

# **Social Tract**

**Module on**

## **Pre and post test HIV counselling**

## **LEARNING OUTCOMES FOR ALL PARTICIPANTS**

After the completion of this module the learner should:

1. Understand informed consent and its implications.
2. Have a good understanding of the diagnosis of HIV and the implications to the client.
3. Understand the importance of pre and posttest counselling.
4. Know how to give both a negative and positive result.
5. Understand the implications of a possible disclosure of a positive result.
6. Have an understanding of suicide.

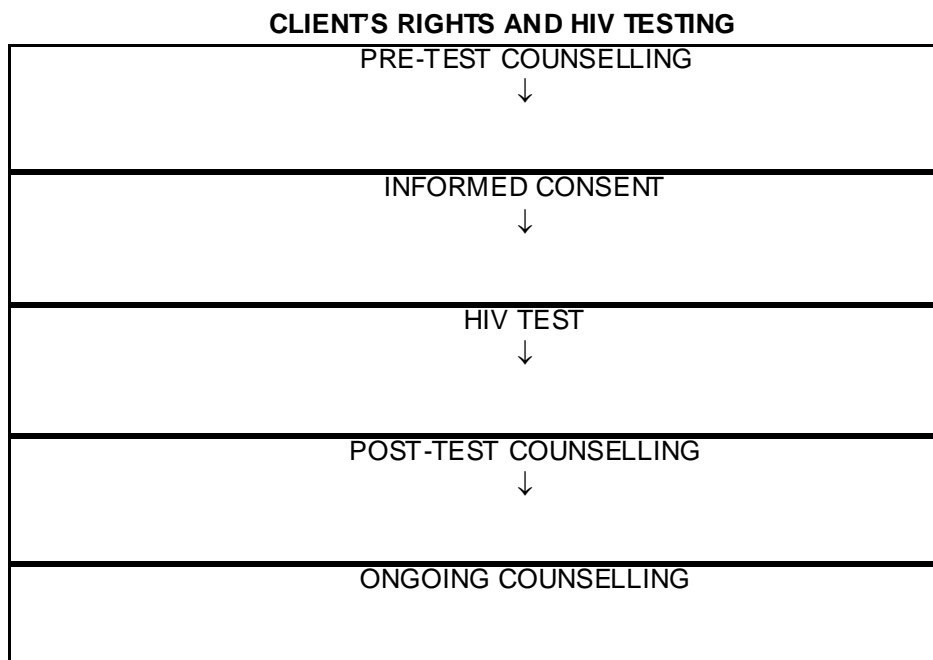
# 1. HIV COUNSELLING

Many health care personnel feel uncomfortable when there is a need to engage in interpersonal relations with a patient. Many medical practitioners have not received training or input in the area of counselling despite it being their role to deliver bad news and to discuss adaptive behaviours with their patients. The role of a counsellor is therefore an ambivalent one for the medical practitioner. In the field of HIV/AIDS, the role of counsellor is demanded when health care personnel are required to inform a patient of their HIV status. Conveying such status alone is not sufficient. It is also important to discuss things such as protecting current and future sexual partners and unborn babies, and high-risk behaviours. It is crucial to equip patients with knowledge about their disease. The lack of resources in the field creates a situation in which social workers, psychologists and other counsellors are not as readily available as the need requires. Should health care personnel not be open to providing basic HIV counselling, none will be received.

Serological testing for HIV without counselling has a psychological, medical and social impact on patients. Thus it is essential that health care personnel begin to prioritise and create opportunities for HIV counselling to take place. It is important to note the following with respect to HIV counselling:

