

Mental Health and HIV/AIDS

Basic Counselling Guidelines for Anti-retroviral (ARV) Therapy Programmes

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- ❖ Basic AIDS Counselling Guidelines (first edition October 2001, reprinted February 2004)
- ❖ Counselling Guidelines on Disclosure of HIV Status (first edition June 2000, reprinted February 2004)
- ❖ Counselling Guidelines on Palliative Care and Bereavement (first edition May 2001, reprinted February 2004)

The above guidelines have been adapted and expanded for use in anti-retroviral therapy programmes by:-

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Mental health and HIV/AIDS series

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Other modules are:-

1. Organization and systems support for mental health interventions in anti-retroviral (ARV) therapy programmes
3. Psychiatric care in anti-retroviral (ARV) therapy (for second level care)
4. Psychosocial support groups in anti-retroviral (ARV) therapy programmes
5. Psychotherapeutic interventions in anti-retroviral (ARV) therapy (for second level care)

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Preface

The AIDS epidemic is one of the most serious public health and social challenges the world has ever faced. It not only destroys individuals, but also families, communities and the whole societal fabric. Worst hit are communities least able to put in place appropriate measures for its containment and control. It is probably the biggest hurdle to the attainment of the Millenium Development Goals.

As a bold measure to counteract it, WHO has launched the 3 by 5 Initiative that, while primarily aimed at providing treatment to millions of people in need of it, also aims at building the elements of the health system that will be needed to deliver it.

Therefore, treating mental disorders of people living with HIV/AIDS has huge humanitarian, public health, and economic consequences; the same applies to providing people in need with appropriate psychosocial support. This is not an easy task, in view of the scarcity of human, technical and financial resources.

The present series is a contribution from the Department of Mental Health and Substance Dependence to the WHO 3 by 5 Initiative, but also goes beyond that. Its production brought together experts on mental disorders in people with HIV/AIDS from around the world. They graciously contributed their knowledge, expertise, energy and enthusiasm to this endeavour. We are profoundly indebted to them all, as well as to the agencies and organizations to which they are connected. The contributors' names are indicated in each of the modules in this series. A special thanks goes to Prof Melvyn Freeman, who steered this illustrious group, sometimes through uncharted waters, with patience and efficiency.

Now, we make this material available, not as a finalized product, but rather as a working tool, to be translated into local languages, adapted as needed, and improved along the way. A set of specific learning/training instruments, related to this series will soon be released, as another contribution to the mammoth task of improving the skills of the human resources available and needed, particularly where the 3 by 5 Initiative is being rolled out. Comments, suggestions and support are most welcome.

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Foreword

Among those affected by or at risk of acquiring HIV/AIDS are people with mental disorders. This happens primarily through two mechanisms:

- (i) some mental disorders make people more vulnerable to infection with the virus (e.g., intravenous drug use, alcohol abuse, major depression and psychotic disorders, developmental disabilities, and other mental disorders that impair judgement and decision-making) and more vulnerable to situations that increase the risk of passing the virus to others; and
- (ii) some forms of HIV infection affect the brain thus creating clinical pictures that initially resemble several different mental disorders.

Unfortunately the interplay between HIV/AIDS and mental disorders goes beyond the mutual facilitation of occurrence. Perhaps the most relevant practical aspect of this interaction relates to adherence to treatment. It is well known that the presence of an untreated mental disorder – particularly depression, psychotic and substance use disorders – considerably decreases adherence to the treatment of any condition, including HIV/AIDS.

The failure of adhering to the proper regimen of anti-retroviral (ARV) treatment carries three major consequences. First, the expected benefit of the treatment does not take place, the clinical situation worsens and mortality increases. Second, the irregularity of the intake of the ARVs brings new resistant strains of the virus, thus complicating its future control. Third, the interrupted or incomplete course of treatment wastes money and other resources that could otherwise have produced more cost-effective results in adherent patients.

In addition, being HIV-positive, or having someone with HIV/AIDS in the family can be stressful for some people with HIV and for carers. In many countries where HIV prevalence is high it is not infrequent to find more than one person with HIV/AIDS in the same household, at the same time. The stress of living with a chronic illness or caring for an ill relative – even if it does not lead directly to a mental disorder such as major depression – may result in a chain of psychosocial reactions that cause considerable pain and dysfunction. Such dysfunction and

distress may decrease resistance and resilience to co-morbid conditions, and contribute to reduced adherence to medical regimens.

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Definition of terms

Affected by AIDS means experiencing psychological, social, or economic problems because a spouse, family member, or close friend is living with AIDS or has died from AIDS.

Anti-retroviral treatment involves using a number of drugs to cut down how quickly HIV replicates (reproduces itself) in the body. It helps the immune system to function normally but does not cure HIV.

Antibodies are substances produced by the body to fight infection. HIV infection leads to the production of antibodies. Although they are not effective in fighting HIV, they can be detected by a laboratory test.

Client refers to a person receiving counselling services.

Confidentiality means that information shared is not revealed to anybody else, except with the permission of the client. Confidentiality is essential in the relationship between a counsellor and a client.

Contraception means prevention of pregnancy during sexual intercourse by using a contraceptive method such as a condom, a diaphragm, contraceptive pills, or hormone injections.

Counsellor refers to the person providing counselling services. This may be a professional accredited counsellor, or may be a person who has developed skills and experience in helping people through their difficulties. This booklet is primarily meant for the latter.

HIV disclosure means revealing or uncovering information about a person's HIV status. There are different types of disclosure:

- ❖ **Voluntary disclosure** refers to when the client willingly shares information about their HIV status with other people. A counsellor should help the client to identify possible impacts on their decision;
- ❖ **Indirect disclosure** happens when clients do not actually *tell* others, but indirectly reveal their HIV status through things that they do (e.g. taking pills openly, changing their diet), being aware that others may recognise what those actions may mean. In cases of indirect disclosure, others may or may not then raise the issue with the person. This may then lead to full disclosure to that person;

- ❖ **Full disclosure** is when the client publicly reveals their HIV status to a person or organisation, for example, a family member, friend, support group or to the media. Before a client discloses their HIV status, a counsellor can assist them to explore who to tell, how and when to tell. In this way, the client remains in control of what to say and how to say it;
- ❖ **Partial disclosure** means that the client will only tell certain people about their HIV status, for example, a spouse, a relative, a counsellor or a friend. Counsellors need to assist their clients to think carefully and prepare them for the range of possible outcomes before disclosing their status. The client may not be able to control what happens, once they have disclosed. Most cases of involuntary disclosure arise from situations where a client decides to partially disclose their status and without their knowledge the information is made public by an individual or organisation;
- ❖ **Non-disclosure** means that the client does not reveal their HIV status to anyone; and
- ❖ **Involuntary disclosure** happens when someone reveals someone's HIV status without their approval or even without their knowledge.

Infected with HIV means carrying the Human Immunodeficiency Virus in your body. This is determined by a positive HIV test and is therefore also referred to as being HIV positive. It also has the same meaning as living with HIV.

Palliative Care is the care of someone who has an illness that cannot be cured. It involves the control of pain, as well as support for psychological, social, and spiritual problems.

Re-infection can occur when a person living with HIV has unsafe sex with another person living with HIV. It can further weaken the body's defences and lead to faster progression to AIDS.

Safer sex means having sexual intercourse with a low risk of transmitting HIV infection. It includes correct use of a condom and sex without penetration (as for instance in mutual masturbation).

Understanding basic counselling

AIDS counselling can mean different things to different people. It is therefore important to agree on what it is and what it aims to achieve. First of all, we need to establish what we mean by counselling.



Counselling includes:

- ❖ Establishing helping relationships with clients;
- ❖ Having conversations that have a purpose;
- ❖ Listening attentively to clients;
- ❖ Helping clients tell their story;
- ❖ Giving clients correct and appropriate information;
- ❖ Helping clients make informed decisions;
- ❖ Helping clients recognise and build on their strengths; and
- ❖ Helping clients develop a positive attitude to life.

Counselling does not include:

- ❖ Giving advice;
- ❖ Making decisions on behalf of clients;

- ❖ Judging clients;
- ❖ Interrogating clients;
- ❖ Blaming clients;
- ❖ Preaching or lecturing to clients;
- ❖ Making promises that you cannot keep;
- ❖ Imposing your own beliefs on clients; and
- ❖ Arguing with clients.

