Community Counsellor Training Toolkit

Module 5

Adherence Counselling

Facilitator Manual

LifeLine/ChildLine Namibia

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Facilitators who use this manual must be trained in both facilitation and advanced counselling skills.

Developed by Lisa Fiol Powers, Family Health International (FHI), Namibia, in collaboration with staff from LifeLine/ChildLine, Namibia.

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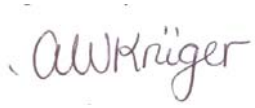
Foreword

In 1988, I started working as a young community liaison officer for a Namibian non-profit organisation. This experience opened my eyes to the tremendous gaps between the values, norms and cultural influences of the country's different ethnic and racial groups and between those living in urban and rural settings. These differences in experience and perspective added to the tension amongst people, leading to a lack of trust and an inability to work together.

Fortunately, Namibians have experienced tremendous social growth since then, as these manuals for training community counsellors demonstrate. They include such sensitive subjects as stigma, coercion and cultural practices detrimental to health. These pioneering learning tools reflect the significant progress made as a result of the great partnerships developed throughout Namibia over the last 18 years. It is heart-warming to witness the openness and trust people from different cultures have achieved by offering counselling to a neighbour, a friend, a stranger.

I am proud to be associated with these manuals. I am proud of every trainer of LifeLine/ChildLine Namibia and every Namibian trainee who contributed. Thanks go to the many partners in faith-based organisations, non-governmental organisations, and the Ministry of Health and Social Services, especially NACOP—Special Programmes Division, which made such important contributions. Ms. Lisa Fiol Powers, a consultant seconded by Family Health International to upgrade and develop these manuals, deserves special thanks. In addition to these dedicated partners, we also want to thank the U.S. President's Emergency Plan for AIDS Relief, which provided funding. We will forever be grateful to you all.



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Acknowledgements

Over the last eight months I have lived, breathed and dreamt about community counselling, training and curricula. Developing the Community Counselling Training Toolkit has been an incredible experience for me. It enabled me to share my passion and concern to provide psychosocial support and counselling to meet the needs of so many around the world, particularly those affected by and infected with HIV. For me, it has been an honour to live and work in Namibia and to share in the lives of so many who are tirelessly working to fight HIV and its effects.

As is true with all curricula development, the entire team creates the finished product. The team I have worked with at Family Health International (FHI) and LifeLine/ChildLine has been especially generous, delightful and supportive.

Let me start by thanking the training team at LifeLine/ChildLine. The training team includes staff trainers Nortin, Frieda, Maggy, Angela and Cornelia, and volunteer trainers Dube, Christine, Hilarie, Emmy, Emelle and Jonas who have been absolutely fabulous to work with. When I rushed to complete drafts of Facilitator Manuals just days before a training workshop, the trainers never lost patience, even though it meant they had limited time to prepare for their sessions. Their enthusiasm and willingness to try new material has never ceased to amaze me. They have welcomed new ideas and significant changes to both the training materials and the methodology. The encouragement and feedback I have received from the trainers has been invaluable! You have been a delightful group of people to work with on this project.

I would also like to thank Amanda Kruger, Hafeni Katamba and Simon Kakuva at LifeLine/ChildLine for recognising the need to make substantial changes in the Community Counsellor Training Toolkit and for their support throughout the process of curricula development, encompassing piloting and testing new material as well as training trainers in process facilitation.

None of this would have been possible without the incredible support from the entire staff at Family Heath International/Namibia. You are all a truly talented, dedicated and fun group of people. I would specifically like to thank Rose de Buysscher for making this whole project possible, not only through the allocation of funds, but also for her support in turning what began as a “harmonisation” into a more extensive project involving significant changes to existing curricula and the design and development of new material. The technical contributions and support for person-centred counselling offered by Dr. Fred van der Veen enabled me to challenge some of the rigid tenets of HIV counselling, and encourage counsellors to focus on their client’s emotional needs rather than adhering to fixed protocols.

Finally, I would like to express my deepest gratitude to Patsy Church for her inspiration and generosity in providing so many resources, for engaging in so many stimulating conversations, for being a cheerleader at times, and for always believing that these materials could make a difference. Patsy tirelessly read through drafts and offered valuable feedback and encouragement. Patsy has not only become a role model, she has become a dear friend.

My hope is that, with this Training Toolkit, community counsellors in Namibia will be better equipped to support their clients emotionally, offering them hope as they wrestle with so many difficult issues such as stigma, loss, coping with their HIV status, death and treatment, as well as financial and emotional uncertainty.

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ADHERENCE COUNSELLING: FACILITATOR MANUAL
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COMMUNITY COUNSELLOR TRAINING TOOLKIT OVERVIEW

Facilitator Guide: This guide introduces the entire training toolkit and contains information on the methodology, philosophy and focus of the curriculum. It is recommended that you read the Facilitator Guide prior to facilitating any of the Toolkit modules.

Module 1: Personal Growth: This first module walks participants through the process of exploring themselves, as understanding and acceptance of oneself is the foundation for becoming a counsellor. Through exploring one's own thoughts, feelings, values and attitudes, one develops self-acceptance, which is the basis for acceptance and empathy for others. By reflecting on one's own experience and then analysing that experience, participants not only develop important reflecting skills necessary for counselling, but facilitators can also assess participants' capabilities to become counsellors. Experiential learning from this module is continuously referred to in subsequent sections of the curriculum.

Module 2: Basic Counselling Skills: This module focuses on the essential counselling skills required for all types of counselling, particularly from a client-centred counselling approach. The emphasis in this module is on practising these fundamental building blocks of counselling, which include listening, reflecting, probing/action and problem management skills. All of these skills are used to build trust, develop empathy, assess the emotional state and general condition of the client, identify key issues or problems and assess their importance, explore options to address these issues, agree on a plan of action with achievable objectives, and organise follow-up sessions to continue the counselling process.

Module 3: General HIV including Sex Education and Sexuality: This module lays out important topics related to HIV, such as prevalence, transmission, prevention, the natural course of the disease, etc. While most of this module is general information, some sessions focus on emotional aspects of the disease, which are then integrated into a counselling framework. Information on HIV would be incomplete without an emphasis on sexuality and relationships, since sex is the most common mode of transmission in Africa. HIV counsellors must be comfortable discussing issues related to sex and sexuality. It is important for trainees to explore their personal values related to sexuality and sexual behaviours before working with clients who may have different values and engage in different sexual behaviours from theirs.

Module 4: HIV Counselling & Testing: The counselling and testing module of this Toolkit focuses on incorporating client-centred counselling with the general Voluntary Counselling and Testing (VCT) topics. Community counsellors are encouraged to use the existing counselling and testing outline as a starting point rather than a fixed protocol. Using the skills acquired during the previous modules, participants then apply them to the specific settings of HIV counselling, testing and follow-up.

Module 5: Adherence Counselling for HIV Treatment: This module applies basic counselling skills in working with clients to support ways of managing HIV at different stages of the disease. This counselling includes preparing clients for

prophylaxis and treatment of opportunistic infections, preparing clients to start antiretroviral treatment and working with clients who return for follow-up visits to achieve and maintain optimal adherence.

Module 6: Counselling and PMTCT: Counselling in the context of PMTCT builds on the basic counselling skills from a person-centred approach. Counselling for preventing mother-to-child transmission includes counselling and testing as well as infant feeding counselling. Counselling in PMTCT is focussed on supporting the mother to make realistic choices about positive living, HIV prevention and family planning.

FACILITATOR INTRODUCTION TO THE ADHERENCE COUNSELLING MODULE

The Adherence Counselling Module of the Community Counsellor Training Toolkit is focussed on adherence to HIV treatment, which includes antiretroviral medication and prophylaxis for opportunistic infections, as well as other treatment. Building on the experiential learning in Personal Growth, the HIV Treatment Exercise that runs throughout this week of training is key to developing empathy for clients' experiences of HIV treatment. Make sure that you present this exercise seriously; urge participants to take their medicines as instructed. Then follow up on the experience throughout the week; this can be done once a day. When following up on participants' experiences of taking their antiretroviral medicines (ARVs), model the types of questions a counsellor should ask his/her client. Be respectful; do not mock or tease participants, and do not slip into the role of the "parent;" this was addressed in "The Roles We Play" in Personal Growth and will be reviewed in this Module during Stage 3: HIV Treatment Maintenance.

The first few sessions review the natural course or progression of HIV from the General HIV & Sexuality Module. Additional information is provided about opportunistic infections, along with a brief explanation of antiretroviral medicines (ARV) and how they work. These sessions are designed to give participants a basic understanding of these concepts. Keep in mind that you are training counsellors, not health professionals. Counsellors should not attempt to answer detailed questions about medical issues. They should always refer clients to doctors, pharmacists, and/or nurses when clients ask medical questions. You can model this as a facilitator by admitting when you do not know the answer to a question. If at all possible, schedule a question and answer session with a doctor during the later part of the week to address all remaining unanswered medically-related questions. These questions can be collected throughout the week on a "Parking Lot" flipchart displayed in the training room.

Issues relating to adherence are addressed in the beginning of this module. These topics include understanding adherence and resistance, disclosure and selecting a treatment supporter, factors influencing adherence, nutrition, and tools for sustaining adherence. After these topics are explored, a model of an interdisciplinary Health Care Team is presented. This team consists of doctors, pharmacists, nurses, social workers and counsellors. Community counsellors are members of this team; their role is to support the client emotionally as he/she prepares for and maintains optimal adherence to HIV treatment.

Most of the time in the Adherence Counselling Module is focussed on understanding and practising counselling in four stages of adherence. These stages are Pre-HIV Treatment Initiation, HIV Treatment Initiation, HIV Treatment Maintenance, and Re-motivation and Treatment Change. Each stage is accompanied by a checklist and a model for a counselling session. These checklists and models are to serve as guides for counselling to keep the counsellor focussed on the primary topics. However, the models should not be used rigidly. Encourage participants to practise their basic counselling skills throughout the role plays for adherence counselling. It is more important to listen to, reflect the feelings

of, and support the client than to follow the outlines presented in these models. As with all other modules of this Toolkit, focus on role plays to practise skills rather than spending a lot of time presenting the materials; putting these counselling models into practise helps participants understand the content much better than if you spend a lot of time didactically explaining it. If at all possible, try to conduct some of the role plays in local languages so that participants can practise counselling in the languages they feel most comfortable. This is possible even when you do not have facilitators who speak all of the languages represented. If there are even two or three participants who speak one language, they can conduct one or two role plays in pairs or triads. You may want to ask them to give feedback in English or another common language so that you can process the role play with them.

The final section of this module is designed to help participants integrate their learning about Adherence Counselling by discussing some adherence scenarios (case studies) and exploring the emotional lifeline of a person living with HIV. Finally, there is a session on self care and counselling skills assessment, both themes that run throughout the Training Toolkit.

Although a session for recorded role plays has not been included in this module, it would be helpful to record role plays to further develop participants' counselling skills through observation and feedback. This is a valuable exercise to repeat, if at all possible. Participants learn a great deal about their counselling manner and skills by observing themselves on tape. If you are able to record role plays, you can facilitate groups to meet and discuss their counselling skills assessments while others are recording.

LIST OF BASIC COUNSELLING SKILLS

Below is a list of the basic counselling skills. You will need to continuously remind participants of these skills as they are practising structured types of counselling.

Empathy*

Listening Skills*

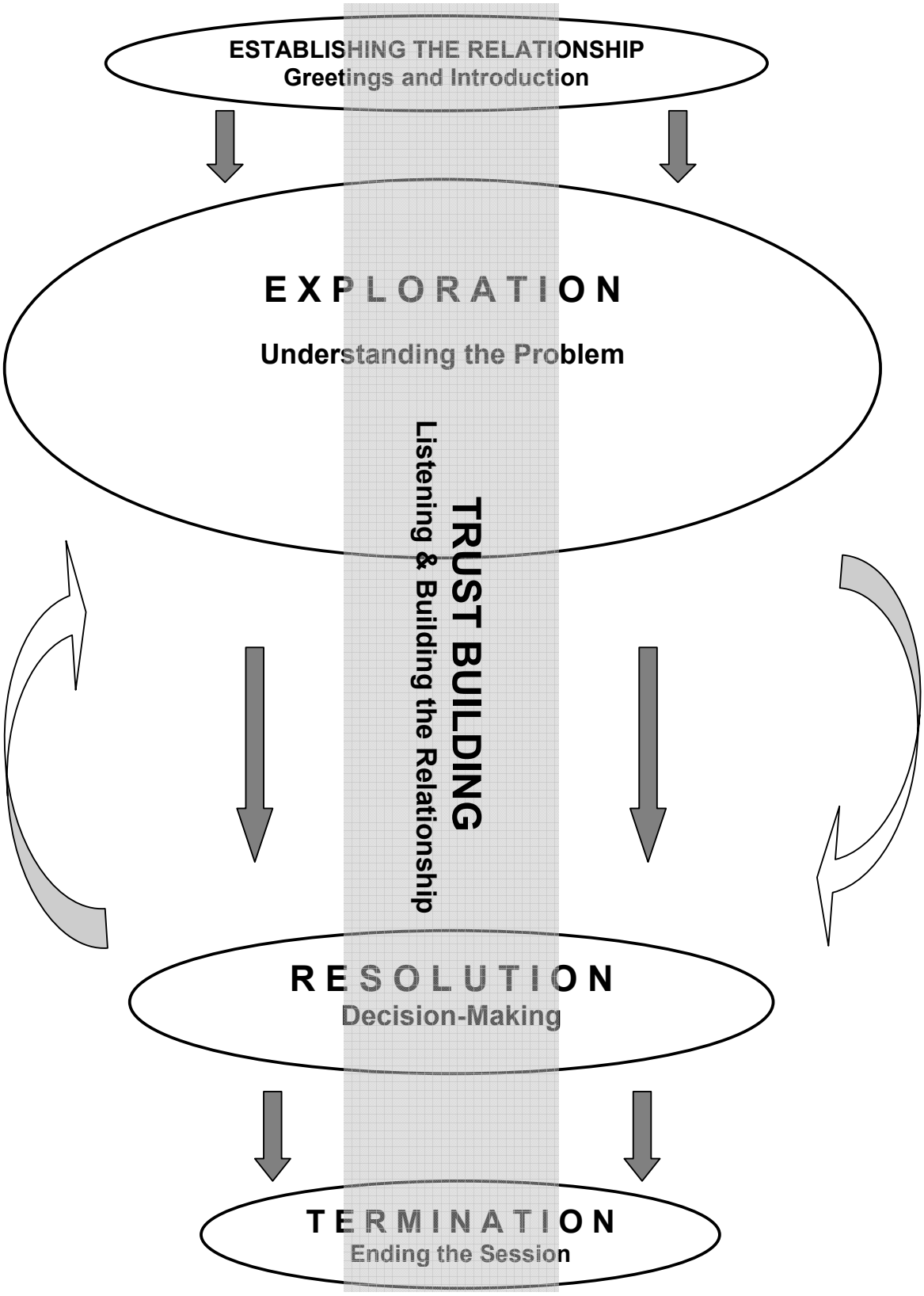
Reflecting Skills:
- **Reflecting Feelings***
- Restating/Reframing
- **Affirmation***
- **Summarising***

Probing/Action Skills:
- **Asking Questions (Clarifying)***
- Interpretation or Making Statements
- Confrontation or Challenging
- Information Sharing and Education

Problem-Solving/Problem Management

* These are the **essential counselling skills**.

MODEL OF A COUNSELLING SESSION



SESSION 1: WELCOME AND INTRODUCTION TO ADHERENCE COUNSELLING

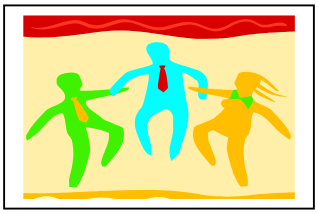
Objectives:

1. Welcome participants and introduce all participants.
2. Introduce the Adherence Counselling Module.

Time: 30 minutes

Session Overview

Activity/Method	Time	Materials Needed
Welcome & Introductions	15 minutes	
Warm-Up Activity: Signature Activity	30 minutes	Small cards or slips of paper Prepared flipchart
Introduction to Adherence Counselling Module	15 minutes	

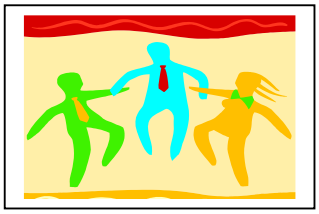


Activity 1

Welcome and Introductions

Time: 15 minutes

Before beginning the workshop, make sure that all participants and facilitators have been introduced. Some groups may have been together for weeks prior to this, but others will need to be introduced. You may play a name game if you wish or simply go around the room with introductions.



Activity 2

Warm-Up Activity

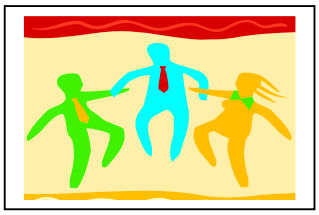
Time: 30 minutes

Preparation: List five categories on flipchart paper. You can make up your own categories, or use some of the following:

Someone who has visited another country
Someone who has five or more siblings (brothers or sisters)
Someone who has flown in an airplane
Someone who has never seen a lion
Someone who has been on a boat
Someone who has met someone famous
Someone who has gone swimming in the ocean
Someone who has caught a fish
Someone who has been on TV

- *Hand out a card or piece of paper (could be A4 paper cut in half or quarters) to each participant.*
- Each of you is receiving a piece of paper. On your paper, write each of the categories written on the flipchart. Leave space beside each category.
- Everyone should wander around the room and find someone who fits each of the categories listed by asking people questions. When you find someone who fits the category, ask him/her to sign your paper.
- You must have five different signatures; you may not have someone sign for two categories on your paper.
- When you have filled up your card with five signatures, you may sit down.
- *Give the participants some time to ask each other questions and wander around the room.*
- *When most participants have completed their cards, ask them to give the names of participants in each category. You can use this as an opportunity to find out more information about participants. Try to include as many participants as possible.*

Note to Facilitator: This activity is a variation on the "Have You Ever…" Game introduced in the Facilitator Guide. You may play that game if you prefer. The purpose of this game is to get to know participants in a different way, especially since many groups may have been in training together for weeks prior to this training.



Activity 3

Introduction to Adherence Counselling Module

Time: 15 minutes

Note to Facilitator: In this activity, you should cover the following topics:

- Outline of the module, highlighting the following:
  - We will review the natural course of HIV and understand treatment for HIV.
  - We will focus on adherence and the factors related to adherence. We will discuss the role of the counsellor in an inter-disciplinary team designed to support the client during treatment.
  - We will discuss important topics for adherence counselling starting before beginning treatment through maintenance and support for on-going treatment. We will be doing several role plays and practising using our basic counselling skills.
- Review the group rules. Make sure you bring the rules pictures/flipchart that the group drew during Personal Growth.
- Cover any housekeeping issues.

Note: Make sure that you prepare your introduction with notes so that it is short and to the point. It does not need to be long, but you will need to cover some main points.

SESSION 2: ADHERENCE COUNSELLING INTRODUCTION: EXPECTATIONS AND CONCERNS

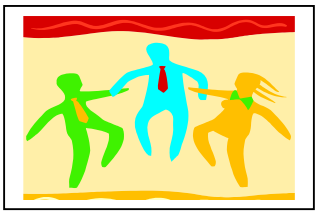
Objectives:

1. Brainstorm knowledge about HIV treatment.
2. Participants share expectations and concerns.

Time: 45 minutes

Session Overview

Activity/Method	Time	Materials Needed
Activity: Mind Map/Spider Diagram What Do You Know?	15 minutes	
Large Group Discussion: Expectations and Concerns	30 minutes	Prepared Flipchart paper Post-Its



Activity 1

ART Pre-Knowledge Assessment

Time: 15 minutes

- Ask the participants to take a few minutes to fill out the ART Pre-Knowledge Assessment.

ART Pre-Knowledge Assessment

I. True or False

1. ART is a cure for AIDS. **(F)**
2. As the viral load increases (gets larger), the CD4 count usually decreases (gets smaller). **(T)**
3. The purpose of ART Maintenance Counselling is to teach the client about HIV/AIDS and ART. **(F)**
4. The window period is the period after starting ART until the drugs start working. **(F)**
5. HIV uses the CD4 cells to grow and replicate or multiply. **(T)**
6. There are no problems with starting and stopping anti-retroviral treatment. **(F)**
7. ARVs must be taken at the same time every day. **(T)**
8. A person's experience of side effects has no effect on adherence. **(F)**
9. A personalised treatment plan is the plan that doctors and nurses make clients follow for treatment. **(F)**
10. The counsellor's responsibility is to tell the client exactly how to adhere to his/her ART. **(F)**
11. ART is treatment for life. **(T)**
12. In Namibia, a person can start ART without a treatment supporter. **(F)**
13. There is a higher risk of HIV transmission from a man to a woman than from a woman to a man through sexual intercourse. **(T)**

II. Matching: Match the word in column A with its definition/statement in column B.

Column A	Column B
14. Adherence **(c)**	a. Currently the best monitor for HIV disease progression.
15. CD4 Count **(a)**	b. A specific plan intended to improve health.
16. Disclosure **(e)**	c. The participation of a client in the plan of care or treatment.
17. Resistance **(f)**	d. Not taking the recommended dose, not taking it at the recommended time, or not taking it in the recommended way.
18. Non-adherence **(d)**	e. The primary step in breaking down stigma.
19. Regimen **(b)**	f. When medication is no longer effective at suppressing the virus.

List 5 things that influence a client's adherence to treatment:

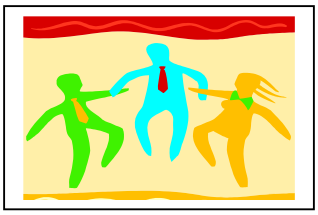
1. _____

2. _____

3. _____

4. _____

5. _____



Activity 2

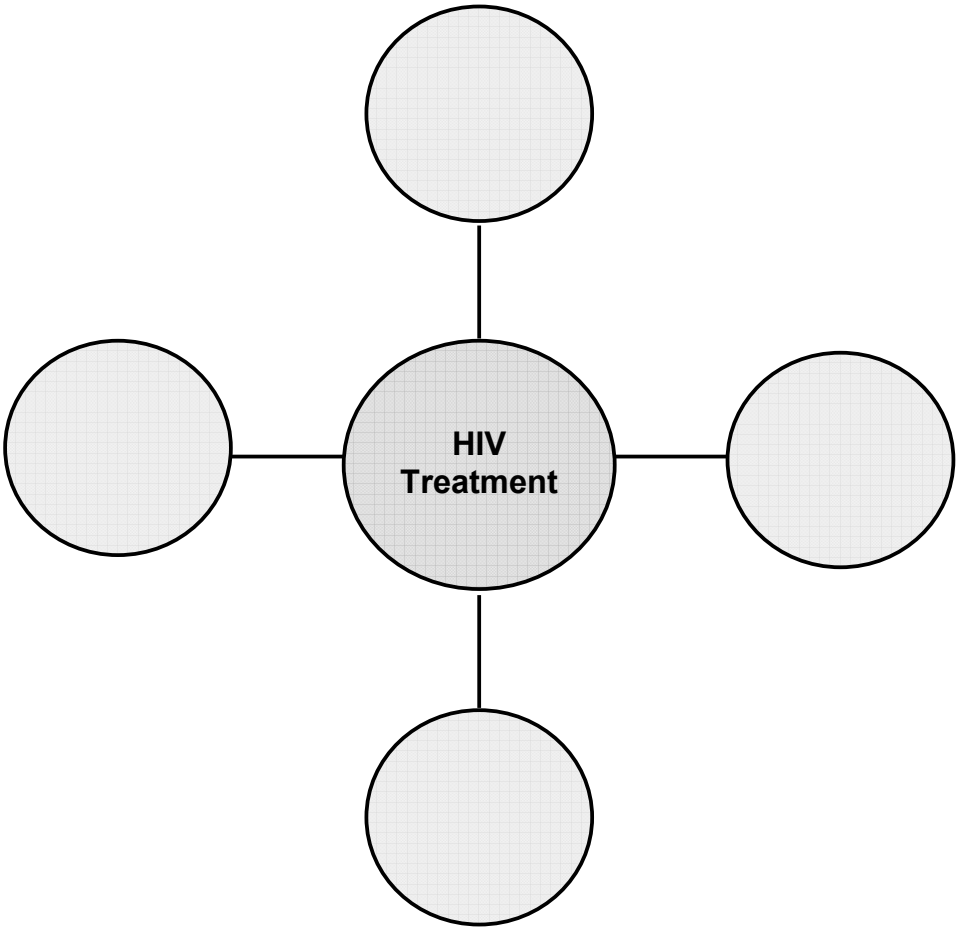
Mind Map/Spider Diagram

Time: 15 minutes

To begin this Adherence Counselling Module, I want each of you to think about what you already know about HIV treatment.

- Have you ever heard of a Mind Map or a Spider Diagram?
- These are basically two names for the same thing. It is a brainstorming technique, and is also a technique that you can use with clients in counselling.
- In the middle of your paper, draw a circle. Inside the circle, write "HIV Treatment." *Display an example of the beginning Spider Diagram/Mind Map.*
- From this circle, you can draw lines and other circles. Different circles could represent different aspects of your knowledge of HIV treatment. Come up with as much information as you can.
- This is not a test, so it does not matter if the information is wrong. I want you to explore what you know about HIV treatment (ART). If one page is not enough, you can always extend your spider diagram onto additional pages.
- You will have 10 minutes to brainstorm.

Mind Map/Spider Diagram: What Do You Know about HIV Treatment?



Processing Questions:

- What was that exercise like?
- Were there any surprises? Did you know more or less than you thought you did?
- How do you feel about the accuracy of the information?

Right now we are not going to look at what you wrote in your mind maps. Please set them aside and we will come back to them later.