1. The counsellor should ensure that his/her **objectives are small, limited and attainable**. By individualizing each patient, the counsellor will be able to have specific and realizable objectives for this particular moment with the patient.
2. It is important that the counsellor draws on his/her own **assessment** skills. Intuition is often important when trying to understand what a patient's needs are; their level of understanding; and the pace at which the counsellor should move with each patient.
3. The counsellor can **help the patient to view their problems differently**. What counsellors communicate is highly valued by the patient. An extreme amount of damage can be inflicted by counsellors who communicate messages that HIV is a punishment; that there is no hope for the patient; and that the patient brought this upon him or her self.
4. By helping to **reduce a patient's anxiety**, where appropriate, the problem can appear more manageable and the patient gains a greater sense of control over the disease. The patient is enabled to make decisions and cope better with the disease.
5. By the counsellor taking too much control over the patient's situation, the patient becomes alienated from what is, in fact, his or her own problem. Although **facilitating empowerment** may be a long-term process, the counsellor's attempt to solve the patient's problem may leave the latter feeling helpless and more confused.
6. It can be very frustrating for counsellors to experience denial as a reaction from patients who receive an HIV positive diagnosis. Sometimes this denial is a result of a lack of sufficient education about the disease. However **denial itself is a normal human reaction** that acts as a defence mechanism. Denial can be a way of coping that protects the patient from anxiety, depression and possibly suicide.
7. It is important that counsellors **do not make assumptions** about the patient's level of knowledge, concerns, values and possible reactions. Such assumptions become a barrier to open communication and may inhibit the patient from making important disclosures or asking significant questions.

8. Many health care personnel feel overwhelmed by their frequent contact with HIV positive patients and the depressing situation that this may present that they resort to falsely reassuring patients. **Complete reassurance should never be given.** This is not only misleading for the patient but also dismisses the implications of the problem and the uncertainty that, ultimately, the patient must resolve.



## 2. INFORMED CONSENT

*When testing for the presence of a terminal disease such as HIV, the informed consent process is of critical importance. Without respect for the autonomy of the patient, informed consent cannot be given. This process involves the provision of unbiased information that has been understood by the patient and is facilitated by a dialogical approach through which the perspective of the client is the focal point.*

South African legislation is well developed with respect to the issue of informed consent. Not only do policies dealing with HIV testing state explicitly that pre-test and post-test counselling must be offered, but the “common law rule on informed consent” states that informed consent is not assured until counselling has been received. This is further supported by the “Guidelines on the Management of Patients with HIV Infection or AIDS” (1994) by the Health Professions Council of South Africa. People who are tested for HIV without their knowledge or against their will are regarded as having had their human rights violated flagrantly.

## 3. HIV DIAGNOSIS

*For many patients, being informed that they are HIV positive can be a traumatic experience. Receiving an HIV positive diagnosis can precipitate a life crisis for an individual.*

*HIV testing without counselling, or inadequate counselling, might result in:*

- *depression or suicide;*
- *“revenge” behaviours that increase the spread of HIV;*
- *further transmission of the HI Virus due to lack of sufficient knowledge about the disease;*
- *and non-premeditated disclosure of serostatus to others, possibly resulting in discrimination, job loss, and/or isolation.*

*Due to such ramifications testing **must** be preceded and followed by appropriate counselling.*

*Effective voluntary HIV testing and counselling can achieve the following goals:*

- 1) reduce the further spread of HIV - a preventive goal
- 2) limit the pain that diagnosis causes - a supportive goal
- 3) educate the patient in order not only to prevent further spread, but also to facilitate the empowerment of the patient, and
- 4) provide a resource link, encouraging the provision of follow-up and exploring options available to the patient.

## **4. INFORMATION ABOUT TESTING FOR INFECTION WITH HIV**

### **The antibody test.**

The HIV antibody test shows if you have been infected with the Human Immunodeficiency Virus (HIV) that can cause AIDS. It is not a test for AIDS (Acquired Immune Deficiency Syndrome).

A positive test result therefore means that you are infected with HIV, and that you may develop AIDS at some stage. The test involves taking a blood sample from your arm. Once HIV enters the body, specific chemicals, or antibodies to the virus, are produced and these are what we look for in the blood test. If antibodies to HIV are found in your blood, you have been infected with the virus.

After being infected with the HIV, people generally produce antibodies and show a positive result by 6 weeks. However, for a few people this may take longer. If you have been at risk of contracting the virus during the 6 weeks before testing, or you have been at particular risk, you will probably need to have a repeat test in 3-6 months.

A negative result to the antibody test means that antibodies have not been detected. If the test has been done more than 3 months after the last risky contact, it generally means that you have not got the virus. It does not mean, however, that you are immune, if you do not protect yourself by safer practices, you could still get HIV.

### **The PCR test**

The Polymerase Chain Reaction (PCR) is a method whereby minute traces of DNA or RNA from infectious organisms or specific parts of cellular chromosomes are magnified to readily detectable levels. The test specificities and sensitivities approach 100%.