The purpose of AIDS counselling is to:

- ❖ Help clients cope with the emotions and challenges they face when:
 - they are worried about being infected with HIV;
 - they have found out that they are infected with HIV; and
 - they are affected by AIDS in their family or among their friends;
- ❖ Help clients avoid infection or re-infection with HIV;
- ❖ Help clients cope better in a crisis; and
- ❖ Help clients who are living with HIV to make choices and decisions that will prolong their life and improve their quality of living.

What makes an effective counsellor?

To be an effective counsellor you need to:

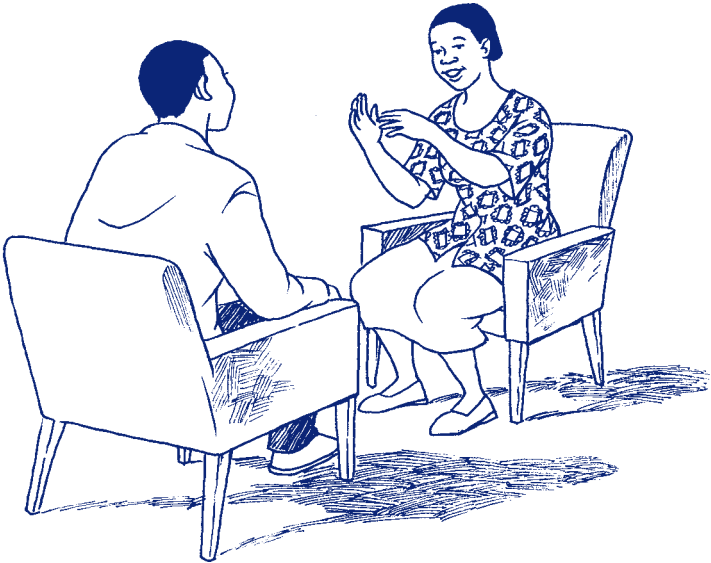
- ❖ Show respect for people;
- ❖ Be an attentive listener;
- ❖ Be compassionate;
- ❖ Be honest and trustworthy;
- ❖ Be knowledgeable;
- ❖ Be patient.
- ❖ Know your limits;
- ❖ Know when and where to refer;
- ❖ Be aware of your own feelings, values, and attitudes;
- ❖ Be impartial and objective;
- ❖ Be positive about yourself; and

To be an effective counsellor you also need to be aware of your role. It involves:

- ❖ Helping your clients identify and prioritise their problems;
- ❖ Providing emotional support to your clients;
- ❖ Helping your clients explore options in life and supporting them in reaching a decision;
- ❖ Assisting your clients in developing problem solving and coping skills;
- ❖ Providing your clients with accurate and relevant information to help them reach informed decisions;
- ❖ Assisting your clients to access other available sources of support and resources;
- ❖ Working together with a team in which confidentiality is maintained; and
- ❖ Maintaining records and ensuring that they are kept safely.

Basic counselling issues

There are many issues that affect a counselling relationship. The following are some that will help you to be an effective counsellor:



Counsellor/client relationship

- ❖ Show respect for your clients. If you do not respect them you will be unable to support them.
- ❖ Clarify your role as a counsellor. This will prevent any confusion over what you can or cannot offer.
- ❖ Maintain neutrality and do not side with any party in case of a conflict.
- ❖ Be honest. Do not say things you do not mean or make promises you cannot keep.
- ❖ Be aware of differences in power or social status between you and your client. A counselling relationship should be based on equality. If you or your client do not feel comfortable with each other, consider referring your client to another counsellor.

- ❖ Avoid counselling close relatives.
- ❖ Establish the time available for counselling to let your clients know how long the sessions will last.
- ❖ Avoid creating dependency. Your role is to empower your clients to cope or deal with their situation, not for them to rely on you.

Confidentiality

Confidentiality is the key to building trust with a client and is central to the counselling relationship.

- ❖ Always discuss confidentiality when you begin counselling a new client. Explain that information that is shared with the counsellor will not be disclosed to others, except in very specific circumstances.

- ❖ *Shared confidentiality*

Explain that there may be times when certain information is shared with family members, or others who are part of your client's support network. However, in all cases, this is only done where it is for the client's benefit and only with the explicit consent of the client in each case.

- ❖ *Limits of confidentiality*

Explain that a counsellor may need to discuss information about a client with another professional or team member in order to get assistance. Where possible the case will be discussed without revealing the client's identity. In any case, if assistance is needed from the team, any information about the client will not go beyond the team.

There may also be times when the counsellor believes that decisions or actions of the client are a threat to the life of the client or others. If this should happen, the counsellor will try to come to an agreement with the client about what action to take. But the counsellor may decide that there is no alternative but to break confidentiality in order to protect lives.

Limits of confidentiality

If you are not sure what to do in a particular case, seek help from a supervisor or another counsellor

Personal values, beliefs, and attitudes

Your own attitude can affect your ability to relate to your clients. You may have strong opinions about:

- ❖ Religion;
- ❖ Life styles, for example drinking, smoking, or commercial sex;
- ❖ Sexual orientation; and
- ❖ Issues such as abortion, disclosure of HIV status, recreational drug use, pregnancy, or breastfeeding.

You are entitled to hold your opinions, but as a counsellor you must never discriminate against clients because their values, attitudes, or beliefs differ from yours. You should not allow your values or beliefs to interfere with the counselling process. If you sense a conflict between you and your client that you cannot overcome, refer the client to another counsellor.

Your personal life experience may affect your work as a counsellor. If you are uncomfortable working with a client, refer the client to another counsellor.

Your own values and beliefs may conflict with the policies of the organisation you are working for. Be aware of this possibility and discuss it with your colleagues and supervisor. If you cannot resolve these conflicts within your own organisation, you will not be able to effectively help your clients resolve their own personal conflicts.

Culture

Note to users: Local adaptation necessary, especially with respect to examples of relevant local practices.

Be sensitive to your clients' culture and tradition. Some traditional practices can increase the risk of HIV infection. But remember that culture is not static, it changes all the time. What may seem a harmful practice today may have once made sense to assure social stability and welfare. You may have strong feelings about practices such as:

- ❖ Polygamy;
- ❖ Wife inheritance;
- ❖ Ritual cleansing;
- ❖ Puberty and sexual initiation rituals.
- ❖ Wife sharing (showing hospitality);
- ❖ Female genital cutting;
- ❖ Scarification; and

Your task as a counsellor is not to challenge these practices, but to get your clients to think critically about them. Many individuals and communities have modified or abandoned harmful traditional practices because they understood why and how these practices were causing harm – not because they were confronted, instructed, or ‘educated’.

Religion

Do not allow your own religious beliefs to interfere with counselling your clients. Different religions have varying views on the following issues:

- ❖ Contraception;
- ❖ Condom use;
- ❖ Medical treatment;
- ❖ Arranged marriage.
- ❖ Mandatory HIV testing;
- ❖ Termination of pregnancy;
- ❖ Male circumcision; and

Respect your clients’ religious beliefs. If the differences in belief between you and a client make it impossible for you to counsel a particular client effectively, refer the client to another counsellor.

Gender

Be aware of the impact of male and female roles on the position of your clients within their family, and on their ability to communicate with their parents or spouses. Some men and women find it very difficult to discuss certain issues with their partners. For example:

- ❖ Condom use;
- ❖ Faithfulness;
- ❖ Disclosure;
- ❖ Getting pregnant;
- ❖ Economic dependence; and
- ❖ Housework;
- ❖ Child care;
- ❖ Division of labour;
- ❖ Domestic abuse;
- ❖ Types of marriage.

You may sometimes be able to help communication by suggesting that you counsel couples or parents and their children together.

Life cycle

People of different ages have different needs, different concerns, and different ways of coping. You have to be sensitive, for instance, to the special needs of

an adolescent girl who is infected with HIV. Her priorities will differ from the priorities of an HIV-positive widow with four children.

As a counsellor you should be aware of your clients' stage in life and offer support that is suited to their specific needs. For example, when you refer a client to a peer support group, make sure that the group includes members of the same age group.



Counselling environment

Be sensitive to the environment where you meet your clients.