Activity 3

Large Group Discussion

Time: 30 minutes

Now that we are all thinking about HIV treatment, I would like us to think about our expectations and concerns for this course.

- Please think of at least one expectation and one concern you have related to this course.
- When you have thought of these, please write each expectation or concern on a separate Post-It note. *Pause and let participants write them down.*
- *When everyone is finished, proceed.*
- We will now take turns sharing our expectations and concerns. When you share, please come up and put your expectations on the "Expectations" Flipchart and your concerns on the "Concerns" Flipchart.

SESSION 3: PERSONAL EXPERIENCES WITH MEDICATION

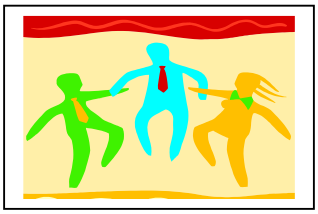
Objectives:

1. Discuss personal experiences of having been on medicine or currently being on medication.
2. Identify the difficulties in adhering to any medication regime.

Time: 30 minutes

Session Overview

Activity/Method	Time	Materials Needed
Small Group Discussion: Personal Experiences Taking Medication	30 minutes	Prepared flipchart with small group discussion questions



Activity 1

Small Group Discussion

Time: 30 minutes

During this week, we are going to be talking a lot about taking medication. In order to understand a bit of what it might be like for our clients, I would like to begin by having each of you reflect on any experiences you have had taking medication. We are going to do this by discussing it briefly in small groups.

- Discuss the following:
  It might be helpful to list the items below on a flipchart so that small groups can refer to them during their discussion:
  - Think about and discuss times in your life when you have been on medication. This could have been medication for a chronic illness like diabetes, for short-term treatments like antibiotics, or medicine for more severe illnesses.
  - For how long did you take medication?
  - Did you experience any side effects?
  - Was it important to take the medication following specific instructions?
  - How were you about taking your medication? Did you remember every dose?
- You will have 15-20 minutes to discuss these issues in your groups.

Processing Questions:
Focus on personal experiences; the purpose of the exercise is to develop empathy.

- In your discussions, what did you find out about taking medication?
- What was easy/hard about taking medication? What specifically made it harder/easier?
- How were you at following specific instructions related to your medication?
- Did your group like taking medicine regularly?
- Why did we do this small group activity?

SESSION 4: HIV TREATMENT EXERCISE

Objectives:

1. Gain an experiential understanding of the challenges of adhering to HIV treatment.
2. Develop empathy for clients' experiences.

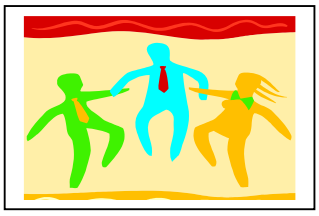
Preparation:

- Have sweets, ideally in 9 different colours and/or sizes: there should be 9 distinctly different-looking sweets.
- Yellow plastic medicine bags: if possible, put the "tablets" in the yellow plastic bags that pharmacies use for medications. Label the bags with the different medication names and put in exactly enough "tablets" for correct dosing through the morning of the final day of the training workshop.
- Prepared flipchart or overhead displaying the three treatment regimens.

Time: 20 minutes

Session Overview

Activity/Method	Time	Materials Needed
HIV Treatment Medication Exercise: Give Instructions	20 minutes	Dummy "tablets" in prepared bags Prepared flipchart with the three drug regimens written on it



Activity 1

Instructions

Time: 20 minutes

Note to Facilitator: It is essential that this exercise is taken seriously in order to be effective. We want to develop empathy for people on ARVs. While you can have fun with the exercise, present the instructions seriously.

- For the purposes of this exercise, which will last for the remainder of this week, each of you is HIV-positive. This week, all of you will be put on HIV treatment.
- Each of you is going to be given a regimen, a combination, of "tablets" that you must take as prescribed for the rest of this week. What this means is that you will be responsible for taking these "drugs" as you have been instructed.

- Please count off in threes and remember your number. *You are dividing them into three groups. Display the prepared flipchart with the regimens listed.*
- Group 1, you will be taking the medication in Regimen #1.
  Distribute the "tablets" in the yellow plastic bags to group 1 and read the instructions.

Note: These "tablets" are not real medicine. These are just sweets.

- Group 2, you will be taking the medication in Regimen #2.
  Distribute the "tablets" in the yellow plastic bags to group 2 and read the instructions.
- Group 3, you will be taking the medication in Regimen #3.
  Distribute the "tablets" in the yellow plastic bags to group 3 and read the instructions.
- Do you have any questions?
- Please take your medicine as "prescribed." Follow the instructions that have been given to you.
- Over the course of the week, we will be asking you how your treatment is going.

Regimen #1 (First-Line Treatment): d4T, 3TC & Nevirapine (NVP)
- d4T is twice per day dosing, with or without food (no food effect).
- 3TC is twice per day dosing with or without food (no food effect).
- Nevirapine (NVP) dosing is once per day for the first 14 days. If you have no sensitivity to the drug, it will be increased to twice per day. This is your first week, so you will be taking NVP only once per day.
- The medications must be taken at the same time every day.

Regimen #2 (First-Line Treatment) AZT+ 3TC & Efavirenz (EFV)
- AZT & 3TC are in a combined pill, twice a day dosing with or without food.
- Efavirenz (EFV) dosing is once per day. It should be taken before going to bed, with or without food.
- The medications must be taken at the same time every day.

Regimen #3 (Second-Line Treatment) AZT, Didanosine (ddI), Lopinavir (LPV) & Ritonavir (RTV)[LPV/r, Kaletra]
- AZT is twice per day dosing.
- ddI is twice per day dosing on an empty stomach with no food two hours before the dose and at least half an hour after dosing. You may only drink water during this 2 ½ hour period, but no eating or drinking any other liquids is allowed.
- LPV/r is twice a day dosing. Take LPV/r with food.
- The medications must be taken at the same time every day.

Note to Facilitator:

- Follow up on the medication exercise several times during the course of the workshop. This can be done right after a break or whenever you have a few minutes.
- When you are following up, make sure that you are modelling the way a counsellor should follow up with a client. Pay attention to how you ask questions, your non-verbal communication and your tone of voice.
- **Be supportive and encouraging**. Do NOT be punitive or judgemental. Do NOT mock or tease participants.
- Remember the "roles we play" from Personal Growth. Do NOT put yourself in the role of the parent with this exercise. You must model the adult role of the counsellor for the participants.

HIV Treatment Follow-up

Below is a list of potential questions to ask as a follow-up on the medication exercise:

- How are you doing with your HIV treatment?
- What time are you taking your medicines?
- What time did you take your medicine last night? What about this morning?
- Many people find it difficult to remember to take their medication two times a day. Have any of you forgotten to take a dose?
- How have you been remembering to take your medicines? Has anyone used any aids to help you remember? Is it working?
- What are you finding easy/difficult about taking ARVs?
- What were your expectations? Is the experience different from your expectations?
- Has anything in your schedule changed as a result of taking medicines two times a day?

You can also follow up by asking participants to bring their "tablets" in after a break. Then you can do a tablet count. Determine how many doses they should have left and follow up on those who have too many or too few doses remaining.

SESSION 5: NATURAL COURSE/PROGRESSION OF HIV REVIEW

(This should have been covered in the General HIV Module.)

Objectives:

1. Identify ways HIV is monitored or measured.
2. Understand the progression of HIV.
3. Introduce WHO Staging.

Key Terms
- Window period
- CD4 Count
- Viral Load
- Opportunistic Infections (OI)

Time: 20 minutes

Session Overview:

Activity/Method	Time	Materials Needed
Presentation/Discussion: Progression of HIV	20 minutes	

Note to Facilitator: This session was covered in the General HIV Module. However, it may be helpful to review some of the key points about HIV progression prior to the session on opportunistic infections. Encourage the participants to come up with the information if possible.

Activity 1

Presentation/Discussion

Time: 60 minutes

CD4 Count

- Currently the best monitor for HIV disease progression
- Number of CD4 cells per cubic millimetre of blood
- Normal range: 600 – 1,200 CD4 cells per cubic millilitre of blood (mL^3), and is generally higher than 500 in uninfected people
- Normal range of CD4 count varies from person to person, day-to-day, and hour to hour.
- As the HIV virus progresses, the number of CD4 cells decline and the CD4 count goes down.
- The CD4 count is one of the measures used to determine when a client should start antiretroviral treatment.
- When the CD4 count falls below 200 cells per cubic millilitre of blood, the body can develop life-threatening illnesses from other infections, which are called opportunistic infections.

Percentage of CD4:

- Measures CD4 cells to total immune system cell (white blood cell) population.
- Normal range: approximately 40%
- If below 15%, the person is at serious risk of being sick or getting an opportunistic infection such as TB or malaria.

Viral Load

- Another measure of disease progression is viral load, or the amount of the virus in the body.
- A viral load counts the number of HIV particles in a sample of blood.
- It is expressed as the number of "copies" of HIV RNA per millilitre of blood. Below 10,000 copies or less is considered low and above 50,000 copies is high.
- Viral load does not measure the virus present in the brain and genital fluids, where the effects of ARVs may vary.
- Currently, viral load tests are not done in the public sector in Namibia.

Relationship between CD4 Count and Viral Load:

- The higher the viral load, the faster the CD4 count reduces.
- The lower the viral load, the slower the CD4 count reduces.
- However, this relationship is not always clear.

Progression of HIV Infection

HIV Infection	Initial infection with HIV virus
Window Period (Acute Phase) *Usually 2 - 6 weeks, but can last up to three months*	No signs or symptoms of disease and no detectable antibodies to HIV. An HIV antibody test would be negative even though the virus is present.
Sero-conversion (production of antibodies) *Brief period after 2 – 6 weeks, may last up to three months*	Development of antibodies: may include flu-like symptoms. About 25% of people experience no illness during this stage and most do not visit health care facilities.
Asymptomatic HIV *Lasts from less than one year to 10-15 years or more*	Antibody tests show up positive but there are no signs or symptoms of illness. (incubation period)
HIV/AIDS – Related Illnesses (Symptomatic Phase) *Lasts months or years*	Signs and symptoms of disease increase because HIV is weakening the immune system. Illnesses are usually not life-threatening at first, but become more serious and longer lasting.
AIDS (advanced HIV disease) *Usually less than one to two years without treatment.*	Terminal Stage: life-threatening infections and cancers occur because the immune system is severely damaged. The client dies when an untreatable illness develops. Life expectancy depends on many factors, including antiretroviral treatment, medication for opportunistic infections and holistic health care, especially nutrition.

Adapted from Helen Jackson. 2002. AIDSAfrica: Continent in Crisis, SAfAIDS, Zimbabwe.

- Clients can live for many years after being infected with HIV.
- Progression of the disease to the advanced stage of AIDS varies in time and from person to person.
    - A small proportion of clients may develop AIDS (advanced HIV disease) in less than 5 years.
    - Another small proportion of clients can live over 15 years without any signs and symptoms of the disease.
    - Most people take an average of 10 years to progress from infection to AIDS (advanced HIV) without any treatment.

Window Period:

- The period between the time of infection and when an HIV test result will be positive. It can range from 2 weeks to 3 months.
- This is because the HIV test does not actually test for the HIV virus in the body; instead, it tests for the antibodies. Remember it takes a while for the B cells to produce the antibody. This time can vary from person to person.
- The amount of HIV virus in the body is very high right after infection because the B cells have not produced the antibodies that defend against the HIV virus.
- A person can infect another person from the moment he/she is infected with HIV.

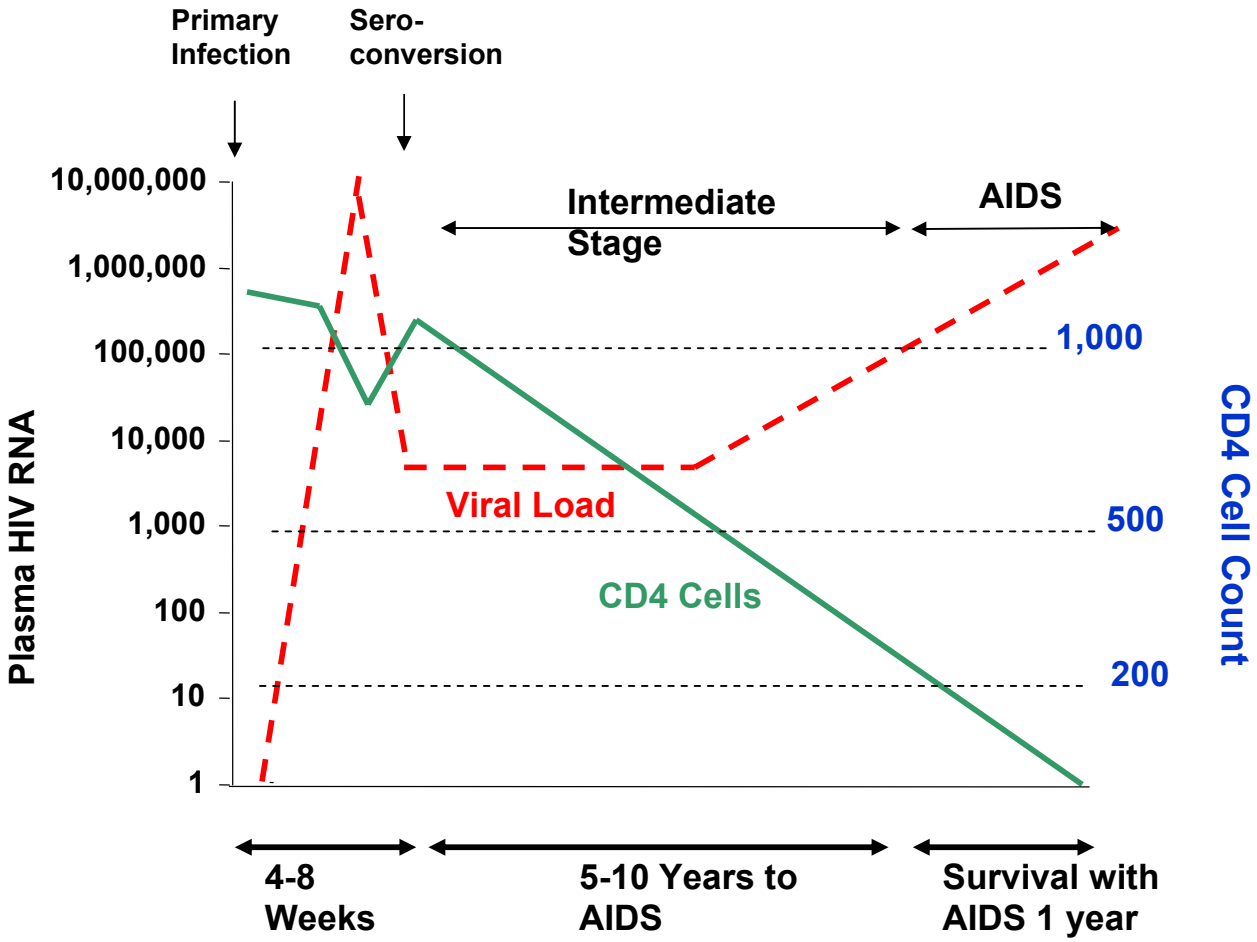
Additional Factors that contribute to HIV infection developing into AIDS (HIV-related disease):

- Infection with different types of HIV virus (multiple strains)
- Natural genetic or biological differences in individuals' immune systems
- Stress on the immune system from general lack of fitness and exposure to other infections, such as parasites
- Repeated STIs (sexually transmitted infections) that keep the immune system busy and appear to speed up HIV replication or growth.
- State of mind, such as anxiety and depression
- Other health stressors such as overtiredness, poor diet or nutrition and heavy drinking.

Opportunistic Infections:

- Infections that attack the body when it is weak, i.e. when the immune system is damaged
- People are at a greater risk of contracting other illnesses are a result of their compromised immune systems due to the HIV infection.
- Opportunistic infections develop during the HIV/AIDS-related illness phase.
- Opportunistic infections cause very serious problems when a person's immune system is weakened by HIV.
- These infections can include the following:
    - Tuberculosis (TB)
    - Malaria
    - STIs (sexually transmitted infections)
    - Pneumonia
    - Oral herpes (sores in the mouth)

CD4 Count, Viral Load and Clinical Course of Untreated HIV Infection in Adults



REVISED WHO CLINICAL STAGING OF HIV/AIDS
FOR ADULTS AND ADOLESCENTS

(Interim African Region version for persons aged 15 years or more with positive HIV antibody test or other laboratory evidence of HIV infection)

Table 1. Revised WHO Clinical Staging of HIV/AIDS for adults and adolescents

Primary HIV Infection

Asymptomatic
Acute retroviral syndrome

Clinical Stage 1

Asymptomatic
Persistent generalized lymphadenopathy (PGL)

Clinical Stage 2

Moderate unexplained weight loss (<10% of presumed or measured body weight)
Recurrent respiratory tract infections (RTIs, sinusitis, bronchitis, otitis media, pharyngitis)
Herpes zoster
Angular cheilitis
Recurrent oral ulcerations
Papular pruritic eruptions
Seborrhoeic dermatitis
Fungal nail infections of fingers

Clinical Stage 3

Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:

Severe weight loss (>10% of presumed or measured body weight)
Unexplained chronic diarrhoea for longer than one month
Unexplained persistent fever (intermittent or constant for longer than one month)
Oral candidiasis
Oral hairy leukoplakia
Pulmonary tuberculosis (TB) diagnosed in last two years
Severe presumed bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)
Acute necrotizing ulcerative stomatitis, gingivitis or peridontitis

Conditions where confirmatory diagnostic testing is necessary:

Unexplained anemia (<8 g/dl), andor neutropenia (<500/mm3) and or thrombocytopenia (<50,000/mm3) for more than one month

Clinical Stage 4

Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:

HIV wasting syndrome
Pneumocystis pneumonia
Recurrent severe or radiological bacterial pneumonia
Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration)
Oesophageal candidiasis
Extrapulmonary TB
Kaposi's sarcoma
Central nervous system (CNS) toxoplasmosis
HIV encephalopathy

Conditions where confirmatory diagnostic testing is necessary:

Extrapulmonary cryptococcosis including meningitis
Disseminated non-tuberculous mycobacteria infection
Progressive multifocal leukoencephalopathy (PML)
Candida of trachea, bronchi or lungs
Cryptosporidiosis
Isosporiasis
Visceral herpes simplex infection
Cytomegalovirus (CMV) infection (retinitis or of an organ other than liver, spleen or lymph nodes)
Any disseminated mycosis (e.g. histoplasmosis, coccidiomycosis, penicilliosis)
Recurrent non-typhoidal salmonella septicaemia
Lymphoma (cerebral or B cell non-Hodgkin)
Invasive cervical carcinoma
Visceral leishmaniasis

SESSION 6: OPPORTUNISTIC INFECTIONS

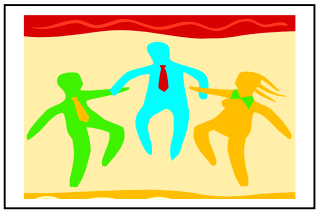
Objectives:

1. Define opportunistic infections.
2. List some common opportunistic infections.
3. Understand opportunistic infections in terms of the natural course of HIV disease.
4. Learn basic principles about TB and other opportunistic infections.

Time: 45 minutes

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Define terms	10 minutes	Flipchart paper Markers
Presentation	35 minutes	



Activity 1

Introduction

Time: 5 minutes

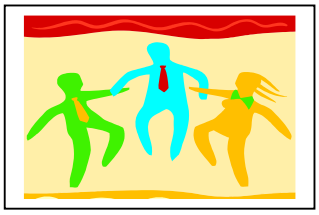
We talked briefly about opportunistic infections when we discussed the progression of HIV. Can anyone remind us what opportunistic infections are?
Let participants respond.

Key Points about Opportunistic Infections (OIs):

- OIs are infections or illnesses that take advantage of HIV-related damage to the immune system. They make someone sick when his/her body is already weakened by the HIV virus.
- They are called "opportunistic infections" because they take the opportunity of a weakened immune system in order to make the person sick. While the immune system is working properly, the body can fight these germs that cause disease, but when the immune system is damaged the germs can grow and make the person sick.
- For an HIV-infected person, the risk of getting opportunistic infections is higher when his/her CD4 count falls below 200.
- Opportunistic infections are serious; they are the main cause of death for people with HIV or AIDS.

Can anyone give us an example of an opportunistic infection?
Let participants respond. Examples could include the following:

- Candida or thrush (oral or genital)
- Kaposi's Sarcoma (skin cancer)
- Pneumonia (PCP)
- TB
- Herpes Zoster
- Cryptococcal Meningitis



Activity 2

Presentation

Time: 35 minutes

Signs and Symptoms of Opportunistic Infections

It is important to be able to recognise the signs and symptoms of opportunistic infections. These are basically symptoms of illness:

- Diarrhoea
- Severe stomach or abdominal pain
- Vomiting
- Significant weight loss
- Loss of appetite
- Sores in mouth or on tongue, i.e. oral thrush, cold sores
- Vaginal thrush, burning or itching
- Fever or night sweats, shaking or chills
- Problems seeing or changes in vision
- Continuous headaches
- Swollen glands for at least three months
- Skin problems, i.e. eczema, psoriasis, dry, itching skin, boils and sores
- Respiratory problems, i.e. colds, flu, bronchitis, pneumonia and tuberculosis
- Cough lasting over 3 weeks
- Swelling, itching, soreness or discharge from the vagina or penis
- Changes in menstrual cycle (period)
- Pain during sex

Tuberculosis (TB)

- TB is an illness caused by a bacterium that usually infects the lungs but can also infect other parts of the body.
- The TB germ can live in your body for many years without causing any signs of infection. You can stay healthy even with the TB germ in your body. You could have the TB germ without knowing it.
- 80% of TB affects the lungs, but TB can affect any organ in the body.
- TB of the lungs (pulmonary TB) is highly contagious; it spreads from one infected person to another by coughing, sneezing or spitting. It actually spreads through the air.
- When the immune system is weakened, i.e. during times of poor nutrition, not enough sleep, too much alcohol or prolonged illnesses like HIV, TB symptoms start.

Why are we learning about TB?

- TB is highly contagious.
- TB is deadly.
- TB can be cured.
- TB is a major killer of people with HIV.

TB can be "latent" or "active:"

- **Latent TB** is when the TB bacterium is in the body but the immune system can control it, so it does not cause illness. A person with latent TB cannot spread it to others. Latent TB can be diagnosed by a skin test performed at the hospital or clinic.
- **Active TB** is when the bacterium is in the body and the person is ill.
- If a person with latent TB becomes infected with HIV, he/she is more likely to develop active TB because his/her immune system can no longer control the latent TB.

Where you are most likely to become infected with TB:

- Hospital and clinics
- Overcrowded places, i.e. houses, bars, shebeens
- Prisons

> Note: These are all places that are indoors, with poor ventilation and no sunlight.

TB and HIV in Namibia

- Namibia has one of the highest rates of TB infection in the world.
- TB is the leading cause of illness and death of people living with HIV or AIDS. They are more susceptible to TB because of their weakened immune systems.
- One-third of HIV-positive people are infected with TB.
- TB leads to rapid progression of HIV; it allows the HIV virus to multiply more quickly.
- People with HIV are more likely to die of TB than those without HIV.

Note: Though HIV and TB are linked, one **cannot** assume that a person with TB has HIV. Not everyone with HIV gets TB, and not everyone with TB has HIV.

Symptoms of TB

- A cough that lasts more than 3 weeks
- Blood in the sputum (spit)
- Chest pain
- Unexplained weight loss
- Loss of appetite
- Extreme tiredness (fatigue)
- Night sweats
- Difficulty breathing (breathlessness)

TB Treatment

- TB can be cured, even if a person is HIV-positive.
- TB treatment is six to eight months long; adherence is very important with TB treatment, just as it is with HIV treatment.
- TB treatment is called DOTS: **D**irectly **O**bserved **T**reatment **S**upport. If the client does not adhere to treatment, or does not finish his/her treatment, the TB germ mutates (like HIV) into a stronger germ that is resistant to drugs so the medication no longer cures the TB germ.
- A person who does not complete treatment can become sick again, continue to spread the bacteria, or can develop drug-resistant TB.

TB Treatment with HIV treatment

- A person who has TB and HIV will usually be treated for TB first and then begin HIV treatment when indicated by a doctor.
- If the client's CD4 count is above 350, then he/she will complete TB treatment before considering HIV treatment.
- If his/her CD4 count is less than 200, the client will begin TB treatment immediately and then start HIV treatment at 8 weeks.
- A person with HIV can take both HIV treatment and TB medication; however, certain HIV treatment medication should be adjusted during the TB treatment.

Other Opportunistic Infections

- Sexually transmitted infections (STIs): these are infections that are transmitted sexually. HIV is also an STI. Symptoms include: unusual discharge from penis or vagina; open sores or ulcers in the genital, groin or rectal areas; warts; and genital pain or itchiness. Most STIs can be cured with antibiotics.
- Thrush (Candida): yeast infection. White stuff on the top of the tongue, cheeks, and in the throat.
- Pneumonia: an infection that weakens the lungs. PCP, pneumocystic carinii pneumonia, is a common OI.

Healthy Living: What to Do to Avoid Opportunistic Infections
(For reference)

1. Good personal hygiene
   - Take a bath at least once a day to keep your body clean.
   - Wear slippers or shoes to avoid small cuts that can cause infection.
   - Brush your teeth after eating.
   - Wash your hands with soap before eating and after using the toilet.

2. Clean water
   - Draw water from sources such as taps, deep wells or boreholes.
   - Store water in clean, covered containers such as buckets, pots or plastic containers.
   - Fetch stored water with clean cups.
   - Avoid making water dirty by dipping your hands in it.
   - Boil water from rivers and ponds before drinking. Boiling water is an important way to kill germs that may cause opportunistic infections.
   - Drink plenty of clean water every day.