As opposed to the antibody test, the "window period" is reduced to 2 weeks (from 6 weeks - 3 months) after exposure to the virus i.e. HIV infection can be detected 2

weeks after exposure. A negative result, if the test was performed 2 weeks after the possible exposure, therefore means that no infection has taken place. Once again this does not mean that you are "immune" to HIV and you should continue to protect yourself by safer practices so as not to put yourself at risk. You can still get HIV.

### **SOME POSSIBLE BENEFITS FROM HAVING THE HIV TEST**

- A negative test result can allay anxiety.
- A positive test result can motivate clients and their partners to reduce or stop high-risk activities.
- A positive test result can prevent unknown transmission.
- A person who tests positive can access appropriate treatment.
- A positive test result in a pregnant woman can allow her to make a decision about possible termination or continuation with the pregnancy, or prevention of transmission to the baby.
- Previous sexual partners or needle-sharing partners can be informed and given the opportunity to take the HIV antibody test.
- The test can produce data on the methods of transmission, the high-risk behaviours and other information relevant to the provision of future services for those with HIV.
- A positive test result can alert doctor, dentists and other services to the need for taking precautions with contaminated blood.
- The test can help assurance brokers to make more informed decisions when issuing life assurance policies.
- The test can, along with other medical information, help employers to make more informed decisions about employing people and in what capacity.

### **SOME POSSIBLE DRAWBACKS FROM HAVING AN HIV TEST**

- The client might get a positive test result.
- The client might have to cope with the idea he/she might develop AIDS and die much sooner than they expected to.
- The client has to live with the uncertainty of waiting to see if and when they will develop symptoms and/or full-blown AIDS.
- The client may develop a depression.
- The client may abuse drugs.
- The client may attempt suicide.
- The client may be subject to prejudice and labelling.
- The client may experience difficulties with relationships.
- The client may experience difficulties in deciding whom to tell, and with issues of confidentiality.
- The client may experience difficulties in receiving medical and dental treatment.
- The client may not be able to obtain life assurance.
- The client may suffer from loss of confidence and control.
- The client may become over-concerned with his/her HIV positive status and feel he/she has to choose to hide this fact.
- The client may be dismissed from work.
- Former difficulties with homosexuality and drug abuse may be rekindled and guilt reactions may follow.

- They may have anxiety about who else they have infected.
- Gay men may feel obliged to come out.
- Members of the medical profession may feel powerless to help.

## 5. PRE-TEST COUNSELLING

**"Pre-test counselling"** - counselling given to an individual before an HIV test, to make sure that the individual has sufficient information to make an informed decision about having an HIV test. During the session the individual should be given an opportunity to make a decision on whether he or she wishes to undergo the HIV test. Pre-test counselling should include discussions on:

- What an HIV test is, the purpose of the test;
- The meaning of both a positive and negative result, including the practical implications such as medical treatment and care, sexual relations, psycho-social implications etc;
- Assessment of personal risk of HIV infection;
- Safer sex and strategies to reduce risk;
- Coping with a positive test result, including whom to tell and identifying needs and support services; and
- An opportunity for decision making about taking the HIV test.

### Pre-test counselling

- Greet and welcome the client and introduce yourself and explain your role.
- Mention the reason for pre-test counselling: that it is a legal and ethical requirement and that it is a test with possibly vast implications and that they need to feel sure about having the test. It is their decision to make. Briefly mention what issues will be covered in pre-test counselling.
- Invite the client to give you any appropriate background information (age, relationship status, living arrangement, occupation, previous test history), remembering that some will be concerned about confidentiality.
- Explain confidentiality and its limits.
- Ask the client the reason for testing and assess through the reply:
  - the urgency to have the test
  - their knowledge of HIV
  - their emotional state.

