person decides to be tested for HIV infection, all necessary arrangements should be made for pre- and post-test counselling.

An effective and successful VCT begins with the introduction of the counsellor to the client, followed by HIV infection risk assessment during pre-test counselling, and the reporting of the results during post-test counselling. VCT culminates in the development of an appropriate intervention strategy to improve the quality of life of the client and to prevent further transmission of HIV in the country. The content and approaches may vary depending on the type of counselling (pre- or post-test counselling, counselling of young people, IDUs, CSWs, etc.), and depending on the specific needs of each client (e.g. prevention of mother-to-child transmission in case of pregnant mothers).¹³

Guidelines for the counsellor for a successful VCT session:

Introduction:

- *Greet the patient*
- *Introduce yourself*
- *Emphasise confidentiality*
- *Emphasise anonymity*
- *Explain the counselling procedure*

Assessment:

- *Ask the client about his concerns*
- *Ask the client about his knowledge of the disease, and its risks*
- *Ask the client about possible risk behaviour*
- *Ask the client about possible support*
- *Ask the client about his possible reaction to the result*

Intervention:

- *Identify first and later priorities*
- *Identify options for the immediate management of test results*
- *Emphasise prevention*
- *Identify other appropriate support*
- *Encourage the client to take charge*

Summary:

- *Summarise what has happened and what still needs to be done*
- *Check that the client has understood the topics discussed*

¹³ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

2.1.1. Introduction

- First greet the client and shake hands if you and the client are of the same sex. Keep a welcoming smile on your face and request the client to take a seat. Exchanging pleasantries, like “How is the weather?” or “Did you have any problems in getting here?” often lighten the atmosphere and help the client to relax. Clients usually take this exchange of pleasantries as a sign of respect and acceptance, but some clients could take this as a sign of the counsellor not taking the situation seriously enough.
- Introduce yourself if the client is visiting you for the first time. Tell also that you offer counselling and testing services for HIV infection. A simple, open-ended question, such as “What brings you here?” or “How can I help you?” shows you are ready to listen.
- Reassure your client that he has come to the right place, that all discussions are strictly confidential, and that nothing will be revealed to any unconcerned person without the client’s permission.
- Ask the client whether he would like to tell his name and/or what he would like to be called during the session. Offer the client the possibility of using a fake name, both for session and documentation purposes.
- Explain the counselling procedure.

2.1.2. Assessment

Not everyone needs to take an HIV test. People, who do not have any risk factors for HIV/AIDS, may still come to a VCT centre for a test. Asking open-ended questions can help identify risk factors for HIV infection and discern who actually needs testing. There are three things that it is important to talk about with each person: sexual history, drug use, and whether or not the person has ever had a blood transfusion.

Encourage your client to speak. Let the client unburden himself, and listen actively in order to acquire the following information:

- What is the client concerned about?
- What does he know about the disease?
- Does the client have any misperceptions about the disease?
- What is his mental state and ability to cope with the situation in case the result is positive?
- Is the client familiar with the risks of the disease?

To assess the possibility of the client having HIV/AIDS, consider the following points:

- What is the frequency and type of sexual practices, and in particular high-risk practices, such as vaginal, anal and oral intercourse without a condom, or unprotected sex with commercial sex workers?

- Does the client belong to a group with a higher prevalence for HIV infections (e.g. IDUs, CSWs, prisoners, refugees, migrant workers, long distance truck drivers, homosexuals, and bisexual men)?
- Has the client received un-screened blood transfusion, organ transplants, blood or blood products?
- Has the client been exposed to non-sterile invasive procedures such as tattooing and scarification?

The following questions should be asked when assessing the need for HIV testing:

- Why is the test being requested?
- Does the client engage in risky behaviour (drug use, unsafe sex)?
- Does the client have symptoms that concern him?
- What does the client know about the test and its purpose?
- Has the client considered what to do, and how he might react, in case the result is positive? In case the result is negative?
- What are the person's beliefs and knowledge about HIV transmission and its relationship to high-risk behaviour?
- Who could provide the client with emotional and social support (e.g. family, friends, etc.)?
- Has the person sought VCT before, if so, when, from whom, for what reason and what was the result?

2.1.3. Intervention

Once you have developed a rapport with the client, and learned about his major concerns, work together to find out the appropriate intervention. In pre-test counselling, the decision to take the HIV test may be the best outcome of the counselling session. In post-test counselling, the ability to absorb the news and the willingness to prevent the transmission of the disease may be the best outcomes of the session.

Following are the major issues to consider when interventions are being discussed during the counselling sessions:

- Identify the first priorities, and what can be done later
- Identify the options for an immediate management of the test result, and assess the future needs of the client
- Emphasise the importance of prevention (re-infection, transmission).
- Identify other appropriate support (family, community, etc.).
- Encourage the client to take charge of his disease.

*Condoms, properly used, represent a proven, effective means for preventing the transmission of HIV, other traditionally sexually transmitted infections and pregnancy. Latex rubber condoms are relatively inexpensive, are highly reliable and generally have no side effects.*¹⁴

2.1.4. Summary

The last, but not least, part of the counselling session is the summarization. Before formally ending the session, narrate what was achieved during the session and what should be achieved during the next session. Each time check what the client has learned, and if there are any misunderstandings that need to be cleared.

General tips for effective counselling:

Be honest with the client

Ask for permission before documenting

Do not create dependency

Strictly adhere to appointment schedules

Try to address feelings of guilt positively

Use language that the client understands (avoid technical jargon)

Support explanations with facts (explain normal physiology where relevant)

Avoid using judgmental language

Be empathetic, not sympathetic

Avoid challenging the client's feelings

Help the client identify his problems

Help the client take responsibility to resolve issues

Do not rush into solutions (counselling cannot be completed in a single session)

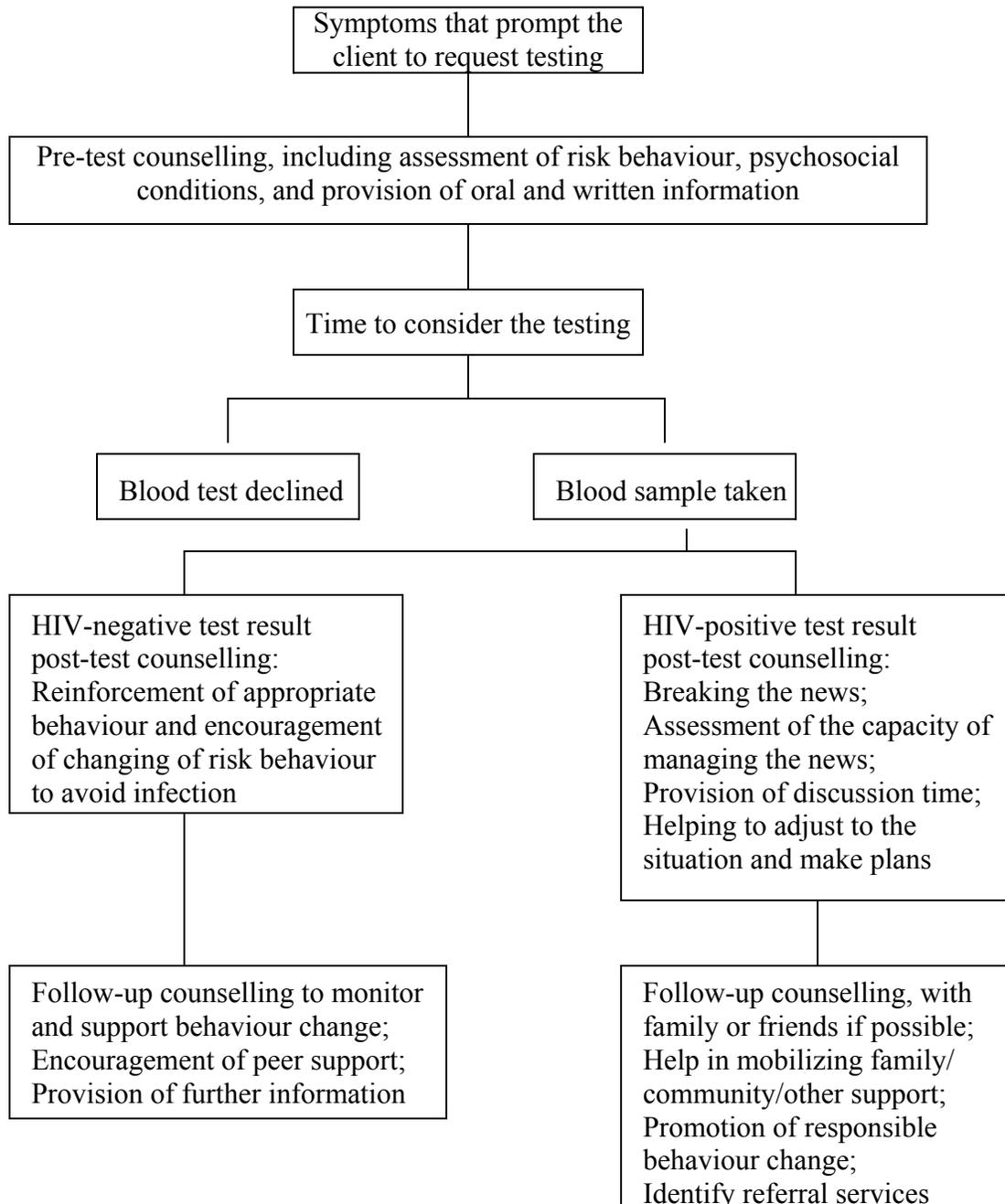
Help the client reach solutions that best suit him

¹⁴ *The male condom.* UNAIDS technical update. UNAIDS best practice collection. UNAIDS, 2000e.

2.2. Stages of VCT

Traditionally, there are three main types of counselling: pre-test counselling, post-test counselling, and follow-up counselling.^{15 16}

Below a chart that describes the usual process of counselling:



¹⁵ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

¹⁶ *Guidelines for counselling about HIV infection and disease*. WHO AIDS Series 8. WHO, 1990.

2.2.1. Pre-test counselling

HIV counselling helps a person make informed choices. However, it is important to note that people who do not want pre-test counselling before taking the HIV test should not be required to do so. In addition, a decision to be tested should be an informed decision. Informed consent implies awareness of the possible implications of a test result, including and awareness of the window period.

The aim of pre-test counselling is to:

- Know the client's personal history of risk behaviour, and if he has been exposed to HIV.
- Assess the client's understanding of HIV/AIDS (including the modes of transmission).
- Assess the client's previous experiences in crisis management.
- Provide information about the advantages and disadvantages of testing, including its technical aspects.
- Discuss testing as a positive step towards behaviour change and the improvement of the quality of life.

Ensure in pre-test counselling that:

- Confidentiality and informed consent for the HIV test has been discussed.
- Existing worries and concerns regarding HIV/AIDS have been identified.
- Knowledge about HIV/AIDS, and in particular its modes of transmission, has been explored.
- Myths, misinformation and misunderstandings related to HIV/AIDS have been clarified.
- Emotional coping mechanisms and the availability of social support has been assessed.
- Implications of knowing whether one is infected have been explained. This includes the implications that HIV/AIDS infection has for marriage, pregnancy, finances, work, stigma etc.
- Ways of coping with a positive HIV test result have been discussed.
- Discussion on safe sexual practices has been carried out.
- Discussions on relationships, especially the benefits of shared confidentiality between the person and his loved ones, have been carried out.

Benefits of pre-test counselling.

Access to pre-test counselling is not always available, and some people might refuse this option. However, in case the test is positive, there are considerable benefits to the client having taken part of pre-test counselling, which include:

- *Improved acceptance of HIV status and ability to cope.*
- *Empowerment, including greater involvement in the care and support to people living with HIV/AIDS*
- *Higher probability of change of behaviour*
- *Reducing the risk of mother to child transmission*
- *Early management of opportunistic infections and information on safe sexual practices and the use of contraceptive devices*
- *Provision of early social and peer support*
- *Normalizing and destigmatizing HIV/AIDS*
- *Instilling hope and addressing the quality of life issues for people living with HIV/AIDS*
- *Planning future care, making a will considering future childcare.*

Each counsellor should have a checklist form for each client in order to be sure that all relevant issues have been discussed. For a pre-test counselling checklist form, see **Annex III**. In **Annex IV** is a slightly different form for pre-test counselling visits, which puts more stress on the health information of the client.

2.2.2. Post-test counselling

The post-test counselling session should begin by trying to put the client at ease. The room must be quiet, without any fear of being disturbed. The counsellor should then tell the client the test result in a clear and direct manner. The result (either positive or negative) should be discussed while being sensitive to the client's feelings. Providing further information might be necessary, although, in case of a positive diagnosis, the client may be in shock, and may not fully take in all the information offered. However, in some circumstances, this might be the only chance to counsel him and asking to repeat the information, or writing down some basic facts, will be helpful. It is important for the client to have time to reflect on the result and to understand the next course of action. Ideally, couple and/or family counselling should be started when appropriate and further follow-up counselling arranged. A form to keep track of a post-test counselling visit is in **Annex V**.

2.2.3. Counselling after an HIV-positive test result

It is often difficult to tell someone bad news. However, most people with a positive result know before the result that they have HIV; a positive test result may be less of a surprise than the counsellor thinks. Prepare yourself by thinking carefully about what you are

going to say, and what the client's responses might be, before revealing the test result. This will make the experience better both for you and for your client.