3. Clean food preparation
   - Wash your hands with soap and clean water before preparing food.
   - Wash fruits and vegetables with clean water before you eat or cook them.
   - Use a clean table or chopping board to prepare food.
   - Serve food and water in clean utensils, i.e. plates, bowls, spoons and cups.
   - Avoid half-cooked meat. Meat that is not cooked properly can be a source of infection.
   - Wash utensils with clean water.
   - Cover food or put it in a clean cupboard away from flies for storage.

4. Maintain cleanliness around domestic and farm animals.
   - Keep animals and pets outdoors.
   - Ask someone else to clean up after animals, especially cats, kittens and chickens, if possible.
   - Always wash your hands with soap after touching pets and other animals.
   - Avoid contact with young animals, especially animals with diarrhoea.

5. Protect yourself from HIV re-infection.
   - If you have unprotected sex, you can be re-infected with a different strain of HIV, even if you are already HIV-positive.
   - If you get re-infected with a different strain off HIV, your immune system will get weaker.
   - HIV treatment does not protect you against HIV re-infection.
   - Protect yourself and your partner: always use a condom or avoid having sex.

6. Take good care of yourself.
    - Eat a balanced diet.
    - Exercise regularly.
    - Get enough sleep.
    - Avoid smoking.
    - Avoid taking alcoholic drinks.
    - Take only the medicines your doctor gives you.
    - Visit your doctor regularly.

Common Opportunistic Infections

(for reference)

Opportunistic Infection	Symptoms	Treatment	What the counsellor can do:
Respiratory Infections: affect the lungs			
Pneumocystis Carinii Pneumonia (PCP)	▪ Cough ▪ Shortness of breath ▪ Fever	Hospitalisation followed by daily dose of co-trimoxazole (antibiotic)	Support clients to take their daily co-trimoxazole
Tuberculosis (TB)	▪ Cough for more than 3 weeks ▪ Weight loss ▪ Extreme tiredness ▪ Night sweats ▪ Difficulty breathing	Anti-TB medication (usually for 6 months) using DOTS (Directly Observed Therapy)	Support clients to take their medication (adherence)
Gastrointestinal Infections: involve stomach and digestive system			
Candida	▪ Pain in mouth and throat ▪ Pain in swallowing ▪ Fever	Anti-fungal drug (fluconazole)	Support clients in taking food and medicine
Diarrhoea	▪ Diarrhoea	▪ Rehydration: drinking sufficient water or oral rehydration fluid ▪ Medication to treat the cause or symptoms of diarrhoea	Help with offering drinks and food to cope with diarrhoea
Neurological Infections: (affect the central nervous system)			
Cryptococcal meningitis	▪ Headache ▪ Fever ▪ Neck stiffness	Hospitalisation, followed by daily fluconazole	Support clients in taking daily medicine
Cytomegalovirus infection (CMV)	▪ Fever ▪ Diarrhoea ▪ Blindness		
Herpes simplex virus (HSV)	Sores around the mouth and/or genitals	▪ Acyclovir tablets (for 1-2 weeks) ▪ Paracetamol for pain	Support clients to keep sores clean and ease pain
Herpes zoster infections	Lesions on the back and other areas of the skin; can affect eyes	▪ Acyclovir tablets (for 1-2 weeks) ▪ Paracetamol for pain	Support clients to keep sores clean and ease pain
Cancer			
Kaposi's Sarcoma	Lesions: purple or blue spots on the skin or in the mouth	Anti-cancer treatment	Support clients to ease pain
Non-Hodgkin's Lymphoma			
Cervical Cancer		Regular pap smear for women for screening	Encourage regular screening examinations

SESSION 7: UNDERSTANDING HIV TREATMENT

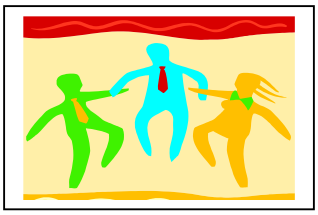
Objective:

1. Explain basic concepts of HIV treatment and how HIV treatment works.

Time: 1 hour (60 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Presentation	45 minutes	Flipchart paper Markers
Pair Activity: Explain HIV Treatment	15 minutes	



Activity 1

Presentation: **What is HIV Treatment (ART)?**

Time: 45 minutes

- **A**nti-**R**etroviral **T**reatment: treatment for HIV.
- It is also called **ARV**: **A**nti-**R**etro**V**iral and **HAART**: **H**ighly **A**ctive **A**nti-**R**etroviral **T**reatment.
- ART consists of a combination of at least three different medicines that are taken together as treatment for HIV infection.
- ART helps reduce the amount of HIV virus in the body and strengthens the immune system.
- With less of the virus in the body, the immune system can become stronger and fight infections more effectively so the client will get sick less often.
- ART is <u>not a cure</u> it is a treatment. It does not get rid of the virus in the body; it suppresses or reduces it.

Effects of ART (HIV treatment): How HIV Treatment Works

1. Slows the growth of the HIV virus by reducing the viral load.
2. Allows the body to replace missing or destroyed CD4 cells, so CD4 count rises.
3. Prevent illnesses occurring due to the weakened immune system
4. Lengthens survival

Who needs to take HIV treatment?

- Not all people with HIV need to take HIV treatment.
- HIV treatment should start when the virus has damaged the immune system to a certain level.
    - This is determined by finding out if the client has developed certain infections and by measuring the level of CD4 cells.
    - A doctor will do blood tests and decide if the client will benefit from HIV treatment.
    - The final decision about starting HIV treatment is made by the Health Care Team, which includes the client.

Note to Facilitator: The information in this section in quite technical. It is not necessary to spend a lot of time explaining this technical information to participants. Remember that we are training counsellors, NOT health professionals. A basic understanding of how HIV treatment works is all they need.

How does the HIV virus replicate, or grow?

- Remember that HIV needs to attach to a host CD4 cell in order to replicate, or grow.
- Once the HIV virus attaches to a CD4 cell, it uses three enzymes (chemicals) to replicate:
    1. Reverse transcriptase enzyme
    2. Integrase enzyme
    3. Protease enzyme
- Without these three enzymes, the HIV virus cannot grow, even if it is attached to a CD4 cell.

HIV replication:

- Replication happens rapidly; the virus produces billions of new viruses every day.
- It takes about 2.6 days for HIV to replicate from the time it enters the CD4 cell until new viruses leave the cell.
- During this process of replication, the virus makes a lot of mistakes; the virus mutates as it replicates.
- Sometimes these mutations create drug resistance. The virus changes and then the ARVs are no longer effective in suppressing the virus.

How does HAART suppress viral replication?

- HAART is a combination of three drugs. These drugs act on the enzymes that the HIV virus uses to replicate.
- The current drugs act on the RTE (reverse transcriptase enzyme) and PE (protease enzyme).
- There are currently no drugs that act on the IE (integrase enzyme).
- By suppressing these enzymes that the virus needs to grow, the drugs keep the virus from growing.
- It is important to note that if HIV treatment is stopped, the virus will start to replicate again and HIV will progress.

Categories of ART Drugs

Category of Drug	Abbreviation	Enzyme Inhibited
Nucleoside Reverse Transcriptase Inhibitors	NRTIs, also called Nukes	Reverse Transcriptase
Non-nucleoside Reverse Transcriptase Inhibitors	NNRTIs, also called Non-Nukes	Reverse Transcriptase
Protease Inhibitors	PIs	Protease

Anti-Retroviral Medications

NUKES Nucleoside Reverse Transcriptase Inhibitors (NRTIs)*	**NON-NUKES Non-Nucleoside Transcriptase Inhibitors (NNRTIs)***	**Protease Inhibitors (PIs)***
Stavudine (**d4T**)	Nevirapine (**NVP**)	Lopinavir/Ritonavir (**LPV/r**); also known as Kaletra
Lamivudine (**3TC**)	Efavirenz (**EFV**)	Indinavir/Ritonavir (**IDV/r**)
Zidovudine (**AZT**)		Saquinavir/Ritonavir (**SQV/r**)
Didanosine (**ddI**)		Ritonavir (**RTV**)
Tenofovir (**TDF**)		Nelfinavir (**NFV**)
Abacavir (**ABC**)		

**Arranged in the order most commonly prescribed in Namibia.*

The current recommended HAART regimens in Namibia (as of the April 2003 Guidelines) include a combination of 2 NRTIs (two drugs from the first column) and a third drug to complement it, either a NNRTI or PI.

Different Names for Drugs: Most of the drugs or medications we are talking about have three different names. This is very confusing when you are first learning about the drugs.

1. Brand names: names companies use to identify their own particular drug.
2. Generic names: name used by all companies for the same drug.
3. Abbreviations: a shortened name for the generic name of the drug. These abbreviations are the names used by most medical professionals.

For instance, you can use the example of chocolate. Chocolate is a generic name for a type of food. Nestle or Cadbury are brand names.

We will be referring to either the generic names or the abbreviations for the drugs in this course. The bolded names listed in the ARV medication chart is the most commonly used name of the drug.

What is a regimen?

- A specific plan intended to improve health.
- A drug regimen is a combination of medications that are prescribed by a doctor to improve a client's health.
- There are different drug regimens for different illnesses, i.e. the treatment of TB has its own regimen of medications that need to be taken to improve health.

In HIV treatment, there are also different regimens. These different regimens are numbered, i.e. first-line regimen (therapy or treatment) and second-line treatment.

First-line Regimen:

- This is the name of a combination of ARV drugs used to "first" treat HIV.
- The first-line regimens or combinations of drugs are chosen because of their effectiveness in fighting HIV. They are also easier to take and usually have fewer side effects than the second-line regimens.

Key Point: Remember the ART regimens always include three drugs.

Note: Depending on availability, clients often will be given different versions of the same drugs when they go to collect their tablets. For instance, some of the drugs can be combined in one pill, so instead of taking three different tablets, the client may only take two. Or a client may be given the same drug but from a different company, so it may have a different brand name.

Review the ART Regimens Chart for further information.

Activity 2

Pair Activity: Explain HIV treatment

Time: 15 minutes

- We are going to do another pair activity to practise explaining HIV treatment and how it works.

Case Scenario: Your cousin tells you that she just tested positive for HIV. She has heard of ART and thinks that she should start taking ART immediately.

- In your pairs, role play the following:
  - Explain what HIV treatment is.
  - Describe how HIV treatment works.
  - Tell her when the body is ready for HIV treatment.
  - Offer suggestions for what she might do.
- *If there is time, switch roles. Move among the pairs to assess their understanding of this new material.*

Processing Questions:

- What was it like to try and explain HIV treatment?
- Did it bring up any questions for you?

ART First-Line Regimens

First-Line Regimen	Special Instructions	Side Effects
d4T, 3TC, & Nevirapine (NVP)	▪ Nevirapine (NVP) will be given once per day for the first 14 days. If client has no sensitivity, it will be increased to twice per day. ▪ May reduce effectiveness of oral contraceptives; barrier contraception should also be used.	▪ Moderate or severe rash, usually during the initial 8 weeks of treatment. Refer to doctor. (NVP) ▪ Nausea with vomiting and abdominal pain. Could indicate other serious side effects; refer to doctor. ▪ Tingling in arms, fingers, legs and toes. May disappear with time. If it gets worse or becomes painful, refer to doctor. (d4T) ▪ Loss of weight in arms, legs, buttocks and face. Clients may think it is associated with disease progression. Support and reassure the client. (d4T) ▪ Headache and nausea (3TC)
AZT, 3TC & Nevirapine (NVP)	▪ Nevirapine (NVP) will be given once per day for the first 14 days. If client has no sensitivity, it will be increased to twice per day. ▪ May reduce effectiveness of oral contraceptives; barrier contraception should also be used.	▪ Moderate or severe rash, usually during the initial 8 weeks of treatment; refer to doctor. (NVP) ▪ Nausea with vomiting and abdominal pain could indicate other serious side effects; refer to doctor. ▪ Headache and nausea (3TC, AZT) ▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness; refer to doctor. ▪ Discoloured nails (AZT)
AZT, 3TC & Efavirenz (EFV)	▪ Efavirenz (EFV) should be taken before going to bed. If side effects are experienced, these should disappear after a few weeks and then EFV can be taken with other drugs in the evening. ▪ Decrease EFV side effects by reducing fat in the evening meal, as high fat levels increase EFV in the blood.	▪ Rash; if it becomes serious or causes concern, refer to doctor. (EFV) ▪ Headache and nausea (3TC, AZT) ▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness; refer to doctor. (AZT) ▪ Central nervous system (CNS) side effects: dizziness, vivid dreams, euphoria and feeling drunk or confused. If experienced, they usually disappear after the first few weeks. ▪ Discoloured nails (AZT)

First-Line Regimen	Special Instructions	Side Effects
d4T, 3TC & Efavirenz (EFV)	▪ Efavirenz (EFV) should be taken before going to bed. If side effects are experienced, these should disappear after a few weeks and then EFV can be taken with other drugs in the evening. ▪ Decrease EFV side effects by reducing fat in the evening meal, as high fat levels increase EFV in the blood.	▪ Rash; if becomes serious or causes concern, refer to doctor. (EFV) ▪ Headache and nausea. (3TC) ▪ Tingling in arms, fingers, legs and toes. May disappear with time. If it gets worse or becomes painful refer to doctor(d4T) ▪ Loss of weight in arms, legs, buttocks and face. Clients may think it is associated with disease progression. Support and reassure the client. (d4T)
d4T, 3TC & Lopinavir (LPV/r)	▪ Lopinavir (LPV/r) should always be taken with a meal or a large snack to increase absorption into the blood. ▪ Reducing fat in the diet can help reduce side effects from Lopinavir.	▪ Tingling in arms, fingers, legs and toes. May disappear with time. If it gets worse or becomes painful, refer to doctor. (d4T) ▪ Loss of weight in arms, legs and face. Clients may think it is associated with disease progression. Support and reassure the client. (d4T) ▪ Headache and nausea. (3TC) ▪ Initially: stomach problems such as loose stools. (Lopinavir) ▪ Long term: intermittent (on and off) diarrhoea and loose stools. (Lopinavir) ▪ High cholesterol and re-distribution of fat in stomach, neck and shoulders. (Lopinavir)
AZT, 3TC & Lopinavir (LPV/r)	▪ Lopinavir (LPV/r) should always be taken with a meal or a large snack to increase absorption into the blood. ▪ Reducing fat in the diet can help reduce side effects from Lopinavir.	▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness; refer to doctor. (AZT) ▪ Headache and nausea. (AZT, 3TC) ▪ Discoloured nails. (AZT) ▪ Initially: stomach problems such as loose stools. (Lopinavir) ▪ Long term: intermittent (on and off) diarrhoea and loose stools. (Lopinavir) ▪ High cholesterol and re-distribution of fat in stomach, neck and shoulders. (Lopinavir)

General Instructions:

- Nevirapine (NVP) should never be taken with TB treatment.
- Efavirenz (EFV) is not recommended for women who wish to be come pregnant or do not use contraceptives.
- Efavirenz (EFV) may affect the unborn child; do not take when pregnant.
- If clients are given other medications from a different doctor, it is important to tell the ART doctor.

Second-Line Regimens

Second-Line Regimen	Special Instructions	Side Effects
AZT, Didanosine (ddI) & Lopinavir (LVP/r)	▪ Lopinavir (LPV/r) should always be taken with a meal or a large snack to increase absorption into the blood. ▪ Reducing fat in the diet can help reduce side effects from Lopinavir. ▪ Didanosine should be taken on an empty stomach (no food or drink like juice, tea or coffee), for two hours before taking medicine and at least ½ hour after taking medicine. ▪ Lopinavir and didanosine should not be taken together; wait at least an hour between taking one drug before taking the other. ▪ May reduce effectiveness of oral contraceptives (barrier contraception should also be used).	▪ Tingling in arms, fingers, legs and toes. It may disappear, but if it gets worse refer to the doctor. (Didanosine) ▪ Severe stomach upset, which may include abdominal pain, bloating and diarrhoea. (Didanosine) ▪ Discoloured nails. (AZT) ▪ Headaches and nausea. (AZT) ▪ Initially stomach problems such as loose stools. (Lopinavir) ▪ Long term, intermittent (on and off) diarrhoea and loose stools. (Lopinavir) ▪ High cholesterol and re-distribution of fat in stomach, neck and shoulders. (Lopinavir) ▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness – refer to doctor. (AZT) ▪ Nausea with vomiting and abdominal pain could indicate other serious side effects – refer to doctor.
AZT, Didanosine (ddI), Indinavir (IDV) & Ritonavir (RTV)	▪ Indinavir and Ritonavir may be taken with food to increase absorption. ▪ Drink a minimum of 2 litres of water in addition to normal fluid intake to avoid kidney stones. ▪ Drink a full glass of water with Indinavir. ▪ Indinavir with Ritonavir and ddI should not be taken together; at least 1 hour should separate the dosing. ▪ Didanosine should be taken on an empty stomach (no food or drink like juice, tea or coffee), for two hours before taking medicine and at least ½ hour after taking medicine.	▪ Tingling in arms, fingers, legs and toes. It may disappear, but if it gets worse refer to the doctor. (Didanosine) ▪ Severe stomach upset, which may include abdominal pain, bloating and diarrhoea. (Didanosine) ▪ Initially stomach problems such as loose stools. (Indinavir and Ritonavir) ▪ Long term, intermittent (on and off) diarrhoea and loose stools. (Indinavir and Ritonavir) ▪ Kidney stones – pain in the lower back, at times extreme. ▪ High cholesterol and re-distribution of fat in abdomen, neck and shoulders. (Indinavir and Ritonavir) ▪ Discoloured nails. (AZT) ▪ Headaches and nausea. (AZT)

SESSION 8: ADHERENCE AND RESISTANCE

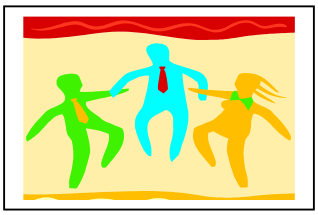
Objectives:

1. Explain the difference between adherence and compliance.
2. Understand how this difference may influence one's attitude and approach towards working with clients on HIV treatment.
3. Define adherence and resistance related to HIV treatment.

Time: 50 minutes

Session Overview

Activity/Method	Time	Materials Needed
Large Group Discussion: Adherence vs. Compliance	20 minutes	Flipchart: "Definitions of Compliance & Adherence" Flipchart paper/Markers
Presentation/Discussion: Adherence and Resistance	30 minutes	Flipchart paper Markers



Activity 1

Large Group Discussion

Time: 20 minutes

Does anyone know what compliance means?
Display the following definition:

Compliance:

- The extent to which the client's behaviour, i.e. for taking medications, following diets, or other lifestyle changes, coincides with medical or health advice.

We have already defined adherence in a previous session. Can anyone tell me what adherence means?
Display the following definition:

Adherence:

- The degree to which a client follows a treatment regimen, which has been designed by a consultative partnership between the client and the health care worker/counsellor. It encourages discussion about the various factors in the client's life that will influence the ability to exactly follow the treatment.
- The engaged and accurate participation of a client in a plan of care.

We need to look at these definitions again and talk about the similarities and differences between compliance and adherence.

Brainstorm a list of similarities and differences. The lists should include the following:

Similarities:

- Both refer to a behaviour that follows advice or treatment.
- Both involve a health care worker.

Differences:

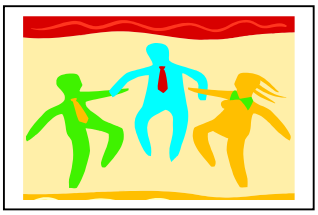
- Compliance implies a value judgement; it assumes the health care worker's guidelines are always right, and the client's behaviour is measured against this standard. This makes is easier to blame the client for any failures in the treatment.
- In compliance, the health care worker is seen as the expert and the client as ignorant.
- Adherence implies a partnership between the client and the health care worker or counsellor.
- Adherence allows for a discussion between the client and the health care worker and a collaborative process to develop a plan or strategy.
- Adherence implies the client's understanding, consent and partnership.

Why do we talk about adherence with HIV treatment? Why is this important?
Let participants think about this and begin a discussion.

Key Points about Adherence in HIV Treatment:

- It is important to involve the client in his/her treatment. Let the client be his/her own expert.
- The adherence plan should be personalised to the individual client. What works for one person may not work for another.
- Adherence fits better with our basic counselling approach. Remember that the client is the expert on her/himself.
- Clients are crucial as members of the health care team.

Activity 2



Presentation/Discussion

Time: 30 minutes

What is **HIV treatment Adherence**?
HIV treatment adherence means that the medication is taken according to the prescribed instructions:

- The recommended dose
- At the recommended time
- In the recommended way

Studies have shown that adherence with HIV treatment means taking at least 19 out of 20 doses. An adherence rate of more than 95% must be sustained in order for the replication of HIV to be controlled. For HIV treatment adherence, this means that a client cannot miss more than one dose a week.

Most people get better with treatment. For many, the treatment works for many years. For some, the treatment does not work or only works for a short time.

What is **non-adherence**?
Non-adherence means that any one of the above three criteria is <u>not</u> met. If the client for any reason is NOT:

- Taking the recommended dose
  OR
- Taking it at the recommended time
  OR
- Taking it in the recommended way

Some examples of **non-adherence**:

- Missed doses, i.e. due to holidays, travel or forgetfulness
- Delayed doses, i.e. not taking the dose on time
- Failing to follow guidelines, i.e. because of social pressures, misinformation
- Drug holidays, i.e. structured treatment interruptions, temporary dislike of taking tablets

The result of being non-adherent is the possible development of drug resistance.

Why does the treatment not work for some people?

1. The tablets do not work if you do not take them.
2. Some of the medicines do not stay in the body for a long time. You have to take these every 12 hours to maintain a consistent level of the drug in the body.
3. If you do not take the tablets every 12 hours each day, the virus changes (or mutates) and the medicines do not work anymore.

What is **resistance**?

- A reduction in HIV's sensitivity to a particular drug.
- This means that a particular drug or combination of drugs, is unable to block replication of HIV, so the virus can continue to grow even in the presence of the drug.
- Some strains of HIV naturally develop resistance to anti-retroviral drugs because of the random mutations that happen regularly as the virus replicates.
- Resistance can make some drugs less effective or even completely ineffective.

How does resistance develop?

- Through lack of adherence or low adherence. For instance, if someone taking ARVs misses many doses, the virus is likely to develop a resistance to some or all of those drugs.
- The more often the client misses doses or takes doses late, the more likely the virus will develop resistance.
- Resistant viruses can also be transmitted through unprotected sex. This is one reason people living with HIV need to avoid re-infection.

Why are we talking about resistance?

- Resistance is a major reason why HIV treatment fails.
- If a client develops resistance to first-line regimens, then there are fewer treatment options. He/she will have to take the second-line regimens.
- Understanding resistance allows us to understand how important adherence is.

Second-line Regimens:

- The second-line regimens are much harder to adhere to because they have more requirements and restrictions about how the medications should be taken.
- Second-line treatments have more severe side effects.
- If a client develops resistance to second-line regimens, there are currently no other treatment options in Namibia.

SESSION 9: ADHERENCE VIDEO

Objectives:

1. Review how ARVs work to slow the progression of HIV.
2. Discuss two different scenarios for adherence.
3. Discuss adherence strategies.

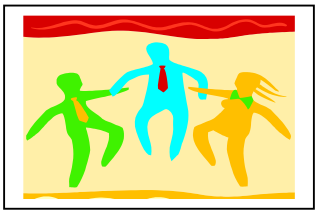
Special Materials Needed:

- Computer to play video DVD
- LCD projector or large TV screen
- Adherence Video (from the Centre for the Study of AIDS, University of Pretoria and Perinatal HIV Research Unit)

Time: 30 minutes

Session Overview

Activity/Method	Time	Materials Needed
Adherence Video & Discussion:	30 minutes	Computer to play video CD LCD projector or TV screen

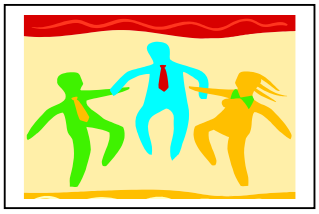


Activity 1

Adherence Video, Part 1: What is adherence?

Time: 5 minutes

Show part 1 of the video.



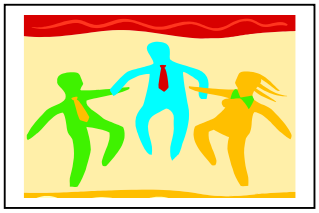
Activity 2

Adherence Video, Part 2: Adherence in Action: The Story of Joseph and Hope

Time: 5 minutes

Stop the video after part 2 of the video to discuss the following questions:

- What factors influenced Joseph's adherence?
  Answers include: no plan for different schedule, i.e. going out, secrecy (did not disclose to anyone), lack of support, did not know what to expect with side effects, and did not respond correctly.
- What factors influenced Hope's adherence?
  Answers include: disclosed to family, received support from others, did not try to hide medication, called doctor when experienced side effects, and continued taking medication.



Activity 3

Adherence Video, Part 3: Adherence Strategies

Time: 5 minutes

Adherence Strategies:

- Disclosure
- Support groups
- Memory aids

Stop video before the social grants section, as the information about social grants is only applicable for South Africa.

Discussion Question:

- ❖ What did you learn from the video?

SESSION 10: DISCLOSURE

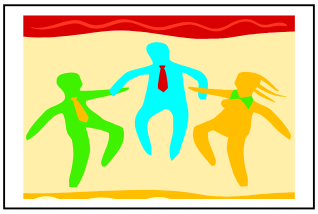
Objectives:

1. Discuss the issues surrounding disclosure of HIV status.
2. Identify ways to address issues of disclosure in counselling.
3. Practise discussing disclosure with a client in a role play.

Time: 1 hour 30 minutes (90 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Large Group Discussion: Disclosure	30 minutes	
Relay Role Play: Discussing Disclosure	60 minutes	Ball or bean bag



Activity 1

Large Group Discussion

Time: 30 minutes

The video we just watched highlighted the importance of disclosure for HIV treatment adherence. In this session, we are going to talk more about disclosure.