Do not make any judgments about the client's reason for testing: HIV is fear inducing for many and there may be many personal reasons for testing, some of which may remain unarticulated.
- If you are the person suggesting the test it is important to explain:
  - why the test is being requested
  - that it is in the interests of treatment

- that testing is voluntary and that refusal to test will have no negative consequences.
- Because this process is anxiety-provoking for some, it is useful to remember to:
  - contain any reactions with empathy and understanding
  - validate feelings, allowing space for personal expression
  - reduce anxiety through a calm and relaxed manner and appropriate reassurance
  - encourage the client to talk about insecurities and feelings that may accompany a crisis.
- Ask the client how much he or she knows about HIV and AIDS, hear what they know and then offer to fill in any gaps in knowledge. This should cover definitions of HIV and AIDS, transmission, symptoms, progression from HIV to AIDS. The amount of information given will depend on the client's pre-existing knowledge, comprehension level and need. It should be precise and clear.
- Discuss the HIV test itself and what it will reveal and not reveal.
- At this point a risk assessment is appropriate. Invite the client, on the basis of information shared, how she or he sees their risk. Give your input and come to a shared understanding of the risk. It is important to give the client ownership of the risk, the test and the result – he or she must “buy in” to the process.
- Explain that you are now going to explore the implications of the test, first the negative result and then the positive result. Ask the client how he or she might feel about a negative result and explore reactions and responses. It is important to cover:
  - the window period and its implications
  - staying HIV negative through safer sex and blood practices
  - if appropriate, a condom demonstration.
- Now explore the positive result: “If your test result comes back positive, what will you do, how will you feel?” Be prepared to contain if the client becomes anxious.
- Explore psychosocial reactions:
  - the client's coping mechanisms (inner resources)
  - family support and concerns
  - friends' support and concerns
  - other possible support (outer resources).
- Explore disclosure to a partner and whether the partner knows the client has come to test. Discuss the relationship implications thoroughly.
- Explore other disclosures to family, friends and previous sexual partners and the risks attached to this. Emphasise that support is important and that there are groups and organisations that can help.
- Explore issues around employment and explain that:
  - termination of employment on the grounds of HIV status is not legal
  - pre-employment testing is not legal

- there is no legal requirement to inform the employer
  - they might be forced to disclose if they became too ill to work
  - they should enquire about medical aid cover
- Discuss other implications: family planning, pregnancy, children, finances, insurances, treatment options, medical costs, stigma, confidentiality, legal, spiritual, sexual, lifestyle and healthy living.
  - Help the client to weigh these implications up into advantages and disadvantages to assist with the decision to test.
  - Assess the client's suicide risk.
  - Discuss the test procedures and repeat information on what the test will reveal and not reveal i.e. it will only reveal the presence or absence of antibodies (if the antibody test is being done) within the limitations of the window period.
  - Ask the client if there are any further questions.
  - Ask the client if she or he is now ready to test and set the process in motion if the answer is yes. Accept that some clients may wish to think further about the matter. It is important that safer sex practices have been discussed. This can be a difficult time. Offer appropriate support. If applicable, discuss coping mechanisms during the waiting period.
  - Complete any informed consent requirements and make an appointment for follow-up counselling for the result.

### ***Pretest counselling observer checklist***

1. Did the counsellor introduce himself/herself and define his role?
2. Did the counsellor briefly outline the aims of pre-test counselling?
3. Did the counsellor get the client to talk?
4. Did the counsellor give advice?
5. Did the counsellor pass judgments or moralise?
6. Did the counsellor show respect for the client?
7. Did the counsellor exhibit empathy?
8. Was the counsellor honest?
9. Did the counsellor seem confident?
10. What were the areas of uncertainty or ignorance as far as the counsellor was concerned and how did he/she deal with them?
11. Did you think information given by the counsellor was correct?
12. Did the counsellor give the client time?
13. Was mention made of further counselling?
14. Did the counsellor check out the client's understanding of important points?
15. Was the session ended in a positive manner?
16. How did the client feel the session went? Would he/she come back?
17. How did the counsellor feel the session went? In what ways does he/she feel things could have improved?
18. Any other points you wish to bring out?

## 6. POST-TEST COUNSELLING

**"Post-test counselling"** - the counselling provided when an individual receives his or her HIV test result. Post-test counselling involves one or more sessions (ideally at least two) and should include discussions on:

- Feedback and understanding of results;
- If the result is negative:
  - Strategies for risk reduction
  - Possibility of infection in the 'window period';
- If the result is positive:
  - Immediate emotional reaction and concerns;
  - Personal, family and social implications;
  - Difficulties a patient may foresee and possible coping strategies;
  - Who the client wants to share the results with including responsibilities to sexual partners;
  - Immediate needs and social support identification; Follow up supportive counselling; and
  - Follow-up medical care.