If you have the opportunity to use a counselling room in a health centre or other institution, you should prepare the counselling environment as follows:

- ❖ Make sure there is nothing that might disturb you in the room. Disconnect or turn off telephones, radios, and computers;
- ❖ Arrange the chairs so that seating is relaxed and informal. Both you and your client should feel comfortable. Do not arrange seating so you face your client across a desk. Instead, place chairs at an angle at a comfortable distance;
- ❖ Place a sign on the door to avoid disturbance (for instance 'Counselling in progress' or 'Do not disturb');
- ❖ Make sure you have a pen and paper for taking notes; and
- ❖ Have other relevant items accessible, e.g. literature, drinking water, tissues, condoms.

Counselling can also take place under a tree, in a compound, in a hospital room. The most important things to remember are:

- ❖ Find a comfortable place to sit where both you and your client can see each other without obstruction; and
- ❖ Ensure that you have privacy. Nobody should be able to observe or to listen to your conversation with your client.

Counselling environment



Privacy, suitable seating, no obstruction between counsellor and clients

The counselling environment may not always be ideal e.g. a crowded home, a hospital bed, a busy clinic. Do the best you can and adapt to the situation if necessary. It is still possible to counsel somebody by finding a quiet corner or by pulling a curtain around a hospital bed.

- ❖ Ensure that you and your client are safe. Some clients are taking risks in talking about personal matters, for instance in a situation of domestic violence. You are responsible to ensure that neither your client nor you are harmed as a consequence of your counselling intervention.

Counselling techniques



Counselling techniques are basic tools to help you be a more effective counsellor. They can also help you overcome some difficult moments in your counselling session. Here are some techniques you may find useful:

Establishing a relationship

You and your client need to get to know each other to establish a free and open interaction. The process of establishing a relationship is sometimes called 'joining'. Here are some steps for joining:

- ❖ Warmly welcome your client and offer a seat;
- ❖ Introduce yourself and allow your client to do the same;
- ❖ Initiate a brief social talk – ask how your client is, chat about the weather, ask about family, etc.;

Be flexible.

For example, when a client comes to you in distress you may need to establish the problem more quickly and 'joining' can happen later. Developing a relationship is an ongoing process that cannot be completed the first time you meet your client. But always discuss confidentiality when you begin counselling a new client.

- ❖ Explain the purpose of the counselling session;
- ❖ Explain your role and how you work; and
- ❖ Explain the concept of confidentiality and assure your client of this.

Active listening

Pay close attention to what your client is telling you, and be seen to pay attention. You will not be able to counsel a client effectively if your client thinks that you are not listening. Here are a few points on attentive listening:

- ❖ Be as relaxed as possible. Put aside other thoughts or concerns of your own;
- ❖ For *this* time, really concentrate on listening to what the client is saying;
- ❖ Show that you are listening by making eye contact. But remember: In some situations direct and continuous eye contact is not culturally appropriate or may seem threatening to clients;
- ❖ Show that you are listening by responding verbally and non-verbally, for example by nodding your head or by saying 'mmm' or 'aha';
- ❖ Observe your client's non-verbal messages (body language). Look at posture, hand movements, and facial expressions. Do they show nervous tension, agitation, depression, etc.? Is the client's body language consistent with his or her story? and
- ❖ Avoid rushing in with a question or comment when there is a silence. Pauses and silent periods give your client time to reflect.

Don't be afraid of silence. The client may be thinking, or gathering courage to say something difficult.

Questioning

Your skill in questioning is an important determinant of the quality of information you receive from your client. You can help your clients more effectively if you have more information about their lives and circumstances.

- ❖ Ask simple and straightforward questions;
- ❖ Ask one question at a time;

Open-ended questions encourage clients to talk, closed questions may limit the conversation. Ask 'can you tell me about your family?' rather than 'do you have children?'.

- ❖ Repeat a question if necessary; and
- ❖ Give your client time to think about the question and to reply.

Empathy

By showing empathy you make your clients feel supported.

- ❖ Show that you understand what your client is going through. For instance, you may say, "That must have been a very difficult experience.";
- ❖ Avoid letting your feelings of concern for clients make you over-involved in their problems; and
- ❖ Don't start talking about your own problems, such as 'I was also beaten last night' or 'I am going through the same thing'.

Empathy is different from sympathy. Empathy is trying to understand a situation from your client's point of view and showing that you care.

Sympathy is feeling and expressing pity for your client. When you show empathy you give your client strength. When you show sympathy you can increase your client's feelings of helplessness or desperation.

Building on your clients' strengths

Your clients may have abilities that they are not aware of, or that they are overlooking because of the difficulties they are facing. One of the aims of counselling is to bring out these inner strengths. To do this, help your clients to:

- ❖ Identify what they have already done to overcome their problem or difficulty;
- ❖ Remember how they have overcome difficult situations in the past; what has worked, and what did not work, and why it did or did not; and
- ❖ Identify a personal goal and work out a plan on how to achieve it.

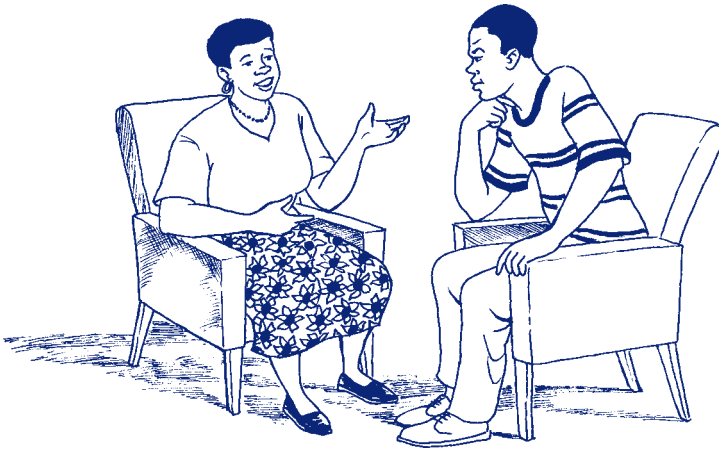
Some useful questions to explore a client's strengths and resources:

- *What have you done about this problem?*
- *Whom have you shared the problem with?*
- *Are there things you could have done differently?*

Summarising

Sometimes it is useful to briefly repeat or summarise what your client has said. For instance:

- ❖ When starting a new session with a client you have worked with before in order to recapture the progress made in the previous session;
- ❖ When clarifying a point that you think particularly important or that you may not have completely understood;
- ❖ Before taking a break;
- ❖ When moving to a new issue or subject in the counselling session;
- ❖ When you are unsure about how to proceed; and
- ❖ At the end of the session.



Practising how to deal with a situation may help some clients.

For instance, if your client has decided to ask her partner to join her in going for HIV counselling and testing, acting out the anticipated conversation with the counsellor may help overcome some of the difficulties of carrying out the decision.

Problem-solving

This is a structured way to look at problems and can be used with a variety of problem situations. For example:

- ❖ Let clients explain the problem as they see it, including feelings and efforts/intentions to deal with problem;

- ❖ Assist clients to break the problem into manageable bits;
- ❖ Identify areas where something can be done now, or which seem important, as opposed to those that could be left till later, or about which little can be done;
- ❖ Help clients to decide which problems to address first;
- ❖ Identify options for what can be done and look at how to deal with any obstacles;
- ❖ Focus on clients' strengths and previous ways of coping which can be used in this situation;
- ❖ Help clients identify and develop new ways of coping;
- ❖ Identify and help clients work out how to access sources of support (family, friends, church, other local resources);
- ❖ Help clients to decide on realistic achievable plan; and
- ❖ Get clients to commit to carrying out first steps of the plan within a certain time-period.

Case example: Problem-solving

David, aged 29 years and HIV positive, recently started ART. His wife died about 9 months ago, before she was able to access ART. David and his three children, aged between 4 and 10, live with his mother, who knows about David's status and that his wife died of AIDS. The children have not been told the reason for their mother's death nor that their father is HIV positive. David and his mother have not told anyone else either, for fear of rejection by the community.

David is unemployed, but gets casual work on a neighbour's garden plot. His mother brings in some money by selling vegetables at the market. The children attend school on and off, but will be dismissed if they do not pay school fees by the end of the month. David and his mother both feel desperate about their situation and concerned for the future of the children.