Why would someone who is HIV-positive disclose his/her status?
Let the participants come up with their ideas. The participants' list might be divided into two categories:

1. Disclosure for support: HIV-positive status may be a crisis in a person's life. He/she will need support, but in order to get real support, he/she will need to disclose his/her status.

2. Disclosure for ethical reasons: An individual's HIV status involves other people, especially sexual partner(s). Not disclosing puts the partner(s) at risk.

Consequences of Disclosure or Non-Disclosure:
This should be a review from VCT.

Let's talk briefly about the consequences of disclosure. There are both positive and negative consequences to disclosure and non-disclosure. First, we can compile a list of some negative consequences of disclosing. *You may want to make two flipchart lists, one for negative consequences and one for positive consequences.*

Now, brainstorm a list of positive consequences of disclosing.

It is important to point out in this discussion that an individual can make partial disclosure, i.e. to disclose to family members or close friends. Also, point out that once a person has disclosed his/her status, he/she cannot take it back.

Note to Facilitator: Make sure that your list of positive consequences is longer than the list of negative consequences. Counsellors may make similar lists with their clients; you are modelling how to do this.

In the beginning sessions of adherence counselling, a client should be encouraged to disclose his/her status. Developing a network of supportive people increases levels of adherence.

Key Point: Disclosure is a process; it does not happen all at once.

Discussing Disclosure in Adherence Counselling

- How would you bring up the issue of disclosure with a client?
  Brainstorm a list of possible questions or ways of talking about disclosure.

Research shows that those who take HIV treatment (ART) in secret have lower levels of adherence.

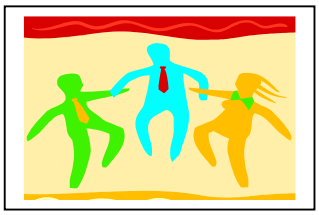
- What would your response be if you found out that your client has not disclosed his/her status to anyone?
  Again, let participants respond. Responses should include exploration of the client's feelings, i.e. fears, denial, etc. Possible probing questions include:
  - What keeps you from sharing your status with the people close to you?
  - Many people do not share their status with others because of fears they have. What fears might keep you from disclosing?
  - When you think about sharing your status with someone [you could actually name a person in your client's life, their mother, girlfriend, etc.], how do you feel?
  - What is it like for you to keep this secret all to yourself?

- How would you discuss to whom the client might be able to disclose?
  Participants should offer their ideas. Some possible approaches:
  - Telling others your status is an important step before starting HIV treatment. If you think about disclosing your status to someone, what would you want that person to be like? What personality characteristics would you want that person to have? Can you think of anyone in your life who has some of those characteristics?
  - Is there anyone in your life who you wished knew about your status?
  - Who do you trust and confide in, in your life? What would it be like to tell that person about your status?

- Discuss the advantages and disadvantages of disclosure to specific people. Just as we have talked about the positive and negative consequences of disclosure, the client must explore the advantages and disadvantages of disclosure for him/herself. Naturally, in order for disclosure to be advantageous, the client must identify more advantages than disadvantages.
- Identify a person or several people to whom the client can disclose his/her status.
- Discuss details of how your client will disclose. Be specific and include the following:
  - Time
  - Place
  - Privacy
  - Ways of raising the issue
  - What will be said
- You can role play the disclosure with your client. You may start by playing the client's role and the client can play the role of the person he/she is telling. Then switch roles so the client is playing his/her own role.
- End by telling the client his/her strengths and how these strengths will assist him/her during this difficult process.

Tips for Counselling and Disclosure:

- Do not impose your views, beliefs or experiences concerning disclosure.
- Disclosure or not is the client's decision. Respect his/her decision.
- Who the client discloses to is also his/her choice. As the counsellor, you can encourage the client to disclose to people he/she lives with, but you cannot decide to whom the client should disclose.
- Try to be available to the client after he/she has disclosed. Talk about how it went.



Activity 2

Relay Role Play

Time: 45 minutes

- We are going to do a relay role play around disclosure, just as we have been discussing.
- *Ideally, the client should be selected ahead of time and should be another facilitator. The focus is on developing counselling skills, so the client should make it easy for the counsellor. Often, participants can be difficult clients.*
- We are going to rotate counsellors and [*Facilitator*] will be the client. I need a volunteer to begin our counselling session.

- *Set up chairs in the front of the room.*
- *Introduce the client, played by a facilitator. You can provide a short scenario to introduce the role play.*
- *Have the first volunteer counsellor start the session. He/she can stop the session when he/she feels stuck or wants to rotate counsellors. The facilitator can also initiate the switch if the counsellor is stuck or his/her focus is straying.*
- *Before you switch counsellors, ask the client how it was for him/her. Then ask the counsellor what he/she did well. It is important to help the participants evaluate their own progress.*
- *After the counsellor has evaluated his/her own performance, the facilitator should offer their feedback. Start with something specific he/she did well, i.e. a question that was asked well or a specific type of body language. Then give feedback on something that needs improvement, i.e. a question that was worded judgementally or a response that did not follow from what the client said. Ask the counsellor or other participants to offer other ways of addressing that situation or wording that question. Finally, end on another positive, which can be more general.*
- Now I need another volunteer counsellor to continue from where we stopped. *You may want specifically to tell the counsellor what topic he/she should start with.*

Note to Facilitator: If the relay role play is not moving, you can have a facilitator step in as the counsellor. This is also a helpful way to model good counselling skills. You do not need to stop after every counsellor rotates in the relay role play. Sometimes it is best to keep going with the counselling session so you do not lose momentum.

SESSION 11: ADHERENCE FACTORS

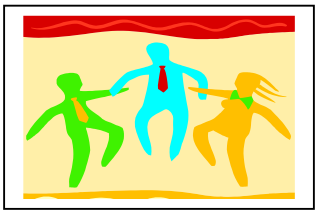
Objectives:

1. Generate ideas about adherence factors.
2. Identify factors that influence HIV treatment adherence.
3. Discuss ways to encourage and support adherence.

Time: 1 hour 30 minutes (90 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Small Group Discussion: Factors that Influence Adherence	45 minutes	Flipchart paper Markers
Small Group Activity: Case Scenario	30 minutes	
Large Group Discussion: Encouraging and Supporting Adherence	15 minutes	



Activity 1

Small Group Discussion

Time: 45 minutes

In a previous session, we talked about adherence and resistance. Why is adherence to HIV treatment so important? What is the relationship between adherence and resistance?

These are very important issues. This is a way to review some of the previous material.

- We are going to break into groups of 4 – 5 people. In your groups, discuss what influences adherence or the factors that affect adherence to HIV treatment. Keep in mind that these factors that influence adherence can be both positive and negative; they could increase or decrease adherence. Be very specific when listing the factors that influence adherence, and include how they influence adherence.

- In your groups, you should come up with at least 20 different adherence factors, but see if you can come up with more than that.

- Once you have come up with as many ideas as possible, it would be helpful to divide these factors into categories. Discuss what influences HIV treatment adherence in the following categories:

- Factors related to the client
- Factors related to the provider or health centre (hospital or clinic)
- Factors related to the treatment regimen

- You will have 20 - 25 minutes to discuss this. Please list all the factors on flipchart paper.
  Make sure participants keep their Participant Manuals closed. We want the participants to think of factors on their own, not copy suggestions from the Participant Manual.

- *When you bring the large group back together, you could have each group report on one of the factors, and the other groups can add any new ideas they had in their groups.*

- *There is a generic list of factors influencing adherence in the Participant Manual, but the lists that are generated in their groups should directly relate to the participants' communities.*

- *Stress the fact that **adherence changes over time**. A client who may start out adhering to treatment may have periods of time where adherence is more challenging. Discuss this when sharing factors relating to adherence.*

Factors That Influence HIV Treatment Adherence

This is a generic list for reference. The list that the small groups generate should be much more culturally appropriate and specific.

Client Factors:

1. Client commitment: people who are committed to and actively involved in their treatment are more likely to achieve high levels of adherence.
   - Adherence rates vary not just between individuals but within the same individual over time.
   - An individual may achieve high levels of adherence sometimes and at others times will exhibit low adherence.

2. Cultural and socio-economic issues:
   - Religious beliefs about illness and medication may influence motivation and adherence.
   - Medication use may disclose HIV status.
   - Stigma may inhibit disclosure and result in low levels of support or adherence.
   - Poverty may prevent people from being able to eat nutritious food.
   - Drug and alcohol use may impair judgement and the ability to take medication on time.
   - Family responsibilities may require adults to place the health care needs of others before their own.

3. Psychological factors: Mental health problems, such as depression, can result in low adherence. Also, an individual's perception of his/her ability or inability to follow a medication regimen and whether one believes he/she can succeed or not can impact treatment adherence.
4. Health beliefs: Beliefs about health and illness, especially the necessity of medication to treat illness, can significantly impact treatment adherence.
    - Expectations of symptom relief can have an effect on adherence. If these expectations are unrealistic, there may be poor adherence.
    - Side effects can make adherence very difficult. A client's concern about potential harm from HIV treatment can be increased by his/her experience of side effects. Missed doses may be a client's attempt to reduce the side effects.
    - People on HIV treatment frequently say low adherence is due to their experiences of side effects.

Provider Factors:

1. Offer support to all: You cannot predict future adherence based on client characteristics. Adherence is not linked to social class, education, gender, race or age.

2. Client education: Clients who understand how HIV treatment works and the importance of adherence seem to have better adherence rates.
    - Very often, clients misunderstand health care providers' instructions.
    - Instructions should be given verbally and in writing. Check that the information that has been given is understood.

3. Medication alerts: People often forget to take their medication. Reminders to take medication are helpful, such as telephone, SMS, pill diaries, charts, medication containers and reminders from family and friends.

4. Multi-disciplinary approach: Clients spend very little time with the doctor. Therefore, other health care professionals, such as nurses, pharmacists, and counsellors, should be involved in supporting client adherence.

5. Provision of on-going support: Adherence is a process, not a single event. Support should be included in follow-up, as studies show that adherence decreases over time.

6. Partnership of Health Care Team with client: Actively involve the client in adherence and his/her whole treatment, and provide support and respect from the Health Care Team.

7. Attitude of health care providers: A friendly, supportive and non-judgemental attitude can help to develop a trusting relationship with the client. This relationship can influence adherence positively.

Regimen Factors:

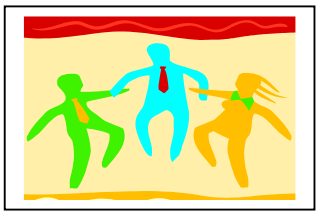
1. Dosing requirements: The difficulty of the requirements for taking the medication, i.e. how many times a day, and food or water requirements.

2. Number of tablets: Combining drugs into one pill has been shown to increase adherence.

3. Side effects: This is the reason why clients report poor adherence.

> **Key Point:** Adherence is dynamic. It changes in each client over time.

Adapted from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand.



Activity 2

Small Group Activity

Time: 30 minutes

- We are going to break into groups of 3 or 4. In your groups, you are going to discuss the following scenario:

> **Case Scenario:** Jacob is a 35-year-old unmarried man with HIV. He is a truck driver, and frequently is away from home for at least three days at a time, going to different cities. He shared the route with another driver, his cousin, who takes turns driving with him. He is occasionally sexually active with women when he is on the road. When he is in his hometown, he stays with his sister. When he is on the road, he sleeps in the truck. He believes that taking ART will help him feel better, but is not sure he will be able to remember to take the medicines on time.

- In your groups, discuss the following:
  - List some of the challenges that Jacob may face in achieving 100% adherence.
  - What are some ways that he may be able to overcome these challenges?
  - What are some of the positive factors that may contribute to adherence for Jacob?

- *After the groups have discussed Jacob's case, discuss their findings in the large group.*

Activity 3

Large Group Discussion

Time: 15 minutes

How do you think adherence can be encouraged and supported? What can you do as a community counsellor to improve adherence?

Lead a discussion about how adherence could be improved. Include what participants think they can do as community counsellors.

Note to Facilitator:

- The purpose of this discussion is to encourage participants to think on their own and to empower them to come up with creative ideas around the issue of adherence. They will have to do this in many discussions with their clients.
- Once again, the facilitator is modelling ways of processing, which is important in counselling. The facilitator is also empowering participants in many of the same ways that counsellors empower clients.

SESSION 12: TOOLS AND SYSTEMS FOR ADHERENCE SUSTAINABILITY

Objectives:

1. Think creatively about ways to help and support adherence with clients.
2. Develop examples of tools that can be used for adherence sustainability in local communities.

Time: 1 hour 15 minutes (75 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Tools & Systems for Adherence	15 minutes	
Art Activity: Make an Adherence Tool	30 minutes	Art supplies (coloured paper, magazines, crayons, markers, scissors, glue, paints)
Large Group Discussion: Share Adherence Tools	30 minutes	

Activity 1

Introduction

Time: 10 minutes

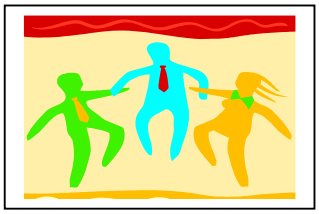
We have talked some about adherence and some of the factors that influence adherence, but we have not talked about tools that could be used to help people remember to take their medicine.

What sorts of things can be used to help clients remember to take their medicines?
Let participants brainstorm tools that can be used. Below is a list of ideas that could be included.

Examples of Tools to Sustain Adherence:

- Pill/tablet boxes: do not assume the clients know how to use pill boxes. Show them how to fill their pill boxes, count their tablets and monitor their adherence.
- Timers/alarm clocks
- Pagers
- Cell phone alarms
- Pictures
- Calendar
- Stickers

Show the examples of adherence tools included in the Participant Manual.



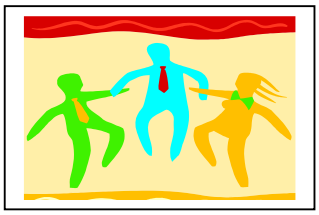
Activity 2

Art Activity: Design an Adherence Tool

Time: 30 minutes

- For the next half hour, we will spend some time designing adherence tools. These could be tools to help clients remember to take their medicine, as well as tools to keep track of the doses they have taken or missed.
- I would like you to think about your communities. Can most of your community members read? What do they understand? What could you use to help people remember to take their ARVs? What about a tool to help them keep track of their doses?
- Each of you is going to design your own adherence tool(s). Be creative in designing them, and make the tools colourful and interesting.
- Make sure the tools that you design could be used by the members of your communities. How exactly would they use your adherence tool?
- If you finish one tool, you can design more adherence tools.

Note to Facilitator: The activity below also can be assigned as homework. Encourage participants to come up with creative tools that would work in their communities.



Activity 3

Large Group Discussion

Time: 30 minutes

- *Allow each participant to share his/her adherence tool(s). Encourage participants to be specific and give details about how the tool should be used.*

Note to Facilitator: You can make this art activity into a small competition.

- Adherence tools can be displayed around the room. Then let everyone wander around the room to look at the "exhibition."
- You could select some judges and have them vote on the first, second and third place adherence tools, or you could have participants vote for their favourite tools.
- Judging should be based on usability and creativity.
- You can provide small prizes, such as pens, notebooks or sweets.
- The winners should present their tools to the large group.

Processing Questions:

- How could you use what we have done here in adherence counselling? *Encourage participants to use the ideas generated by their colleagues. Clients also can be encouraged to design their own adherence tools just as we have don, or to enlist the help of their families or friends in designing adherence tools.*

- Will the same tools work for everyone?
  You may want to highlight some tools designed by different participants and ask what tools might work best for various clients.

HIV Treatment Regimen Chart: 28 Day Chart

(example for reference)

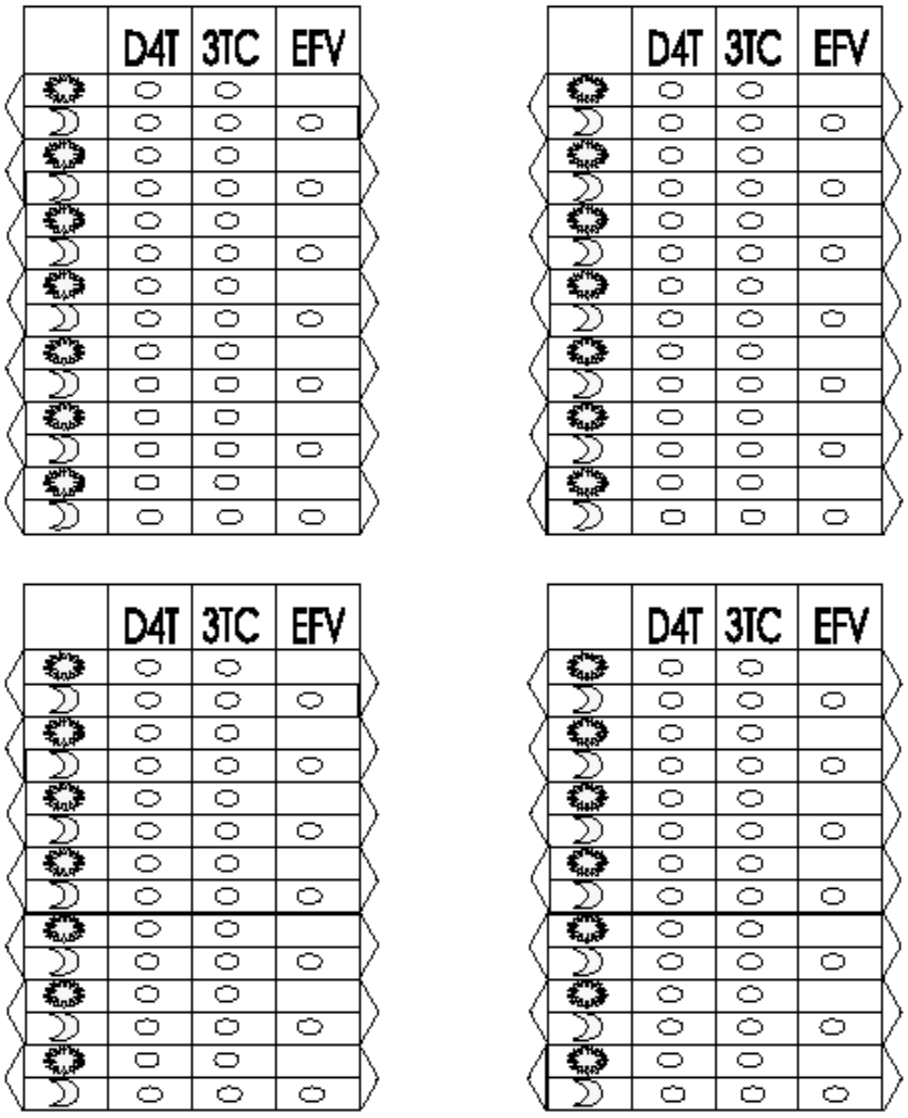
Name______________________________ Month _________________________

Day	d4T	3TC	Nevirapine (NVP)
	AM ☼ PM ☽	AM ☼ PM ☽	AM ☼ PM ☽
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Example of weekly diary cards for an illiterate patient

4 weeks' supply (Regimen 1)

Copies can be handed out with instructions to fill pill boxes (egg carton) with a week's supply on an identifiable day, e.g. Sunday.



This is not a line of treatment to follow.
It is only an example of how illustrations can be used to assist patients.
Actual pictures of the tablet could further assist the patient.

SESSION 13: NUTRITION

(From General HIV Module)

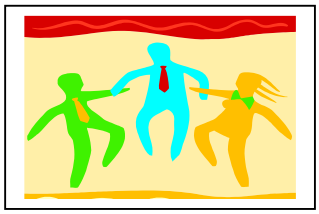
Objectives:

3. Understand the basic concepts of nutrition.
4. Identify key nutritional needs for people living with HIV.
5. Design a three-day nutritional diet for a person living with HIV.
6. Discuss challenges to good nutrition.

Time: 1 hour 45 minutes

Session Overview

Activity/Method	*Time*	Materials Needed
Presentation/Discussion	30 minutes	Flipchart paper Markers
Small Group Project: Design a 3-Day Menu/Diet	45 minutes	Art materials
Large Group Discussion	30 minutes	



Activity 1

Presentation/Discussion

Time: 30 minutes

What is nutrition? What about good nutrition?

Definition of good nutrition: Eating foods each day that give you the vitamins and minerals you need to keep your body strong. There is no single food that has everything our bodies need. Good nutrition means eating a variety of foods.

<u>Basic Food Groups</u>:
Does anyone know what the basic food groups are?

1. Fruits & vegetables: full of vitamins and minerals that are good for the body
2. Protein: good for muscle development and the immune system
3. Carbohydrates: provide the body with quick energy
4. Fat: how the body stores energy
5. Dairy: this is sometimes included as a food group, and contains some protein and fat

Can you give me some examples of foods in each of these food groups?
Make sure they include foods that are locally available and traditional foods. Make sure to include foods from different traditions and different parts of the country.

Now we should talk about how much of each of these food groups we should eat each day. *Refer to "Getting the Right Nutrition."*

HIV and Nutrition:

When your body fights infection, it needs more energy and you need to eat more than normal. This is sometimes difficult for people living with HIV, because when we are sick, we usually eat less than normal. In addition, many of the opportunistic infections related to HIV as well as the side effects of HIV and/or treatment may reduce a person's appetite or make it difficult to eat.

People living with HIV need to eat:

- Lots of protein, especially low-fat protein such as chicken breasts, fish, lean cuts of pork and beef and low-fat dairy products.
- 5 – 6 servings of fruits and vegetables per day. In order to get all the different vitamins and minerals, eat a variety of different-coloured fruits and vegetables.
- Carbohydrates provide energy. Half of one's diet should consist of carbohydrates such as grains, i.e. maize meal, bread, cereal, porridge, rice, pasta, vegetables and fruits. Try to eat whole grains.
- Eat very little sugar, sweets and cool drinks. They have very few nutrients and the sugar can cause side effects like thrush (Candida) to become worse.
- Have a serving or more of nuts, seeds or beans every day. These include peas and peanuts.
- Eat when hungry; it is good to snack, but make sure they are healthy snacks. Ideally, include protein and some carbohydrates in snacks.
- Drink 1 –2 litres of water every day.
- Yoghurt is good for digestion.
- Avoid: sweetened drinks (cool drinks like Fanta, Coke or sweetened fruit juices), sweets (cookies, candies) and junk food (chips, crisps, fried food).

Key Points:
- Eat a variety of foods.
- Eat small but frequent meals.
- Eat starchy food, i.e. bread, porridge, potatoes, rice, pasta, with every meal.
- Eat fruit and vegetables every day.
- Eat meat and dairy foods (milk, yogurt, cheese) every day.
- Drink lots of water every day.

Activity 2

Small Group Project

Time: 45 minutes

- Break into four groups. *You may want to count off in fours to create the groups.*
- In your groups, you will be designing a three-day menu or diet for someone living with HIV. Make sure that your menus include a variety of locally available foods.

Note to facilitator: You can also do this small group activity as a homework assignment. If you do, make sure that you follow up the next day to review the groups' menus.

- Put your diets on flipchart paper and make them as interesting as possible: include pictures and lots of colours.
- You will have 30 minutes to design and draw your diets. Then we will discuss them in the large group.

Activity 3

Large Group Discussion

Time: 30 minutes

Allow each group to present their menus to the large group. OR If you have limited time, you could simply have the groups post their menus in the training room.

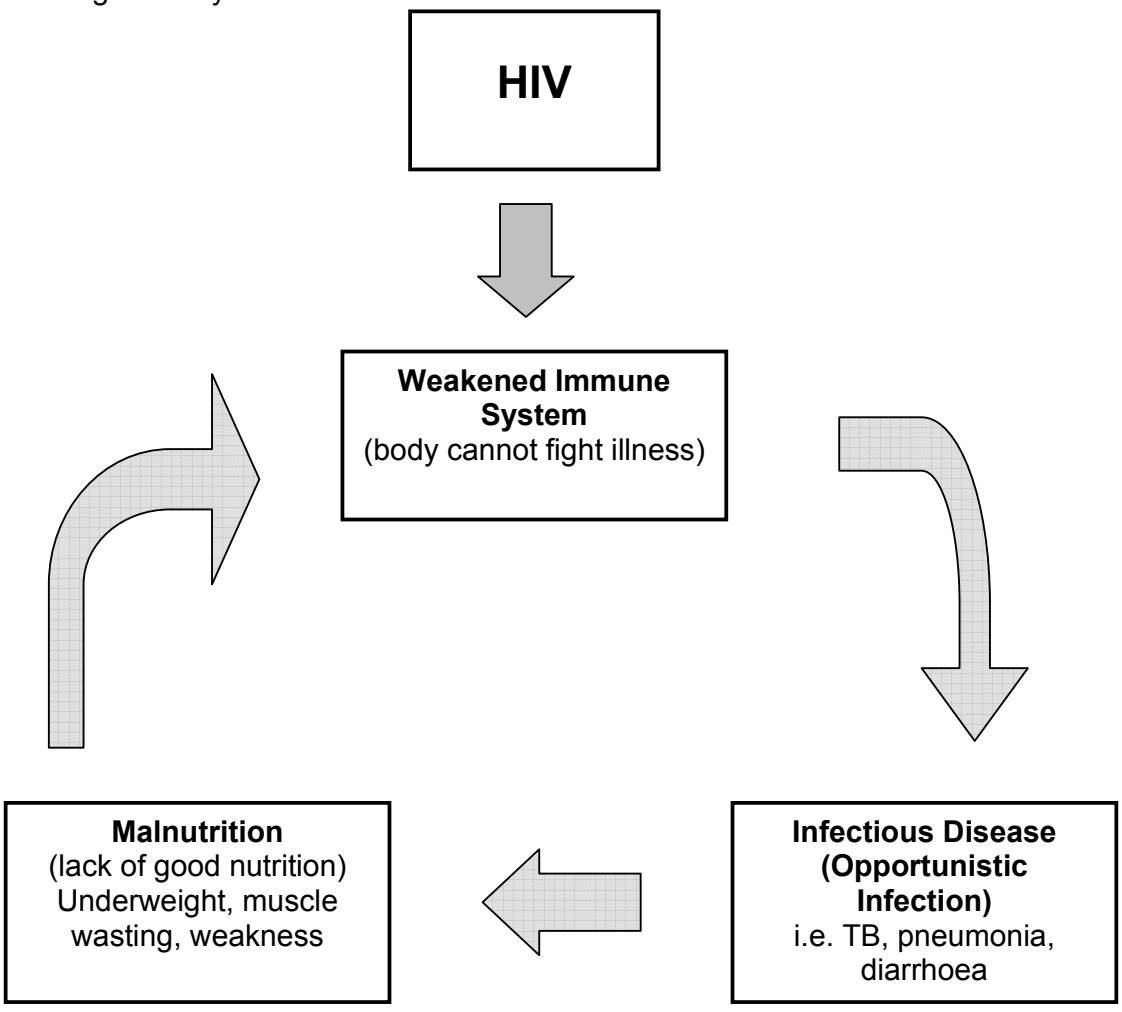
- How well did the groups do in using locally available and traditional foods? Is it possible to have a nutritious diet using traditional foods? *Make sure that participants understand that they and their clients can have a healthy diet simply by introducing more fruits and vegetables that are in season.*
- Would you make any adjustments to these menus? Are there any things that are included in these menus that should not be there?
- What was it like to do this activity?
- Do you think nutrition is important in relation to HIV? If so, how?