## 7. POST-TEST COUNSELLING: NEGATIVE RESULT

- Prepare yourself for the result-giving by:
  - checking you have the right result
  - making sure you understand what the results mean
  - making sure you have enough time.
- Greet and welcome the client and check their readiness to receive the result.
- Give the result calmly and professionally.
- Wait for the client's response. Accept and normalise any response and feelings that have been evoked.
- You may wish to explore with the client:
  - what the test result means to them
  - how the waiting period was
  - who they may wish to tell about the result.
- It is extremely important to help the client stay negative and stress that the client is our partner in the epidemic and that we wish to assist them to stay negative. It is therefore important to discuss:
  - safer sex and blood practices
  - relationship issues around safer sex
  - negotiating skills]
  - assertiveness

- self-responsibility.
- Remember that some clients:
  - are repeat testers and may be “worried well”
  - feel immune or reckless
  - are fatalistic
  - are depressed
  - may feel “survivor guilt”
  - are left feeling angry after being put through test trauma
  - may have anxiety attacks.
- Encourage the client to ask any questions and help them feel “worked through” about the result.
- Make any follow-up appointment if necessary.

## **8. POST-TEST COUNSELLING: POSITIVE RESULT**

### **FIRST SESSION**

- Prepare yourself for the result-giving by:
  - Checking you have the right result
  - Making sure you understand what the results mean
  - Making sure you have the time to spend with the client
  - Being sure you are emotionally ready.
- Greet and welcome the client and ascertain that the client is ready for the result.
- Give the result calmly, professionally and empathically.
- Wait for the client’s response. Accept and normalise any response and feelings that have been evoked.
- Common feelings are shock, disbelief, numbness, anger, guilt, blame, loss, sadness, hopelessness, helplessness, fear, anxiety, agitation or even a seeming indifference and denial.
- At this time the client needs to feel the presence of the counsellor and that she or he is able to contain feelings. The client may forget or block out this period but will remember you were there for them.
- The client is facing multiple loss: health, future, normality, fitting in, sexuality etc. and it may be useful to think of the client as having to grieve and mourn for these losses.
- If the client is symptomatic, there will be a sense of urgency.
- Be mindful of the possible mode of infection and the implications of this for coping and strategies: being infected through rape, a needle stick, an infidelity or a loving relationship will create unique dynamics.
- The counsellor may feel helpless and there is often a need to over-reassure. Allow all feelings to occur naturally – there is usually time to make decisions.

- Answer any questions compassionately and appropriately but be careful not to collude with over-intellectualisation. Work with feelings. Give them written information if possible. If appropriate, discuss disclosure to at least one supportive person and ascertain whether there is a partner involved. If necessary, discuss how this person will be told and if the client cannot, how to negotiate safer sex until the disclosure has happened.
- Plan in a clear and concrete manner how the client will manage the next 24 hours.
- Give appropriate contact numbers and arrange a follow-up appointment, for the next day if possible.
- Before the client has left, assess their suicide risk and respond accordingly.

## **SECOND SESSION**

- Allow the client to lead the session. Provide a safe and caring environment. Do not overwhelm the client and if necessary, allow the following issues to be discussed at the client's pace.
- Help the client to know that experiencing pain and working through feelings is a part of healing. Validate all feelings. Answer all questions and give information and resources.
- Explore the client's current relationship and disclosure to the partner: be prepared to give thorough assistance with the "telling", if necessary being there when it happens. Explore other disclosures to:
  - past or future sexual partners
  - health care providers
  - insurers
  - family and friends
  - the employer.
- Discuss legal concerns and rights of HIV positive people. Stress that rights go with responsibilities.
- Discuss welfare options including disability grants and how these are accessed.
- Explore concerns around children to include;
  - pregnancy and its risks
  - prevention of vertical transmission
  - termination
  - family planning
  - guardianship of orphans
  - decisions about testing children.
- Explore medical options which include:
  - follow-up tests and what they mean
  - developing a health plan with a state clinic or private practitioner or managed care programme
  - available treatments and costs
  - alternative health options (including traditional healers).

