

## 2. PSYCHOSOCIAL CARE AND SUPPORT

### 2.1 Introduction

HIV/AIDS is more than just a medical problem as it brings with it a host of psychosocial issues at the personal, inter-personal, family and social levels. The impacts and ramifications of HIV infection and disease run throughout the whole course, from the time of infection through the development of disease to the terminal stages. Psychosocial support (which is an all-encompassing concept that includes counseling, spiritual support, welfare support and social/interpersonal support) should therefore be part and parcel of the continuum of care from prevention to treatment and care to discharge planning right up to home based care. It forms the crosscutting glue that binds the provision of holistic HIV/AIDS prevention, care and support.

### 2.2 Counseling for primary prevention of HIV infection

Primary prevention counseling is indicated in a number of situations, which may include the following:

- During treatment for STIs
- Before and after HIV testing
- When deciding to have a baby
- Before marriage
- Suspected HIV infection in adults and infant

It usually entails an in-depth exploration of risk during which the client is encouraged to identify, understand and acknowledge the behaviours and circumstances that put him/her at increased risk for acquiring HIV/AIDS as well as assisting clients in taking maximum responsibility for risk prevention/reduction. Primary prevention counseling includes the following:

### 1. First task:

Provide clients with general information on HIV AIDS, including modes of HIV transmission and clarify any misinformation and misconceptions about means of preventing transmission of HIV/AIDS with respect to:

- Use of condoms
- Multiple partners
- Safer sex
- Injecting drugs and sharing needles

### 2. Second task:

Facilitate a process whereby clients engage in a personalised HIV/AIDS risk assessment by establishing an atmosphere that conveys a non-judgemental, collaborative and creative interest in the exploration of those HIV/AIDS related issues that have relevance to the client. This requires communication skills and the requisite attitudes of respect and acceptance that will make it easier to:

- Facilitate client's awareness of their personal risk for HIV infection by reviewing the client's sexual, medical and drug use history.
- Collaborate with the client in identifying the categories and range of behaviours in his/her past that could have placed him/her at risk of HIV infection.
- Review client's current circumstances and behaviours and again identify those aspects of his/her lifestyle that pose real and potential risk for HIV infection.

### 3. Third task:

Facilitate personalised risk-reduction decision-making and planning where you:

- Focus on risk reduction measures that relate to the client's specific HIV related risk behaviours and the circumstances that affect these behaviours.
- Help the client identify current and potential barriers to implementing and sustaining risk-reducing behaviours.

- Help the client come up with a reasonable personalized risk-reduction plan towards HIV/AIDS prevention
- Help clients anticipate possible barriers to the implementation of the risk-reduction plan and rehearse ways of overcoming them.

**POINTS TO REMEMBER DURING COUNSELING**

- Keep the session focused on HIV risk assessment and reduction. (Goal is risk reduction).
- Include an in-depth personalized risk assessment.
- Explore previous attempts to reduce risk and identify successes and challenges.
- Acknowledge and provide support for positive steps already made.

### **2.3 Counseling in relation to HIV testing**

Counseling related to HIV testing has been given quite a lot of attention and this has led to the development of various protocols for Voluntary Counseling and Testing (VCT). This is so because VCT for HIV infection is often seen as an entry point for HIV prevention, care and support. For the yet uninfected, it often helps them to stay HIV negative by reinforcing risk-free behaviours. It encourages clients to come up with personalized risk reduction plans and to put them into practice. For those who are HIV positive, VCT helps them to deal with the immediate psychosocial impacts of their positive HIV status. In the long term however, VCT needs to be complimented or supplemented by supportive, crisis and bereavement counseling in order to help clients deal with the chronicity and roller-coaster nature of their illness as well as the possibility of premature deaths.

### 2.3.1 Pre-test counseling

Pretest counseling is counseling offered to clients before they take an HIV/AIDS test. Anyone considering being tested for HIV for whatever reason should be counseled before testing regardless of whether it is the clients themselves who have requested the test or whether it is the health worker who is suggesting the test. Pre-test counseling requires a supportive, non-judgemental and caring environment in which the clients will feel free to talk about their risk-related behaviours, their fears, worries and their motivation for HIV- testing.

For pre-test counseling to be comprehensive the following areas need to be covered during the session:

- Client's history of HIV counseling and testing.
- Why the HIV test is being considered/suggested.
- Client's understanding of HIV transmission and prevention.
- As part of considering whether HIV testing is indicated, it is important to assess client's risk-history by exploring the following:
  - Sexual history including STIs
  - Exposure to invasive medical procedures (modern and traditional)
  - History of intravenous drug use

To help clients arrive at an informed decision on whether or not to be tested they should be provided with information with regards to the following:

- The HIV testing procedure to be followed
- The Window period
- The meaning of positive, negative and indeterminate test results
- Length of time between testing and the availability of results
- Confidentiality of test results within the testing context.