What are some of the challenges to good nutrition?
Let participants identify the challenges and brainstorm some solutions. Below are some issues that could come up, but the point is to try and make small steps towards good nutrition:

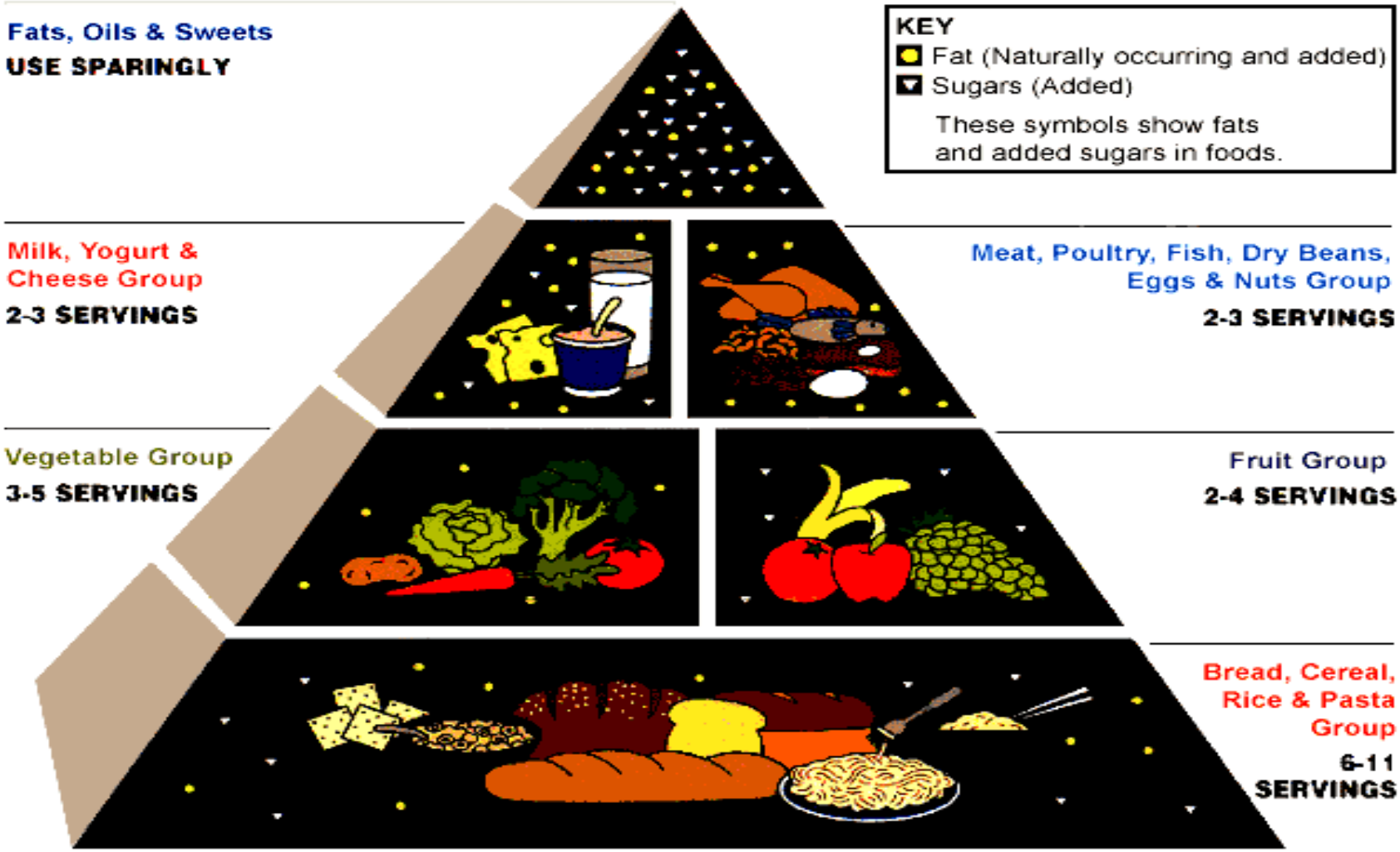
- Lack of money: often nutritious food is more expensive.
- All-or-nothing thinking: even having one or two more fruits or vegetables once a week is better than nothing, i.e. having an apple instead of crisps.
- Availability of nutritious food: eat what is in season. Many people grow fruits and vegetables locally.

Vicious Cycle of HIV and Malnutrition

Malnutrition is not having enough food to eat, or not eating nutritious food or food that is good for you.



GETTING THE RIGHT NUTRITION



SESSION 14: BENEFITS AND LIMITATIONS OF HIV TREATMENT

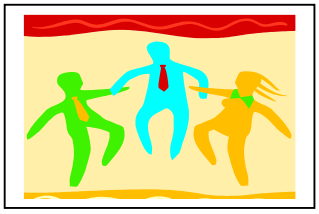
Objective:

1. Identify the benefits of and limitations to HIV treatment.

Time: 40 minutes

Session Overview

Activity/Method	Time	Materials Needed
Written Activity: Advantages & Disadvantages of HIV treatment	15 minutes	
Large Group Discussion: Benefits and Limitations of HIV treatment	25 minutes	

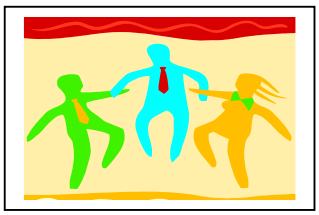


Activity 1

Written Activity: Advantages and Disadvantages

Time: 15 minutes

- Please take out a sheet of paper or open to a clean page in your notebooks.
- I would like each of you to create a list of advantages and disadvantages of HIV treatment. BUT, I want you to do this from a personal perspective, as if you were the client preparing to go on HIV treatment.
- What do you think the advantages and disadvantages would be for you personally? If you were living exactly as you are now and preparing to begin HIV treatment, what would that mean for your life? What would be good about it? What would be bad about it?
- You have 15 minutes to make your list.
  Encourage participants to make these lists personal, i.e. if they have children or a family, how this would influence their of HIV treatment.



Activity 2

Large Group Discussion

Time: 25 minutes

- I am not going to ask you to share what you wrote on your list, although you can share them in this discussion if you would like.
- I want us now to think about the broader benefits and limitations of HIV treatment.
- See if you can take an advantage or disadvantage from your personal list and make it into a general benefit or limitation.
- *Let the participants generate as many ideas as possible.*
- *You may want to have someone write the brainstormed list on a flipchart. Make sure that you make any specific benefit or limitation into a broader category so that it can apply to most people.*

Below is a chart highlighting some key benefits and limitations of HIV treatment.

Benefits and Limitations of HIV Treatment

Benefits/Advantages	Limitations/Disadvantages
HIV-positive people on HIV treatment live healthier, longer lives than HIV-positive people not on HIV treatment.	No cure
	Life-long treatment
	ARVs suppress the virus but do not eliminate it
	Strict adherence required, i.e. timing, frequency and dosing
	Close monitoring required.
Delayed onset of opportunistic infections	Risk of resistance
Quality of life improves, and clients can work	Side effects may reduce life quality.
Reduces transmission from mother to child	Long-term effects of HIV treatment unknown.
	Transmission may still occur.
Parents stay alive longer, so there are fewer orphans	
People are encouraged to go for VCT and to disclose their status.	More drugs and different services needed.
	HIV can still be transmitted sexually while on HIV treatment.

Processing Questions:

- Why is it important to understand the benefits and limitations of HIV treatment?
- Are the advantages and disadvantages of HIV treatment the same for everyone?
- Why did we do this exercise? Why did we first list personal advantages and disadvantages?
  Point out that community counsellors will be doing this with their clients who are considering HIV treatment. Personal advantages and disadvantages are unique to each person.

SESSION 15: INTER-DISCIPLINARY TEAM AND THE ROLE OF THE COMMUNITY COUNSELLOR

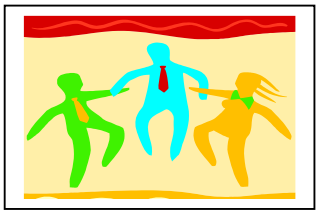
Objectives:

1. Describe the interdisciplinary team recommended for HIV treatment adherence.
2. Identify roles for team members in HIV treatment adherence.
3. Identify community counsellors' roles in the Health Care Team for HIV treatment adherence.

Time: 1 hour 30 minutes

Session Overview

Activity/Method	Time	Materials Needed
Warm-Up Activity: Team Building	20 minutes	
Large Group Discussion: Adherence Team	20 minutes	"Inter-Disciplinary HIV Treatment Adherence Team" Model
Small Group Discussion: Roles of Adherence Team Members	50 minutes	Flipchart paper Markers Post-Its



Activity 1

Warm-Up Activity: Team Building

Time: 20 minutes

Round 1:

- Everyone, please gather here. *Select an area that has plenty of room*.
- Please face me. Now I want you to take hold of two people's hands: they could be in front of or behind you. You cannot hold the hands of the people standing next to you.
- *Select one participant or ask for a volunteer before starting this activity; the volunteer will be part of the tangled circle*. Now, [*volunteer's name*] will untangle you. You may not speak or move without being instructed. You may only follow [*volunteer's name*] instructions.
- *Give the volunteer some time to try and untangle the group. You many need to remind the participants that they cannot move on their own or speak.*

Processing Question:

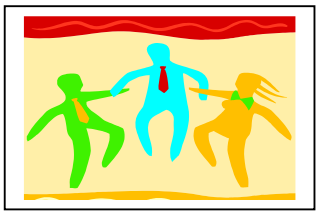
- ❖ What was that like?
  Make sure to ask both the volunteer leader/problem solver as well as the whole group.

Round 2:

- We are going to do the activity again, but this time, the rules are going to change. We are not going to have one person trying to untangle you; you can all take part in the untangling. You may also talk to one another.

Processing Questions:

- ❖ What was that like? How was it different from the first time?
- ❖ What is easier or more complicated?
- ❖ What was the process used in actually untangling the group? *OR* How did you end up getting untangled?
- ❖ Why did we do this exercise? What do you think the purpose could be?



Activity 2

Large Group Discussion

Time: 15 minutes

Adherence is a team commitment. But who is the team?
Let the participants offer their answers.

Display the "Inter-Disciplinary HIV Treatment Adherence Team" Model.

> **Key Point:** Adherence should involve the **entire community**, not just health care professionals.

- Larger Community: You can extend this to the whole country of Namibia. It could include national government programs, NGOs, etc. Can you think of examples of what could be included as adherence support in the larger community?
  Let participants brainstorm a list.

- Local Community: This could include the private sector, NGOs, local organisations and local government programs. This is the community surrounding where the client lives. Can you think of examples of what this could include?
  Let participants brainstorm a list.

- Health Care Team: First, I want you to take a look at this model. Who is at the centre of the Health Care Team? Why is this?
  Remind participants of adherence vs. compliance. The client is the expert on him/herself and therefore is the most important person in HIV treatment adherence.

- Members of the **Health Care Team** include:
  - Client
  - Doctors
  - Pharmacists
  - Nurses, including enrolled nurses
  - Community counsellors
  - Social workers
  - Treatment supporter
  - Community volunteers, such as home-based care workers, translators, etc.

Activity 3

Small Group Discussion

Time: 40 minutes

Roles of the HIV treatment Adherence Health Care Team

- We are going to break into groups of 4 or 5. In your groups, discuss the roles and tasks of different members of this large adherence team that we have been talking about.

- First, make a list of all the tasks you think are part of the Inter-Disciplinary Health Care Team's responsibility. Write each of the tasks on a Post-It.

- Then divide these tasks among the following Health Care Team members:
  - Doctor
  - Pharmacist
  - Nurse
  - Counsellor
  - Treatment Supporter
  - Client

- You can write the different team members on flipchart paper and then stick the Post-Its with a task or role with the correct Health Care Team member.

- You will have 20 minutes to discuss this in your small groups.

- *Remember to circulate among the groups so that you can help them during their discussions as needed.*

- *Bring the large group together and have each group present a Health Care Team member's responsibilities. Encourage discussion and allow groups to change their minds about who should be responsible for different tasks.*

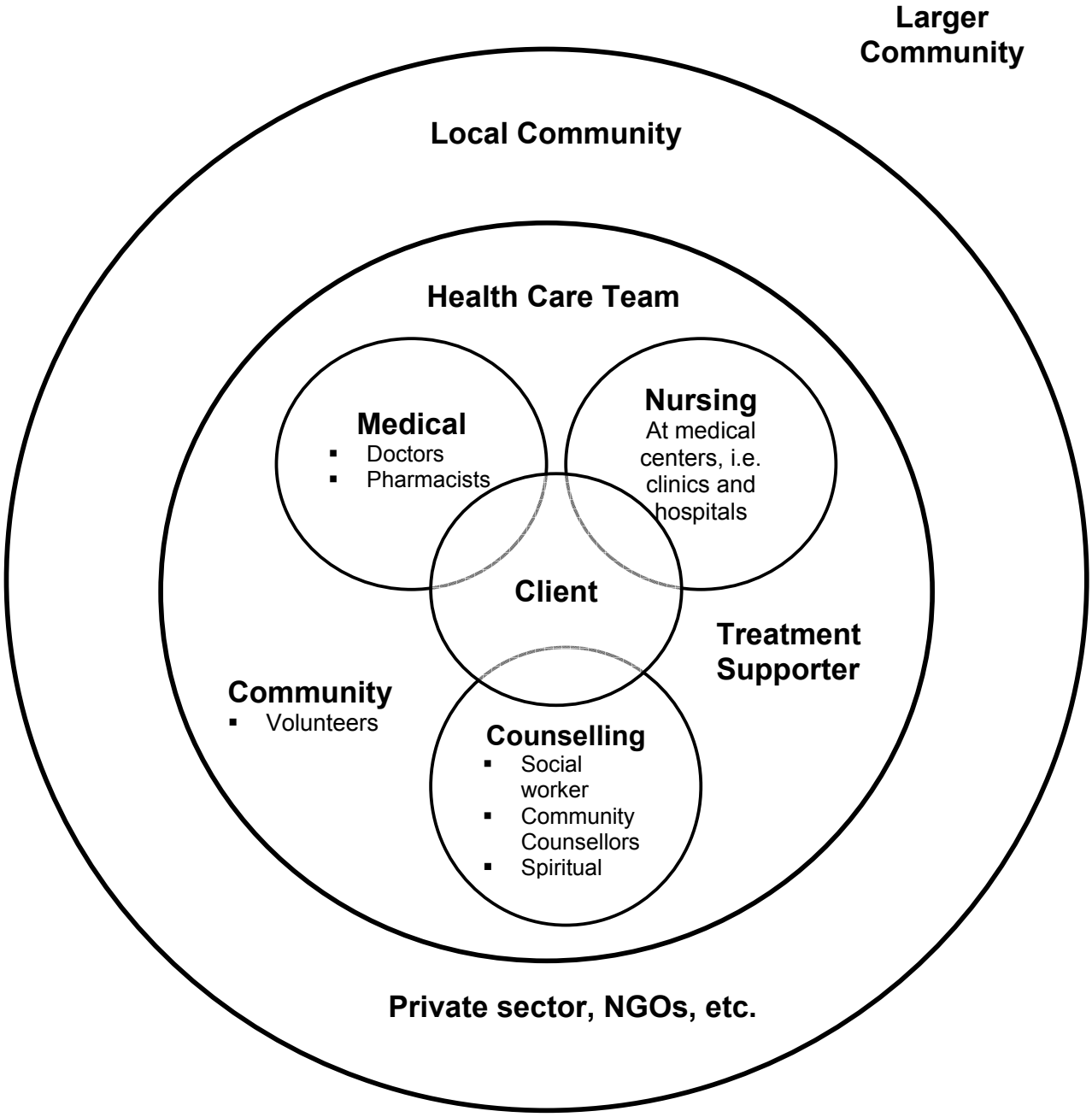
Note to Facilitator: Alternatively, you could go through each Health Care Team member by having a representative from each group come forward and share the role of that team member. They can then note the roles on the flipchart displaying the Inter-Disciplinary Team.

- *Once you have discussed all the Health Care Team members, focus on the list of the roles and responsibilities of community counsellors.*

Key Points:

- Point out that doctors, pharmacists and nurses are the ones who provide medical information, such as information on medication, side effects, treatment regimens, etc.
- The Community Counsellors' primary role is to **support the client emotionally**. There is no one else in the health care team whose role is to support the client. The counsellor can do this by: listening to the client's experiences and supporting the client in healthy living and adherence, assessing the client's understanding, and exploring issues and potential solutions for adherence. Community counsellors are NOT information givers or trained health workers.

Inter-Disciplinary HIV Treatment Adherence Team



SESSION 16: HIV TREATMENT GUIDELINES & TREATMENT SUPPORTER

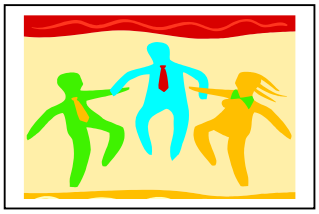
Objectives:

1. Review the Namibian guidelines for HIV treatment.
2. List the social criteria for starting HIV treatment.
3. Explore the role and characteristics of a treatment supporter.

Time: 60 minutes (1 hour)

Session Overview

Activity/Method	Time	Materials Needed
Presentation/Discussion: Namibian Guidelines for HIV treatment	15 minutes	
Small Group Discussion: Treatment Supporter	45 minutes	A4 paper, Markers, Presstik



Activity 1

Presentation/Discussion

Time: 15 minutes

- As we have already mentioned, HIV treatment and adherence is a team effort. The Health Care Team should work together to determine the client's preparedness for HIV treatment.

- The doctor and nurses will determine the client's eligibility according to the medical criteria. There are many things they have to consider and tests they need to do in order to determine medical eligibility for HIV treatment.

Basic Medical Criteria for ART in Namibia

Adults:
CD4 Count<200, WHO Stage III or IV

Pregnant Women:
CD4 Count<250, WHO Stage III or IV

Children:
Based on CD4 percentage

- The social criteria and client preparedness is determined by the entire Health Care Team.

Social Criteria used to determine if a client is eligible for HAART in Namibia:
- Has lived at a fixed address for the past 3 months
- Has ready access to a designated treatment centre for follow-up
- Client is committed to long-term HAART, adherence to treatment, practising safer sex, and allowing home visits if indicated
- Client has identified someone at home, in the community, or at the workplace to serve as a therapy supporter

Taken from MoHSS. April 2003. Guidelines for HAART in Namibia.

- As a counsellor, you will be involved with the whole Health Care Team in determining whether a client meets the social criteria for beginning HIV treatment.
- *Go over the social criteria carefully; make sure participants understand each section of the criteria.*

Activity 2

Small Group Discussion

Time: 45 minutes

In the Namibian guidelines for HIV treatment, the social criteria require the client to select a treatment supporter before he/she can start on HIV treatment. However, the Ministry of Health and Social Services (MoHSS) does not clarify exactly who the treatment supporter should be or what his/her role is.

Let's talk for a minute about what you think the role of the treatment supporter should be.
Let the participants brainstorm some potential roles for the treatment supporter and list these on flipchart paper. There is no right answer, as each client may require different things from his/her treatment supporter.

We are going to break into small groups and discuss characteristics of a treatment supporter. Look at personality characteristics as well as practical factors in selecting a treatment supporter. These can include things such as where the treatment supporter should live, if he/she should be related to the client, etc.

- Break into groups of 4 – 5. Brainstorm a list of personality characteristics and practical factors for treatment supporters.
- Write each of your characteristics or factors on a separate sheet of A4 paper.

- Then prioritise your list: rank the characteristics in order from what is most important to what is least important.
- Finally, post your papers on the wall nearest your group. Display them according to rank of importance, with the most important characteristic at the top and the least important one at the bottom.
- You will have 20 minutes to do this exercise.
- *Bring the large group together and have each small group share their list of characteristics for treatment supporters.*

Processing Questions:

- ❖ How different is each group's list?
- ❖ How different do you think it would be if our clients came up with a list like this?
- ❖ Can we agree on any factors or characteristics for treatment supporters that are universally important?
- ❖ How can we help our clients select treatment supporters?
- ❖ What did we learn by doing this activity? How should this influence our counselling?

SESSION 17: HIV TREATMENT ADHERENCE COUNSELLING OVERVIEW

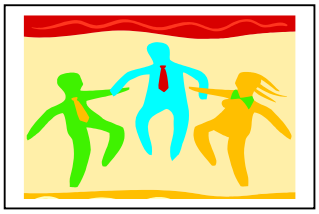
Objectives:

1. List the four stages of HIV treatment adherence counselling.
2. Identify the purpose for each stage of HIV treatment adherence counselling.

Time: 50 minutes

Session Overview

Activity/Method	Time	Materials Needed
Activity: Folding Paper Instructions	20 minutes	5 sheets of A4 paper 5 blindfolds
Presentation: HIV Treatment Adherence Counselling Model	30 minutes	HIV Treatment Adherence Counselling Model



Activity 1

Folding Paper Instructions

Time: 15 minutes

- I need five volunteers to come up to the front of the room. Each of you is going to be blindfolded. *You may also just have them close their eyes.* You may not peek and also, you may not speak.
- I am going to hand each of you a piece of paper. I will give you instructions for what to do with the piece of paper. Follow those instructions exactly, but remember, no peeking or talking!
    - Fold the paper in half.
    - Tear off the bottom right hand corner of the paper.
    - Fold the paper in half again.
    - Tear off the bottom left hand corner of the paper.
- Now all of you can take off your blindfolds (or open your eyes). Please show your papers to everyone.

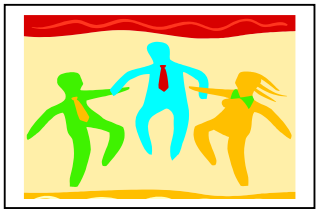
Processing Questions:
It is highly unlikely that all four pieces of paper will have been torn in the same way.

- What happened? Were all of you watching? Did each of the volunteers follow the instructions?
- *Ask the participants:* Were my instructions clear?
- *Ask the volunteers:* Did each of you understand the instructions? Could you hear me and did you understand what I was saying?

- If everyone followed the instructions and all the volunteers understood me, how can the papers look so different?
- What can this activity show us?
  Refer to Communication and Perceptions from Personal Growth.
- Why did we do this activity? How does it relate to adherence counselling and HIV treatment?
  Refer to Understanding Behaviour Change from Basic Counselling Skills.

Key Points:
- People have different perceptions, and the same simple instructions can mean different things to different people.
- It makes no difference how smart or literate someone is.
- What we have meant and what another person may have understood are often very different.
- Everyone followed the instructions correctly, but the results were very different.

Key Point: Many think that by giving instructions to a client on how to take ARVs, the client will adhere. However, there is a lot more to adherence than giving instructions. This is what adherence counselling is about.



Activity 2

Presentation

Time: 30 minutes

It is helpful to think about HIV treatment adherence counselling as having a number of stages. These stages are helpful for the whole Health Care Team, but are most important for the client to go through. These stages are key to understanding adherence as an ongoing process.

The four stages of ARV adherence counselling are:
1. Pre-HIV Treatment Initiation
2. HIV Treatment Initiation
3. HIV Treatment Maintenance
4. Re-Motivation or Treatment Change

In this session, we will be looking at the whole HIV treatment adherence counselling model and briefly discussing each stage of adherence counselling. In later sessions, we will discuss each stage of adherence counselling in detail, and practise role plays to understand and develop the skills needed.

Refer to the HIV Treatment Adherence Counselling Model.

- HIV Treatment Adherence Counselling begins after a client already knows his/her HIV-positive status.
- Remember that HIV treatment is treatment for life, at least until a cure is found. Therefore, this adherence model is for the duration of treatment, for the rest of the client's life.
- While this model clearly outlines separate counselling sessions in each stage, remember that this may not always work. Sometimes a number of sessions may be combined in order to best meet the needs of the client.
- A high level of adherence can best be met if this four-stage model of adherence counselling is followed. It allows the client to take an active role in the treatment process and gives him/her the time to fully understand and develop a successful adherence plan.