Breaking the news

Ask the client what he has been thinking about since taking the test. Find out what worries or questions he might have. Arrange for enough time to talk about the issues he raises. When you give the result, use a neutral tone of voice. You might say, "Your HIV test result was positive", and then wait for the client to respond. A neutral tone and a moment of silence allow the client to feel his own feelings rather than respond to yours.

First reaction

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

Sometimes a person will not accept the result of a positive test. He will insist that he is negative and that there has been a mistake in the results. Do not argue with him. Tell him that tests are verified several times, but show your willingness to repeat the test if the client insists. People who deny the truth are often those most in need of support; ask them to return for another meeting.

While you should not deny the client's feeling of worry, it is helpful to talk about things positively. For example, many people believe that having HIV means that they will die very soon. Talk about how long it usually takes to become ill. Some people have lived for over fifteen years with the virus. Teaching people ways to stay healthy will help build a feeling of strength at a time when they may feel powerless. Try to help your client overcome harmful thoughts and focus on solving problems. Help people plan for the future and remind them that they are not going to die tomorrow.

Breaking the news

- *Give results simply and clearly*
- *Allow time for the result to sink in*
- *Check that the client has understood the situation*
- *Discuss the meaning of the result and its implications at personal, family and social level*
- *Explore who to tell and how to tell among the family, friends and employers, if applicable*
- *Manage immediate emotional reactions*
- *Check for immediate follow-up and referral support*
- *Review options and resources*
- *Review immediate plans, intentions and actions*¹⁷

¹⁷ *Tools for evaluating HIV voluntary counselling and testing.* UNAIDS Best Practice Collection. UNAIDS, 2000a.

Exploring the sharing of confidentiality

While the counsellor must guarantee the confidentiality of the test results, he should recognize that the burden of secrecy can be detrimental to PLWHAs and can affect their ability to cope with their infection. The counsellor should explore with the clients the possibility of sharing confidentiality with their loved ones, and discuss the potential advantages and disadvantages of sharing test results with other people.

- Sharing results with other family members can provide psychological support, as well as the necessary care and help needed in planning for the future.
- Sharing results with other healthcare workers can ensure, for example, that a woman receives the best information and care possible for herself and her child over the course of her pregnancy and eventually her illness.
- Sharing results with other HIV positive people in support groups can contribute to knowledge and coping skills.

Counsellors should help HIV positive clients decide who, if anyone, to share information about their status with. Counsellors should never disclose the test results to anyone else, except at the express request of the client.

Providing written information, support services, and a follow-up meeting

Hearing about a positive HIV test result can bring out many strong feelings: the client may not be able to concentrate, and may not hear what you are saying. Try to give written information to each person who is able to read, so that he can later read about what he did not hear or understand during the post-test counselling session. Free condoms, only when appropriate, can be given out during this session, together with advice on how to use them and where to get more. Make an appointment for the client to come back to hear about health services, support groups for PLWHAs, crisis counselling, and programmes for IV drug users.

*Main concerns for those who test HIV positive:*¹⁸

- *Understanding and maintaining safe behaviour to avoid future HIV re-infections. Access to condoms and contraceptives*
- *Information on therapy options, including costs, and earlier access to appropriate medical care*
- *Understanding how to reduce HIV transmission from mother to child, if applicable*
- *Access to counselling in reproductive health settings, and to interventions such as feeding facilities, health benefits and need for contraception (if applicable)*
- *Access to family planning services for women who choose to avoid pregnancy because of their HIV status*
- *Learning about HIV infection, its implication for health, and how to avoid HIV transmission to uninfected sexual partners*
- *Learning about good nutritional values and positive living*
- *Access to social support (including material and financial support)*
- *Access to support groups (family, community and religious groups) that provide emotional support and facilitate subsequent adjustment to the situation*
- *Sharing of HIV status with partner, family or close friends*
- *Future planning for one's future and for one's dependents, including making a will*

¹⁸ *HIV Voluntary Counselling and Testing: a gateway to prevention and care.* UNAIDS Best Practice Collection. UNAIDS, 2002b.

Recommendations to HIV-infected persons

- Inform former and current sexual partners about your HIV infection and recommend that they avail of VCT services. If you are unable or unwilling to notify former and current sexual partners personally, request health workers or public health agencies to notify or help with notifying such partners.
- Either decide to avoid sexual intercourse, rigorously restricting sexual contact to activities (e.g. hugging, caressing) that do not involve sharing of semen, vaginal and cervical secretions or blood, or discuss the precautions that need to be taken to minimize the risk of HIV transmission through sexual activity (e.g. the use of a condom).
- If you both decide to engage in penetrative sexual intercourse, learn how to use a condom correctly, as consistent correct use will reduce the risk of HIV transmission.
- Strictly avoid sexual intercourse when you or your partner has an infection or a lesion in the genital, anal or oral areas, and during menstruation.
- Avoid pregnancy. HIV-infected women who are pregnant should know about the health hazard to themselves and their unborn child, and be provided relevant counselling services. HIV-infected men should discuss the hazards of pregnancy with their partners.
- Do not donate blood, plasma, semen, breast milk, body organs or other tissues.¹⁹

It is of utmost importance that the counsellor keeps track of all matters discussed with an HIV positive client during the post-test counselling sessions. A form to assess the post-test counselling sessions is in **Annex VI**.

2.2.4. Counselling after an HIV-indeterminate test result

An indeterminate HIV test result is confusing. It either means that the person is newly infected and has just begun to produce HIV antibodies, or that something else in his blood causes a partially positive test by mistake. In case of an indeterminate result, the counsellor should give the client a clear explanation of what such a test result means. The period of uncertainty following an indeterminate test result may be three months or even longer. It is important for the counsellor to stress the essential information related to the prevention of transmission: sexual activity, drug use, donation of body fluids or tissues, and breastfeeding. The uncertainties associated with this period may lead the client to have acute and severe psychological problems, and the counsellor must be prepared to assess and manage such issues or to make appropriate referrals, if possible.

In **Annex VII** is a post-test counselling form for indeterminate results that counsellors should fill for each client.

¹⁹ *Guidelines for counselling about HIV infection and disease*. WHO AIDS Series 8. WHO, 1990.

2.2.5. Counselling after an HIV-negative test result

A complete session of post-test counselling is also important for people who have received a negative test result. Counselling a person with a negative result is, in many ways, like counselling a person who is positive.

The counselling session can start with general questions about the client's thoughts since the pre-test counselling session. Ask if he has any questions before you tell him the result. Give the result in a positive tone and congratulate him. After giving the result, give him time to respond with his own feelings and thoughts. Most people feel relieved to receive a negative test result. Explain to the client that a negative test result means that he does not have HIV infection, provided he hasn't been exposed to HIV infection during the preceding six months.

The counsellor must explain about the so-called "window period", the period in which a person exposed to HIV infection has not yet developed HIV antibodies and will appear negative on the test. This result is called the false negative result. The window period on average lasts about 8 to 12 weeks. If the HIV status of a person is unclear, counsel them to return for a repeat test in 3 to 6 months. Ensure protection in the meanwhile, explaining that the client could become infected at any time. This is an ideal time to discuss sexual practices and preferences, potential drug use (particularly injecting drug use), and other risky behaviour. The person will probably be open to learning about safe sex practices and modifying risk behaviour. Free condoms can be given out during this session together with advice on how to use them and where to get more when needed.

It is important for the client to realize that a negative result does not give immunity to HIV infection in the future. Discussing risk behaviour and methods of prevention are vitally important.

The main concerns for those who test negative:

- *Learning how to prevent future HIV infections*
- *Being aware about the high risk of transmission to child if the mother is newly HIV-infected during pregnancy or is breastfeeding*
- *Sharing the result with the partner*
- *Where to get condoms and other contraceptive means if the partner is positive or when his serological status is not known*
- *Continuing the risk of occupational exposure*
- *"Worried well". This refers to people who are at very low risk of HIV infection but worry in an exaggerated manner about being infected. This phenomenon is more common in low prevalence countries, such as Pakistan, where there are extensive HIV/AIDS awareness programmes that can lead to hypochondria.*

In **Annex VIII** is a post-test counselling form for negative results that counsellors should fill for each client.

2.2.6. Follow-up counselling

The majority of people attending VCT, regardless of testing positive or negative, need follow-up counselling. It helps improve the quality of life and enhances the ability to cope and make informed decisions about ongoing care. Some PLWHAs, or those with a high-risk behaviour, do not like to be referred for the fear of the disclosure of their identity, and prefer to avail follow-up counselling at VCT centres. Follow-up VCT counselling should therefore be flexible and provide ongoing counselling to all those who need it.

A checklist was not developed because of the nature of the issue and it would be hard to address them in a rigid form. The follow-up should be flexible and compatible with the needs of each client.

2.2.7. Bereavement counselling

Many families and friends lack social support during the illness of a PLWHA, and after his death. Bereavement counselling should be available already before the death of a loved one and continue as long as there is need. Some people may accept the death in a short time, but for others it can take even years. Often the survivors blame themselves for not having done enough to ease the life of the ill person.

Bereavement counselling should:

- Give people an opportunity to discuss the events that lead to the death, about the death itself, and about the possible rituals after the death.
- Reassure people that feelings of disbelief, denial, sadness, pain and anger are normal.
- Provide people with an opportunity to express those feelings and other concerns.
- Enable family members and friends to accept the loss and start to look towards the future.

Part III
VCT needs of specific groups

VCT needs of specific groups

An HIV epidemic does not affect all sectors of the society equally. Some groups are particularly vulnerable to HIV for a variety of reasons, and each group needs different VCT strategies. For example, CSWs in Pakistan – due to their illegal status – are usually unable to negotiate for safe sex with their clients. Their prime need is to learn more skills of negotiation. On the other hand, IDUs are at risk as ignorance of HIV/AIDS is combined with the practice of sharing needles. Their need is to be aware of the existence of street-based harm reduction services and to be involved in the on-going education and information programmes.

In Pakistan, where the prevalence of HIV infection is still low, making available VCT services for high-risk groups is a high priority.²⁰ To identify local vulnerable groups and to meet their special needs, developing specific VCT strategies for each of them, is the road to pursue. It is also very important to make condoms available at VCT centres, especially for youths who usually find access to other outlets problematic.

The male condom, if used correctly and consistently, is the leading method of protection against HIV infection and other sexually transmitted infections. Condoms are relatively cheap and have no side effects. For a person already infected with HIV, condom use during sexual intercourse is very important, both to avoid onward transmission, and to prevent re-infection with HIV, which could make the condition worse.²¹ Female condoms are much more expensive than male condoms, and much less common. Their biggest advantage is, besides protecting against HIV, STIs and unwanted pregnancies, that they give women the power of decision and negotiation.²²

²⁰ *Technical Consultation on Voluntary HIV Counselling and testing: Models for implementation and strategies for scaling of VCT services.* WHO/UNAIDS, 2001.

²¹ *The male condom.* UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 2000e.

²² *The Female Condom.* Gender & AIDS Fact Sheet. UNAIDS, 2002.

For maximum protection against HIV infection, condoms must be used correctly. Make sure that your clients understand and follow the instructions:²³

- Use a new condom every time you have intercourse.
- Always put the condom on the penis before the intercourse.
- Put the condom on when the penis is erect.
- In putting the condom, squeeze the nipple or empty space at the end of the condom in order to remove the air. Do not pull the condom tightly against the tip of the penis; leave some empty space at the end of the condom to hold semen.
- Unroll the condom all the way to the base of the penis.
- If the condom gets torn during the intercourse, withdraw the penis immediately and put on a new condom.
- After ejaculation, withdraw the penis while it is still erect. Hold the rim of the condom as you withdraw, so that the condom does not slip off.
- Remove the condom carefully so that semen does not spill out. Dispose of used condoms in a closed receptacle for waste.
- If a lubricant is needed, use water based one, since petroleum jelly may damage condoms.
- Do not use saliva as a lubricant, it can transmit infection, and may lead to the breaking of the condom.
- Store condoms away from excessive heat, light and moisture, as these cause them to deteriorate and perhaps break.
- Condoms that are sticky, brittle or otherwise damaged should not be used.

Besides the normal VCT counselling described in the previous chapters, and meant for the public at large, there are specific groups of vulnerable people that need extra consideration during their counselling sessions. Below are discussed separately women, including pregnant women, IDUs, CSWs, MSM, healthcare workers, young people, children and couples. Also blood donors are handled as a separate group.

3.1. Women^{24 25}

Although HIV/AIDS used to be considered a disease that affects men rather than women, especially in developing countries even more than half of new infections are found in women. Women are also the ones who are more affected by the disease from the social point of view, as they are the ones who remain home, away from education and

²³ *Guidelines for counselling about HIV infection and disease.* WHO AIDS Series 8. WHO, 1990.

²⁴ *Counselling for HIV/AIDS: The National Guidelines.* National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

²⁵ *Women and AIDS.* UNAIDS point of view. UNAIDS Best Practices Collection. UNAIDS, 1997b.

productive work, to care for family members who have HIV/AIDS. Pregnant women with HIV/AIDS, unwittingly, can transmit the disease to their unborn children and to the future generations.

HIV/AIDS prevention efforts in Pakistan cannot be successful if women remain either ignorant about the disease or powerless to protect themselves from it. HIV/AIDS in general is a disease that concerns people with high-risk behaviour, but most Pakistani women who have HIV/AIDS have contracted it from their husbands.