During a regular session, his adherence counsellor asked David whether he was managing to take his medication with food. David burst out that this was the least of his worries and, for the first time, told the counsellor about the

situation at home. The counsellor listened closely and then said he could see how difficult this must be.

The counsellor asked whether there was anyone among David's family and friends who could help them. David insisted that he could not disclose his status to anyone. He mentioned how a neighbour had been treated when people found out that he was HIV positive. The counsellor decided to leave this issue for the moment and concentrate instead on the most pressing problems: so little money coming into the home and the children being dismissed from school. The counsellor asked David what he had tried so far and what he thought he might do.

After some discussion, David said he could ask the neighbour for work on his plot on a more regular basis. If the neighbour could not afford to pay him more money, he could give David vegetables for his family or for his mother to sell. They discussed a good time to raise the subject and how the neighbour might respond. Together, they worked out a plan for David to try to talk to his neighbour at the weekend.

To help with the children's school fees right away, the counsellor gave David a letter to the department of social services asking for financial support, as the family had no income. David seemed relieved to have something to do about his situation and agreed to report back at their next session.

Always remember that your clients know more about their lives than you do and that you can learn from them.

The counselling process

Counselling can take place in many different settings and under different circumstances. The following outline of the counselling process should not be read like instructions for cooking food that must be followed, but rather like a memory aid for important aspects of the process, to be adapted to the situation in each instance.

Preparing for a counselling session

- ❖ Know how much time you have for the session.
- ❖ Know when you are available for further appointments.
- ❖ Make sure your state of mind will not interfere when counselling your client. If you have personal problems you must deal with them outside the counselling interview.
- ❖ Be presentable.
- ❖ If you have seen the client before, check your notes from previous sessions.
- ❖ Collect relevant materials that might be useful to your client.

Beginning a counselling session

- ❖ Greet your clients and establish a relationship (see page 9).
- ❖ If it is a new client, collect the necessary background information (contact details, who referred the client, family situation).
- ❖ Agree on how long the session will last.
- ❖ Agree on the language to be used in the sessions.
- ❖ Explain and discuss confidentiality, shared confidentiality and the limits of confidentiality.
- ❖ Explain your role and the way you work.
- ❖ Inform your clients that you would like to take notes and ask for their permission.
- ❖ Establish an agreement between yourself and your clients on what you can expect from each other – a basic verbal contract.

Conducting a counselling session

- ❖ Discuss the reason for the visit.
- ❖ Help your clients identify their problems and work out which should be dealt with first.
- ❖ Provide relevant information to enable your clients to make informed decisions.
- ❖ Explore past strategies for overcoming problems, outcomes of those strategies, and implications for new strategies.
- ❖ Help your clients explore possible options and solutions to their problems.
- ❖ Support your clients in making choices and taking decisions, and discuss the possible implications of each choice.
- ❖ Assist your clients in finding ways to cope with their situation.

Ending a counselling session

- ❖ Summarise what has been discussed and review your clients' action plan.
- ❖ Ask your clients how they felt about the session and about any other feedback they would like to give.
- ❖ Ask clients if they have any further questions.
- ❖ Acknowledge your client's contribution to the session.
- ❖ Agree with your clients on what to do next and how to work together in future.
- ❖ Set a date for the next counselling appointment.
- ❖ If appropriate, make any referrals that were discussed in the session.
- ❖ Accompany your clients to the door.



Types of HIV/AIDS-related Counselling

Supportive counselling

The purpose of supportive counselling is to provide emotional and psychological support to people who are living with HIV and to people and families who are affected by AIDS. It offers encouragement and hope and helps them cope with their situation. It forms an important part of all types of counselling, but may be the primary form of counselling offered to some clients.

Some elements of supportive counselling are to:

- ❖ Allow the person to develop trust in you and feel at ease;
- ❖ Get to know them, in particular about what HIV and AIDS means to them;
- ❖ Provide support and reassurance to the client and help them to accept themselves and to 'live positively';
- ❖ Assess the person's ability to cope and help your clients identify additional sources of support to meet their spiritual, social, health care, legal and material needs. Examples are counselling organisations, home care programmes, church groups, self-help groups of people living with HIV and, tuberculosis treatment programmes;
- ❖ Provide referrals to any of these services as needed;
- ❖ Provide counselling on survival skills, positive living, fighting discrimination, palliative care and bereavement, preparing wills, and property rights for survivors; and
- ❖ Assist your clients in their efforts to solve other problems that may be related to their HIV status or to the fact that they have been affected by AIDS in their family.

Clients will require supportive counselling for an extended period of time, sometimes for years. It is the clients rather than the counsellors who should decide for how long counselling may be necessary.

Coping mechanisms

It is important for clients to try to find positive ways of coping with stress and anger. There are many options, for example, song, prayer, meditation, long

walks, spending time with family and friends, or joining a support group. A counsellor can help the client to explore what works best for them.

Counselling for disclosure

Whilst disclosure of HIV status can result in negative reactions from the people around us, it is also advocated as a way to reduce stigma and to protect uninfected partners. For someone about to start anti-retroviral treatment, disclosure may remove the need for secrecy in taking medication and provide additional sources of support and encouragement for adherence.

However, despite their need for support, many people feel unable to tell relatives or friends about their HIV status for fear of stigma and rejection. Even if they do reveal their HIV status they may not receive the emotional support and information they need or expected. They may be overwhelmed by thoughts and fears about the future, the possible consequences to them and others, feelings of guilt, anger, shock and despair. People may need support to tell family members about their HIV status, and the family may need support to cope with their feelings about the information.

In other words, disclosure is a complex process and there are many factors to consider before disclosure takes place. This is why counselling is essential.

The client's decision

If someone opts for disclosure, they may need your support. They will need to decide who to tell, how and when to tell them. Disclosure is to be encouraged, but it is important that people take time to think through the issues carefully. Their choices can have major implications. Therefore it must be *their* decision.

"You have to decide for yourself if it is the right thing to disclose your status. It is helpful when you can be open, but you shouldn't judge others who may not be ready to divulge their status."

However, what counsellors think and feel about disclosure can powerfully influence that decision. For example, if counsellors believe that widespread disclosure is key to fighting discrimination and the HIV/AIDS epidemic, this may lead them to put subtle pressure on clients to disclose before they are ready to do so. On the other hand, counsellors' fears for the safety of their clients may

mean that, as soon as clients mention any concerns about disclosure, they drop the subject. This means that they are not able to help clients to review how realistic their fears are, or ways to begin a process of opening the way for later disclosure.

The process of disclosure and counselling

Disclosure is a process and not an event. It is a major decision that can have consequences for the person living with HIV and those around him or her. It is important that people do not rush into disclosure, but think it through carefully and plan ahead. In counselling, counsellors can assist clients with their planning by suggesting what could happen and helping the client to control the process of disclosure.

The counsellor can help take the client through the steps outlined below.

- ❖ Discuss the implications of disclosure fully, to help the person consider in advance the reactions of family, friends, work colleagues and others. The counsellor can help the client to decide whether to disclose or not disclose by exploring with them what reasons they have to disclose as well as the possible consequences of disclosure and non-disclosure (see some of these below).
- ❖ The counsellor needs to work with the client on the implications of disclosing to people or groups who may not be receptive or open to hearing this news.
- ❖ Talk about how current and future sexual partners can be protected from infection and how disclosure to them might be done.
- ❖ Help the client to take time to think things through. Make sure it is what they want to do.
- ❖ Help the person develop a plan on how they are going to go about disclosing. This should cover any preparations they need to make before disclosure, who they will inform first, how and where they will disclose and the level of disclosure.
- ❖ Discuss with the client steps they can take to prepare people before disclosing to them. These could include the client talking more about HIV issues, but not referring to him- or herself, to test the reactions of particular people to possible disclosure by the client at a later stage. Indirect disclosure (see Definition of terms) is sometimes used in this way.
- ❖ Role-plays and using an 'empty chair' to represent someone to whom the client wishes to disclose can help the client develop skills and confidence for when they do disclose.