Stage 1: Pre-HIV Treatment Initiation

- In stage 1, the client already knows his/her HIV-positive status. He/she has been tested for HIV.
- In this stage, the client begins to think and talk about the possibility of beginning anti-retroviral treatment.
- This discussion happens between the client and the counsellor, as well as involving other members of the Health Care Team, such as doctors and nurses. The client also should be encouraged to discuss starting treatment with his/her friends and family.
- The counsellor must explore the client's thoughts and feelings about HIV treatment and what this would involve.
- The **purpose** of the first stage:
    - Educate client on HIV/AIDS and introduction to HIV treatment
    - Determine client's HIV treatment readiness: does he/she meet the MoHSS criteria?
    - Establish full commitment to treatment
    - Prepare client for what treatment involves
    - Select and involve treatment supporter
    - Develop a personalised treatment and adherence plan

Stage 2: HIV Treatment Initiation

- Once the client meets the MoHSS criteria and is informed and committed to treatment, he/she can begin HIV treatment.
- At this stage, the client may experience a wide range of feelings and thoughts. The client is required to make lifestyle adjustments and faces issues that might make adherence difficult. He/she should be able to explore and address all of these issues with his/her Health Care Team.
- The **purpose** of the second stage is to:
  - Tailor the HIV treatment regimen to the client
  - Discuss side effects
  - Develop a personalised adherence plan
  - Problem solve about factors that may lower adherence.

Stage 3: HIV Treatment Maintenance

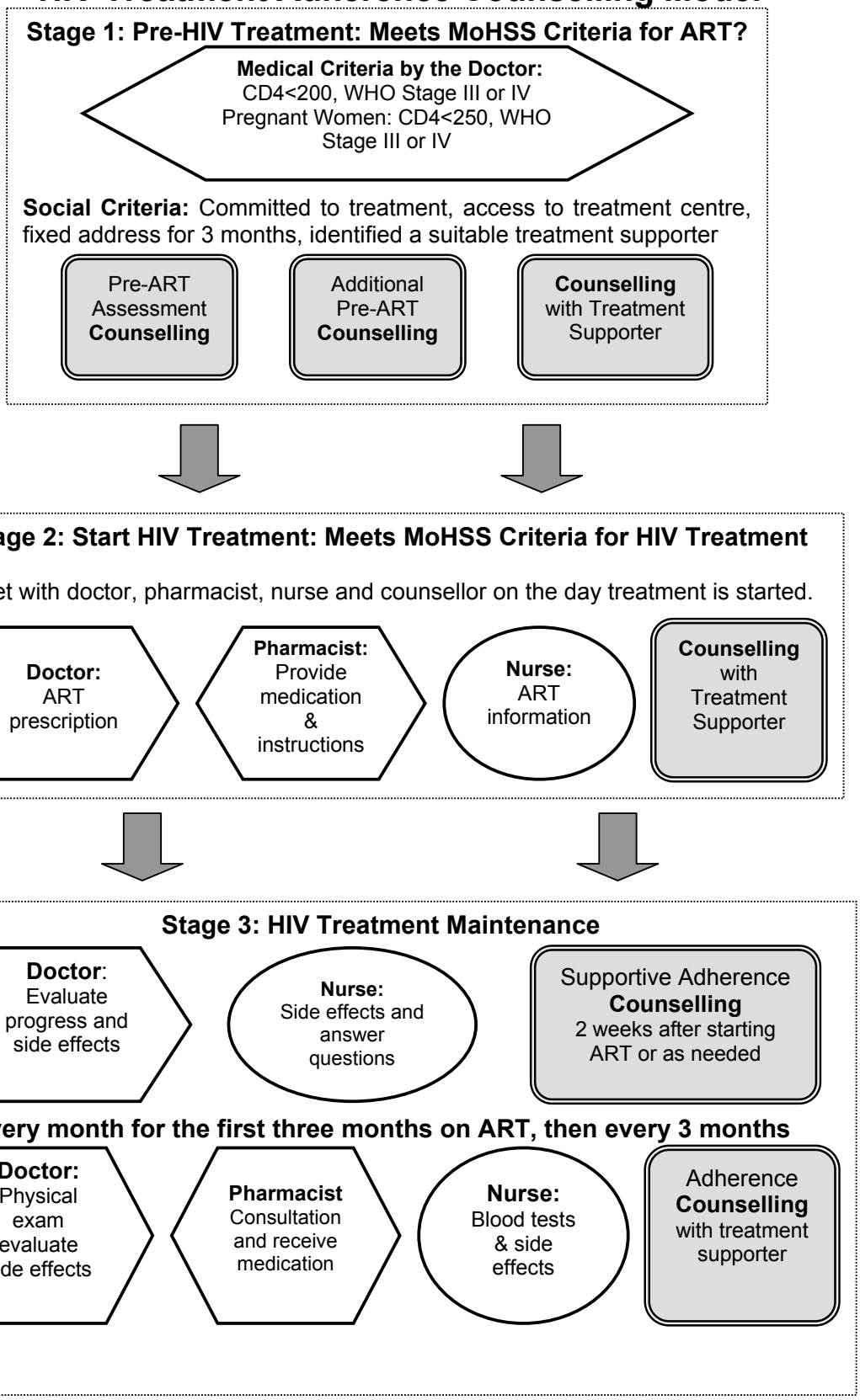
- Once the client has started on HIV treatment, other issues may come up. These could include how to deal with side effects and factors that influence adherence.
- Counselling at this stage should focus on listening to the issues the client is dealing with and helping him/her to identify problems and develop strategies for solving them.
- The **purpose** of the maintenance stage is to:
  - Simplify the HIV treatment regimen
  - Avoid drug interactions and minimise side effects
  - Discuss client's coping mechanisms and reinforce strengths

Stage 4: Re-Motivation or Treatment Change

- Clients may continue with the same regimen but require ongoing re-motivation and support from the Health Care Team to maintain high adherence.
- After a period of time, clients may need to change their treatment regimen. This could be for a number of different reasons, such as treatment failure, toxicity (very severe side effects), or non-adherence. If treatment is changed, the client will need to be counselled about his/her new treatment regimen.
- The **purpose** of the fourth stage is to:
  - Re-motivate the client on the same regimen, provide support, and make adjustments to the adherence plan
  - HIV treatment adjustment or change: develop new adherence plan, problem-solve factors that influence adherence

Adapted from Kerry Saloner. February 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. Supported by The Centre for the Study of AIDS, University of Pretoria and the Perinatal HIV Research Unit, University of the Witwatersrand.

HIV Treatment Adherence Counselling Model



Stage 4: Re-Motivation or Treatment Change

Re-Motivation

- Re-motive the client/client on the same ART regimen.
- Re-assess adherence and commitment

Re-Motivation **Counselling**: Re-assess adherence, adjust adherence plan

Nurse: Monitor side effects, check adherence

Treatment Change

- ART adjustment or change due to toxicity (very severe side effects), non-adherence (resistance) or treatment failure.

Doctor: New treatment regimen prescription

Pharmacist: Provide new drug regimen and instructions

Nurse: Blood tests and new instructions

Adherence **Counselling**: Develop adherence plan with new drug regimen, with treatment supporter

SESSION 18: STAGE 1: PRE-HIV TREATMENT INITIATION

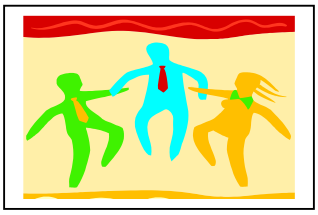
Objectives:

1. Discuss overview and goals of Pre-HIV Treatment Initiation Counselling.
2. Identify topics and issues to be discussed in Pre-HIV Treatment Initiation Counselling.
3. Review checklist and model of counselling sessions.
4. Develop skills by practising a Pre-HIV Treatment Initiation Counselling Session.

Time: 2 hours 45 minutes (165 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Goals of Pre-HIV Treatment Initiation	15 minutes	
Small Group Discussions: What should be pre-HIV treatment counselling consist of?	45 minutes	Flipchart paper Markers
Presentation/Group Discussion: Pre-HIV Treatment Initiation Checklist	45 minutes	
Relay Role Play: Pre-HIV Treatment Counselling Session	60 minutes	Ball or Bean Bag



Activity 1

Introduction

Time: 15 minutes

Review the Pre-HIV treatment Initiation Chart. This provides an overview for what the Health Care Team is focussed on during this stage of adherence counselling.

Pre-HIV Treatment Initiation

	Task	Whose responsibility?
I.	**Client Education** about HIV infection and HIV/AIDS disease stages. (Usually done by the nurses)	Health Care Team
II.	**Introduction to HIV treatment** and adherence programme. Discuss risks and benefits of HIV treatment.	Health Care Team
III.	**HIV Treatment Readiness Assessment:** The Health Care Team needs to assess the client on the following:	Health Care Team
	1. **Medical Component:** meets the Namibian guidelines for the medical criteria	Doctor and Nurses
	2. **Counselling Component**: meets the Namibian guidelines for the social criteria Assessment is made through several (usually 3-5) counselling sessions.	Community Counsellor & Health Care Team
IV.	**Establish Client's full commitment** to HIV treatment before moving to Stage 2, HIV Treatment Initiation.	Health Care Team

Recipe for Successful HIV Treatment:
Key Ingredients

- Provide information, education and support prior to HIV treatment initiation.
- Ensure HIV/AIDS and HIV treatment education.
- Encourage the client's belief in the need for treatment and adherence.
- Provide information on difficulties of following treatment regimen and on side effects.
- Establish a foundation for long-term adherence through support and counselling.

Pre-HIV Treatment Initiation Counselling:

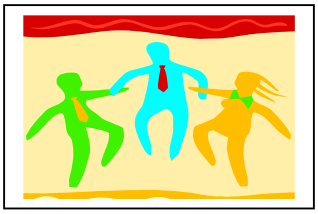
- Should begin at least two to four weeks before starting treatment, but can begin much earlier than this. Pre-HIV treatment initiation counselling can begin as soon as a client tests positive for HIV.
- A person with HIV can be monitored for years before needing to start HIV treatment.
- Pre-HIV Treatment Initiation Counselling will require at least two counselling sessions before beginning treatment. It can take 3 – 6 sessions, depending on the commitment and preparedness of the client.

What do you think are the goals of pre-HIV Treatment Initiation Counselling? *Let participants respond. You want to encourage them to focus on the purpose of this stage of adherence counselling, as this will help participants remember what to focus on during counselling.*

Pre-HIV Treatment Counselling has three main goals:

- To assess the client's understanding of HIV treatment and adherence.
- To assess the client's commitment and readiness to take HIV treatment medication.
- To develop a personalised treatment plan, taking into account factors influencing adherence and the client's lifestyle.

Key Point: Starting ART is NOT an emergency. The client must be assessed, properly prepared for, and committed to treatment.



Activity 2

Small Group Discussions

Time: 45 minutes

What should adherence counselling consist of?

- Divide into groups of 3 –5.
- In your groups, you are going to spend 20 minutes discussing what needs to be included in adherence counselling. Think about what needs to be discussed and explored with the client in counselling sessions before he/she begins HIV treatment. Organise this information and structure your counselling sessions, for instance, what needs to be discussed first, second, etc.

Note to Facilitator: You want to get the participants thinking about what is important in adherence counselling. This will help them remember the issues to be discussed for the rest of the session. There are no strict rules about adherence counselling. Participants can adapt the counselling to suit them, as long as key issues are addressed and they demonstrate respect and empathy for the client.

- Each group will have the opportunity to share your pre-HIV Treatment Initiation Counselling Model with the large group. Please designate a reporter or creatively come up with a way to present your model to the large group.

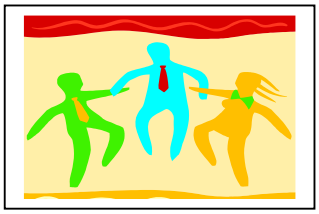
Key Points:

- Counselling is NOT just giving information or education.
- The counsellor must explore and listen to the client.
- Do not forget your basic counselling skills, especially reflecting skills.
- Telling the client of the importance of adherence will not necessarily make him/her adhere!

- *Give each group a chance to present. Make sure to highlight key issues and question items that are less important.* ***Keep the discussion focussed on counselling, not advice or education!***

Key Points about the Pre-HIV treatment Initiation Counselling Checklist:

- You do not have to follow this precise format. This is not VCT.
- All issues/topics should be discussed with the client, but not necessarily in this particular order.
- Ideally, this checklist should be covered over several counselling sessions. There it too much to explore and discuss in one session.
- Your role is to explore and assess the client's understanding and concerns, NOT simply to give information.
- Do not forget your basic counselling skills.



Activity 3

Presentation/Group Discussion

Time: 45 minutes

Note to Facilitator: Try to make this session interactive. Ask participants questions to involve them in the discussion. Highlight topics that participants did not mention in their small groups. Encourage participants to read the material in the Participant Manual as homework in the evenings.

Pre-HIV Treatment Initiation Counselling Checklist

- Focus on how to ask questions. Keep in mind that the counsellor is exploring, supporting, and assessing, NOT simply giving information.
- Encourage the client to talk and tell their history, specifically their HIV history.
- Remember the person-centred counselling approach we discussed in Basic Counselling. Remember that the client is the expert on him/herself.
- *Refer to the Model of Stage 1: Pre-HIV Treatment Initiation Counselling.*

1. History

- Find out how the client feels about his/her HIV status, how they found out and when.
- Do NOT ask the client how he/she was infected with HIV. You do not need to know how he/she got the virus.
- Use your basic counselling skills, specifically reflecting skills, i.e. reflect feelings and restate/rephrase.

2. Knowledge Assessment

- The doctor, nurses and pharmacist are the people who will be primarily giving information to the client about HIV progression and HIV treatment. These medical professionals have the background and more complete knowledge of these issues, so it is best if they provide this information to the client.
- Our role as community counsellors is to <u>make sure the client understands what he/she has already been told</u>.
- Your role is also to <u>support the client emotionally</u> through this process.
- Be careful not to only give information. Instead, find out what the client already understands. Ask questions like: “Can you tell me what you understand about HIV treatment?” or “What is your understanding of the importance of adherence?”
- If the client does not understand or has a misconception, you can correct him/her at that point. Do this gently; build on the part of the client’s understanding that is correct.
- If you do not know the correct information, tell the client this. It is OK to say that you do not know: you are <u>not</u> a medical professional. You can then refer the client back to a nurse or the doctor. You may even go with the client to have his/her questions answered.

3. Disclosure/Treatment Supporter

- In order to adhere to HIV treatment, the client needs a lot of support. Therefore, it is important to assess who they have disclosed to and how it was received.

- In this stage, you will also be talking with the client about a treatment supporter. The Namibian treatment guidelines require the involvement of a treatment supporter. For some clients, this will be easy; they may have a number of people they could choose from. For others, this may be much more difficult, and you may have to help them determine who might make a good treatment supporter. *Refer to the "HIV Treatment Guidelines & Treatment Supporter" session.*

- How would you talk about a treatment supporter with a client?
  Facilitate a short discussion about this.

- For some clients, selecting a treatment supporter will involve disclosing his/her status to the supporter.
  Refer to the Disclosure Session.

- The issue of a treatment supporter should be discussed during the first counselling session. Ideally, the treatment supporter will come to later counselling sessions with the client.

4. Assess Healthy Living/Lifestyle

- Intimate Relationships/Patterns of Sexual Behaviour: Establish the client's sexual patterns, i.e. if he/she is in a committed relationship or has multiple partners, if he/she practises safe sex, etc.
  - Remember that one of the social criteria for starting HIV treatment in Namibia is practising safer sex. What exactly does practising safer sex mean?
    Explore this with participants. While it is not clearly defined in the guidelines, safer sex can include: abstinence or condom use (both male and female), as well as the use of other contraceptives. Pregnancy prevention can be part of "practising safer sex."
  - Be careful to probe non-judgementally and without asking leading questions; otherwise, the client will only tell you what you want to hear.
  - Brainstorm some questions you could ask. Stress how to ask these questions, using supportive and open body language.
  - Important points to stress with your clients: HIV can still be transmitted while on HIV treatment. Although the risk of transmission is reduced due to reduced viral load, the risk of re-infection is still present.

- Substance Use: Assess the client's use of any substances, including alcohol, drugs (legal and illegal) and caffeine.
  - Currently, there is nothing in the Namibian HIV Treatment Guidelines prohibiting the use of alcohol. However, alcohol use can influence adherence.

- Excessive alcohol consumption often leads to non-adherence due to forgetting, depression, vomiting or reduced food intake.
- Brainstorm some questions you could ask. Stress how to ask them, using supportive and open body language.

- Diet/Nutrition/Exercise: A healthy diet full of nutritious food is important, both for overall health and the effectiveness of HIV treatment.
  - Assess what the client eats and when.
  - You can also give the client some suggestions for nutritious foods that are readily available. *Refer to the Nutrition Session.*
  - Brainstorm some questions you could ask.

- Rest: Rest is also an important part of healthy living
  - Brainstorm some questions you could ask.
  - You may also offer suggestions for better rest if a client is having trouble. What could those suggestions include?
    Include things like going to sleep at the same time every night, exercise, calming activity before going to sleep, i.e. reading a book or having cup of tea or warm milk.

- Stress/Management: Identify stresses in the client's life and assess how he/she handles them.
  - Brainstorm some questions you could ask, as well as stress management techniques.

- Long-term Plans: Often, clients who have been living with HIV and have experienced some sickness may not have thought about long-term plans. The purpose here is to explore what the client wants to do in years to come. HIV treatment often gives people many more years of healthy living, so they are able to live longer and do more than they had expected.
  - Why are long-term plans important to discuss in adherence counselling?
    Let participants offer their suggestions.
  - *Discuss ways to talk about long-term plans.*

5. HIV Treatment Readiness: The whole Health Care Team is assessing the client's readiness for beginning HIV treatment, but as the counsellor, you should focus on the client's personal motivation, commitment and emotional response.

- Motivation: Explore the client's motivation; everyone has different reasons for wanting to start HIV treatment. Listen; do not assume you know.
  - How would you do this?
    Possible responses: You can explore it by asking open-ended, non-judgemental questions. Also, pay attention to the client's behaviour related to counselling: does he/she come on time and is he/she committed and motivated in the counselling sessions?

- Advantages/Disadvantages: Explore the client's personal advantages and disadvantages for treatment. It is important that the client does not begin HIV

treatment expecting everything to be solved. There are definitely some disadvantages, and the client needs to be realistic about this.

- Commitment: HIV treatment is life-long treatment that is difficult to adhere to; therefore, clients must be very committed.
    - How would you find out about the client's commitment level? *Explore how to recognise this and what questions to ask.*
    - Pay attention to the following things related to commitment: disclosure to family and friends, involvement of family and friends in healthy living and treatment, commitment in relationships, i.e. committed and stable relationships with friends and family.

- Emotional Responses: What kinds of emotions can you expect from a client beginning HIV treatment?
  Let participants respond.
    - A client's emotions will be varied, and they may change from hour to hour. Explore this with the client and normalise all of his/her feelings.

6. **Factors Influencing Adherence**: When exploring adherence factors with clients, it is important to personalise them. You want to understand what factors the client thinks will influence his/her adherence, both positively and negatively. *Refer to the adherence factors lists compiled during the "Adherence Factors" session.*

- When exploring adherence factors with clients, you may want to begin with a general question, such as, "What sorts of things do you think will influence your adherence to HIV treatment? Think of things that will influence your adherence, both positively and negatively."

- If the client cannot think of things or only thinks of things in one or two categories, you can explore each of the categories on the Pre-HIV Treatment Initiation Checklist with him/her.

- The purpose of exploring adherence factors with a client in counselling is to help him/her be realistic about the difficulties and challenges of taking ARVs. It also helps to determine what to focus on in the client's personalised treatment plan.

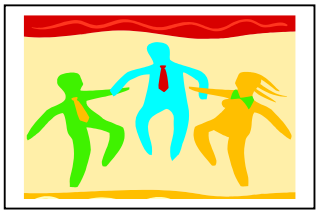
7. **Personalise a Treatment Plan**: The tendency is to try to make every client's treatment, or adherence, plan the same. However, each plan for treatment needs to be unique to that individual. Remember, the client is the expert on him/herself.

- Empower the client to be actively involved in his/her treatment; encourage the client to educate him/herself and to ask a lot of questions.
    - We talked about empowering clients in the Basic Counselling Module. How does this apply in adherence counselling?
      Let participants discuss.
    - How exactly do you empower the client in counselling?
      Let participants share their ideas. It is important to discuss this in order to keep the focus on the counsellor's role.

- Brainstorm how to adhere to HIV treatment: This is where you identify solutions or techniques for dealing with the client's adherence concerns.
    - Based on what were identified as the client's factors that influence adherence, discuss ways that the client can overcome the factors that might negatively affect adherence.
    - *Refer to the "Tools and Adherence for Adherence Sustainability" session.*
    - *Refer to the Problem Management session of the Basic Counselling Skills Module.*

- Lifestyle Adjustments: Make sure the client understands how much HIV treatment will influence his/her lifestyle. Be realistic about this and help the client anticipate these changes. How might you talk about this with a client? *Discuss ways to explore and ask questions.*

- Assessment Tools: Clients need to take responsibility for monitoring their treatment plan.
    - Explore how the client plans to monitor and assess his/her HIV treatment. How will he/she remember to tell the doctor if he/she has missed any doses?
      Encourage participants to come up with ideas for monitoring progress, such as medication diaries, calendars, and pill charts.



Activity 4

Relay Role Play

Time: 60 minutes

- We are going to do a relay role play.
- [*Facilitator]* is going to be the client and you all will take turns being the counsellor. When you as the counsellor get stuck or you want someone else to take over, you can stop and ask for another volunteer counsellor.
- Here is the scenario. *Read the scenario below.*

Role Play Scenario: Hafeni, a 30-year-old client, has come for pre-ART counselling. He has already consulted with the doctor and nurse, and he meets the medical criteria for ART.

- Is there a volunteer counsellor to start this pre-HIV treatment counselling session? *Pass the ball to the volunteer.*

Note to Facilitator:

- You can set up chairs in the front of the room so that it seems more like a counselling session.
- This role play works best when you have two facilitators. One can play the role of the client and the other can facilitate the relay role play process. It also helps to initiate the change of counsellor if the volunteer counsellor starts to stray or lose focus.
- Do not allow a poor counsellor to continue in the role play too long.
- You can also have a facilitator demonstrate as one of the "relay counsellors." This is helpful when you want to move the counselling session along or if you want the participants to see a good example of counselling skills.

- *Before you rotate counsellors, provide feedback in the following way:*
  - *Ask the client how he/she feels.*
  - *Ask the counsellor what he/she did well. You can also ask him/her what was particularly challenging.*
  - *Give your feedback, making sure you "sandwich" it. Start with a specific thing the counsellor did well, i.e. warm tone of voice, a question that was asked well, etc. Then offer a suggestion for how to improve. Remember, it should be very specific, i.e. how to word a question. Finally, end with another positive; this can be more general. You may want to take notes during the sessions so that you can provide very specific feedback.*

Tips for Providing Feedback During Relay Role Play:

- It works best to only have the counsellor evaluate him/herself and then to have the facilitator provide feedback, being sure to sandwich the feedback and be very specific.
- Asking for participant feedback on the counsellor's performance takes a lot of time and does not always provide constructive feedback. Time is usually better spent on the role play itself.
- Involve the participants by getting their suggestions on how a question could have been better phrased or how to create a more supportive atmosphere.

Note to Facilitator: It is suggested that you add additional role plays if you have the time. Basic counselling skills take a great deal of practise, especially when applied to different types of HIV counselling. You could add relay role plays in small groups or triads. This is particularly important with adherence counselling, as there are too many topics to be addressed in one counselling session.

- Do we have another volunteer counsellor to continue the session from where we left off? *You may want to tell the new counsellor where he/she should start or on what you want him/her to focus.*

Processing Questions:

- ❖ How was that experience?
- ❖ Can you describe what is similar to other types of counselling you have learned about? What is different?
- ❖ For those of you who played the role of the counsellor: what was especially challenging?
- ❖ Did you find anything easy?

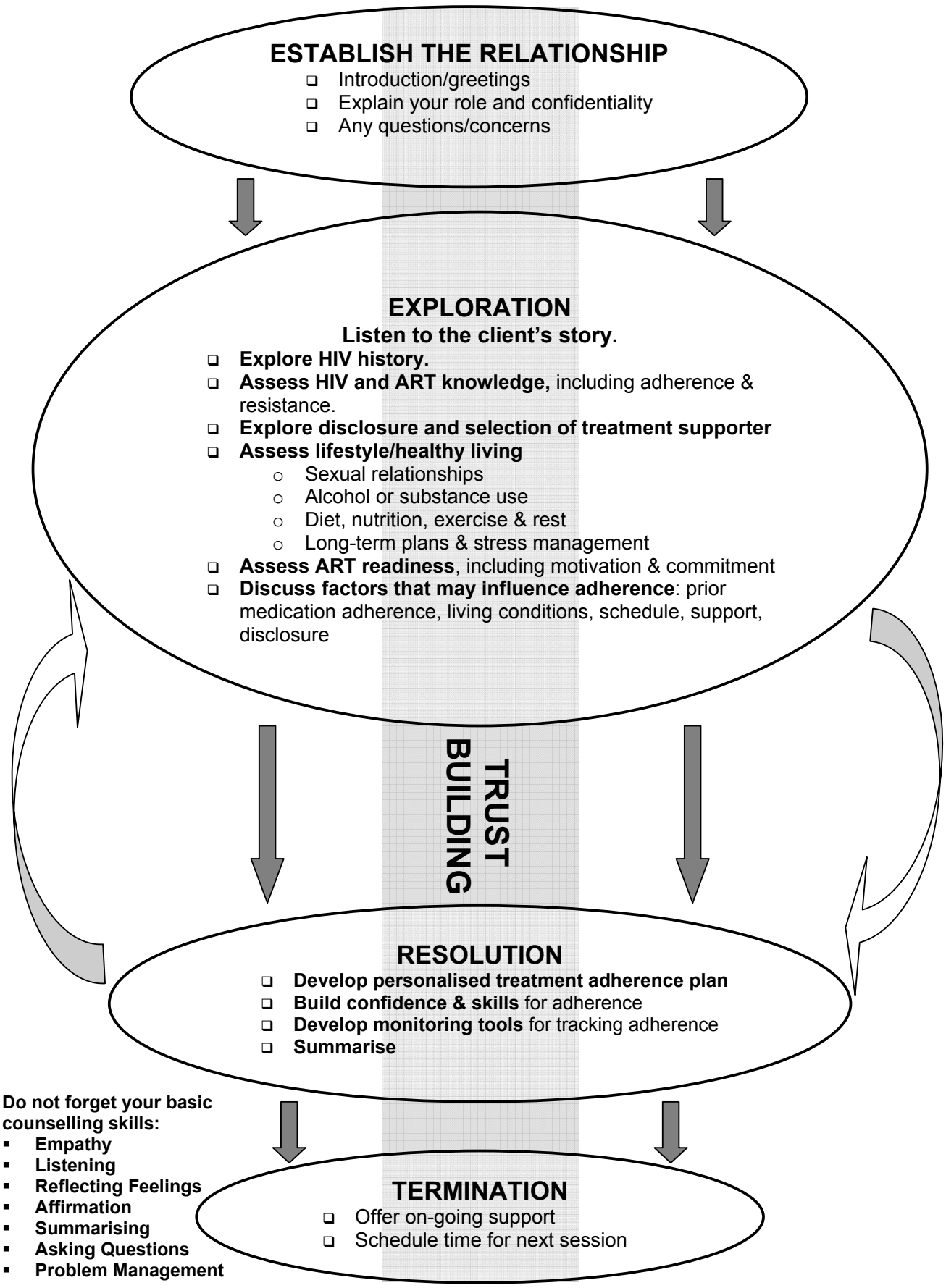
Stage 1: Pre-HIV Treatment Initiation Counselling Checklist

Encourage the client to tell his/her story and to share his/her experiences; this is trust building.