AIDS prevention campaigns often fail women by assuming that they are at low risk, or by urging prevention methods that women have little or no power to apply, such as condom use, abstinence and mutual fidelity.

3.1.1. Special needs, vulnerability to the virus and VCT strategies

Although there are women who engage in high-risk behaviour, the fact is that most women contract HIV/AIDS from their one sexual partner, their husband. This means that women are rendered vulnerable mostly from the socio-economic and educational point of views: many women do not have enough factual information about HIV/AIDS and its modes of transmission, and even if they have, they do not have the power to negotiate for safe sex. Usually it is the husband who decides about the use of a condom, and not many allow its use inside the marriage. Women are particularly vulnerable to HIV infection for the following reasons:

Biological vulnerability

Risk of transmission of HIV/AIDS from men to women is many times higher than from women to men. Women are more vulnerable to sexually transmitted infections (STI), which further increases their vulnerability to HIV infection. The vulnerability of women increases when they are either very young or old.

Social and economic vulnerability

Prevention of HIV/AIDS requires the ability to abstain from sex, use a condom, or have a faithful marital relationship. All these entail the empowerment of women, which unfortunately does not exist in most of the classes of the Pakistani society.

Illiteracy and limited access to health care facilities

Unfortunately, there is a high rate of illiteracy among women. In addition, women have limited access to healthcare facilities. The result is that many women remain ignorant about HIV/AIDS and do not benefit from the available services and resources.

Mother-to-child transmission

Mother-to-child transmission (MTCT) of HIV is the major reason why children get HIV/AIDS. Most cases of transmission occur at the time of labour and delivery (more than 60%). The risk of HIV transmission from an infected mother to her child can be

reduced by 50% by giving a short course of Zidovudine starting from the 36th week of pregnancy, and by avoiding breastfeeding.²⁶

VCT strategies

VCT, carried out in the framework of pregnancy and reproductive health services, could be a starting point for the counselling and voluntary testing of healthy and asymptomatic women and their partners. Some reproductive health settings, such as STI clinics, paediatric services, and family planning clinics, could provide testing to women and men planning pregnancy, while antenatal services could test pregnant women and their partners.^{27 28}

VCT has benefits beyond the prevention of transmission from mother to child. It contributes to an increase in safe behaviour at the individual level, and is likely also to reduce the ignorance, fear, and stigma associated with HIV infection in the population at large. Where possible, and when the women agree, it is advantageous to involve the male partner in the counselling sessions. Ideally, women should have counselling available to them before they become pregnant.²⁹

3.1.2. Pre-test information and counselling

Most of the time women become concerned about HIV/AIDS and come to a VCT session when their husbands or children are diagnosed with HIV/AIDS. It is important for the counsellor to understand that a woman like this is dealing with two crises at the same time: the husband's or child's illness, and her own feelings and emotions.

It is often preferable for women counsellors to counsel women as this helps them feel safer during the session. It is important that pregnant women receiving VCT have adequate time to discuss their own needs and not just about the prevention of MTCT (mother-to-child transmission), and that there are links with other services that can provide ongoing support and care for women with HIV after the delivery.

In pre-test counselling, individuals should be given an opportunity to assess their own risk of infection together with a counsellor. It is also important in pre-test counselling to emphasize the benefits of HIV testing and the implications of the results. Unless women and their partners fully understand the benefits of an HIV test, they are unlikely to choose to have one.

²⁶ *Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries: elements and issues*. UNAIDS Best Practices Collection. UNAIDS, 1999b.

²⁷ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

²⁸ *HIV Voluntary Counselling and Testing: a gateway to prevention and care*. UNAIDS Best Practices Collection. UNAIDS, 2002b.

²⁹ *Counselling and HIV/AIDS*. UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 1997a.

Information about existing means of reducing the transmission of HIV from an HIV positive mother to her children should be given during pre-test counselling. The clients should be told that, in the absence of any intervention, less than half the babies born to HIV-positive women contract the virus from their mother. The clients should also be told that a positive result would allow them to make important decisions about their own lifestyle, nutrition and health care, decisions that may have a major impact on their survival, even in situations where antiretroviral combination treatments are not available.

The following should be discussed during pre-test counselling:

- Information about the sexual transmission of HIV and how to prevent it.
- Information about the transmission of HIV from mother to child, and possible interventions.
- Information about the process of HIV testing.
- Assurance of confidentiality and discussions about shared confidentiality and couple counselling.
- The implications of a negative test result, including promotion of breastfeeding.
- The implications of a positive test result, costs and benefits of potential interventions, including their own and their child's survival, and possible exposure to stigma.
- Counselling for risk assessment.

3.1.3. Post-test counselling

The main goal of post-test counselling is to help women understand their test results and the implications these results have.

Negative results

The aim of post-test counselling, following a negative test result, is to help the client to understand what is safe behaviour, and how to continue maintain it in order to avoid future infection. The second aim is to encourage possibly breastfeeding women to continue the practice to promote the health of the infant.

The information already given during pre-test counselling about the prevention of sexual transmission of HIV should be reinforced, and the particular importance of avoiding infection during pregnancy and during breastfeeding should be stressed. When the partner is infected, or when his serological status is not known, the importance of prevention information and counselling is greater still. Information on where to get condoms and other contraceptive means should be given.

Positive results

When a woman discovers that she is HIV positive, she has to face the stress of disclosing this news to her partner and family. Even if the woman was infected by her partner, she will need considerable support when revealing her condition to others. HIV-infected

women often feel extremely lonely and isolated, as the fear of social stigma compels them to keep the condition secret. Many women fear being abandoned and deprived of the support of the family, friends and community organizations. Helping the women re-establish connections with their family and other social groups is often a major task in counselling. Helping women take part in peer support groups can also be an important counselling strategy.

The aim of post-test counselling is to help the client to:

- Decide whether to share her HIV status with anyone, and if so, with whom.
- Choose to terminate her pregnancy where it is medically advised and available.
- Choose antiretroviral therapy where available.
- Understand the feeding options of the infant, and choose the best option available.
- Learn more about the HIV infection and its implications for the client's health.
- Access support groups and health services that promote positive living.
- Make choices about future fertility.

A positive result is a pre-requisite for the two interventions thought to be most effective in reducing the transmission of HIV from mother to child: antiretroviral therapy (ARV) and avoidance or abbreviation of breastfeeding. Where antiretroviral therapy is available, the counsellor should explain its benefits and the importance of adherence to the regimen. The counsellor should also make clear that, while research continues, it is thought that the benefits of antiretroviral therapy may be diminished by breastfeeding. Unless antiretroviral therapy drugs are provided free, the counsellor should discuss the cost of the therapy and help the client assess her family's ability to bear the costs of a full treatment.

The counsellor should tell HIV-positive, pregnant clients the following:

- *Explain the delivery process (e.g., maintaining confidentiality through ARV administration in labour)*
- *Explain the implications of a positive result for the baby and for future children*
- *Explain the implications a positive result has on infant feeding (e.g., benefits and risks of breastfeeding), and information on feeding options*
- *Provide information about family planning*
- *Inquire about previous use of ARV*
- *Discuss ARV and its role in pregnancy*³⁰

³⁰ *Tools for evaluating HIV voluntary counselling and testing.* UNAIDS Best Practices Collection. UNAIDS, 2000a.

3.1.4. Practical interventions

Combat ignorance

During both pre- and post-test counselling, promote the improvement of education for women, including education about their bodies, STI, and HIV/AIDS. Teach women and girls how to say no to unwanted or unsafe sex. Provide women-friendly services.

Access to healthcare

Ensure that girls and women have access to appropriate healthcare and HIV/AIDS/STI prevention services. Promote voluntary counselling and testing, and teach about condom use. Make these services easily available without embarrassment. Refer women to services that are convenient and acceptable to them.

Build safer norms

Counsel all your clients, both women and men, about having respect for girls and women, and encourage them to engage in responsible sexual behaviour.

3.2. Injecting drug users

Injecting drug use is not the most common method of drug use in Pakistan, but it is thought to be on the rise. IDUs are, though, at a very high risk of contracting HIV/AIDS through the widespread sharing of contaminated needles. In addition, recent reports suggest that IDUs engage in unprotected sexual activity, often with CSWs.³¹

Injecting drug use is a practice that is both illegal and socially stigmatised in Pakistan. Because many drug users have experienced social stigma and unpleasant encounters with the law, they may distrust or fear government or hospital based social services. VCT services that are part of such institutions may, therefore, be unlikely to attract drug-using clients

3.2.1. Special needs and VCT strategies

It has been observed that motivated former drug users, after receiving appropriate training, provide very effective VCT services. Drug users accept them more readily and communicate better with them. Similarly, VCT services that are complemented with a needle (syringe) exchange programme (NEP) are more effective in reducing harmful behaviour and the transmission of HIV infection than traditional VCT services.^{32 33} Other examples of more successful VCT programmes for drug users are those

³¹ *National HIV/AIDS Strategic Framework 2001-2006, Pakistan*. Ministry of Health and UNAIDS, 2001.

³² *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

³³ *HIV Voluntary Counselling and Testing: a gateway to prevention and care*. UNAIDS Best Practices Collection. UNAIDS, 2002b.

coordinated with existing HIV prevention and social service outreach programmes that go to the places that drug users frequent.

3.2.2. Pre- and post-test counselling

Intervention studies indicate that personalized, interactive prevention counselling models using goal-setting strategies might be effective in reducing injecting drug use and sexual risk behaviour.³⁴ While HIV counsellors should discuss risk reduction with their clients during both pre- and post-test counselling, they should also understand that IDUs may not be willing or able to change certain types of behaviour, such as their drug use or having unprotected sex. In these cases, HIV counsellors should discuss safe methods of practicing these behaviours, such as not sharing needles or sterilizing needles and syringes before sharing. When possible, all IDUs should be supplied with new syringes and condoms both during pre- and post-test counselling. It would be appropriate for a VCT centre to refer injecting drug users to rehabilitation centres and to needle exchange programmes for further counselling.

3.3. Commercial sex workers

Commercial sex work is illegal in Pakistan, and therefore it is practiced in secrecy. This makes it difficult to determine the true extent of commercial sex work. Some reports suggest increasing commercial sex business in the country.³⁵ This increase can be attributed to changes in social, economical, cultural and religious values, besides an increase in population mobility.³⁶ Many people enter into sex business for economic reasons, either being homeless or having an unemployed or drug addicted husband. Others are coerced into sex business through kidnapping and trafficking.

A sex worker is defined as an individual who exchanges sex for money/materials, but the definition also includes indirect forms of exchange that are not traditionally perceived as sex work.³⁷ In most parts of the country, sex workers lack access to VCT, are subject to stigma, discrimination, police violence and exploitation. Many sex workers are drug addicts.

The HIV/AIDS epidemic has highlighted the need of responding on three levels:^{38 39}

³⁴ *Technical Consultation on Voluntary HIV Counselling and testing: Models for implementation and strategies for scaling of VCT services.* WHO/UNAIDS, 2001.

³⁵ *Sex work and HIV/AIDS.* UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 2002d.

³⁶ *Population mobility and AIDS.* UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 2001a.

³⁷ *Technical Consultation on Voluntary HIV Counselling and testing: Models for implementation and strategies for scaling of VCT services.* WHO/UNAIDS, 2001.

³⁸ *Voluntary Counselling and Testing (VCT).* UNAIDS technical update. UNAIDS, 2002a.

- Prevention of entry into sex work
- Protection of those involved in sex work
- Assistance in exiting from sex work

Each of these responses can, in turn, be addressed on three levels:

- Individual
- Community
- Policy making

3.3.1. Special needs and VCT strategies

VCT for CSWs needs to be sensitive to the problems of stigma and illegality associated with commercial sex in the country. Sex work usually provides the CSW with a livelihood and thus stopping some or all risk behaviours may reduce his/her ability to earn a living. Furthermore, sex workers may be under considerable pressure to perform especially risky activities (e.g. sex without a condom), either through financial inducement or coercion by the pimp or client. Counsellors must understand these issues, and help the CSWs find ways to work around or lower the obstacles they face when trying to reduce their risk. In some cases, counsellors may want to work closely with community organizations that empower and support sex worker's desire to keep healthy and safe.^{40 41}

VCT has the following aims and strategies, when related to CSWs:

- Making VCT providers more sensitive about sex work
- Making VCT services youth friendly
- Integrating VCT services with STI, RH and social support services
- Promote safe sexual behaviour among sex workers and their clients
- Promote condom availability and teach their correct use
- Teach CSWs skills to negotiate safe sex with their clients

3.4. Men who have sex with men (MSM)

Male homosexuality exists in Pakistan, though many men who have sex with other men do not see themselves as homosexual. Many are also married or have sex with women.

³⁹ *Sex work and HIV/AIDS*. UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 2002d.

⁴⁰ *HIV Voluntary Counselling and Testing: a gateway to prevention and care*. UNAIDS Best Practices Collection. UNAIDS, 2002b.

⁴¹ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

However, it is hidden, resulting in an alarming lack of prevention and care services for them.^{42 43 44}

MSM are frequently involved in anal sex. Unprotected penetrative anal sex carries a high risk of HIV transmission, especially for the receptive partner. The presence of untreated STI can greatly increase the risk of HIV transmission. Oral sex is also common between MSM. While HIV could be transmitted through such sex if not protected by a condom, the risk is generally considered low. Multiple sex partners, unprotected anal sex and the hidden nature of MSM all contribute to the high number of HIV/AIDS cases. Due to societal pressures, most MSM get married and thus risk transmitting HIV/AIDS to their wives and children.