- ❖ Help the client to realise that once a decision to disclose has been reached, it may be easier to start with those nearest to them: relatives, family, friends, or someone they are very close to and trust.
- ❖ When a client has decided to disclose their HIV status to someone, assist them to think about the likely response. They will need to assess how much the person they plan to disclose to knows and understands about HIV and AIDS. This will help the client decide what they need to tell the person and how to tell them so it is less traumatic for both of them.
- ❖ It is important for a client to be strong enough to allow others to express their feelings and concerns after their disclosure. A counsellor can assist the client to work on these issues over time.
- ❖ Prepare the client for a shocked and even hostile reaction from some people that they will disclose to. This sometimes happens, but you can reassure the client that with time, most people close to them should learn to accept their HIV status.
- ❖ Arrange to see the person again – at a date and time agreed by both of you – to review this process.
- ❖ Counsellors should help to protect their clients from the undue pressure to disclose which they may experience.

"I would make my disclosure to the persons closest to me, and only when I am prepared"

Case example: Facilitating disclosure

As part of adherence planning, the counsellor asked Nomsa whether a family member could help her remember to take her medication at the right times. "Oh, no," said Nomsa, "I haven't told anyone at home that I'm HIV positive. They would throw me out of the house." Because of Nomsa's fear, the counsellor herself felt too anxious to risk exploring the question further.

A few weeks later, when that counsellor was on holiday, Nomsa met with another counsellor. Nomsa had been taking vitamins on schedule to practise for ARVs and had forgotten a number of times. The second counsellor asked whether someone at home could help her remember.

Nomsa repeated her fear of rejection by her family. Rather than dropping the subject, the second counsellor asked Nomsa why she felt this way. Nomsa had heard of this happening to other people and she didn't want to take the chance. The counsellor agreed that it was possible, but asked Nomsa to talk about her own family. What did each one know about HIV/AIDS? What had they said about people infected with HIV? How had they reacted to other problems in the family?

Talking in this way, Nomsa was no longer so sure that her family would react badly. Now, she felt that her sister Palesa especially might be open to helping her. Together, Nomsa and the counsellor worked out a plan for Nomsa to test Palesa's reaction, first by talking with her about HIV/AIDS to find out about Palesa's knowledge and attitudes in general.

At the next session, Nomsa reported that Palesa seemed reasonably open about HIV/AIDS. Palesa criticised one man for not supporting his HIV positive girlfriend. For the next step, Nomsa practised telling Palesa that she needed to talk with just her about something serious and confidential. If Palesa agreed, Nomsa would then disclose her status, tell her about taking ARVs and the importance of taking the medication correctly, and ask for Palesa's help in reminding her to take her medication.

Together, the counsellor and Nomsa tried to think of all the ways that Palesa might react and how Nomsa could deal with each one. Most likely, Palesa would be shocked and upset at first. Perhaps she would need time to take in the news. At the worst, Palesa might refuse to be involved, but Nomsa felt that Palesa would not tell anyone else and would eventually be prepared to help her. The counsellor and Nomsa still felt anxious, but they also felt that they had worked through things carefully and that the risks were less than the likely benefits.

Potential benefits of disclosure

People thinking about revealing their HIV status need to be clear about whether to choose partial or full disclosure. If they are able to disclose their HIV status, it can have the following benefits:

- ❖ Disclosure can help a person accept their status and reduce the stress of coping on their own. “A problem shared can be a problem halved”;
- ❖ Disclosure can help a person access the medical services, care and support that they need;
- ❖ Disclosure can help people protect themselves and others. In particular, openness about HIV status may help women negotiate for protected sex;
- ❖ Disclosure means that people may be better equipped to influence others to avoid infection;
- ❖ As more people disclose their HIV status, it will help to reduce the stigma, discrimination and denial that still surrounds HIV and AIDS;
- ❖ People may suspect the person’s HIV status, particularly if they show symptoms of AIDS. Openness about their HIV status can stop rumours and suspicion. It can also reduce the stress caused by ‘keeping a secret’; and
- ❖ Disclosure promotes responsibility – it can help the person’s loved ones plan for the future.

Possible negative consequences of disclosure

The stigma attached to HIV and AIDS means that disclosure can sometimes lead to negative consequences, especially in the short term. This could include:

- ❖ Problems in relationships, whether with sexual partners, family and friends, community members, employer or work colleagues;
- ❖ The experience of rejection. People who have disclosed their HIV status may feel that people are constantly judging them. They need to be prepared for this and be ready to make full use of the support that is available; and
- ❖ Disclosure can result in pressure being placed on people living with HIV or AIDS to assist in AIDS work and become role models.

Possible negative consequences of not disclosing

Sometimes it seems that there is too much to lose by disclosing HIV status. But non-disclosure can also have major consequences. It is useful to discuss with the client the following potential consequences of non-disclosure.

- ❖ *Lack of support* – family and friends may not give the support the client needs and they will have to deal with everything on their own.
- ❖ *Risk* – placing others at risk of infection, particularly sexual partners and increasing the risk of re-infection for the client.
- ❖ *Lack of care* – the client may be unable to access appropriate medical care, counselling or support groups if they are not open about their status.
- ❖ *Suspicion* – people may become suspicious of the client’s actions because they do not understand their HIV status.

“My view is that going public is an important way to reduce stigma. The more we reveal our HIV status, the more difficult it is for society to stick to its attitudes towards people living with HIV or AIDS”.

Counselling around relationships

Working with Individuals on their relationships with others

Clients may talk about difficulties in their relationships with others, or, sometimes, ask you to see them together with their partner or another family member to help them sort out difficulties. There is likely to be a range of difficulties, some more difficult or complex than others e.g. conflict with partner, disagreements with treatment supporter, well-intentioned interference by other family members. The following are some guidelines in talking with the client (or with the client together with another person):

- ❖ Be prepared to find out about both sides of a story, don’t take sides;
- ❖ Ask for the story, including circumstances (what was it about, who was/is involved, when did it start/what started it, has this happened before, what did each person do/say, how did you feel then/how do you feel now, how do you understand the other person’s point of view, what has happened since then/where are things now?);
- ❖ Look at options for dealing with the difficulty, including getting others to mediate; and
- ❖ Develop a specific plan (if the other person is not present, when, where, how to approach the other person).

Counselling is not always restricted to individual clients. You may sometimes find yourself counselling groups, couples or families.

Working with couples



There may be times when the counsellor needs to work together with the person and their partner. Here are some things for you to keep in mind when working with both people.

- ❖ Always remember to **protect and build the relationship of the couple**: For example, by sticking to the view that 'disclosure is best', this may, in fact, do damage to the relationship AND the only source of support that one partner has.
- ❖ **Accept only informed consent**: It can be very difficult to obtain true consent when one partner is in the same room as a manipulative partner. Rather be sure about the client's true request, by spending a few minutes with each of them alone.
- ❖ **Create an environment of free expression** as best as possible: This may be helpful in some relationships and more destructive in others. Although we aim to foster trust, it is sometimes necessary to counsel the couple separately.
- ❖ **Try not to centralise yourself** as the counsellor: Part of your role is to facilitate communication between the couple. If they are already able to communicate with each other, you are present as a source of support and factual information. Enhance, don't undermine, the existing strengths of the relationship.

- ❖ **Actively open communication** between the partners: Is each one 'hearing' what the other is saying – both in their verbal and non-verbal communication? At times you may need to be a voice to amplify or clarify messages directed from one partner to the other.
- ❖ **Remain neutral:** It is not your role to take sides and, in fact, by supporting one partner over the other you may lose their trust, presence and hope in the counselling process. Be aware of a natural tendency to side with the same-sex partner as you.
- ❖ **Make the couple aware of their strengths:** Try to find at least one strength that exists in the relationship, or else focus on each individual's strengths. The couple would not be sitting together with you if they didn't care somewhat about each other and/or the relationship.
- ❖ **Make your role as counsellor clear:** Your role is to support BOTH parties; to remain neutral; NOT to deliver the/a message from one to the other; to clarify misunderstandings; and to provide factual information.

Case example: Working with couples

Over the past six months, Thembi had attended the clinic for pre- and post-HIV test counselling, preparation for anti-retroviral treatment (ART), counselling and now support counselling for adherence. When Thembi disclosed her HIV status to her husband a month ago, he did not respond to the news and had not mentioned the subject since.