1.	**History** ❑ **HIV history**: year of diagnosis, why tested ○ How long have you known your HIV status? ○ Can you tell me the story of how you learned your status? *OR* How did you find out your HIV status? ❑ **Attitude towards HIV status**: ○ How do you feel about your HIV status?
2.	**Knowledge Assessment**: Check the client's understanding. ❑ **HIV treatment**: Client needs to understand HIV treatment as life-long treatment, not a cure. ○ Can you tell me what you understand about HIV treatment? ❑ **Importance of adherence** ○ What do you understand by HIV treatment adherence? ○ Why do you think adherence is so important with HIV treatment? ❑ **Consequences of non-adherence**: resistance ○ What might happen if you do not take your medicines as prescribed? ○ One of the main purposes of our counselling is to find ways to help you adhere to HIV treatment and to support you in that process.
3.	**Disclosure/Treatment Supporter** ❑ **Disclosure**: ○ Have you told anyone about your status? If so, who? When? ❑ **Reactions from others**: ○ How did the person/people you told respond? ❑ **Household disclosure**: ○ Does anyone you live with know your status? If so, who? ❑ **Discuss treatment supporter**: Define who this should be, qualities of a good treatment supporter, and how to select this person. ❑ **Identify treatment supporter**: You may need to discuss how to ask the person or how to disclose to him/her.
4.	**Assess Healthy Living/Lifestyle** ❑ **Intimate Relationships/Patterns of Sexual Behaviour**: ○ Can you describe your relationships? Can you describe your sexual behaviour? ○ Do you have more than one sexual partner? ○ In your sexual relationships, do you do anything to prevent the transmission of HIV? What about preventing pregnancy? ❑ **Substance Use**: drugs or alcohol ○ Do you use any drugs? If so, what? How often? ○ Do you ever drink alcohol (beer/wine)? If so, how often? How much do you usually drink? ○ How many drinks did you have last week? ❑ **Diet/Nutrition/Exercise**: ○ What do you normally eat for breakfast/lunch/dinner? ○ Do you eat at other times of the day? ○ Do you exercise? If so, what do you do? How often? ❑ **Rest**: ○ How much sleep do you normally get at night? ○ Do you ever have trouble sleeping?

	❑ **Stress Management**: o Can you identify anything as a problem in your life? o How do you deal with problems? ❑ **Long-term Plans:** o What do you want to do in 2 years? o What do you want your life to be like in 5 years?
5.	**HIV Treatment Readiness** ❑ **Motivation**: o Why do you want to start HIV treatment? ❑ **Advantages/Disadvantages of being on HIV treatment**: o What do you see as the good things about starting HIV treatment? o What about any negative or bad things about being on HIV treatment? ❑ **Commitment**: o We have talked a lot about adherence. How are you feeling about committing to life-long HIV treatment? ❑ **Emotional responses**: o When you think about starting on treatment, how do you feel?
6.	**Factors Influencing Adherence** ❑ **Prior medication adherence**: o Have you ever taken medication before? If so, for how long? How often? o Did you have trouble remembering to take your tablets? ❑ **Views about being on medicine**: o How do you feel about being on medicine? o Do you have any concerns about that? ❑ **Living Conditions**: o Where are you staying now? How long have you been living there? ❑ **Schedule:** o Can you tell me about your normal daily schedule? o What time do you normally get up/go to sleep? o Do you take care of anyone, such as children or an elderly relative? ❑ **Support**: o Who do you get support from? Do they know your status? ❑ **Difficulties of adherence**: o What do you think will be hard for you about being on HIV treatment?
7.	**Personalise a Treatment Plan:** Remember, the client is the expert on her/himself. ❑ **Empower** the client to be an **active participant** in his/her treatment plan. ❑ **Brainstorm how to adhere to HIV treatment.** o Many clients develop ways of remembering to take their medicines. Let's talk about how you might be able to remember to take your medicines. ❑ **Lifestyle Adjustments**: o How will HIV treatment fit into your daily schedule? o Will you have to change anything in your life in order to adhere to HIV treatment? If so, what? ❑ **Assessment Tools**: Develop tools for assessing the treatment plan, i.e. medication diaries, calendar, pill chart, etc. o It is important to tell your doctor if you are late or forget to take your medicines. How are you going to keep track of this?

STAGE 1: PRE-HIV TREATMENT INITIATION



Do not forget your basic counselling skills:

- **Empathy**
- **Listening**
- **Reflecting Feelings**
- **Affirmation**
- **Summarising**
- **Asking Questions**
- **Problem Management**

SESSION 19: MANAGING SIDE EFFECTS

Objectives:

1. Identify key side effects of HIV treatment.
2. Describe how to recognise side effects and what to do about them.

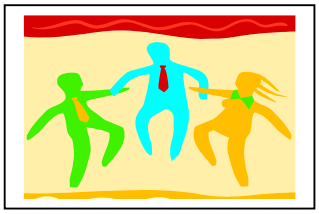
Preparation:

Cut slips of paper listing side effect tips (included)

Time: 1 hour 30 minutes (90 minutes)
With optional activities: additional 105 minutes

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Side Effects	15 minutes	
Presentation/Discussion: Side Effects: What to Look For and What to Do	45 minutes	Flipchart paper Markers
Game: Side Effect Matching	30 minutes	Slips of paper with side effect management tips
Small Group Activity (optional): Discuss Side Effects with First-Line Regimen	45 minutes	
Art Activity (optional): Side Effect Posters	60 minutes	Flipchart paper Markers, coloured pencils and crayons



Activity 1

Introduction

Time: 15 minutes

Make sure that everyone understands what a side effect is. Discuss what the difference is between side effects and symptoms, as sometimes it is difficult to distinguish between a side effect and a symptom.

Symptom: a physical condition which shows that you have a disease; the condition is a result of the disease.

Side effect: an effect that a drug has on your body in addition to treating an illness.

Can you think of any side effects to common drugs?

Examples:

Aspirin: If used a lot, a person can have burning stomach and a few even get bleeding in the stomach.

Coffee: It tastes good and keeps you awake, but at night it can be horrible when you cannot fall asleep.

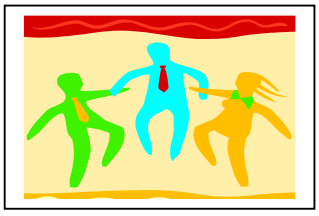
Some facts about side effects:

- 40% of HIV treatment clients will not experience any side effects.
- Many side effects will resolve themselves within a few weeks or even days.
- However, 80% of clients who experience side effects will need help in dealing with them.

Why are we learning about side effects? You are not medical doctors and we do not expect you to be.
Start a short discussion about why knowing about side effects is important.

Possible answers include:

- Supporting the client
- Helping clients manage their side effects
- To prepare clients for what they could experience
- To improve adherence



Activity 2

Presentation/Discussion

Time: 45 minutes

The tolerability of HIV treatment regimens is one of the important factors of treatment success. Being aware of these side effects beforehand has been shown to help clients understand, accept and continue on their medication through the challenges of the side effects. Therefore, it is important to talk with clients about the potential side effects and give the client tips for how to deal with them.

<u>Adjustment Period</u>:

- When starting a new HIV treatment regimen, there is a period of time when the body is adjusting and adapting to the new drug. This period is called the adjustment period.

- Symptoms of the adjustment period:
  - Headache
  - Nausea
  - Fatigue (tiredness)
  - Muscle pain in the arms
  - Occasional dizziness
- These symptoms may start about one week after beginning HIV treatment and last up to 4 – 6 weeks.
- Most of these side effects will disappear once the body has adjusted to the new medication.
- Warning clients about these adjustment side effects can prepare them and ease their concerns if they experience some of these side effects.

Note to Facilitator: There is a lot of material to present about side effects. The best way to involve participants is ask them what each side effect is and what they have done if they have ever experienced this illness. This works especially well with the following side effects: fatigue, nausea & vomiting, diarrhoea, headaches, rashes, and menstrual problems. You may choose to focus on a few of the primary side effects.

Bottom Line: All clients must consult their doctor if they think they are experiencing drug side effects. Some of the side effects may be very serious, and even potentially fatal.

Side Effects: What to Look For and What to Do

1. **Fatigue**: This is tiredness even after you have rested. Tiredness, both physical and psychological, i.e. having trouble concentrating, that does not go away.

   - What to look for**:** Take note of how long you have been feeling this way, when, i.e. is it only in the morning?, how often and how it affects you and your functioning.
   - Fatigue can be caused by the HIV itself or other factors besides the medication. Other factors could include: stress, alcohol, poor diet, lack of sleep, overwork or other medical conditions.

Tips/What to do about Fatigue:

- Go to sleep and wake up at the same time every day. Changes in your sleep schedule can actually make you more tired.
- Avoid alcohol, as it worsens the fatigue.
- Try to get some exercise. Exercise eases stress and often makes you feel stronger and more energetic.
- Keep easy to prepare, nutritious foods on hand for times when you are too tired to cook. It is important to eat well.

2. **Peripheral Neuropathy**: Numbness, tingling or burning in the hands, arms, feet or legs. This is caused by damage to the nerves. It may be caused by the HIV itself or be a side effect of the medication; it is primarily a side effect of D4T and ddI.

   - What to look for: Burning, stinging, stiffness, tickling or numbness in the feet, toes or hands.

NOTE: Peripheral neuropathy can be very serious. Tell your doctor about any symptoms, as nerve damage is permanent.

Tips/What to do about Peripheral Neuropathy:

- Tell your doctor.
- Wear loose-fitting shoes and cotton socks. Wear padded slippers around the house. Good circulation around the feet can help reduce the effects.
- Massage your feet. This reduces pain temporarily.
- Soak your feet in cool water.
- Do not walk too much at a time.
- Keep feet uncovered in bed.

3. **Anaemia**: This is a depletion, or a shortage, of red blood cells that supply oxygen to different parts of the body. The result of insufficient oxygen in your blood is fatigue. Anaemia is a common symptom of HIV and a side effect of AZT.

   - What to look for: Tiredness or fatigue (also see Fatigue)

Tips/What to do about Anaemia:

- Tell your doctor.
- Anaemia can be monitored by regular blood tests.

4. **Nausea and Vomiting**: This is very common during the adjustment period. However, persistent vomiting can lead to serious medical problems, such as dehydration, chemical imbalance, weight loss, etc.

   - What is the difference between nausea and vomiting? Nausea means the person feels like vomiting but very often does not.

   - What to look for: If a client is experiencing severe abdominal pain, trouble breathing and disorientation, refer him/her to the doctor. If vomiting more that three times a day, also refer client to the doctor. Vomiting may interfere with your ability to take your medicine and keeping the correct balance of medicine in your body, i.e. vomiting up the medicine.

Tips/What to do about nausea and vomiting:

- BRAT diet (bananas, rice, applesauce and toast) helps with nausea and vomiting.
- Keep dry crackers next to your bed. You can eat a few in the morning before you get out of bed. This can help reduce nausea.
- Avoid rich, spicy, strong smelling and greasy food.
- Try drinking peppermint, chamomile or ginger tea to calm the stomach.
- Cold carbonated drinks, such as ginger ale or lemonade, can help reduce nausea.
- It is important to replace fluids if you are vomiting, especially when it is hot outside. You could drink broth (clear soup), juice or iced pops.
- Take note of how often you are vomiting. If it continues, go to the doctor.

5. **Headaches**: ARVs can cause headaches, but headaches can also be a result of stress. Managing stress is critical to reducing headaches.

   - What to look for: If headache is accompanied by fever, disorientation, altered consciousness, blurred vision or convulsions, refer to the doctor.

Tips/What to do about headaches:

- Take over-the-counter medication like paracetamol, aspirin or ibuprofen.
- Lay down in a quiet, dark room with your eyes closed. Place cold washcloths over your eyes. Massage the base of your skull with your thumbs, and/or both temples gently.
- Hot baths may help relieve tension headaches.
- An occasional headache is normal, but if the headache does not go away or you regularly wake up in the morning with headaches, talk to your doctor.

6. **Diarrhoea**: This can be a serious side effect that must be responded to quickly. Diarrhoea can also be due to other things besides the medication, such as bacterial infections.

   - What to look for: Take note of how often and for how long diarrhoea persists. This is important information for the doctor. Diarrhoea can easily lead to dehydration. If a client has diarrhoea more that 5 times a day for 5 or more days and weight loss of more than 2 kgs, refer to the doctor.

Tips/What to do about diarrhoea:

- BRAT diet (see nausea & vomiting). Also eat oatmeal, cream of wheat and soft bread that is not whole grain.
- Anti-diarrhoeal medication like Lomotil and Immodium can help.
- Avoid skins of fruit and vegetables, as they are high in insoluble fibre and can make diarrhoea worse.
- Avoid milk products and greasy or very sweet foods; they can make diarrhoea worse.
- Drink lots of fluids, i.e. water, ginger ale, chicken or beef broth, and herbal tea.
- Drink between meals instead of with meals.
- Avoid caffeine, i.e. tea, coffee, Coke.
- Tell your doctor.

7. **Weight Loss**: Weight loss can be a serious problem with HIV, and should always be discussed with your doctor.

   - What to look for: Any loss in weight, but especially weight loss without any changes in diet or exercise.

Tips/What to do about weight loss:

- Monitor your weight loss. Discuss with health care workers to determine the cause of the weight loss. Is it stress related, accompanied by nausea or vomiting, associated with new medication, the result of diarrhoea, or something else?
- Eat foods that are high in protein.
- High protein shakes that are low in sugar can help in gaining weight.

8. **Dry Mouth**: It is uncomfortable and can make chewing, swallowing and taking medicine difficult. Dry mouth also can affect one's sense of taste and cause further mouth problems, such as tooth decay and thrush (oral yeast infection).

Tips/What to do about dry mouth:

- Drink plenty of liquids during and between meals.
- Avoid sugary or sticky foods and caffeinated drinks, as these also dry out your mouth.
- Rinse your mouth throughout the day with warm salted water.
- "Slippery elm" or "liquorice" tea lubricates the mouth and is pleasant tasting.
- Doctors can prescribe mouth rinses or a synthetic saliva or anti-dry mouth medication if necessary.

9. **Rash**: This is a very common side effect of treatment, specifically for Nevirapine, Efavirenz and Nelfinavir. Rash is often more severe in women.

   - What to look for: Monitor the skin for discolouration and changes in its surface: is the skin a different colour and does it feel different than normal, i.e. is it bumpy? If the skin peels, blisters or forms sores, refer to the doctor immediately.

Tips/What to do about rash:

- Use medicine like calamine lotion or antihistamines to soothe and comfort the skin.
- Use unscented, non-soap cleansers or oatmeal soaps.
- Do not take very hot showers or baths, as the heat will irritate the skin.
- Keep skin clean and dry.
- Drink plenty of water to keep skin hydrated.
- Avoid synthetic fabric; instead wear natural fabrics like cotton or silk.
- Stay out of the sun. Rash-affected areas should be protected from the sun, i.e. wear long-sleeves or a hat, etc.
- Tell your doctor, especially if the rash gets worse, if it involves the eyes or mouth, or if you feel ill at the same time.

10. **Menstrual Problems**: These problems include irregular, heavier, lighter and/or painful periods, or even the stopping of menstrual bleeding altogether. Ritonavir has been known to cause heavy (excessive) menstrual bleeding.

    - What to look for: Women should track their menstrual bleeding and note any significant changes.

Tips/What to do about menstrual problems:

- Period problems can be related to many different issues, such as weight loss or stress levels. Consider what else is happening in your life.
- Hot water bottles or heating pads can help menstrual cramps. Place them over your lower stomach or back. You could also take a hot bath.
- Mild exercise, like walking or stretching, increases the blood flow and may reduce period pain.
- Oral contraceptives: Check to see that these will not interact with your HIV treatment. Talk to your doctor.

11. **Kidney Stones:** These are often a side effect of Indinavir, as crystals of Indinavir collect in the kidneys and can cause severe pain.

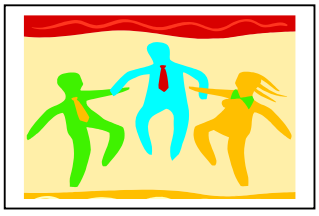
- What to look for: Severe pain from kidney stones happens suddenly. Clients often have no warning.
- Kidney stones take time to develop.
- Unlike other ARVs, Indinavir is processed through the kidneys; other ARVs are processed through the liver.

Tips/What to do about kidney stones:
○ Drink lots of water. Take Indinavir with a full glass of water and drink at least 1 ½ litres of water daily in addition to normal fluid intake. ○ Increase water intake during hot weather and if drinking any alcoholic beverages.

12. **Central Nervous System (CNS)**: Nightmares, sleeplessness, sadness or worry; often side effects of Efavirenz.

- What to look for: Difficulty concentrating, confusion and abnormal thinking. Also, mood swings such as agitation, aggression, depression and euphoria (extreme happiness). Insomnia (inability to sleep) and vivid dreams.
- These side effects are the reason clients are instructed to take Efavirenz before going to bed.

Tips/What to do about CNS problems:
○ Eat a low-fat meal before taking Efavirenz. High fat increases the absorption of Efavirenz and increases the side effects. ○ Adjust meal times so you eat a while before taking Efavirenz. ○ Keep records of symptoms to report to the doctor.



Activity 3

Game: Side Effect Matching

Time: 30 minutes

Preparation: Cut slips of paper listing side effect tips. Make sure that you only include tips for side effects that you have highlighted in the previous discussion.

- We are going to play a matching game. You are going to match side effects with Tips or What to Do.

- Here is how it works. I am going to give each of you at least one piece of paper; some of you will receive two. On each paper is a tip or suggestion of what to do about a side effect.

- I am going to call out a side effect. If your tip goes with that side effect, you should come to the front of the room with me.

- Remember, there is often more than one tip for each side effect, so quite often, more than one person will be coming to the front. Also, keep in mind that the same tip can apply to multiple side effects.

Note to Facilitator: In order to prevent participants from looking at their notes during the game, you can have them stand up and gather in the middle of the room or in a line against the wall before distributing the tips.

This game is an active way to remember and review the side effects and what to do.

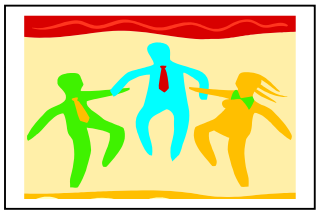
Game: Matching Side Effects with Tips/What to Do
(cut into strips and distribute to participants)

Go to sleep and wake up at the same time every day.
Get some exercise.
Wear loose-fitting shoes and socks.
Tell your doctor.
Stay out of the sun.
Avoid rich, spicy, or strong smelling foods.
Keep crackers next to your bed. Eat them before you get out of bed in the morning.

Avoid milk products.
Keep your feet uncovered in bed.
Avoid greasy foods.
Avoid sugary or sticky foods.
Avoid caffeine, such as coffee, tea or Coke.
Replace fluids by drinking broth, juice or iced pops.
Drink lots of liquids, especially water.
Use a hot water bottle or heating pad.

Avoid eating the skins/peels of fruit and vegetables.
Lay down in a quiet, dark room and place cold washcloths over your eyes.
Rinse your mouth throughout the day with warm salted water.
Soak your feet in cool water. Massage your feet.
BRAT diet (bananas, rice, applesauce and toast)
Take over-the-counter medications like aspirin, ibuprofen, or paracetamol.
Take a hot bath.

Drink plenty of liquids during and between meals.
Eat foods with high protein.
Use unscented, non-soap cleansers.
Do not take very hot baths or showers.
Drink between meals instead of with meals.
Walk or stretch to increase blood flow.

Small Group Activity  **(Optional)**

Time: 45 minutes

- Please divide into groups of four. You should discuss the following treatment regimen: D4T (Stavudine), 3TC (Lamivudine) and Nevirapine (NVP)

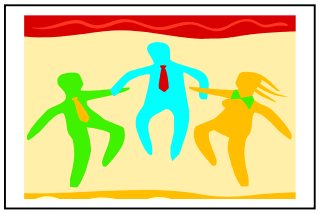
NOTE: Adaptation
You could also have different groups discuss different treatment regimens if you wish.

- Using the information provided, discuss the following:
  - Identify the common side effects and any food restrictions of each drug.
  - Identify any side effects that require immediate referral to a physician (doctor).
  - Identify things the client could do to ease the discomfort of the side effects.
- *Discuss the groups' responses in the large group*.
- *You may also have participants break into pairs or triads to role play a counselling session in which a client is experiencing some of these side effects.*

Activity 5

Art Activity (Optional)

Time: 60 minutes



Note to Facilitator: As there is a lot of information to know about side effects, the following activity will help the participants practise and learn this information. Time permitting, you can do the activity during the workshop, but the project could also be assigned as homework. Then on the following day, you could have the groups briefly review their presentations in front of the large group.

- Provide as many different coloured markers, coloured pencils and crayons as possible for this activity.

- *Divide the large group into small groups of 3 – 5 participants each.*
- *Each group will be assigned a side effect; you can also assign each group two or even three side effects. It is also possible to have all groups design posters with important information about HIV treatment side effects in general.*

- On flipchart paper, you will design a poster that provides basic information about the side effect(s) your group has been assigned. Keep in mind that the poster you are designing is for the members of your community. Many of them are not able to read well, if they can read at all, so use many pictures and make it colourful and interesting.

Below are some different ways to share the small group posters with the large group:

- *Each group can present their side effect posters in front of the large group.*
- *You can turn the activity into a competition and determine a winning group based on the clarity of the information and the creativity of the poster. You can also provide prizes.*
- *The posters can be displayed around the room as an art exhibit. Allow the participants to move around the room and view the posters. Then follow up with questions to review tips for easing the discomfort of side effects.*

Side Effects Chart
(For reference)

Side effect	What client can do	Seek help/go to clinic
Tiredness	➢ Get up and go to bed at same time every day ➢ Get some exercise ➢ Keep easy to prepare foods in house	➢ You are too tired to eat or move ➢ You cannot swallow or eat enough to feel strong
Headache	➢ Rest in a quiet, dark place ➢ Place cold cloths on your eyes ➢ Rub the base of your head or your temples with your thumbs ➢ Take a warm bath ➢ Avoid coffee, Coke, tea and other foods with caffeine ➢ Take paracetamol	➢ Your vision becomes blurry or unfocussed ➢ Paracetamol does not relieve the pain ➢ Headaches are frequent or very painful ➢ Your neck is stiff
Tingling or pain in feet and hands	➢ Wear loose fitting shoes and socks ➢ Keep feet uncovered in bed ➢ Walk a little, but not too much ➢ Soak feet in cool water ➢ Rub feet and hands	➢ The tingling does not go away or gets worse ➢ The pain prevents you from walking
Dry Mouth	➢ Rinse your mouth with clean salted water ➢ Suck on crushed ice or sip clean water ➢ Avoid sweets and drinks such as coffee and Coke	➢ You also have spots (white or red) on your tongue or in your mouth
Diarrhoea	➢ Eat frequent small meals ➢ Eat easy foods: bananas, rice, toast, applesauce ➢ Avoid milk products ➢ Do not eat spicy or greasy foods ➢ Peel fruits and vegetables before eating ➢ Drink lots of clean water and tea ➢ Take ORS (oral rehydration salts)	➢ There is blood in the stool ➢ You also have a fever ➢ You have more than 4 watery or soft bowel movements per day ➢ You are thirsty but cannot eat or drink properly
Nausea, vomiting and low appetite	➢ Take HIV treatment drugs with food ➢ Eat frequent small meals ➢ Eat bland foods (rice, porridge) ➢ Take sips of tea or ORS until vomiting stops ➢ Do not eat greasy or spicy foods ➢	➢ You have sharp pains in your stomach ➢ You also have a fever ➢ You are vomiting blood ➢ Vomiting lasts more than 1 day ➢ You are thirsty but cannot drink or eat
Hair loss	➢ Protect hair from damage: do not dye, straighten or plait ➢ Do not buy products that promise to grow hair back	

Side effect	What client can do	Seek help/go to clinic
Anaemia	➢ Increase foods with iron, such as fish, meat, chicken, spinach, asparagus, dark leafy greens and lima beans. ➢	➢ You have been feeling tired for 3-4 weeks and it is increasing. ➢ Both of your feet are swelling.
Dizziness	➢ If you feel dizzy, sit down until it goes away. ➢ Try not to lift anything heavy or move quickly. ➢ Take Efavirenz right before going to sleep. ➢ Avoid driving a car, motorcycle or bicycle when dizzy.	➢ If the dizziness lasts more than 2 weeks
Unusual or bad dreams	➢ Try to do something that makes you happy and calm right before going to sleep. ➢ Avoid alcohol and street drugs ➢ Avoid food with a lot of fat	➢ If you cannot sleep for 3 or more nights
Feelings of sadness or worry	➢ Talk about your feelings with others (family, friends, other PLWHA) ➢	➢ If you have serious, sad or very worrying thoughts ➢ If you are thinking of harming yourself ➢ If you are very aggressive or very scared
Difficulty concentrating	➢ Use reminders for important tasks, i.e. notes to yourself or help from family members ➢ Allow extra time for activities	
Skin rash	➢ Keep the skin clean and dry ➢ Wash with unscented soap and water ➢ Use calamine lotion for itching ➢ Avoid hot baths or showers ➢ Avoid the sun if you have a rash	➢ Rash is accompanied by general ill feeling, fever, muscle or joint aches, blisters or mouth sores, inflammation of the inside of the eyelids, swelling of the face or tiredness

Family Health International, Adherence Support Worker Training: Facilitator's Guide. Zambia.