Anal sex, which is often practiced in sex between men, carries a high risk of transmission of HIV, when the virus is present and when condoms are not used.

3.4.1. Special needs and VCT strategies

Securing the participation of MSM is essential for the development and implementation of comprehensive HIV interventions in the country. VCT services should not only address personal factors directly related to health (e.g. risk practices, condom use, STIs), but also address social factors, such as enhancing self-esteem and empowerment. VCT services for MSM should include education on safe sex, the use of condoms, and the promotion of lower risk sexual practices as alternatives to penetrative sex. High quality condoms and water-based lubricants should be made available.

MSM are a highly stigmatized community in the country. There are no opportunities for them to openly discuss their fears and concerns. VCT services provide a "safe space" where they can discuss their personal issues, assess their risk, get STI care, and appropriate referrals.

3.5. Healthcare workers

Healthcare workers who deal with HIV/AIDS patients on a day-to-day basis often suffer from psychological distress. Emotional involvement with the patient, and frustration at the lack of effective therapies, can place health workers at risk of depression, withdrawal, and in extreme cases, suicidal tendencies. Counselling of healthcare workers should be an

⁴² *HIV Voluntary Counselling and Testing: a gateway to prevention and care.* UNAIDS Best Practices Collection. UNAIDS, 2002b.

⁴³ *AIDS and men who sex with men.* UNAIDS point of view. UNAIDS Best Practices Collection. UNAIDS, 1998a.

⁴⁴ *Sex work and HIV/AIDS.* UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 2002d.

integral part of all healthcare programmes where the exposure to HIV-infected patients is high. Counselling should seek to minimize stress. Also work schedules should be set in a way to provide frequent changes of environment and tasks. Just as counselling those who are HIV-infected, counselling of healthcare workers should be accessible, consistent and confidential.^{45 46}

3.5.1. Special needs and VCT strategies

It is important to educate and counsel healthcare workers after occupational exposure about the measures to take in order to prevent transmission during the follow-up period. HIV-exposed healthcare workers should be told that, although HIV is infrequently transmitted through an occupational exposure, they should abstain from sex or use condoms and avoid pregnancy until they receive a negative follow-up test result. In addition, they should not donate blood, plasma, organs, tissue, or semen. If a woman is breastfeeding, she should consider discontinuing.^{47 48}

Health-care workers should also be briefed about post-exposure prophylaxis; the risks of acquiring HIV infection from occupational exposure; the limitations of the current knowledge of the efficacy of ARV therapy when used as post-exposure prophylaxis; the toxicity of the drugs involved; and the need for post-exposure follow-up (including HIV testing), regardless of whether antiretroviral therapy has been taken or not.

3.5.2. Accidental risk

How to prevent injuries:

- *Do not put caps back on needles*
- *Do not bend or break needles*
- *Remove used needles from your work areas*
- *Put needles and other sharp instruments in a “sharp box” after using them*
- *Wear gloves when handling a patient’s secretions, when injecting, and when drawing blood*
- *Bandage all cuts and nicks on hands before putting on gloves*
- *Wash hands immediately if they have and body fluid on them, and also wash them after seeing each patient*
- *Pass sharp instruments back into a tray and not into an open hand*

⁴⁵ *Counselling and HIV/AIDS*. UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 1997a.

⁴⁶ *Guidelines for counselling about HIV infection and disease*. WHO AIDS Series 8. WHO, 1990.

⁴⁷ *Counselling for HIV/AIDS: The National Guidelines*. National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

⁴⁸ *Revised Guidelines for HIV Counselling, Testing, and Referral*. Technical Expert Panel Review of CDC HIV Counselling, Testing, and Referral. CDC, 2001.

<i>Cleaning needles and other instruments</i>	
<i>Boiling</i>	<i>30 minutes</i>
<i>Steam</i>	<i>30 minutes</i>
<i>Dry heat oven</i>	<i>30 minutes</i>
<i>(77°C or 170°F)</i>	

3.5.3 Follow up-testing

Follow-up testing might be appropriate for clients whose test result is negative, but who have not had time to develop detectable antibodies after a recent occupational exposure to HIV. Follow-up testing should be conducted in a timely manner so that clients who actually are HIV-infected can receive appropriate antiretroviral treatment and support services as soon as possible.

Most infected persons will develop detectable HIV antibodies within three months of exposure. If the initial negative HIV test was conducted within the first three months after exposure, repeat testing should be considered only after the window period, in order to rule out the possibility of a false-negative result. If the follow-up test is nonreactive, the client is likely not HIV-infected. However, if the client was exposed to a known HIV-infected person, or if client concern remains, a second repeat test might be considered more than six months after the exposure. Rare cases of seroconversion only 6-12 months after known exposure have been reported. Extended follow-up testing beyond six months after exposure, to account for possible delayed seroconversion, is not generally recommended, and should be based on clinical judgment and the individual client's needs.

3.6. Young people

The majority of new HIV infections in Pakistan, like elsewhere in the world, occur among young people through unprotected sexual intercourse. There are increasing efforts to interest young people in utilizing VCT services. In Pakistan, young people's knowledge about sexual and reproductive health and the availability of respective services is generally not very high. Communication with parents about sexual issues is rare, and most information comes from friends or informal healthcare sectors and it is often not correct. Lack of skills to negotiate safe sex, poor access to contraceptives, and vulnerability to sexual abuse, put young people at the highest risk of contracting HIV infection.

*Young people of both sexes account for most of the current HIV infections in the world today. Their experience demonstrates how a combination of personal, service-related and societal factors can influence vulnerability.*⁴⁹

3.6.1. Special needs and VCT strategies

For VCT to be effective for young people it must take into account the emotional and social contexts of young people's lives, such as the strong influence of peer pressure (e.g. to use drugs or alcohol) and the development of sexual and social identities. VCT must also be "user-friendly", offered in non-threatening, safe and easily accessible environments. Counselling should be age-appropriate, using examples of situations that are familiar and relevant to youth, and using a language that is non-technical and easily understood.

Anonymous VCT services may be preferable to some young people. However, different cultures may have their own requirements and social expectations that prevent young people from accessing VCT services without parental consent. Although VCT services must always take into account any relevant laws regarding the rights and autonomy of minors and the responsibilities of parents for their children, they must also remember that the dignity and confidentiality of the young person must be protected and respected.

3.6.2. Pre- and post-test counselling

Young people who test positive need help in coping with their status, and in disclosing it to their families and sexual partner(s). Both HIV-positive and -negative young people report that maintaining the practice of safer sex after VCT is often difficult. This means that young people need regular encouragement and support, i.e. ongoing counselling and appropriate referrals.

3.7. Children

In Pakistan, there is growing risk of HIV/AIDS among children as more and more women are being diagnosed with the disease. Children themselves may be infected or

⁴⁹ *Expanding the global response to HIV/AIDS through focused action: reducing risk and vulnerability; definition, rationale, and pathways.* UNAIDS Best Practices Collection. UNAIDS, 1998b.

they may be part of a family, in which one or both of the parents are either infected or have died of AIDS.⁵⁰

3.7.1. Special needs and VCT strategy

Children with HIV, even young ones, need to know that they are sick. Younger children may only need to know a little bit about HIV. Give them short, simple answers to their questions. Older children understand more and need correct information and honest answers. If they do not get this information from you or their family, they may get the wrong information from someone else.

When children have clinical signs suggesting a possible HIV infection, VCT can provide a confirmatory diagnosis. The counselling session may include both child and parents. Counselling sessions should generally not be long. The counsellor should help the parents give explanations to the child or adolescent. Information and knowledge may be the only protection against discrimination at school. The counsellor should make use of what is said and done during the interview, and use the child's or family's own words to form the next sentence. It is also important to promote the child's self esteem and self image and emphasize how well he is coping.

3.7.2. Pre-test counselling

The counsellor should tell the parents, that it might be better for them to inform the child about the HIV test result. The result should be told in a way that the child can understand what the disease means. As a general rule, the child should be included in interviews with the parents and, where appropriate, with grandparents and siblings. The counsellor can then observe the reactions of both the child and the other family members. The counsellor should not discuss such issues as sexuality without parental permission. Older children can be seen either alone or with the family, as the children prefer. Family members who are counselled together may find it easier to make the necessary adjustments for supporting the children, while protecting themselves from any risk of infection. If the child is seriously ill or dying, the parents may need to see the counsellor alone.

3.7.3. Post-test counselling

An HIV-positive child can have special counselling needs in order to understand and cope with his own illness, to deal with discrimination by other children or adults, and to cope with the illness and deaths of HIV-infected parents or other family members.

HIV-negative children who are affected by HIV through the illness of a parent or a sibling also have special counselling needs, such as coping with the emotional trauma of

⁵⁰ *Counselling and HIV/AIDS*. UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 1997a.

seeing their loved one ill or dying and dealing with the social stigma related to HIV. Older children may need counselling related to developmental issues, such as sexuality and the avoidance of risk behaviour, or coping with and healing from childhood sexual abuse that has put them at risk for HIV infection. In all cases, counselling provided to children should use age-appropriate educational and counselling methods.

3.7.4. Rape and sexual abuse

Young people are often particularly vulnerable to rape, especially from people close to their families. However, young people are often reluctant to report rape or sexual abuse or to seek counselling and VCT following sexual assault. There are some NGOs in the country who are specifically working on rape and sexual abuse. Development of referral services with these organizations may prove helpful to these children.⁵¹

3.8. Couples, partners and family members

A high rate of sero-discordancy among married couples has been noted in many parts of the country although couples cannot be considered as such a vulnerable group. However, a different approach should be used when counselling couples, worth discussing separately. VCT can be provided to couples wishing to attend the sessions together, both before and after testing.⁵² Experience shows that couples and families, who attend VCT at the time of the disclosure of the HIV status and the means of transmission, lead a better life and support each other more than non-VCT couples. This disclosure is very stressful for the infected person, and without the support of VCT some families are separated.^{53 54}

Couple counselling overcomes the problems of disclosure to partners, and has been successful wherever it has been promoted.

⁵¹ *Technical Consultation on Voluntary HIV Counselling and testing: Models for implementation and strategies for scaling of VCT services.* WHO/UNAIDS, 2001.

⁵² *Counselling and HIV/AIDS.* UNAIDS technical update. UNAIDS Best Practices Collection. UNAIDS, 1997a.

⁵³ *Counselling for HIV/AIDS: The National Guidelines.* National AIDS Control Programme, Government of Pakistan and UNAIDS, 2001.

⁵⁴ *HIV Voluntary Counselling and Testing: a gateway to prevention and care.* UNAIDS Best Practices Collection. UNAIDS, 2002b.

Recommendations to the sexual partners of known HIV-infected persons

- Avail of VCT services in your area for counselling and testing. If the HIV serological test is negative and you are clinically healthy, and if the last unprotected sexual or needle-sharing exposure to your infected partner was six or more month ago, it can generally be assumed that you have not acquired HIV infection from that exposure. If your last exposure was less than six months ago, or if you continue to have sexual intercourse with your infected partner, repeat tests will be necessary to determine whether infection has occurred. If you were negative on an initial serological testing, see the recommendation below.
- Be aware that avoiding sexual intercourse with an HIV-infected person or rigorously restricting sexual contact to activities that do not involve sharing of semen, vaginal and cervical secretions or blood (e.g. hugging, caressing) is the only way of eliminating the risk of acquiring HIV infection from that person. If this is not acceptable, the use of a condom is an alternative, but it is not without risk. Although the precise effectiveness of condoms in preventing HIV infection is unknown, their correct and consistent use will reduce the risk of transmission.
- Avoid all sexual intercourse when either you or your sexual partner has an infection or lesion in the genital, anal, or oral area, and during menstruation.
- If you are pregnant, find out and seek VCT services. If you are HIV positive consult your doctor for PMTCT.
- Do not donate blood, semen, breast milk, body organs or other tissues. ⁵⁵

3.8.1. Special needs and VCT strategies

VCT services for couples require considerable sensitivity to the problems and needs of couples. Couple and family counselling in general depend on the HIV status of the parents and the children. The couple should be counselled about the risk of HIV transmission to the wife, if the husband is infected, with the subsequent transmission to lactating infants and to future children. The counsellor must be aware of these risks and provide factual information to the couple in a manner that is easily understood. It will then be up to the clients to make an informed decision about whether to have children or not. Similarly, if the wife is HIV infected, the couple should be counselled about the potential risk to the baby during pregnancy, labour, delivery and breastfeeding.

3.8.2. Benefits of VCT for couples

VCT can help couples that may be considering having children to:

- Weigh up the risks and advantages of pregnancy
- Make choices about contraception

⁵⁵ *Guidelines for counselling about HIV infection and disease.* WHO AIDS Series 8. WHO, 1990.

- Make choices about preventing future HIV infection, including condom use and not sharing injecting needles in case of drug use.
- Support one another in decisions about the care and feeding of the infant
- Make decisions about future fertility
- Choose behaviours, which reduce the risk of contracting or spreading HIV

3.8.3. Pre-test counselling

During pre-test counselling couples can discuss what they propose to do after hearing their test results. This will help the couple be prepared for their results. It is the responsibility of the counsellor to provide factual information about the risks of HIV transmission and then allow the clients to make an informed decision about HIV testing.