Thembi worried that this lack of support was affecting her ART adherence. She was even more concerned that her husband was angry with her and that this news was destroying their relationship. Noticing how much stress the relationship was causing, the counsellor gently encouraged Thembi to talk a bit more about it. It appeared that Thembi was afraid of raising the subject with her husband again as she feared his anger. Her self-esteem had also dropped as her husband no longer had any physical contact with her. She was feeling worthless and that she was not good enough for him.

Thembi asked the counsellor to let her husband know that she wished for his [forgiveness], as she still loved him very much. The counsellor explained that his role was not to deliver news or messages to other people but rather to

provide information and support. The counsellor did not want to disempower Thembi by doing things that she was able to do for herself but rather to assist when Thembi needed particular help. He said that Thembi was welcome to bring her husband along to a counselling session.

When Thembi arrived with her husband, the counsellor supported her and encouraged her to tell her husband the things that she wanted him to know. Thembi explained her feelings and concerns and also asked her husband why he was so angry with her. At last, her husband replied. He explained that he wasn't angry with Thembi at all. Instead he had been feeling guilty and scared since Thembi told him that she had HIV. He must have been the one who infected Thembi because he had been unfaithful in the relationship and he knew that she had been true to him. He said that the news that Thembi had AIDS was almost like news that he had AIDS too. He was scared that they would both die soon.

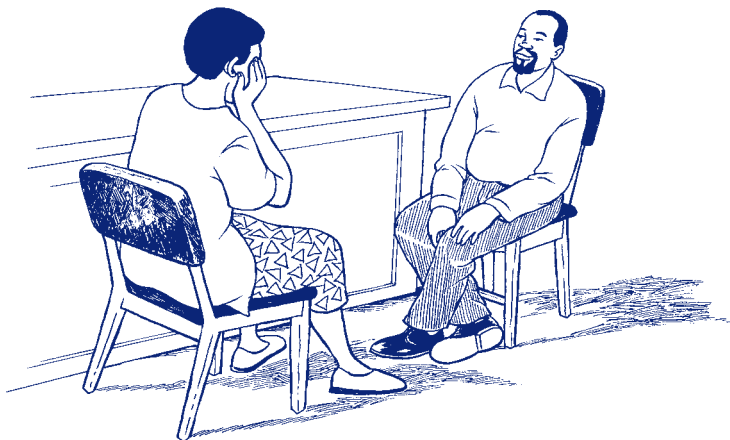
Thembi was relieved to hear that her husband was not angry with her. She tried to explain the difference between HIV and AIDS and how they could live a healthy life for a long time. The counsellor gave Thembi's husband useful information about HIV and AIDS and talked about ART and the importance of adherence. Thembi's husband decided to take an HIV test and to consider going onto ARTs himself. He realised that he could take control of his health and that he and his wife were in the same boat together. They could help each other to remember to take their drugs and find ways to have safer sex from now.

Crisis counselling

Clients who are distressed, in shock, or in an acutely difficult situation require crisis counselling. Not everyone responds to events in the same way, but many people experience the following as crises:

- ❖ Getting positive results (especially without proper pre-test counselling);
- ❖ Anticipated or actual lack of support or rejection by partner/family/ friends/ employer;
- ❖ Life changes as a result of illness e.g. job loss, being ejected from one's home, changes in financial status;

- ❖ Needing to change medication due to side-effects or resistance;
- ❖ Beginning to show symptoms suggesting the onset of AIDS or marked deterioration in health status; and
- ❖ Death of someone close to them from AIDS.



Important elements of crisis counselling are:

- ❖ Assess the situation and deal with any urgent needs;
- ❖ Ensure your clients' and your own safety;
- ❖ Let clients express their emotions;
- ❖ Identify your clients' most urgent problems;
- ❖ Assist your clients to work out what to do about their most urgent problems; (see section on problem solving);
- ❖ Help your clients identify sources of support, that can help them out of their current difficulty or distress, e.g. family, friends, a shelter, a child protection agency, other organisations;
- ❖ Help clients to identify things they will do starting when they leave the session; and
- ❖ Plan follow-up counselling.

As you do the above, keep these points in mind:

- ❖ Remain calm and stable, convey confidence;
- ❖ Focus on reducing tension, but don't make light of the way a client perceives the problem ("cheer up, its not as bad as you think");

- ❖ Repeat information/summarise frequently if a client seems to be too distressed to take in what is being said;
- ❖ Adapt what you do and say, taking account of how much a client is feeling helpless and lacking control and what a client is capable of doing or deciding at the moment;
- ❖ Don't agree to do anything for clients that they could do for themselves; and
- ❖ Aim to restore your clients' sense of competence and control over the situation as far as possible: let clients know that doing something, however small, will begin to make them feel better, more in control and more hopeful.

Sometimes in a crisis, clients express an intention to harm themselves. This may not always be an active intention to commit suicide, but should be taken seriously. (See page 30, Dealing with Suicide.)

Case example: Counselling in a crisis

Radisha has been on ART for 18 months. Early side-effects did not last long and she was doing well on the medication until recently when she had repeated diarrhoea and 'flu-like symptoms. The nurse responsible for her follow-up care gave her medication to help overcome these opportunistic infections. Today, as usual after a check-up with the doctor, Radisha went to see the counsellor.

She came into the counselling room in tears and was too agitated to sit down at first. When she was a little calmer, the counsellor asked what had happened. The doctor had said it seemed as if the ART was no longer working well for Radisha. After taking her blood, the doctor asked Radisha to come back in a week for the results so that they could decide whether to change to new medication.

Radisha said that it was clear that she had AIDS and was dying. Even if she changed to the new medication, it would probably not help her for long. "What's the point of going on?" she asked. "At least if I was dead, all this would be over – I'm so tired of struggling all the time."

The counsellor asked Radisha to talk more about her feelings of wanting to die. Radisha responded that she did not really mean that: "What would happen to my children?" she said. All the same, this was a terrible blow.

The counsellor reflected Radisha's feelings of fear and despair. She reminded Radisha that she had felt much the same when she first learned that she was HIV positive and, again, when she needed to go on ART. "What kept you going then?" asked the counsellor. Radisha talked about her children – that it was important to stay alive until they could care of themselves – and about the support of her sister and a close friend. The counsellor suggested that these still seemed important reasons. Radisha sighed, but agreed that they were, especially her children.

When Radisha seemed ready to discuss next steps, the counsellor summarised what Radisha had told her about the doctor's words. "If I understood you correctly, the doctor has not definitely decided to change the medication. If there really is a need to change, you have all the experience of using the old medication to help you adjust to the new." The counsellor and Radisha went back over her previous experience, identifying what had been helpful.

After some time, Radisha seemed calmer. She talked about telling her sister and friend what had happened. She also talked about what she needed to do in the next week to prepare herself and her family for a possible change in medication. She agreed that it would be helpful to have her sister come with her to the next appointment with the doctor. The counsellor asked Radisha to call her the following day to tell her how she was feeling. She offered to see Radisha again, if necessary. Radisha seemed calmer and in control of her feelings as she left. She promised to keep the counsellor informed about what happened.

Dealing with Suicide

People with HIV/AIDS may think or talk about committing suicide and may attempt and, in some cases, succeed in committing suicide. When someone talks about or threatens suicide, this may be his/her way of dealing with a crisis (see above), or it could be a response to prolonged stress (e.g. as a result of lengthy illness or pain).

Talking about suicide: some facts

- ❖ Talking about suicide may be how the client expresses just how anxious, sad and desperate he or she is feeling. It may not necessarily indicate a definite decision to commit suicide. But talk of suicide should always be taken seriously and explored further. Do not dismiss it as 'manipulative', 'not serious'.
- ❖ Asking about suicidal thoughts/plans does not make it more likely that person will commit suicide.
- ❖ If the counsellor raises the issue, the client may feel relief at being understood and this may reduce the risk of suicide.
- ❖ In case of severe depression/shock, especially where the client seems to have limited or no support system, you should ask about whether the client has suicidal thoughts. (Have you ever thought about harming yourself?).

Counsellor knowledge and attitudes

Many counsellors will never come across a suicidal client. But if they do, they need to put aside personal beliefs and feelings about suicide in order to deal effectively with the situation. If referral resources are available, it is best to consult with and, if necessary, refer the client. If not, counsellors need to do what they can to ensure the safety of the client.