In addition client's decision on testing will be aided by

- Discussing the possible implications of test results (be they positive, negative or indeterminate).
- Exploring the issue of confidentiality as it relates to significant others in the client's life, who might need to be informed for whatever reasons and discussing the potential benefits and adverse consequences of shared confidentiality.
- Reviewing client's history of dealing with personal crises (what crisis, how handled, who helped) and discussing possible reactions to a positive HIV result.
- Identifying social support systems (the family, support groups, fellowships) that are potentially available to the client and which the client may choose to access in times of need.

Having done all this, one should ascertain if the client still wants to go ahead with the test and then obtain the necessary informed consent (verbal or written) before commencing testing.

#### **NOTE**

**Pre-test counseling is intended to provide the client with the necessary informational and relational support to make a truly informed decision about whether or not to be tested for HIV. It is not intended to persuade the client to be tested. Therefore, regardless of whether or not the client decides to be tested, the pre-test counseling process undergone should have an empowering effect on the client (vis-à-vis risk assessment and risk reduction planning both of which are crucial in primary and secondary prevention of HIV infection).**

### 2.3.2 Post-test counseling

Post-test counseling is counseling given to clients coming to receive their test result. It is designed to help the client deal with any immediate emotional reactions to the HIV test results and to come to terms with their sero-status and ultimately, to support clients in risk reduction. In order for clients to benefit from post-test counseling it is recommended that the client should receive results in person, as it is crucial to assess the client's understanding of test results as well as facilitating client's expression of reactions and feelings. A number of health workers and counselors may be apprehensive about giving clients their test results (especially when the results are positive) and undertaking the necessary post-test counseling as they feel ill-prepared to deal with the resultant emotional reactions. It is important to stress here that when pre-test counseling has been done adequately post-test counseling will be easier to do.

**NOTE: Take time with pretest counseling, do it well, do not rush to test, make sure the consent the client gives is truly informed and what follows thereafter should be that much easier to deal with.**

### 2.3.3 If the test result is positive

If the HIV test is positive proceed as follows:

- Assess client's readiness to receive results.
- Give results in simple and clear terms and check understanding
- Allow time for expression of emotions.
- Discuss what the results mean to the client and their implications at the personal, relational, social and other levels.
- Revisit the discussion on client 's social support systems and explore the pros and cons of disclosure of status to significant others (whom, how, when, and their likely reactions)
- Revisit the personalized risk assessment and reinforce risk reduction plans and decisions on positive living i.e. (safer sex,

exercise, drug and alcohol use, smoking, nutrition, early treatment of opportunistic infections, use of ARVs, stress management etc).

**Note that the client may not be in a psychological state to absorb a lot of information at this stage. It is therefore necessary to arrange follow up sessions for additional psychological and social support as needed.**

Before terminating the post-test counseling session with an HIV positive client it is necessary to:

- Assess the client psychological reactions to and coming to terms with being HIV positive
- Provide realistic reassurance about clients status
- Discuss client's immediate plans following the session.
- Provide information on available psychosocial support networks e.g. ZNNP+, The Centre, MAC, NAC and others in the client's catchment areas.

#### **2.3.4 If the test result is negative or indeterminate**

If the test result is negative or indeterminate then do the following:

- Assess client's readiness to receive results.
- Give results in simple and clear terms and check client's understanding of the test result.
- Allow time for expression of emotions.
- Discuss what the results mean to the client and their implications at the personal, relational, social and other levels
- Revisit the issue of the window period and discuss any need for retesting.
- Revisit the personalized risk assessment and discuss risk reduction plan so as to reinforce client's commitment to remaining negative.

- Provide information on psychosocial networks in the client's catchment area that are committed to the prevention of HIV transmission.

## **2.4 Counseling in relation to on-going care and support for the infected and affected**

### **2.4.1 Information giving**

The HIV/AIDS scenario is forever changing. New information is coming to light everyday and new developments in the areas of care and support are the order of the day. One of the fundamental needs that arise from this is the need for up- to- date information. Yet uncertainty still pervades the field and impacts on many lives. A key ingredient in supportive counseling is empowering clients with the necessary factual information that enables them to make timely decisions, access needed care and support and to live positive lives. Supportive counseling should therefore provide clients with information on:

- Disease progression and importance of early treatment of O.I (immunity).
- Nutrition/hygiene, exercising and how to live positively.
- Antiretrovirals, their availability or otherwise, how they work, side effects and cost.

### **2.4.2 Psychological Support**

Due to the roller coaster and episodic nature of HIV disease clients may require on-going psychological support. For many of them more than one session may be required as a follow up on issues discussed in pre-test and post-test counseling. Such psychological support aims to help clients develop problem-solving skills so that they can assume/resume authority over their lives by taking clients through the following stages:

- Problem identification - the client is helped to articulate what exactly is the current problem/issue/concern

- Problem exploration - how is it a problem, for whom is it a problem, when is it a problem, etc
- Exploring possible solutions - weighing the pros and cons of alternative solutions to the problem.
- Decision making and implementation - choosing the most pragmatic options and coming up with realistic plans that are most likely to be achievable and supporting clients in implementing their decision through either being there for them or be working with them with other support services in the community.