3.8.4. Post-test counselling

In case of a negative result, information given during pre-test counselling about the prevention of sexual transmission of HIV should be reinforced, and the particular importance of avoiding infection during pregnancy and breastfeeding should be stressed. In case of only one spouse being infected, or when his serological status is not known, the importance of prevention information and counselling is further emphasized. Information on where to get condoms and other contraceptive means should be given.

Post-test counselling helps the couple understand their HIV test result. When the results are discordant, both the couple and the counsellor face a challenging situation, but post-test counselling can help save the relationship and prevent further transmission of the infection. Post-test and follow-up counselling can help the couple overcome feelings of anger or resentment, which in some cases can lead to violence, particularly against the woman. It also helps the couple accept safe sex practices to prevent transmission to the uninfected partner. Stigma for not having a child sometimes becomes so strong to bear that sometimes couples find it hard to stick to safe sex practices. Post-test couple counselling can help these couples to better understand the advantages and disadvantages of having a child in such situation, and discuss other feasible options with them, such as adopting a baby. Couple counselling for HIV can also be provided as part of premarital counselling, and can continue after the testing.

3.8.5. Families with an HIV-infected child

Counselling families with an HIV-infected child requires considerable sensitivity. Parents usually feel guilt for transmitting the virus, and grief at the thought of losing the child. These emotions are normal and should be openly discussed and explored. Parents must be helped to deal with their own emotions so that they can provide a level of stability at home. The counsellor should provide practical advice about caring for the child at home, or refer the family to other services that are better equipped to help the family. It is

important that the counsellor encourages the family to show affection to the child, and to treat the child as normally as possible. The counsellor should also encourage the parents to tell the child about his condition as soon as the child is able to understand and cope with the piece of news. The disclosure helps the child adjust to his condition and promotes access to other necessary resources.

3.8.6. Families of PLWHA

Families of PLWHA primarily require HIV/AIDS counselling, but it is not common to find such families attending a VCT centre and availing of its services. The type of care required will depend on the stage of infection: as the patient's condition deteriorates, the demands on the family increase. The time, energy and emotional involvement required will increase and draw the family away from other activities and responsibilities. At the same time, the family may experience the same fears (e.g. ostracism and recrimination) as the infected person. Counselling of family members may be increasingly necessary with the progress of the infection. This is particularly true in situations where HIV/AIDS generates fear and rejection.⁵⁶

Families are also likely to need technical support. It may be necessary to provide them with medication, disinfectants, etc. Regular visits of by health workers, as well as the counsellor, may be an important form of support. The financial needs of the family have to be considered, and the role of the community will have to be explored.

⁵⁶ *Guidelines for counselling about HIV infection and disease.* WHO AIDS Series 8. WHO, 1990.

What the family of PLWHA should know

- *HIV/AIDS does not spread through social contact*
- *HIV/AIDS does not spread through skin contact*
- *PLWHA need nutritious food to provide energy, proteins and vitamins*
- *PLWHA need to be touched and caressed*
- *Sexual intercourse with an HIV/AIDS infected person without a condom can transmit HIV*
- *Blood, vaginal secretions and semen of PLWHA are contagious. If a care provider needs to handle infected blood or other body fluids, gloves should be worn and hands should be washed with soap and water immediately after exposure*
- *Soiled clothes and utensils that have been in contact with body fluids of the patient should be boiled with a detergent and/or soaked in a disinfectant. Any spillage of blood or other body fluids should immediately be decontaminated with a disinfectant, e.g. chlorine bleach. Household liquid chlorine bleach usually contains 5% chlorine, and can be diluted 1:10*
- *Solid waste should be disposed of in a hygienically controlled sanitary landfill or pit latrine*
- *Solid waste materials at home should be considered infectious. They should preferably be burned. If this is not possible, they should be deposited in a domestic or public hygienically controlled sanitary landfill or pit latrine*

3.9. Blood donors

The primary objective of blood transfusion services is to provide a safe and adequate blood supply. Counseling of blood donors is an essential part of achieving this objective.

The group of blood donors is a heterogeneous category of people. Besides being healthy citizens, concerned for the welfare of others, blood donors can also be poor people selling their blood for money. Some of them might be long-distance truck drivers, or IUDs who need to finance their addiction. Although blood donors themselves are not at risk during the donation – as long as the facilities are clean and hygienic – they can be, however, the source of HIV/AIDS and hepatitis. Due to the multifaceted nature of the problem it would be appropriate to arrange VCT counselling specific for hepatitis B and C together with HIV/AIDS counselling.

VCT services for blood donors should be comprised of the stages described below.⁵⁷

3.9.1. Pre-donation information

Effective pre-donation discussion and pre-donation counselling is needed to encourage appropriate donor self-deferral, to promote health maintenance, and to encourage regular donation by healthy donors. Donors who have blood-transmitted infections, such as HIV, HBV or HCV, should be sent to alternative resources for proper referrals.

Pre-donation information consists of oral or written information given either to individual potential blood donors or groups of potential donors. Usually the information is given by the donor recruiting team some time before the actual blood donation takes place. Schoolteachers, health educators and mass media can also distribute pre-donation information, and it should cover the following:

- The need to recruit people for a regular safe donor pool.
- The procedures involved in giving blood.
- The fact that the blood is tested for HIV, hepatitis B and C, and other infectious agents, and why it is tested.
- The possible consequences of learning that one has HIV or hepatitis B or C infection
- Information about HIV, hepatitis B and C, and other blood-transmissible infections, including the routes of transmission, their natural history and the ways of prevention.
- Procedures to ensure the confidentiality of the test results.
- Why and where to go, other than to Blood Transfusion Services, if the donor thinks that he or she may have been exposed to HIV, hepatitis B or C, and wants more information.

Whenever possible, sufficient time should be allowed between recruitment and the donation sessions to allow potential donors to absorb the information. Pre-donation discussions are an important first attempt at encouraging donors at risk to self-defer from Blood Transfusion Services facilities. These sessions also provide an important opportunity to engage the potential donor in discussions of infection prevention, which may then be carried on to others members of the community.

3.9.2. Pre-donation counselling

Pre-donation counselling provided to individuals before blood is taken. Pre-donation counselling involves the following:

⁵⁷ *Guidelines for blood donor counselling on Human Immunodeficiency Virus*. International Federation of Red Cross and Red Crescent Societies, World Health Organization Global Program on AIDS, 1994.

- Explaining the HIV test and the tests for other blood-transmitted infections.
- Explaining the implications of knowing one's HIV, hepatitis B and C status: the emotional, social and financial consequences, as well as the effects on family and work, that may result from learning one has HIV or other blood-transmitted infections.
- Explaining to uninfected donors the need to avoid future infection by maintaining a low-risk behaviour.
- Encouraging self-deferral if donors think they may have been exposed to HIV, hepatitis B or C and other blood transmitted infections, and advising on where else donors can be tested if they so wish.
- Explaining post-donation procedures for both infected and uninfected donors.
- Securing the donor's informed consent to donate.
- Discussing the possible options for referral and future care if their test result is positive.

Informed consent is the donor's voluntary agreement to have his or her blood tested after sufficient information has been given. Prisoners, and other persons with no power over their blood donation, cannot give informed consent either to the donation or to the testing, and therefore should not be recruited or permitted to act as blood donors.

*Any information obtained during the VCT, or through screening of blood should remain strictly confidential. It must not be used as a basis for stigmatisation or discrimination in the community.*⁵⁸

In **Annex IX** can be found the pre-blood donation-counselling checklist that can be used to verify that all necessary items have been discussed with the potential blood donor.

3.9.3. Post-donation information, counselling, and referral

Appropriately trained staff imparts this type of important information during individual face-to-face counselling. Post-donation counselling should take place as soon as possible after a positive result is reliably obtained, and it is aimed at helping the donor cope with the psychological impact of a positive result. In some settings, post-donation information is provided together with counselling to those found to be HIV-negative, in order to encourage their continuous low-risk behaviour.

Post-donation counselling and referral involves the following:

- Giving the donor time to grasp the news about the status.
- Giving enough time and an opportunity to ask questions.

⁵⁸ *Blood safety and HIV*. UNAIDS Technical update. UNAIDS Best Practices Collection. UNAIDS, 1997c.

- Helping the donor with the emotional and practical impact of the positive result.
- Offering options for continued care for infected donors and their families and/or partners through referral to appropriate organizations and facilities.

Post-donation counselling may involve recognizing and managing acute psychological reactions to the disclosure of a HIV infection. It should therefore be provided only by staff with specific training, or by staff who have direct access to those who can manage psychological reaction, and who are capable of recognizing the need for referral and follow-up. Appropriately trained volunteers could provide such counselling.

A fully implemented blood donor information and counselling programme has the following potential benefits:

- *The waste of collected blood units, as well as the costs from collecting HIV-infected blood, would be minimized*
- *Blood donor HIV, HBV, and HCV prevalence would be reduced to below the national average*
- *An uninfected donor pool would result*

Part IV
Referrals and Linkages

Referrals and Linkages

VCT has been shown to be more effective when developed in conjunction with support services such as medical, social, emotional, legal, family planning, STI, and antenatal services, as well as in conjunction with support groups for PLWHA, community groups, NGOs and CBOs.

In Pakistan, there are some care and support services available both in the governmental and non-governmental sectors. It is highly important that VCT counsellors are aware of these services and are able to make appropriate referrals for PLWHA who have special medical needs. The package of STI care may be available for them.

In VCT, referral is the process by which immediate client needs for care and supportive services are assessed and the clients are assisted in accessing those services (e.g. setting up appointments, providing transportation). Referral should also include follow-up efforts necessary to facilitate initial contact with care and support service providers.

A referral system should be developed in consultation with NGOs, community-based organizations, hospital directors, and other service managers, as well as with networks of PLWHA. Regular meetings among service providers should be held to review and improve the referral system.⁵⁹

4.1. Development of a referral system

4.1.1. Assessing the client's referral needs

The assessment of the client's referral needs should include the examination of his willingness and ability to accept and complete a referral. Service referrals that match the client's self-identified priorities are more likely to be successfully completed than those that do not. Precedence should be given to the medical care referral needs of the HIV-infected clients, as well as to the prevention and support services aimed at reducing the risk of further transmission. When a provider cannot make appropriate referrals, or when the client's needs are complex, clients should be referred to a case management system.

4.1.2. Planning the referral

Referral services should be responsive to clients' needs and priorities in concordance with their culture, language, sex, sexual orientation, age, and developmental level. In

⁵⁹ *Revised Guidelines for HIV Counselling, Testing, and Referral*. Technical Expert Panel Review of CDC HIV Counselling, Testing, and Referral. CDC, 2001.

consultation with clients, providers should assess and address any factors that make completing the referral difficult (e.g., lack of transportation or child care, work schedule, cost). Research results indicate that referrals are more likely to be completed if services are easily accessible to the clients.

4.1.3. Helping clients access the referral services

Clients should receive all necessary information to successfully access the referral service (e.g. contact name, eligibility requirements, location, hours of operation, telephone number). Research has indicated that providing assistance (e.g. setting an appointment, addressing transportation needs) promotes the completion of referrals for some clients.

Clients must give consent before the identifying information, needed to complete the referral, can be shared. Outreach workers and counsellors/educators can be an important and effective resource in helping the clients identify their needs and in planning successful referrals. Referrals are more likely to be completed after multiple contacts with outreach workers.

VCT centres can arrange for facilities for visiting mobile workers on set dates at set locations in order to reduce the problems of the clients (referral, finding the right place, transportation etc.). Alternatively, brochures with all the requisite information, contact numbers and address can be handed out to the clients.

4.1.4. Documenting and follow-up of the referrals

Providers should assess and document whether the client accessed the referral services. If the client did not, the provider should determine the reason; if the client did, the provider should determine the client's degree of satisfaction. If the services were unsatisfactory, the provider should offer additional or different referrals. Documentation of referrals made, the status of those referrals, and client satisfaction should help providers better meet the needs of the clients. Information obtained through the follow-up of referrals can identify the obstacles that hamper the completion of the referral; can help assess the responsiveness of referral services in addressing the client's needs; and can identify the gaps in the referral system.

4.1.5. Training and Education

Providers should ensure that VCT staff members receive adequate training and continuing education in the implementation and management of referrals. Training and education should address the available resources and the methods for managing referrals. It should also promote the understanding of the factors that are likely to influence the client's ability and willingness to use a referral service (e.g. his readiness to accept the service, competing priorities, financial resources). Referrals are more likely to be

completed when a provider is able to correctly evaluate a client's readiness to adopt risk-reducing behaviours. Research indicates that cross-training increases knowledge and the understanding of community resources among the providers, and can thus indicate gaps in services.

4.1.6. Authority

Staff members who do referrals must have the necessary authority to accomplish a referral. Supervisors must ensure that staff members understand referral policy and protocol and have the necessary support to provide referrals. This requires the authority of one provider to refer to another provider (e.g. through memoranda of agreement), or to obtain the client's consent for the release of medical or other personal information.

4.1.7. Advocacy

Staff members who negotiate referrals must possess the knowledge and skills to advocate for clients. Such advocacy can help the clients obtain services by mediating barriers to access to services and promoting an environment in which providers are better informed regarding the needs and priorities of their clients..

4.2. Typical referral needs

4.2.1. HIV testing

Some VCT services may not have the facilities to diagnose HIV/AIDS. Therefore, clients may be referred to diagnostic laboratories for their HIV testing after pre-test counselling. Some VCT services may have initial screening facilities for HIV/AIDS, but for the confirmation of the result they may refer to other services.