Assessing suicide risk

- ❖ Assess risk in order to decide how best to manage the situation. Consult with a colleague and, if unsure, refer if at all possible.
- ❖ Keep a record of what you are told and observe, how you manage the situation and the reasons for what you do.
- ❖ Find out about the client's situation – consider:
 - what provoked the suicidal thoughts or intention?
 - is there some specific crisis e.g. financial crisis, marital strain (especially when linked with HIV status or illness)?
 - when the counselling session ends, where will the client go and what are the circumstances there (any possibility of changing it)?
 - is there any genuine support that could be drawn in (e.g. from family members)? and

- what factors might help to prevent the client from carrying out an intention (e.g. religious beliefs, fear of dying, shame about suicide, concern about family)?
- ❖ Consider and ask about factors that usually suggest high risk (especially where you suspect suicidal thoughts, even although these are not directly expressed):
 - current suicidal thoughts or previous suicide attempts;
 - pre-existing mental disorder or a recent psychiatric admission;
 - history of or reported current alcohol or drug abuse;
 - history of impulsive behaviour;
 - recent social disruption (e.g. bereavement, marital break-up, job loss); and
 - social isolation or rejection or lack of support.
- ❖ Check the client's mental state for any of these characteristics:
 - extreme depression, ideas of killing self or others, out of touch with reality, irrational beliefs about others or self (e.g. everyone is against me, I do not deserve to live) despite evidence that indicates otherwise, extreme anxiety or panic symptoms, very agitated, delirious.
- ❖ Assess how definite and clear the client's plans are:
 - abstract thoughts and vague plans (which may reflect the client's feelings rather than a definite intention to kill him/herself); or
 - a definite plan which really could result in death and with the means available to carry it out (e.g. has made a will, written a farewell note, has stock of pills or gun available, has worked out when to carry out plan).

Managing the situation

- ❖ Follow general crisis counselling guidelines, especially to remain focussed on the immediate problem.
- ❖ Where the client has a definite plan and means to carry it out, try to keep the client where he/she is safe until you can make arrangements to ensure his/her longer-term safety.
- ❖ Where the client does not have a definite plan, try to develop workable alternatives with the client (including linking him/her with supports) and a plan for what to do in the short-term (24 hours).
- ❖ If you judge your relationship with a client to be strong, consider making an agreement that, if the client starts to think about suicide again, he/she will

contact you before doing anything to harm him/herself. But do not rely *only* on an agreement of this kind – you must also have other reasons to believe the client will be safe.

- ❖ Arrange as a minimum to have contact with the client within the next 24 hours and a follow-up appointment as soon as possible after that.
- ❖ If you do not feel confident about the situation, refer if at all possible.
- ❖ If the client shows signs of depression (see IMAI Acute Care Guidelines), refer to secondary level care for treatment.

Case example: Dealing with suicide

When Nicola was diagnosed HIV-positive, she felt that she could not face any further difficulties. HIV infection was the result of an awful rape eight months earlier. Nicola had been ashamed to talk to her family about the rape. Only her mother knew and Nicola avoided talking to her about it. She had withdrawn from her social circle and felt safer staying at home.

The day Nicola went to the clinic to be tested, the counsellor praised Nicola's bravery and said that the health care team would be there to support her. The counsellor encouraged Nicola to return to the clinic frequently for follow-up counselling and to talk about anti-retroviral treatment. When Nicola did not return for a follow-up session, the counsellor decided to visit her at home.

Nicola looked surprised to see the counsellor, who explained that she had been wondering how Nicola had been since the session at the clinic. Nicola asked the counsellor in and introduced her to her mother as "someone from the clinic". She took the counsellor to her room, so that they could talk privately.

The counsellor asked how she had been feeling. At first, Nicola seemed reluctant to talk, but the counsellor probed gently, showing Nicola that she was concerned and wanted to hear more. Nicola described her anger and feelings of isolation. She was afraid of living with HIV, others knowing her status, being raped again and others finding out about the first rape. The counsellor explained that women who have been raped often feel shame and fear, and that these feelings can be overcome. However, the counsellor could see that Nicola was

not really paying attention to what she said. Instead, she kept on repeating that life was no longer worth living.

The counsellor remarked that she could hear just how bad Nicola was feeling and wondered whether Nicola had had any thoughts about killing herself. Nicola nodded and calmly said, “Yes. . . it feels like the only solution right now.” Without judgment, the counsellor listened to Nicola and then probed to find out what plans Nicola had. Slowly, it came out that Nicola had a prescription for sleeping tablets from her GP and some painkillers left over from an earlier injury. She had heard that if you took these tablets with alcohol, you would die and this is what she planned to do. The counsellor enquired when she intended to carry out the plan. Nicola replied that she needed time to make a will and to write a note to her mother to explain that suicide seemed the only way to get over the shame she had brought to the family and to avoid imposing the burden of HIV on the family.

The counsellor empathised with Nicola and expressed her concern for her. Although Nicola did not have a fully worked out plan, there was a risk she would take further steps towards suicide. The counsellor therefore felt it important to try to involve others. So she pointed out that Nicola felt it was important to explain her actions to her mother. The counsellor asked whether Nicola would allow her to call her mother to join them, so that she could explain how she was feeling and why. At first, Nicola was reluctant, but eventually she agreed and the counsellor called Nicola’s mother to join them.

The counsellor said that she knew that Nicola’s mother was aware of some of the difficulties that her daughter had experienced and that there was something more she needed to tell her. With the counsellor’s encouragement, Nicola told her mother that, on top of everything else, she had now found out she was HIV positive and that there seemed no point in going on living. Nicola’s mother looked devastated. The counsellor encouraged her to respond and Nicola’s mother said that none of what had happened was Nicola’s fault and that she would do whatever she needed to do to help her. The counsellor emphasised what a difficult time this was for Nicola and that it was understandable that she was depressed and saw no way out. But, she said, there were things that

could be done, especially with her mother's support. Nicola looked relieved to have others aware of just how bad she was feeling.

The counsellor felt that involving Nicola's mother had eased Nicola's desperation and that she would be unlikely to act on her plans, at least for a while. She emphasised that she was committed to supporting and assisting Nicola and her mother and that there was also an experienced team of people available to work with them. She asked Nicola and her mother to come in to the clinic the next day to meet with some of the team members. They both agreed.

Meanwhile, the counsellor asked Nicola to let her take charge of the medication she had mentioned, saying that the team might be able to suggest other kinds of medication to help her get through the depression. Nicola then fetched the medication and gave it to the counsellor.

The counsellor left an emergency telephone number that Nicola agreed to call if she had thoughts of harming herself, or for her mother to use if she was concerned. Nicola felt supported and understood and her mother seemed to understand how serious the situation was.

The counsellor emphasised the importance of Nicola and her mother coming to the clinic the next day. She said that During future sessions they would discuss how Nicola could build her self-esteem and begin to find positive ways of living.

For more detailed guidelines on managing suicide, refer to: 'Preventing suicide: A resource for primary health care workers', published by the WHO Department of Mental Health in 2000 and available from the WHO.

Grief and bereavement: counselling people who are dying and their families

- ❖ Be aware of your own losses and feelings that could influence your counselling.
- ❖ Remember that people can grieve for 'what might have been' and in anticipation of losses, not only when a loss such as death actually occurs.
- ❖ Don't avoid using words such as death and dying. Ask about needs, fears and worries about dying.



- ❖ Acknowledge that this is a difficult time. Ask about other hard times in their lives and how they managed to get through those times.
- ❖ Encourage those affected to talk to each other and to share feelings, such as guilt, relief, pain, or anger.
- ❖ Listen rather than talk. Allow time for thought and silence.
- ❖ Encourage the use of rituals that help channel the grieving process, e.g. making memory boxes, arranging memorials.
- ❖ Discourage a bereaved person from making big decisions whenever possible, e.g. change of job, home, town. Their emotional state makes it hard for practical decisions to be taken.
- ❖ Encourage those affected to tell you about the person who has died.

For more detailed guidelines on counselling around grief and bereavement, see 'Counselling Guidelines on Palliative Care and Bereavement', published by Southern African Aids Trust, 2001.