### **2.4.3 Social and Welfare support**

HIV infection and disease tends to be chronic. In the early phases clients are able to carry on leading independent and productive lives. However, there comes a time when clients and their primary care givers may need social and welfare support. Such support may be available from Government Services such as Social Services, and the National AIDS Trust Fund through District, Ward and Village AIDS Action Committees. It may also be available from the many non-governmental and AIDS Service Organizations that are operating in many communities. However, clients in need can only access such social and welfare support if they are aware of its existence and where and how to access it. Those involved in supportive counseling should therefore have up to date information on the range of support services that are available in their catchment areas. At the very least, they should have the latest copies of the directories of counseling and psychosocial support services that are published annually. Supportive counseling should therefore facilitate:

- Client's identification and articulation of social needs - food, transport, health services, financial support.
- Exploration of the support systems that are and could be available to the clients (family members, neighbours, support groups e.g. churches, NGOs, CHBC group, social welfare).
- Planning of how clients can best manage their problems through accessing and/or mobilization of resources for their benefits.

## 2.5 Counseling in relation to prevention of opportunistic infections

Although the supportive counseling discussed previously will help clients to come to terms with their HIV infection and to live positive lives, the nature of HIV disease is such that at some point in time they may succumb to opportunistic infection. When this happens it may constitute a blow that may precipitate a psychological crisis. It is therefore important to offer clients psychosocial support aimed at preventing and/or delaying the onset of opportunistic infections.

In this regard clients need to be furnished with:

- Information on immunosuppression and depletion, common opportunistic infections, modes of infections and how to recognize early warning signs of opportunistic infections.
- Information on healthy life style to prevent OIs.
- Advice on the importance of seeking early treatment for OIs.

This information needs to be complimented by counseling that is aimed at motivating clients towards the secondary prevention of opportunistic infections. Such counseling will cover:

- The benefits, for the individual client, of seeking early treatment and emphasising that most OIs can be treated and that prophylaxis treatment is available e.g. cotrimoxazole for PCP.
- The burden of disease for the individual and caregivers in the family and what help is potentially available to lessen the burden e.g. home based care.
- Adherence issues related to pill burden, cost and accessibility of treatments that may become obstacles to prevention of opportunistic infections.

In addition counseling for secondary prevention of OIs will include:

- Supporting care givers by providing them with necessary information
- Providing clients and caregivers with the necessary supplies for infection control, treatment and care.

- A care-management approach that facilitates a well co-ordinated discharge plan that networks clients with service providers at the various levels, from the hospital to the clinic to the community and ultimately to the home.

## **2.6 Counseling in relation to terminal issues in HIV/AIDS**

With HIV/AIDS, there are multiple losses that are experienced by both the infected and the affected clients throughout the whole continuum from the day one finds out that one is infected with HIV to the development of opportunistic infections up to the terminal stages of the disease. Clients experiencing such losses are likely to benefit from bereavement counseling aimed at helping them navigate their way through the following stages of bereavement:

- Shock
- Anger
- Denial
- Bargaining
- Depression
- Acceptance

For many people, diagnosis with HIV infection /AIDS throws into bold relief the issue of their own mortality and when people contemplate death, spiritual issues tend to come to the fore. When this happens they may benefit from spiritually focused counseling. Many health workers / clinicians and counselors however feel ill equipped to offer such counseling. In such instances they should:

- Recognise and acknowledge the client's spiritual needs
- Identify the client's spiritual affiliation.
- Encourage them to discuss issues with members of the spiritual religion that they are comfortable with and to seek spiritual support whenever needed.

### 2.6.1 Bereavement counseling

Bereavement counseling may be necessary to help clients deal with unfinished business and will usually involve:

- Discussing cultural issues that are important and need to be attended to, e.g., rituals, customs, spiritual, and how and when.
- Helping the client settle any outstanding grievances between him/herself and others (clearing the air).
- Making or revising a will and planning the future for those dependents who will be left behind

### 2.6.2 Letting go

In addition clients may need help with letting go and coming to terms with dying.

Talking about death and dying is very difficult for a lot of people as the subject is considered taboo. Many dying patients/clients are therefore denied the opportunity by their relatives, friends and even health workers to ventilate their concerns about their dying. It is for this very reason therefore that counsellors need to either work through their own issues about death that may become obstacles in their work or to be honest enough about their shortcomings and make appropriate referrals so that the client is not denied a needed service.

To help dying clients let go and come to terms with their dying the following issues may need to be discussed during counseling:

- Their fears and feelings about dying.
- Whether or not to die at home.
- Funeral and memorial arrangements
- Support available after client's death - for individual members of family to help them deal with the relative's death.

In providing bereavement-related psychosocial support there may be need to involve other significant members of the client's family in order to provide

them with the necessary psychological preparation on the realities of death and to help maintain a balance between living and dying within the family system. Where indicated referrals to appropriate organizations /counselors that specialize in bereavement (such as Island Hospice) should be made.

**NOTE: Refer to the section on the The Dying Patient in Chapter 17 on Home Based Care for more details.**