4.2.2. HIV/AIDS counselling, care and support

After VCT counselling those clients that need it may be referred for follow-up counselling, irrespective of their status. Seropositive clients should be referred to care and support counselling, which is an integral part of ongoing care and support services. Seronegative clients should also be referred to care and support counselling, especially if their family or friends have HIV/AIDS.

4.2.3. Medical care and treatment

HIV-infected clients should be referred to medical services for further clinical evaluation and management. Screening and prophylaxis of opportunistic infections is important for HIV-infected persons. In addition, the co-infection of HIV and other communicable diseases (e.g. TB, STDs, and hepatitis) can, if untreated, pose a risk to susceptible community members. Therefore, the providers of VCT services should be familiar with the appropriate screening tests (e.g. TB), vaccines (e.g. hepatitis B and C), prophylactic STI and TB treatment, and the clinical evaluation of active TB to ensure that these communicable diseases are identified early and that appropriate clinical referrals are made, even if clients forego outpatient HIV treatment.

4.2.4. Family planning

Women who choose to avoid pregnancy in the future because of their HIV infection should be referred to family planning services. Women who opt for two years of replacement feeding should also receive advice on contraception. If they choose to bear more children, they should be encouraged to delay a new pregnancy for at least two years.

4.2.5. TB clinics

Tuberculosis is the most common opportunistic infection and the leading cause of death among HIV-infected persons in Pakistan. TB is so common in the country that often people get exposed to it in early childhood and become susceptible to the disease. If a person like this gets an HIV infection later in life, also TB is reactivated. Research has shown that with tuberculosis-preventive therapy (TBPT), usually Isoniazid 300 mg daily for 6 months, the incidence of clinical TB in people with HIV can be halved. It is, however, important to screen the patients for active TB before TBPT is given. Therefore referral to a TB clinic is of critical importance in the prevention and management of TB infection among PLWHA.

4.2.6. Partner counselling and referral services

HIV-positive clients should receive adequate information, or be referred to proper services, in order to help them disclose their condition to their spouses, partners or the people with whom they share their injecting drug equipment. The clients should let these people know that they have been exposed to HIV and how they can access VCT.

4.2.7. PMTCT and reproductive health services

Much has been learnt in recent years about the prevention of mother-to-child transmission (PMTCT) through antiretroviral therapy and other interventions. These

interventions rely substantially on the identification of those pregnant women who are infected with HIV. Following VCT, counsellors should refer pregnant women to reproductive health services for appropriate antenatal care and PMTCT.

4.2.8. Prevention and treatment of drug or alcohol use

Clients who use drugs should receive appropriate information or be referred to substance abuse prevention and treatment services and/or needle exchange programmes. All IDUs must be referred to harm reduction programmes or needle exchange programmes during post-test counselling, irrespective of their HIV status.

4.2.9. Psychiatric help services

Clients who have a mental illness, developmental disability, or difficulty coping with their HIV diagnosis should receive psychiatric help or be referred to appropriate mental health services.

4.2.10. Spiritual care

Although the immediate emotional needs of people following VCT may be met by the HIV/AIDS counselling service, some people may require spiritual care to continue a positive and productive life. Such people may be referred to spiritual care, depending on the client's background and religious inclination. Prayer leaders (Imam), peers, and religious scholars can be considered in this regard. However, it is advisable that they have received information or training concerning the emotional and medical needs of PLWHA.

4.2.11. Rape and sexual abuse victims

Young people are often particularly vulnerable to rape, especially from people close to their families. However, young people are often reluctant to report rape or sexual abuse or to seek counselling and VCT following a sexual assault. There are some NGOs in the country who are specifically working on rape and sexual abuse. Development of referral services with these organizations may prove helpful to these young people.

4.2.12. Legal services

Clients who test positive and who are discriminated against, or whose basic human rights are violated, should be referred to legal services for assistance and support. Clients who express their need to have a last will drawn or to secure medical insurance, or sufficient

legal coverage for their family and children, can also be referred to legal services. PLWHA may also be referred to legal services to defend and enforce their rights.⁶⁰

4.2.13. STI clinics

Clients who are at an increased risk for HIV are also prone to contract other STIs. All clients who suffer from any STI should be referred to STI clinics for STI management and prevention. WHO has developed guidelines for the syndromic management of STIs, and the National and Provincial AIDS Control Programmes in Pakistan have trained a number of physicians on these guidelines. All VCT services should have a list of these trained physicians and they should be contacted for the referral of STI patients.

4.2.14. Screening and treatment for viral hepatitis

Many clients who are HIV-infected, or are at increased risk for HIV, are also at increased risk for acquiring viral hepatitis (B and C). MSM and IDUs should be vaccinated against hepatitis B following HBV and HCV screening. Those who are found to be infected by either virus may be referred to gastroenterologists for further clinical evaluation and management.

4.2.15. Social support

Some PLWHA may need help to make plans for their future and for the future of their dependents. HIV counsellors should be knowledgeable about social services that help people with these decisions. Material and financial support is sometimes requested, and counsellors need to be aware of any available services, although these are often limited in developing countries.

4.2.16. Other services

Clients might have multiple needs that can be addressed through other HIV prevention and support services (e.g. assistance with housing, food, employment, transportation, child care, domestic violence, and legal services). Addressing these needs can help the clients accept medical services and adopt and maintain a behaviour that reduces the risk of HIV transmission and acquisition. Clients should receive referrals appropriate for their identified needs.⁶¹

⁶⁰ *Criminal law, public health and HIV transmission: a policy option paper*. UNAIDS best practices collection. UNAIDS, 2002c.

⁶¹ *Revised Guidelines for HIV Counselling, Testing, and Referral*. Technical Expert Panel Review of CDC HIV Counselling, Testing, and Referral. CDC, 2001.

Part V
Monitoring and evaluation

Monitoring and evaluation

A monitoring and evaluation system should be established from the onset for both counselling and testing. Counselling and testing protocol may vary from one programme to another, as it should be based on the goals and objectives of the programme. But whatever the approach taken is, VCT must be regularly evaluated to determine whether it satisfies client needs and is provided in accordance with the pre-determined protocol. Supervisors must be aware of HIV prevention counselling goals and the necessary counsellor skills. Quality assurance for VCT should contain the following elements.⁶²

5.1. Training and continuous education

Basic training in VCT is recommended for all counsellors and supervisors. They also are trained in the transmission and prevention of HIV and other sexually transmitted infections; the diagnosis and monitoring of the disease; the natural history of HIV; common opportunistic infections among AIDS patients; the principles of management and treatment; prevention and control; and other HIV prevention and support services available in the community (e.g. services related to IDUs, reproductive health, TB programme, and health care facilities).

5.1.1. The selection of a VCT trainer

The following eligibility criteria may be considered in the selection of trainers for VCT services:

- Basic graduate level qualification in medical or social sciences with particular regard to psychology.
- Experience in HIV/AIDS and related fields.
- Experience in counselling and testing.
- Experience in community mobilization.
- Experience in staff management.
- Future commitment to work in VCT services.
- Ability to speak in a loud and clear voice.
- Will to use a language that participants can easily understand.
- Ability to cope with conflicts when they arise.
- Ability to display a wide range of genuine human emotion.
- Confidence about his/her ability to work as a VCT trainer.

⁶² *Tools for evaluating HIV voluntary counselling and testing*. UNAIDS best practices collection. UNAIDS, 2000a.

5.1.2. The characteristics of a VCT training programme

A VCT training programme should have the following characteristics:

- The use of national guidelines on VCT as resource material.
- The adoption of a training module in the training programme for VCT counsellors. The training module should have clearly defined learning objectives and include a minimum of set standards to ensure uniformity to the training. The focus should be on knowledge, attitude, and skills
- The training of VCT counsellors on the tasks that can be expected of them during real life situations.
- The active participation of trainers in group discussions and their periodic exercise in each of the training modules.
- The provision of immediate feedback information to the trainees to enable them to self-evaluate their performance. If they do well on an exercise, and are reinforced immediately, what is learnt is more likely to be retained. Immediate feedback also allows misunderstandings to be corrected before they become strong beliefs.
- The individualization of instructions. Trainees may learn at different speeds and in different ways. For optimal learning, the instruction must be flexible enough to allow each trainee to proceed at a comfortable pace. Each trainee should ask questions and receive explanations to the extent necessary for him to understand and acquire skills and knowledge.⁶³

5.1.3. Counsellor selection, training and support⁶⁴

The questionnaire for counsellor selection (**Annex X**) is a tool not designed to evaluate the individual counsellor's counselling skills and competence, which will be covered in the section on counselling evaluation (**Annex XII**). Rather, the questionnaire highlights the counsellor's perceived adequacy of his selection, the training support he receives, and his work satisfaction. In this evaluation, the counsellors are the respondents.

The questionnaire is a semi-structured interview that should be carried out individually by a trained researcher. Additional points and comments may be recorded where appropriate. As the interview will require some time to conduct, and there might be not enough researchers available, a small group of counsellors could be trained to fill in the questionnaire. They should be non-judgmental and allow the interviewees to express their anxieties freely.

⁶³ *Global Program on AIDS*. National AIDS Program Management: a Training Course. 14 Course Director Guide. WHO, 1993.

⁶⁴ *Tools for evaluating HIV voluntary counselling and testing*. UNAIDS Best Practice Collection, UNAIDS 2000, pp 26-29.

5.2. Monitoring

The more is known about how HIV/AIDS spreads, the more interest has been shown in the monitoring and evaluation of successful programmes and the impact the virus has on affected people, their families and communities.⁶⁵ Monitoring and evaluating the efficacy of VCT, usually has had a stress on the prevention, risk reduction and behaviour change potential of VCT. But, also the quality of the services should be monitored, how VCT enables people to accept their HIV-positive status, cope with the disease, and access appropriate services.⁶⁶ Regular and frequent supervision and monitoring is essential to maintain quality control also over laboratory services.⁶⁷

5.2.1. Supervision of counselling sessions

Direct observation of counselling sessions can help ensure that objectives are being met. Supervisors can perform this task periodically, with client consent. Sessions might also be audiotaped – again with client consent – or the sessions can be demonstrated through role-play scenarios between the counsellor and the supervisor. Observation and feedback should be structured, and the outcome should be constructive, not punitive. Supervisors should support positive elements of the counselling session and provide constructive comments regarding content areas needing improvement. Observation and feedback should be conducted regularly for routine counselling.

Staff discomfort with observation typically wanes over time; many counsellors report that the sessions are useful in enhancing skills. When observation is offered routinely, clients seldom refuse to participate. A suggested timeframe for routine, direct observation of an HIV prevention counsellor by the supervisor is twice monthly for the first six months, monthly for the second six months, and quarterly for counsellors with more than one year of experience. After observation, supervisors should provide feedback preferably within the same week.

5.2.2. Case conferences

Regularly scheduled meetings of counsellors allow supervisors to judge each counsellor's skills and areas needing improvement. These meetings can also help counsellors learn techniques from their colleagues. Case conferences are an opportunity for counsellors to discuss specific or problematic questions asked by clients. The result is a better understanding of the concerns that clients, who are HIV-infected or at increased risk for HIV, face. Case conferences can help offset counsellor fatigue and "burnout" by providing a positive outlet for dealing with difficult situations. Discussion might focus on

⁶⁵ *National AIDS programmes: a guide to monitoring and evaluation*. UNAIDS, 2000.

⁶⁶ *Tools for evaluating HIV voluntary counselling and testing*. UNAIDS Best Practice Collection, UNAIDS 2000.

⁶⁷ *Knowledge is Power: Voluntary HIV counselling and testing in Uganda*. UNAIDS case study. UNAIDS, 1999a.

a hard-to-address client or specific elements (e.g. developing acceptable and practical risk-reduction plans with clients who deny the magnitude of their HIV risk). Frequency of case conferences should be balanced with client volume, with efforts made to meet at least monthly.

5.3. Evaluation

The following tools for VCT evaluation have been developed with the aim of evaluating not only the implementation and effectiveness of VCT in HIV prevention, but also ways of assessing the acceptability and quality of services. It also aims to assess the effectiveness of VCT in enabling people with HIV to better accept and cope with their infection and access appropriate services.

5.3.1. VCT counselling readiness

The success of VCT in Pakistan depends to a large extent upon the political commitment to VCT as part of the overall HIV prevention and care programme. NGOs can also play an effective role in advocacy and in setting up projects to demonstrate the need for and the benefits of VCT. But a centre is not ready to start VCT counselling before certain pre-determined aspects are functioning. A list of these aspects is described in **Annex XI** in the form of a questionnaire for national and provincial AIDS programme managers, coordinators of counselling services, NGOs coordinators involved in VCT activities, and policy makers.

5.3.2. Evaluation of counselling quality and pre- and post-test counselling content⁶⁸

HIV-related counselling has been divided into pre-test, post-test, follow-up counselling, diagnostic HIV counselling (where testing is not available), and counselling associated with specific interventions, such as the prevention of mother-to-child transmission (see chapter 3.1.). In the same way, counselling assessment will have to be adapted to the types of counselling (individual, couple, family and children) and may vary considerably if counselling is for young people, drug users, sexual workers, etc.