- Explore lifestyle changes which include:
  - cutting down on alcohol and substances
  - getting sufficient rest and sleep
  - appropriate exercise
  - dealing with stress
  - eating a proper balanced diet
  - use of supplements and immune boosters
  - safer sexual behaviour and re-infection
  - safer blood practices and infection control.
- Work appropriately with hope and empowerment by:
  - supporting the client's realistic hopefulness and being encouraging without discounting the client's concerns or avoiding talking about death and dying
  - focusing on promising research
  - focusing on quality of life issues
  - encouraging the client to take control of his/her health
  - encouraging the use of resources
  - stressing that people with HIV are living productive lives
- Assess the client's suicide risk and respond appropriately.
- Assess the need for future support and contract for appropriate number of sessions.
- In sum, focus on the whole person as social, emotional, sexual beings with medical, legal and financial needs.
- If necessary, access your own support systems and debrief when appropriate.

## 9. DISCLOSURE OF HIV POSITIVE STATUS

*Whether or not to disclose their HIV-positive status is a difficult decision for HIV-infected individuals to make because disclosure (or non-disclosure) is often followed by major and life-changing consequences. Counsellors should help their clients to carefully consider the benefits as well as the negative consequences disclosure may have for them.*

### POTENTIAL BENEFITS OF DISCLOSURE

- Can help the client to accept their status and reduce the stress of coping on their own.
- Can help the client to access the medical services, care and support that they need.
- Can help the client to protect themselves and others. Openness about HIV status may help women to negotiate safer sex practices.
- It could help to reduce the stigma, discrimination and denial that surround HIV/AIDS.
- Disclosure promotes responsibility – it may encourage the client's loved ones to plan for the future.

## **POSSIBLE NEGATIVE CONSEQUENCES OF DISCLOSURE**

- Lack of support from family and friends, leaving the client to deal with everything on their own.
- Placing others at risk of infection, particularly sexual partners and increasing the risk of re-infection for the client.
- Not being able to access appropriate medical care, counselling or support groups.
- People may become suspicious of the clients' actions and behaviour.

## **COUNSELLING GUIDELINES FOR DISCLOSURE**

*'Disclosure is a process, not an event.'* The counsellor should assist the client in carefully thinking through the pros and cons of disclosing their HIV status and planning ahead before they do it. Clients should decide if they want full disclosure i.e. publicly revealing their status or partial disclosure i.e. only certain people – spouse, relative or friend.

## **COUNSELLING PROCESS OF DISCLOSURE**

- Allow the client to develop trust in you and feel at ease.
- Discuss the implications of disclosure fully, to help the client consider in advance, the reactions of family, friends, work colleagues and others.
- Help the client to develop a plan. This should include whom they will inform first, how and where they will disclose and the level of disclosure.
- Prepare the client for a shocked and even hostile reaction from other people. Reassure clients that people close to them will probably learn to accept their HIV status over time.
- Assess the client's ability to cope and establish their sources of support.
- It is important for a client to be strong enough to allow others to express their feelings and concerns after their disclosure. Assist the client to work on these issues over time.
- Provide the client with information and support to 'live positively' and give information on safer sex practices.
- Counsellors should protect their clients against undue pressure to disclose.
- The counsellor should be willing to mediate the disclosure process if the need arises.
- Identify sources of support, such as support groups for people living with HIV/AIDS, church members and counselling organisations.
- Arrange to see the client again at a time and date agreed by both of you to review this process.

## **10. SOME NOTES ON SUICIDE**

### **Recognised signs of depression and suicide risk:**

- change in personality: sad, withdrawn, irritable, anxious, tired, indecisive, apathetic
- change in behaviour: can't concentrate on school, work, routine tasks
- change in sleep pattern: oversleeping, insomnia, sometimes with early waking
- change in eating habits: loss of appetite and weight, or overeating
- loss of interest in friends, sex, hobbies, activities previously enjoyed
- worry about money, illness (real or imaginary)

- fear of losing control, going crazy, harming self or others
- feeling helpless, worthless, “nobody care”, “everyone would be better off without me”
- feeling of overwhelming guilt, shame, self-hatred
- no hope for the future, “it will never get better, I will always feel this way”
- drug or alcohol abuse
- recent loss: through death, divorce, separation, broken relationship, or loss of health, job, money, status, self-confidence, self-esteem
- loss of religious faith
- nightmares
- suicidal impulses, statements, plans, giving away favourite things, previous suicide attempts or gestures
- agitation, hyperactivity, restlessness may indicate masked depression