Case example: Grief and Bereavement counselling

As an adherence counsellor in an ART project, Maria worked with a client, Pedro, for a number of years. She had witnessed a first treatment failure and change to another drug combination. On the new drugs, Pedro's condition stabilised, but his CD4 count remained low. One day, Pedro told Maria that he knew that it was only a matter of time before his condition got worse again. This seemed so unfair to him, when other people took risks and escaped infection. And now, even though he had stuck to the treatment, it was not really working for him. Maria listened to Pedro and remarked that he seemed angry because of his ill luck.

Pedro continued to talk in this way for some weeks, but eventually seemed to put those feelings behind him and spoke only about the side-effects caused by the drugs. Maria noticed that he seemed more withdrawn than usual and Pedro told her that he was considering stopping the drugs, because they were making him feel very sick and he was going to die anyway. He also spoke again, as he had not done for a long time, about the guilt he felt about his wife's death from AIDS some years earlier.

Maria encouraged him to express these feelings and Pedro broke down and wept. Maria let him cry. When he became calmer, she talked about how difficult it must be for him, regretting what might have been, feeling sick most of the time, thinking about death. Pedro looked relieved and said that he was afraid of dying on his own and worried about what would happen to his mother.

Maria suggested that he share these concerns with his mother and family, so that, together, they could plan how to manage these matters. He could make a will saying what should happen to his belongings and what sort of funeral he wanted. Pedro asked Maria to help him talk to his family and arrange for a will. Both Pedro and his family then seemed more able to prepare for his death, whenever that might be.

Over the next few months, Pedro's immune system began to fail and he had repeated opportunistic infections. Maria visited him at home to encourage him

to continue taking his drugs, but found him more and more withdrawn. His family found this very difficult – they wanted to be with him and show their love, but he wanted to be on his own. Maria spent time with the family, helping them to see that Pedro needed time to come to terms with his own death, which was clearly now very near. She encouraged them to be nearby for him, but not to insist that he respond to them.

One Monday morning, Maria heard from Pedro's mother that he had become very ill over the weekend and passed away before the ambulance arrived. Maria asked Pedro's mother if she would like to come in to talk to her the following day and perhaps bring Pedro's sister as well. Pedro's mother said she would.

Pedro's mother and sister spoke with Maria at length about Pedro's last hours and about feeling sadness and loss, but also some relief because of all his pain at the end. Maria listened and reflected these feelings, and then encouraged both women to share a good memory of Pedro.

Pedro's mother had called their priest and felt relieved that he was there when Pedro died. Maria reminded them about Pedro's will and how he wanted the funeral to be conducted. They discussed arrangements, including how to tell other family members about his death. Maria encouraged them to keep in touch with their priest and with other family members who could support them over the next few weeks.

Referral systems

Many of your clients have needs that you will not be able to meet. One of your roles is to identify sources of information and support for your clients. These may include:

Support groups

Among the most useful sources of emotional and psychological support are other people who face or have faced the same problems. In many communities, you can find self-help groups of people living with HIV, survivors of domestic violence, children who have been sexually abused, or people who are bereaved or otherwise affected by AIDS. These groups offer support and encouragement by allowing people to share their experience and to learn from one another. People in difficulties often feel alone, abandoned, and misunderstood. Talking to others who had the same experience helps to overcome this isolation.

Keep yourself informed about services available in your community and how to help your clients gain access to them.

Directories

Some organisations produce social service directories. These directories may list addresses, opening times, contact persons, and types of services offered. Find out if such directories exist in your community and have them at hand to help you refer clients in need. If there is no directory, create your own by collecting information about options that are available in your community in a notebook that you can refer to.

Clinics and hospitals

Many of your clients require health care services. Find out which clinics offer voluntary counselling and testing for HIV. Find out where to access tuberculosis screening and treatment services. Find out if there is a hospital that provides services for the prevention of HIV transmission from mother to child. Be sure

that when you refer a client to a medical service, you know where and when this service is being offered.

Religious organisations

Churches, mosques, traditional groups, and other religious organisations can offer spiritual support to your clients.

Hospice

In some communities hospice services are available. These offer palliative care to clients or family members who are dying of AIDS. Make sure you know to access any services of this kind.

Home-based care

Home-based care programmes provide a variety of support services. They may just consist of social support, i.e. the visit of a volunteer who may help with house work and provide company; they may include the visit of a nurse to provide medical treatment and palliative care; or they may include material support such as food baskets and household items. Inform yourself about the type of home care services available in your community and how to refer a client to them.

Other local services

Your client may need other services such as social welfare provided by local government, traditional healers, legal aid, or police protection. Make sure you know how to access these.

Record-keeping

It is helpful to keep records for the following reasons:

- ❖ As a reminder of what you discussed in previous sessions;
- ❖ As a reminder of anything you agreed to do or found out;
- ❖ In case you need to refer the client;
- ❖ For identifying sources of support;
- ❖ For planning and organising;
- ❖ For report writing; and
- ❖ For checking progress and assessing what has been achieved.

Records contain confidential information and must be kept in a safe and secure place. No-one else except you and your supervisor or members of your team who are directly involved with this client should see the records. If you place your records in a filing cabinet, make sure that it is locked and that the key is in a safe place. If you are carrying records with you to your house or on a home visit to a client, you will have to separate the files. Carry only what is absolutely necessary for you to work, and leave other confidential information in a safe place. If you cannot guarantee that records will be secure, you may need to reconsider whether it is wise to keep anything but the bare minimum of information about clients.

Your records should contain the following information:

Date:

Name:

Client number:

Address:

Age:

Sex:

Marital status:

Type of marriage:

Family details: (family tree)

Occupation:

Religion:

Language preferred:

Problem/Issues:

Service provided:

Need for further service, e.g. referral, specific action:

Date of next session:

Most counsellors keep the name and address of their clients separate from other information so that if the records are lost, stolen, or read by an unauthorised person, nobody will be able to tell whose notes they are.

Counsellors at FACT Mutare in Zimbabwe and WAMATA in Tanzania carry a notebook that contains the name, address and assigned number of each client. All other information is put on a form that the counsellors use to write their notes during sessions. These forms do not show the names or addresses of the clients, only their number. The forms are then filed at the office of the organisation for safekeeping.

Sources of support for the counsellor

Counsellors are dealing with difficult situations and therefore need support themselves.

- ❖ Share your concerns and experiences with others but always make sure to protect the confidentiality of your client.
- ❖ Where possible, join group meetings with other counsellors. You may be able to join a professional counselling association which can provide you with information and support.
- ❖ Join other groups or work with other organisations in your community in order to maintain a social network outside your work environment.
- ❖ If you are working in an organisation, seek advice and assistance from your supervisor regularly, for example in a weekly debriefing or co-counselling session.

Case example: Finding support

Pedro's sudden death (see the case of Grief and Bereavement Counselling on page 37) came as a shock to Maria, his adherence counsellor. She did not have a chance to say good-bye and wondered whether she could have done more to help Pedro.

As soon as she put down the 'phone after the call from Pedro's mother, Maria went to find another counsellor and, without using names, told her that a client she had worked with for a long time had just died. She talked about her own feelings – loss because she had been counselling this client for a number of years, concern about whether she had done enough to reconcile him with his family and anger at the loss of yet another client.

The other counsellor let her talk and acknowledged her feelings: "I'm glad you shared this with me – it's difficult to bear those feelings on your own. What can you do to get through this time and still help the family?" Maria thought about this for a few minutes, then said: "I think I would like to write down

some of what I remember about this client before he became so ill – he was courageous and sometimes very funny. Perhaps the family will let me share my memories at the funeral. If you don't mind, I would also like to be able to talk with you again, if I feel the need." The other counsellor readily agreed to this: "Of course – I know I'll need your support some time as well."

Stress management

Counselling work may cause physical and emotional stress. To avoid stress and to deal with it effectively when it arises:

- ❖ Rest whenever you feel overworked;
- ❖ Take regular holidays;
- ❖ Do something different, e.g. read a book, do gardening;
- ❖ Socialise;
- ❖ Talk about your feelings;
- ❖ Exercise;
- ❖ Meditate or pray;
- ❖ Eat a healthy diet; and
- ❖ Get enough sleep.

*Taking care of yourself
is as important as
taking care of other
people*

Ongoing training

- ❖ Talk to your supervisor about training opportunities.
- ❖ Attend professional seminars and lectures.
- ❖ Read journals, newsletters and other publications that deal with your area of work.