To assess the standards of counselling taking place in the various contexts of HIV testing, care and support services, forms are provided in **Annexes XII, XIII and XIV**. The forms can also be used to help in the training and assessment of individual counsellors during their training or follow-up review. In the evaluation of counselling quality and content, the forms should be completed by an external assessor (counselling supervisors, trained

⁶⁸ *Tools for evaluating HIV voluntary counselling and testing*. UNAIDS Best Practice Collection. UNAIDS, 2000 pp 30-35.

counsellors). Although the elements contained in the forms are fairly inclusive, the counsellor may be evaluated on the protocol he/she has been trained to follow.

The standards assessed are based on the performance skills of the counsellors and these are best assessed through the observation of real counselling situations. Not more than three to five sessions need to be observed at each counselling site. For each selected counsellor, an observation could be made on the first counselling session conducted on the day of monitoring. When only one or two counsellors work at a site, three to five counselling sessions could be selected at random. Before the observer sits in, the client is informed about the observation and its purpose, and consent is sought. The observer must ensure that he/she is as unobtrusive as possible and does not disrupt the counselling session. Assurance of confidentiality must also be given. Immediate feedback to the counsellor by the trained supervisor is advised, with an opportunity for the counsellor to express his/her opinions and concerns.

5.3.3. Evaluation of client satisfaction⁶⁹

The aim of VCT services is to enable people to know and understand their HIV status. The aim for those testing seropositive is to access care and support at an earlier stage, to cope better emotionally with their infection, to plan for their and their dependents' future, and to prevent HIV transmission to their sexual partners. The main aim for those testing seronegative is to be able to make decisions about their sexual behaviour, or other risk behaviour, in order to continue remaining negative.

In the attempt to evaluate clients' satisfaction after counselling, generic tools have been developed to be used by experienced researchers. A semi-structured interview to be carried out individually is proposed in **Annex XV**. The interviewer should be trained to be non-judgmental and allow the interviewee to express his/her anxieties. Additional points and comments may be recorded where appropriate. As the interviews will require some time to carry out, a small sample of people should be interviewed. To avoid a selection bias, a convenience sampling method can be used: all people receiving counselling within a specific period (e.g. one week) will be asked by their counsellor to attend an exit interview. The interviews will be voluntary, and the clients should be assured that they are anonymous and confidential.

5.3.4. Evaluation of the operational aspects of the sites and services

Counselling sessions should be conducted in a private space where discussions cannot be overheard. Clients should not have to wait for long periods between testing and counselling, and information could be provided for the necessary waiting time (e.g. through videos). Periodic time-flow analyses or client surveys can be used to evaluate

⁶⁹ *Tools for evaluating HIV voluntary counselling and testing*. UNAIDS Best Practice Collection. UNAIDS, 2000, pp 44-48.

adequacy of space, client flow, and the length of the waiting period. An appointment system can be adopted for later sessions to reduce waiting times

In the evaluation of VCT services, their accessibility, convenience, privacy, confidentiality, linkage, HIV testing methods, cost sustainability, and services for special and vulnerable groups should be evaluated. As few VCT centres are working in the country, it would be appropriate to interview the managers of all sites (**Annex XVI**).

5.3.5. Monitoring and evaluation of blood donation counselling

Blood Transfusion Services' (BTS) counselling activities require regular monitoring along with the other service elements. Evaluating the effects of blood donor counselling will enable BTS to assess its capacity to meet the needs of its donor population. Specific quality control mechanisms are also necessary to ensure the consistency of the counselling. Internally, regular staff meetings and case conferences can help to monitor and improve counselling quality. These meetings will be the responsibility of the identified supervisor of the counselling staff. External quality control will be the responsibility of the national or regional focal point or committee for counselling, which will also co-ordinate links between the formal and informal health and social resources involved in blood donor counselling.

Both quantitative and qualitative evaluation should be performed. Evaluation is easier to do when its design is incorporated in the initial development of blood donor counselling. Both forms of evaluations should be reviewed yearly to ensure that they are still relevant.

The following general questions may be asked when evaluating BTS counselling:

1. To what extent does pre-donation information/discussion result in donor self-deferral and donor uptake?
2. Does counselling reduce donations from those with HIV, hepatitis B or C and other STIs, and how is this reflected in cost?
3. To what extent does counselling reveal psychosocial difficulties, and how does this alter the quality of blood donation procedures?
4. Do BTS-based information giving, discussion and counselling affect subsequent risk behaviour or future intentions to donate blood?
5. What is the quality and consistency of links with companion agencies for counselling, testing?
6. What procedural and structural issues appear to aid or impede the development of blood donor counselling and the beneficial impact of counselling on donors?

Monitoring is a descriptive process supported by statistics, case files and records that can be analysed to determine the following types of information:

- The number of people who come for pre-donation counselling, and then go on to donate blood
- The number of pre-donation sessions
- The illnesses detected at physical check-ups prior to donations.

- The different types of risk histories and the number of donors found to be HIV positive.
- The involvement of loved ones in the donation process.
- Post-donation counselling and referral process, and where donors were referred.
- Psychosocial issues raised in blood donation counselling.
- The amount of time taken for post-donation counselling.
- The costs of providing blood donor counselling, and the savings made from the reduction of HIV-positive donations.

Information obtained can be used to improve the quality and relevance of counselling activities, to help refine counselling training and for annual reports.

Part VI
Special Issues

Special Issues

6.1. Encouraging beneficial disclosure⁷⁰

UNAIDS and WHO encourage beneficial disclosure. This disclosure is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for the individual client, and for his/her sexual and drug-injecting partners and family; leads to a greater openness in the community about HIV/AIDS where there is need to prevent the onward transmission of HIV/AIDS.

Such beneficial disclosure not only maintains ethical principles, but also has a public health function, as it encourages people to access HIV prevention and care services. This is achieved by establishing a climate of trust between healthcare providers and those that need HIV services, respecting them as people who can and will make the right decisions regarding their behaviour. Beneficial disclosure also serves the goal of demystifying the HIV/AIDS epidemic. As more people feel able and willing to disclose their status, the number of individuals and families, who are openly involved in dealing with the epidemic in positive and supportive ways, grows within a community, and indeed within the nation. As a consequence, discrimination, stigma and secrecy are reduced.

Nevertheless, preconditions are necessary to the promotion of beneficial disclosure and the encouragement of people to access prevention and care programmes. People must have access to VCT services in which they can learn their HIV status and receive support and referral in dealing with the news. Furthermore, they must have an incentive to learning their status in terms of it meaning greater social support, access to healthcare options, and an increased ability to live in a constructive way with their status, be it negative or positive. Finally, they must not fear stigma and discrimination if found to be HIV positive.

Healthcare workers should be more empowered to handle the medical, as well as the psychosocial, management of clients with HIV/AIDS. This should include training and empowerment regarding universal precautions against the transmission of infectious diseases, as it is the fear of transmission of HIV among healthcare workers that often leads to stigma and discrimination against PLWHA. Experience has shown that the impact of this training in health settings needs regular monitoring and staff updates to ensure that infection control procedures are maintained.

⁷⁰ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

Recommendations to encourage beneficial disclosure:

- Conduct public information campaigns and community forums aimed at promoting tolerance, compassion, understanding, and the reduction of fear, stigma and discrimination.
- Encourage participation of PLWHA in public information campaigns and in HIV/AIDS programmes and policy formulation.
- Establish more VCT services, including in rural areas and for marginalized groups.
- Support governmental agencies, NGOs and CBOs to produce community-based services, including VCT, family outreach, community support, positive living, support groups, and care options more widely available.
- Encourage the media to report on HIV/AIDS in a responsible, non-discriminatory and non-sensational manner.
- Train health care workers in the management of HIV and universal precautions, in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train other professionals (social workers, police, lawyers, judges) in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train key personnel in non-health employment settings, including human resource management in industry, in promoting non-discriminatory practices in the workplace.
- Enact or reform of laws, administrative guidelines and professional codes of conduct to prohibit discrimination and breaches of confidentiality related to HIV status.
- Create legal support services for those who have suffered discrimination based on HIV status.

6.2. Encouraging ethical partner counselling (partner notification)^{71 72}

The objectives of partner notification are to:

- Prevent HIV transmission to people who may be exposed either sexually or through needle-sharing
- Improve the care and support of PLWHA.

Partner counselling can be done by the HIV positive person him/herself, or by the health care provider, or through the combined efforts of both:

⁷¹ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

⁷² *The role of name-based notification in public health and HIV surveillance*. UNAIDS Best Practices Collection. UNAIDS, 2000d.

- (a) **Source referral:** the approach by which an HIV-positive person is encouraged to counsel his/her sexual/drug-injecting partners concerning their possible exposure to HIV. This is done without the direct involvement of healthcare providers. In this approach, the healthcare provider works with the HIV-positive person regarding the nature of the information to be passed on to their partner(s), and the ways of doing it.
- (b) **Provider referral:** the approach by which the HIV-positive person gives his/her partners' names to a health care provider who then confidentially counsels the partner(s) directly. In this approach, the healthcare provider does not disclose the name of the HIV-positive person to the partner, only provides the information that the partner is likely to have been exposed to HIV infection. This is done with the consent of the source client or patient.
- (c) **Conditional referral:** The health care provider of the source client or patient obtains the names of his/her partners, but allows the source client a period of time to counsel the partners' him/herself. If the partners are not counselled within this time period, the healthcare provider counsels the partners, without naming the source patient or client concerned.

Partner counselling/notification has a long history as one possible aspect of the public health response to STIs, other than HIV/AIDS, such as syphilis and gonorrhoea. There is current debate whether, in the context of the transmission of HIV/AIDS, the status and/or name of the HIV-positive person should be disclosed mandatory to his or her sexual or drug-injecting partners.

However, in the history of partner counselling, there is no clear data indicating that the mandatory counselling of partners is more effective in preventing transmission than the voluntary counselling of partners. It does appear that when people think that they will be forced to notify their partners, or that their status will be revealed without their consent, they choose not come in for STI testing, counselling or other prevention and care services. This has been true in the case of syphilis and gonorrhoea even though, unlike HIV/AIDS, these are curable and carry much less stigma and discrimination than HIV/AIDS. It is even more likely that a policy of mandatory partner counselling will deter people from using HIV testing and counselling services, because there is greater incentive to fear testing and disclosure due to the serious stigma and discrimination surrounding HIV/AIDS.

In general it appears that mandatory partner counselling schemes are not necessary, because voluntary partner counselling schemes can accomplish the critical goals. Voluntary partner counselling schemes can help to create a climate of confidence that will attract people to HIV testing and counselling services so that more people learn their HIV status. Among those who do come to healthcare facilities, and are faced with a decision of notifying partners or not, it appears that most people agree to do so, on a voluntary basis, after counselling. Finally, in the context of a generally voluntary partner-counselling program, the small number of cases where persons refuse to notify their partners can be taken care of on an individual basis, as described below.

Thus, for reasons of principle and because it is more feasible and successful, UNAIDS and WHO encourage ethical partner counselling. Ethical partner counselling is based on the informed consent of the source client or patient and, where possible, maintains the confidentiality of source client or patient, that is, his/her name is not revealed to the partners being counselled. This will often be extremely difficult to maintain in the context of marital relationships, and requires the provision of counselling and support to both spouses to ensure the prospect of abuse and discrimination is minimized or eliminated. Ethical partner counselling also takes into account the serious consequence of not counselling partners – the possible transmission of the HIV infection. This consequence requires an ethical weighing of the benefits and harms that are likely to occur if and when there is refusal on the part of an HIV positive person to counsel partners.

In light of this, UNAIDS and WHO encourage ethical partner counselling programs which:

- Employ serious counselling and persuasion towards the counselling of partners.
- Where the source client refuses to notify his/her partner, empower the healthcare provider to make ethical decisions based on the potential harms and benefits to the parties, and decide whether to counsel the partner(s) without the consent of the source client, in the circumstances outlined.
- Provide social and legal support for the source client, and other relevant parties (spouses, partners, family members) to protect them from physical abuse, discrimination and stigma, which may result from partner counselling.⁷³

6.2.1. Partner counselling by healthcare providers without consent

There will be some cases where the HIV positive person (source client) does not wish to, and may refuse to, notify his/her partner(s) or allow them to be counselled by the health care provider. It is important to bear in mind that such refusal is most often due to a fear of rejection by partners and family, to a fear of stigma and discrimination, and/or to a fear of being blamed for the infection of others. It may also involve feelings of despair, remorse and guilt. Refusal to notify partners is very seldom due to a desire of the HIV-positive person to place another person deliberately at risk of HIV infection.

For some, the consequences of their HIV status becoming known by their partners are severe. This is particularly the case for women who live in societies where women suffer social, economic and legal disadvantages because they are women. In such places, the woman is often blamed for her own infection, and well as for the infection of her husband/partner, even though it is likely that she was infected by her husband/partner. The reaction to her disclosing her status may also include physical violence and abandonment, whereby she (and her children) is thrown from the home and given no economic or social support. Thus, women may have very valid reasons for fearing to disclose their status to a husband/partner.

⁷³ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

Given the possible serious consequences of counselling partners (discrimination, abandonment, violence) and of not counselling partners (transmission of HIV infection), counsellors and healthcare workers must be trained to handle the difficult ethical decisions to be made in each case. In every case, all the potential harms and benefits of partner counselling or non-counselling should be weighed. In most cases, with counselling and with a demonstration of support, the HIV-positive person will agree to notify partners. Initial support may take the form of notification in the presence of the counsellor and/or in the presence of another family member who will provide support, and protection, if necessary. Furthermore, there should be follow-up in the case and referral to other support services to ensure that the couple or family can cope with HIV/AIDS.

But in cases where the source client refuses to notify, following repeated efforts to persuade him/her to do so, and where the failure to notify creates a danger to a partner whose identity is known to the counsellor (in legal language “an identifiable risk to an identifiable third party”), the counsellor should be authorized to counsel the partner(s) without the consent of the source client. In making this decision, the counsellor should ensure that the following factors are present:

- The HIV-positive person (source client) has been thoroughly counselled as to the need for partner notification/counselling.
- The counselling has failed to achieve the appropriate behavioural changes, including the practice of safe sex.
- The source client has refused to notify, or consent to the counselling, of his/her partner(s).
- A real risk of HIV transmission to an identifiable partner(s) exists.
- The source client is given reasonable advance notice of the intention to counsel by the health care worker.
- The identity of the source client is concealed from the partner(s) if this is possible in practice.
- Necessary follow-up is provided to ensure support to those involved, and to prevent violence, family disruption, etc.⁷⁴

⁷⁴ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

To encourage ethical partner counselling, UNAIDS and WHO recommend the following:

- Develop national policies and public health legislation on partner counselling that protect the principles of confidentiality and informed consent, and provide for the limited and clearly defined circumstances under which partner counselling may take place without consent.
- Develop public health legislation that authorizes health care providers to decide, on the basis of each individual case and ethical considerations, whether to counsel partners without the consent of the source client, under certain circumstances.
- Hold consultations among health care providers, government and affected communities about how to encourage ethical partner counselling and protect people who disclose their status through such counselling.
- Provide training and guidelines for health care providers and counsellors about how to protect confidentiality and informed consent in the context of partner counselling; how to encourage and assist voluntary partner counselling; how to make difficult ethical decisions in cases where there is refusal to counsel partners; and how to counsel partners in ways that harm is minimized and support is provided.
- Promote the establishment of professional ethical codes between healthcare and social service providers, which require respect for confidentiality, and informed consent, in the context of partner counselling, and provide penalties for unethical conduct.
- Establish mechanisms for accountability and modes of laying complaints within healthcare institutions and within communities when healthcare providers and other professionals counsel partners unethically.
- Support practical legal and social measures that address the vulnerability of people, particularly that of women, to stigma, physical violence and abandonment, including projects in the community, which will assist in providing treatment, care, emotional support and protection from discrimination to those involved in partner counselling.
- Promote and support community projects about the responsibility to protect oneself and others from HIV infection, particularly among men and boys.⁷⁵

In **Annex XVII** is found a form for partner notification.

⁷⁵ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

6.3. Appropriate use of HIV case reporting

Some countries have recently considered whether they should implement a policy of named HIV case reporting. Under such a policy, healthcare providers would be required to report by name all HIV cases diagnosed by them to a health authority. Other forms of case reporting involve the use of a code, sometimes called a “unique identifier”, for each case; or the reports provide information on cases anonymously. Named case reporting has been promoted as a means to open up the HIV/AIDS epidemic; decrease denial; improve access to prevention and care services for individuals affected by HIV/AIDS; and obtain more accurate information on the prevalence and incidence of HIV and AIDS for surveillance purposes.

While AIDS case reporting has been implemented in most countries, implementation of HIV case reporting has been much more limited. Many countries started to collect information of HIV cases at the beginning of the epidemic, but later dropped the practice when the infection became widespread. Reasons for dropping the practice were the high cost and complexity of maintaining the system, the lack of effective treatment or preventive options once people were discovered to be HIV positive, and the little additional benefit for surveillance purposes.

However, there has been a recent trend in high-income countries to employ HIV case reporting, as well as AIDS case reporting. This trend is based on the fact that, where anti-retroviral treatment is available, the access to and use of these drugs has dramatically decreased the incidence of AIDS, resulting in AIDS cases no longer being an accurate base by which to calculate back to HIV incidence and prevalence. Furthermore, in these countries, case reporting of HIV cases helps to monitor the access of HIV positive individuals to appropriate services and treatment, including the use of anti-retrovirals.⁷⁶

⁷⁶ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

Recommendations for the appropriate use of HIV case reporting:

- In resource-poor countries where access to HIV testing and effective treatment are limited, and where there is insufficient infrastructure to maintain confidentiality, avoid case-based reporting of HIV and employ sentinel surveillance within the framework of second generation HIV surveillance.
- Where there is wide access to, and use of HIV tests, established surveillance systems for communicable diseases, security and confidentiality of data, and access to anti-retroviral treatment, consider the use of HIV case reporting to provide information to monitor HIV incidence and prevalence, and to increase access to treatment, patient compliance, and long-term follow-up.
- Ensure that the surveillance methodology employed does not interfere with prevention or care activities, for example, by allowing breaches in confidentiality that would make people afraid to take advantage of voluntary counselling and HIV testing services.
- Ensure confidentiality and security of information through the development of policy; infrastructure (e.g. data-storage and transmission systems that ensure the physical security of data; electronic security of computer files); increased capacity of health professionals to receive, report, and use data; and legislation that protects against breaches of confidentiality.
- Increase public confidence in surveillance and protect the right to privacy through the enactment of regulations, policies and laws that preclude the non-public health use of the data.
- Where name-based or coded reporting is employed, assess periodically the extent to which incomplete reporting, incomplete diagnosis, or duplication of cases is compromising the utility of the received data.
- In the use of sentinel surveillance that is unlinked, ensure that personal identifiers are removed from blood specimens in a way that does not permit re-linkage.
- Strengthen the means and frequency by which the results of surveillance are disseminated in ways that open up the epidemic; reinforce prevention and care programmes; reduce fear, stigma and denial; and avoid the further stigmatisation of certain groups of people, e.g. migrants, refugees, sex workers, men having sex with men.⁷⁷

⁷⁷ *Opening up HIV/AIDS epidemic*. UNAIDS and WHO, 2000f.

6.4. PLWHA and nutrition

Good nutrition is very important for PLWHA. A HIV-positive person needs to increase the amount of food he eats to maintain the lean body weight. A balanced diet is important, including plenty of protein and whole grain foods, with some sugar and fat. An exercise programme will help build and maintain muscle. Plenty of liquids are necessary to help the body deal with the effect of medication. Another important aspect is food safety, keeping the kitchen clean, washing food, and being careful about food preparation and storage. If the tap water isn't pure, only bottled water should be drunk. Before taking nutritional supplements, expert advice from a health care provider should be asked.⁷⁸

6.4.1. Why is nutrition important?

Good nutrition means getting enough macronutrients and micronutrients. Macronutrients contain calories (energy): proteins, carbohydrates, and fats. They help to maintain body weight. Micronutrients include vitamins and minerals. They keep cells working properly, but will not prevent weight loss.

Good nutrition can be a problem for many people with HIV. When the body of a PLWHA fights an infection, it uses up more energy and thus the patient needs to eat more than usually. But when they feel sick, they eat less than normal. Some medications can upset the stomach, and some opportunistic infections can affect the mouth or throat. This makes it difficult to eat. Also, some medications and infections cause diarrhoea, which causes the body to actually use less of what is eaten. Weight loss might mean either losing fat, or losing lean body weight like muscle. When too much lean weight is lost, the body chemistry changes. This condition, which can kill the patient, is called the wasting syndrome or cachexia. If more than 5% of lean body weight is lost, it could be a sign of wasting, and a doctor should be consulted.

6.4.2. Nutrition guidelines for PLWHA

PLWHA should eat more for extra muscle weight helps fight HIV. Especially proteins and starches are important, with moderate amounts of fat. Meats, fish, beans, nuts and seeds are good sources of protein, which helps build and maintain muscles.

Carbohydrates are a source of energy. Complex carbohydrates come from grains, cereals, vegetables and fruits, and are a good source of fibres and nutrients. Complex carbohydrates release energy slowly, over time. Simple carbohydrates, or sugars, release energy quickly. Sugars are found in fresh or dried fruit, honey, jam or syrups.

⁷⁸ *Nutrition: Fact Sheet Number 490*. New Mexico AIDS Info Net, 2003.

Some fats are needed as they give extra energy. The "monounsaturated" fats in nuts, seeds, canola and olive oils, and fish are considered good fats. The "saturated" fats in butter and animal products are considered bad fats.

A moderate exercise programme will help the body turn food into muscle. PLWHA should not exercise too strenuously, but incorporate light exercise into the daily activities. Drinking enough liquids is very important. Extra water can reduce the side effects of medications. It can help avoid a dry mouth and constipation. It should be remembered though, that drinking tea, coffee, cola soft drinks, cocoa or alcohol could actually make the body lose liquids.

Proteins help the body grow and heal. Foodstuffs with a high amount of proteins include fish and other seafood, meat (e.g. beef, lamb and goat), fowl (e.g. chicken and duck), eggs, milk, cheese, beans, rice, peas, dark green vegetables, cereals, nuts, and soybean products.

Carbohydrates give the body energy. Starches and sugars are types of carbohydrates. Starches are found in corn, rice, wheat, oats, noodles, and plain and sweet potatoes. Sugars are found in sugarcane, beets, refined sugar, candy, honey, and fruit. Starches in potatoes and wheat give the body a steady source of energy. Refined sugars, such as candy, give the body only sugar and no other nutrients. Eating too much sugar can cause tooth decay and gum diseases.

Fats and oils help the body store energy. There is twice as much energy in fat as in proteins or carbohydrates. This means that eating fats and oils helps people gain weight. The problem with excess fat is that it causes heart disease and excess weight. This is usually not a problem for PLWHA, who are trying to gain weight. Foods with fat include oil, butter, margarine, nuts, soybean, coconut, milk and red meat like beef, lamb and goat.

Vitamins and minerals are necessary for a person's health. They are contained in many different foods. A varied diet is important for a person's health, as it is a source of a variety of vitamins and minerals.⁷⁹⁸⁰

6.4.3. Food safety

It is very important to protect PLWHA against infections that can be carried by food or water. Hands must be washed before preparing food, and all kitchen tools and work areas have to be kept clean. All fruits and vegetables have to be washed carefully. No raw or undercooked eggs or meat should be eaten, and the juices from raw meat should be cleaned up quickly. Leftovers should be kept refrigerated and eaten within three days.

⁷⁹ HIV, Health and Your Community. A Guide for Action. R. Granich, J. Mermin, 2001.

⁸⁰ Fact sheets on HIV nutrition are available at www.larklands.net and at www.daair.org.

Expired food should not be bought nor eaten. Some germs are spread through tap water. If the public water supply isn't totally pure, only bottled water should be drunk.

6.4.4. Supplements

Some people find it difficult to go shopping and prepare meals all the time. Supplements can help them maintain their body weight and get the vitamins and minerals they need. PLWHA should not use products designed for weight loss, even if they claim to contain everything needed for good nutrition. The health care providers can help choose the right supplements. .

6.5. Recommendations to prevent the sexual transmission of the HIV infection

- Be aware that if you have a mutually faithful relationship with your sexual partner, if both you are seronegative, and if neither of you is exposed to contaminated blood, e.g. by using intravenous drugs or sharing needles, you are not at any risk of a sexually transmitted HIV infection.
- If you intent to have sexual intercourse and are not in a mutually faithful sexual relationship, be aware that your chance of acquiring HIV infection is influenced by the following three main factors.

1. The choice of your sexual partner(s).

The risk of infection is directly related to the possibility that your partner may be infected; for heterosexual and homosexual partners, this varies considerably according to the nature of their exposures. Therefore:

- Do not have sexual relationships with casual or unknown partners.
- Do not have sexual relations with people who may use or have used injectable drugs.
- Do not have sexual relations with people who have many different sexual partners, such as male or female sex workers.

2. The number of sexual partners.

The greater the number of partners with whom you have sexual intercourse, the greater the likelihood that you will encounter a partner with HIV infection. Therefore, reduce the number of sexual partners to the greatest possible extent.

3. The type of sexual behaviour practiced.

If you are considering sexual relations with someone whose infection status or sexual or injecting drug use history is unknown to you, abstention form sexual intercourse or rigorous restriction of sexual contact to activities that do not involve the sharing of semen, vaginal and cervical secretions or blood – such as hugging and caressing – will

eliminate the risk of acquiring HIV infection. In all other instances, the routine correct use of condom is strongly recommended.⁸¹

6.6. Recommendations to healthcare providers

- Be aware of and sensitive to sexual behaviour that places people at risk of HIV infection.
- Obtain a sexual history routinely. Be non-judgmental.
- Educate patients about HIV transmission and its prevention, including the avoidance of partners at high risk of infection (e.g. IDUs, MSM etc.).
- Offer VCT to people at increased risk of HIV infection.
- Find out what services and resources are available within the community so that people can be referred appropriately.
- Where resources and programmes exist, be prepared to provide additional support through counselling, peer groups, and other services for HIV-infected persons and their sexual partners, or at least refer them to public health or other medical facilities for such support.
- Encourage the patient to refer his sexual contacts to VCT services.
- Assist HIV-infected and non-infected users of injecting drugs to avoid sharing needles and to avail themselves of VCT services and other relevant programmes.⁸²

⁸¹ *Guidelines for counselling about HIV infection and disease.* WHO AIDS Series 8. WHO, 1990.

⁸² *Guidelines for counselling about HIV infection and disease.* WHO AIDS Series 8. WHO, 1990.