Symptom Management Guide

Symptom	What to do?
Loss of weight, wasting syndrome	• Increase energy intake by eating more fats and oils • Increase protein intake: meat, fish, dairy products, eggs beans, nuts, seeds • Exercise to maintain or increase muscle mass
Loss of appetite or anorexia	• Eat with family and friends • Eat snacks; eat small amounts often • Avoid alcohol and cigarettes • Drink liquids that provide energy: milk, juice, or tea with milk after or between meals • Add herbs or spices to increase flavour • Exercise before a meal
Nausea or Vomiting	• Eat frequent small meals: less spice, not fried or high in fat, and cold or room temperature. • Eat dry, salty biscuits, dry toast • Drink herbal and spice teas or juices • Avoid lying down until 20-30 minutes after eating • Rest between meals
Mouth or Throat Sores	• Rinse mouth or gargle often with mouthwash or warm salt water. • Eat soft, mashed foods such as soft porridge, noodles, oatmeal, yoghurt, mince meat, eggs, pumpkin, sour milk and paw-paw. • Avoid foods that irritate, like spicy foods, i.e. chillies, curries, and acidic foods, i.e. oranges, tomatoes, lemons, vinegar. • Avoid sugary foods (cakes, sweets, etc.) with ulcers.
Changes in Taste	• If meat is not appealing, eat other protein foods: beans, nuts, milk, poultry, fish or eggs • Use spices and herbs to improve flavour • If no mouth sores, add lemon juice to food • Maintain good oral hygiene: clean teeth and use an antiseptic mouth wash • Avoid drinking liquids from a tin
Diarrhoea	• Boil drinking water, and cook and store food safely and properly • Replace electrolytes with ORS (Oral Rehydration Salts), bananas, paw-paw, potatoes, and cooked spinach. • Dilute fruit juices with water and add a pinch of salt • Avoid foods high in processed sugar, i.e. sweets, cool drinks • Eat easy to digest foods: rice, toast, omahangu/pap, fruit, cooked beans, oatmeal, and yoghurt • With fat mal-absorption, avoid high fat foods: butter, oils, and fried foods • Eat small quantities of food often
Metabolic Changes	• Reduce intake of high fat and foods with added sugar • Increase physical activity, such as walking, jogging, swimming, or gardening. • Adhere to HIV treatment dosage and schedules
Anaemia (iron deficiency)	• Eat foods high in iron, such as meat, poultry, eggs, beans, and fortified cereals • Eat high-iron foods with foods high in vitamin C, such as citrus fruits and juices, paw-paw, mangoes, tomatoes, and avocadoes • Avoid tea with iron-rich meals because tannins in tea inhibit iron absorption.
Vitamin A deficiency	• Increase fruit and vegetable intake, especially sweet potatoes, carrots, pumpkin, squash, melons/paw-paw, and vitamin-fortified cereals

Source: Government of the Republic of Namibia, Ministry of Health and Social Services. Draft 2005. Nutrition Management of HIV/AIDS: A Resource Guide for Clinical and Community-Based Health Workers. Windhoek, Namibia.

SESSION 20: STAGE 2: HIV TREATMENT INITIATION

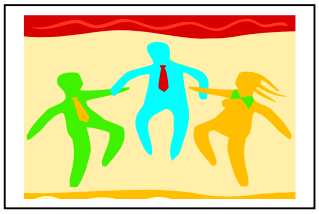
Objectives:

1. Identify key topics in HIV Treatment Initiation Counselling.
2. Review HIV Treatment Initiation Checklist.
3. Role play HIV Treatment Initiation Session to practise skills.

Time: 2 hours (120 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Goals of HIV Treatment Initiation Counselling	15 minutes	
Presentation/Discussion: HIV Treatment Initiation Checklist	45 minutes	
Relay Role Play: HIV Treatment Initiation Session	60 minutes	Ball or bean bag



Activity 1

Introduction

Time: 15 minutes

Review the HIV Treatment Initiation Chart below. This provides an overview for what the Health Care Team is focussed on during this stage of adherence counselling.

HIV Treatment Initiation Chart

	Task	Whose responsibility?
I.	**Client education and understanding** of antiretroviral treatment.	Health Care Team
II.	**Instructions on HIV treatment regimen**: which medications, when to take, correct dosing, side effects, etc.	Doctor, Nurses and Pharmacist
III.	**HIV Treatment Preparedness:** The Health Care Team needs to prepare the client on the following: 1. **Medical component** 2. **Counselling component**	Health Care Team Doctor and Nurses Community Counsellor
IV	**Establish client's full understanding** and reinforce **commitment** to HIV treatment.	Health Care Team

* Notice the purpose is more specific and is focussed on the specific regimen.

HIV Treatment Initiation Counselling takes place on the day the client receives his/her medication and begins HIV treatment.

- Counselling should always be done with the treatment supporter present.
- HIV Treatment Initiation Counselling takes place after the client has met with the counsellor a few times, usually 2-4 sessions.

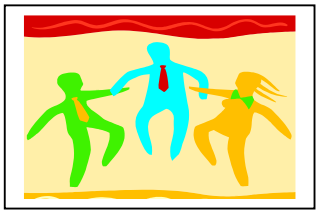
The aims of HIV treatment Initiation Counselling are:

- Assess and reinforce client's understanding of his/her HIV treatment regimen instructions.
- Review the client's personalised adherence plan.
- Boost client's confidence in his/her ability to adhere to HIV treatment.

How is HIV Treatment Initiation Counselling different from Stage 1: Pre-HIV Treatment Counselling? How is the focus different?
Let participants discuss this.

Key points:

- Pre-HIV Treatment: Explore HIV treatment as an option and work on developing a treatment plan that is personalised to the client.
- HIV Treatment Initiation: Reinforce client's choice to begin HIV treatment, review the treatment plan he/she already has developed and empower the client for adherence to treatment. The treatment supporter should be part of the counselling during the HIV Treatment Initiation stage.



Activity 2

Presentation/Discussion

Time: 45 minutes

HIV Treatment Initiation Checklist

1. **HIV Treatment Readiness**
   - You have already assessed the client's readiness in Pre-HIV Treatment Initiation Counselling. Here you are exploring how the client is feeling, as well as his/her expectations, hopes, and concerns about treatment.
   - We need to talk about how to explore this with clients. What would you do, say or ask in order to hear how the client feels about starting HIV treatment? *Let participants respond. You are stressing the fact that there is not one way to do this.*

- Pay attention to conflicted feelings and validate everything the client is feeling.
  Validate: accept all feelings the client expresses. It is OK to have conflicted feelings, i.e. excited and scared at the same time.

2. Regimen Instructions Assessment

- In order to assess whether the client understands how to take his/her medicine, you have to listen to the client.

- DO NOT tell the client how to take the drugs. LISTEN to the client tell you how he/she is planning to take his/her medicine. How do you ask? *Have participants think of ways to phrase the questions.*

- Make sure the client understands that the medications are only for him/her. The client should not share medicine with others. He/she must take all the doses and continue with the medication, even if he/she feels better.

- Also ask about late or missed doses. Below are the general instructions for missed doses. Remember that you are listening to the client's understanding of the instructions he/she already has received. Keep in mind that there are many variations to the instructions for missed doses, depending on the specific medication. You will need to check with the doctor about the specific instructions for missed doses with each particular regimen.
  - Do not take two doses at the same time.
  - Do not take the missed dose close to the time of the next dose.
  - Take the missed dose if within 3 hours of the scheduled time.
  - If you are more than 3 hours late for a dose, drop the missed dose and take the next dose on time as scheduled. Make note of the missed dose, along with the reason for missing the medication.

- Only provide information on how to take the regimen if your client gives you incorrect information.

- If the client tells you the correct instructions, encourage him/her. Use this as an opportunity to build the client's confidence in his/her ability to adhere.

3. Treatment Supporter

- There are many ways that clients can use the treatment supporter. Can we list some ways that a client can involve the treatment supporter?
  Let participants brainstorm a list.

- There is no right way to involve the treatment supporter; this depends on the relationship of the treatment supporter with the client. Let the client personalise this as well.

- Below are some suggestions for the role of the treatment supporter:
  - Reminding client of regular drug doses at the right time.
  - Identifying serious side effects and seeking medical help.

- Provide help with common side effects.
- Collecting medication in case of an emergency.

4. Factors Influencing Client's Adherence

- Remember to personalise the adherence factors for your specific client. However, there are some common adherence issues.

- Side Effects:
  - *Read the following statement:* In countries where HIV treatment has been available for a long time, about one in six people stop taking treatment because of the side effects or inability to maintain the strict drug regimen.
  - What does this statement mean to you? How do you interpret it? *Let participants respond.*
  - Make sure the client understands the potential side effects of his/her ARV regimen. Once again, listen to him/her tell you what the side effects are.
  - The client should also know what to do if he/she experiences these side effects.
  - How would you explore the client's knowledge of side effects? *Let participants offer their ideas.*

Key Point: The key to coping with side effects is to know what to watch for and to have a plan in place to respond if or when problems occur.

- Personal Adherence Concerns: Explore all adherence concerns, as well as potential solutions.
  - You may discuss this here or when discussing the personalised adherence plan.
  - What sorts of questions would you ask to explore these concerns? *Get participants' ideas and suggestions.*

- Identify Personal Positive Adherence Factors: Encourage client to identify personal factors or characteristics that will help him/her adhere to HIV treatment.
  - You can also offer ideas some of your own. How would you do that? *Let participants generate their own ideas.*
  - It is important to boost the client's confidence.

5. Personalised Adherence Plan

- Review the client's personal plan for adherence; this includes what time of day he/she will take the tablets and how the client will remember to take them.

- Make sure clients are specific about their plans.

- Include the treatment supporter in the adherence plan.
- Has the client anticipated problems and how to resolve them?

- Make sure the client is realistic. For instance, it is unreasonable for someone to expect to always remember to take his/her tablets. How is he/she going to remember?

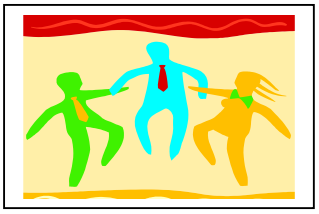
- What kinds of questions would you ask in this part of the counselling session?
  Let participants respond.

6. Monitoring Adherence and Treatment

- Assess the client's understanding of how he/she should monitor his/her adherence. The client should also understand how the clinic/hospital will monitor his/her progress.

- Once again, ask the client to explain this to you so that you can listen to him/her instead of telling the client how to do it.

- Schedule a date and time for the next appointment.



Activity 3

Relay Role Play

Time: 60 minutes

HIV treatment Initiation Counselling Session

We are going to do another relay role play, but this time we will also have another role, which is the treatment supporter.

- I need two volunteers, one to be the treatment supporter and the other to be the counsellor. [*Facilitator*] will be the client.

- *Make sure that you get different volunteer counsellors. It is important that different participants practise their skills and not only the same active participants every time.*

- Only the role of the counsellor will change. Remember that if you get stuck or want to switch, just stop and ask for a volunteer to take over.

- *Before starting the role play, have participants refer to their ART Regimen Charts so they know the specifics for this regimen.*

Role Play Scenario:
A 35-year-old woman has already been counselled twice. She has met the medical and social criteria for treatment and is now ready to start ART. She has studied through primary school and lives with her husband, who is also infected but not on treatment. She is a part-time domestic worker.

She has a CD4 count of 96 and has agreed to start treatment. Her treatment regimen is d4T, 3TC and Nevirapine (NVP). She has already met with the doctor and pharmacist to receive her drugs.

She has come with her husband; he is her treatment supporter.

Note to Facilitator:
- To make this scenario more realistic, it would be helpful to have some "medications" that the client brings in. These do not need to be real medications; sweets will work for this exercise. Write the basic instructions for each "medication" on the pharmacy bags.
- This type of counselling session is similar to Stage 1: Pre-ARV Initiation, so participants should start to master some of these skills, especially how to ask questions.
- Focus on quality counselling skills during this relay role play.

- *When the session is over*: Before we provide feedback to each of the counsellors, we will give each of them a chance to evaluate their own performances first.
- *After counsellors have evaluated their own performance*, *you can provide feedback. Remember to be specific.*
- *You could also evaluate each counsellor's performance after the relay role play is over. This is especially helpful if you do not want to break up the counselling session. Start with the first counsellor: have him/her evaluate his/her performance and then give feedback. Then go the second counsellor, etc.*

Processing Questions:

- What do you think about HIV Treatment Initiation Counselling?
- What do you think will be challenging/easy about HIV Treatment Initiation Counselling?

Tips for Helping Others Learn How to Take HIV Treatment:

- Do not assume that the client can read or understand what is written on his/her prescription. You should explain it to the client verbally and offer to write it or have it translated into his/her local language.
- Do not assume that the client already had the medication explained to him/her by the doctor or pharmacist, or that he/she understands it. Ask the client to tell you what he/she understands.
- Do not assume that the client will remember what you say. If he/she can write, you can encourage the client to write the instructions down by him/herself.
- Involve the treatment supporter; ask him/her to remember as well or to write the instructions down. This way, he/she can act as a "back-up" if the client is confused, does not understand, or does not remember the instructions for taking his/her medicine.
- Pictures can be helpful for reminding the client when and how much medication to take.

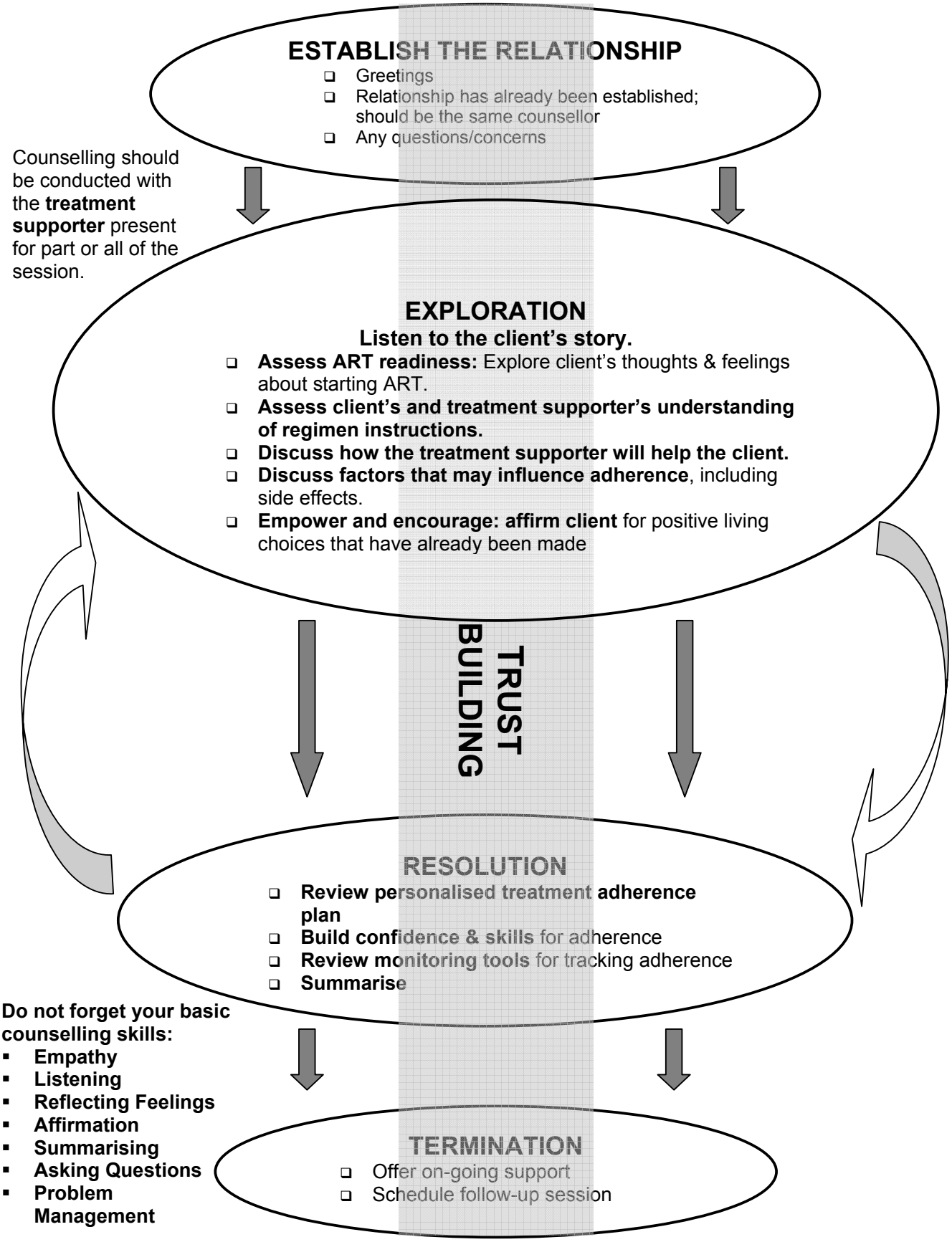
Stage 2: HIV Treatment Initiation Counselling Checklist*

1.	**HIV Treatment Readiness** ❑ **Emotional responses**: Explore how the client feels. o How are you feeling about starting your ARV regimen today? ❑ **Expectations**: Make sure expectations are realistic. o What are your expectations for treatment? ❑ **Concerns**: Listen to concerns. o Do you have any concerns about treatment and adherence?
2.	**Regimen Instructions Assessment:** Make sure the client understands how to take his/her medication. Listen to the client's understanding. ❑ **ARV Regimen**: Assess client's understanding. o Can you explain to me what you understand about your treatment regimen? o When are you supposed to take each of your tablets? o Are there any special requirements for taking these drugs, i.e. food or drink requirements? ❑ **Late and Missed Doses**: Reinforce the importance of taking tablets on time. o What will you do if you are late with a dose? o Do you know what to do if you miss a dose?
3.	**Treatment Supporter** ❑ **Role of Treatment Supporter** o We have discussed your treatment plan. How can your treatment supporter help? o How can you and your treatment supporter work as a team? ❑ **Verify Understanding:** Make sure the treatment supporter also understands the ARV regimen and requirements.
4.	**Factors Influencing Client's Adherence**: Personalise it. ❑ **Side Effects** o Many people on HIV treatment say that the side effects of the drugs affect their adherence. Let's talk a little bit about that. o Has anyone explained to you some of the side effects you can expect with your HIV treatment regimen? If so, can you explain them to me? ❑ **Personal Adherence Concerns**: Explore any and all adherence concerns, and help client think of solutions. o What sorts of things do you think will affect your adherence? o If the client cannot think of any potential problems, offer some: "What about a change in your routine, such as when you travel or family comes to visit you?" OR "How will you feel about taking your medication in front of people?" ❑ **Identify Personal Positive Adherence Factors**: help the client identify characteristics about him/herself, lifestyle or past experiences that will help the client adhere to HIV treatment. o Can you think of any things about yourself or your life that predict adherence to HIV treatment? If the client cannot think of anything, offer some suggestions, i.e. "You have told me about your skills in organisation; this skill will be very useful with HIV treatment adherence."

5.	**Personalised Adherence Plan** ❑ **Empower** the client: boost his/her confidence, but be realistic about the treatment plan. ❑ **Lifestyle Adjustments** o How are you planning to fit HIV treatment into your daily routine? o Do you anticipate any challenges with this? How will you overcome them? ❑ **Memory Aids**: Explore use of cell phone, pictures, and reminders. o How are you going to remember to take your drugs? o Do you have a plan to help you remember to take your medication? ❑ **Support:** Encourage support from others in addition to the treatment supporter; include family, friends, community, church, etc. o Where are you going to get the support you need for HIV treatment adherence?
6.	**Monitoring Adherence and Treatment**: Personal role and health facility's role in monitoring HIV treatment. ❑ **Personal Monitoring Tools**: suggest pill diaries, charts, etc. o Why is it important to monitor your own adherence? o How are you going to keep track of your adherence? ❑ **Hospital/Clinic Monitoring**: Make sure client understands the health care facility's monitoring plan. o Can you explain how the clinic will be monitoring your progress on HIV treatment? o When are you supposed to return to the clinic? o Schedule next appointment.

** Counselling should be conducted with the treatment supporter.*

STAGE 2: HIV TREATMENT INITIATION



Do not forget your basic counselling skills:

- **Empathy**
- **Listening**
- **Reflecting Feelings**
- **Affirmation**
- **Summarising**
- **Asking Questions**
- **Problem Management**

SESSION 21: STAGE 3: HIV TREATMENT MAINTENANCE

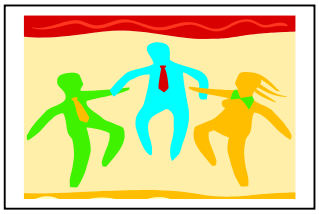
Objectives:

1. Identify the issues to be covered in HIV Treatment Maintenance Counselling.
2. Review the HIV Treatment Maintenance Checklist.
3. Practise counselling skills for maintenance counselling.
4. Identify three roles in relationships: parent, child and adult.
5. Apply these roles to the counselling setting.
6. Role play counselling in the adult role.

Time: 2 hours 10 minutes

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Goals of HIV Treatment Maintenance	5 minutes	
Presentation/Discussion: HIV Treatment Maintenance Checklist	25 minutes	HIV Treatment Maintenance Counselling Checklist
Relay Role Play: HIV Treatment Maintenance Counselling	40 minutes	2 Balls
Review Discussion: The Roles We Play	20 minutes	
Role Play	40 minutes	



Activity 1

Introduction

Time: 5 minutes

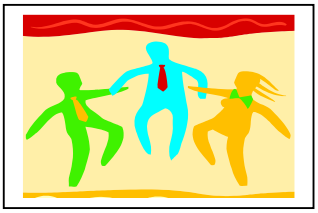
Goals of HIV Treatment Maintenance:

- Medically: The doctors and nurses monitor the client's drug interactions and experience of side effects. They also monitor the CD4 count and other measures through blood tests.
- Counselling: Offer continued support and reinforce commitment to HIV treatment.

*Remember: adherence changes over time. Someone may be adherent when he/she starts treatment, but this can change.

What might influence adherence to treatment over time?
Let participants brainstorm some ideas. Responses could include:

- Moving
- Change in marital status
- Having children
- Job change
- Break-up of a relationship



Activity 2

Presentation/Discussion

Time: 30 minutes

Note to Facilitator:
- Since you have already reviewed several checklists for adherence counselling, this presentation can be more of an overview.
- Involve the participants in finding a variety of ways to ask questions. This skill must be stressed over and over again.
- Another way to do this would be to have participants discuss what needs to be addressed in HIV Maintenance Counselling and come up with their own list.

HIV Treatment Maintenance Checklist

1. **Overall Functioning**: In this section, you are exploring how the client is doing on HIV treatment and how he/she feels about being on HIV treatment.

   - The counsellor should offer support and encouragement.

   - Keep in mind that when a client first starts on treatment, he/she has a number of expectations. What might happen to the client emotionally if he/she experiences a lot of side effects?
     Let participants respond. Emphasise that our health and how we are doing physically is linked directly to how we feel.

   - Affirm the client for what he/she has done to adhere to treatment.

2. **Regimen Adherence**: Explore <u>how</u> the client is taking his/her HIV treatment. Is he/she following the treatment instructions?

- It is crucial that questions are NOT asked in a judgemental or leading way. You want the client to answer honestly instead of telling you what he/she thinks you want to hear. You can do this by carefully wording your questions.

- Can you think of ways to ask questions about regimen adherence? *Participants should be able to come up with examples of non-judgemental and non-leading questions.*

3. **Factors Influencing Adherence**: Explore what specifically helps or hinders adherence for your client.

- Counselling about Side Effects: Remember, the doctor has already met with the client and discussed side effects. Your role is to understand how your client's side effects are affecting his/her life and to help your client cope with them.
  - Empathise with client's difficulties with his/her treatment regimen.
  - Do not underestimate the daily challenge of side effects and other symptoms of HIV treatment.
  - Never minimise what the client is experiencing.
  - Assess the side effects' influence on the functioning ability of the client. How much of a problem is the side effect for the client? Is it manageable or not? Do not assume that the client is capable of dealing with his/her side effects.

- Explore the client's adherence concerns while also reinforcing the positive things he/she has done with the treatment plan. Make sure to comment on what the client has done well.

- Explore areas that are difficult for adherence. Discuss options to overcome these barriers.

4. **Personalised Adherence Plan**: You are trying to understand how the client has adapted to being on HIV treatment.

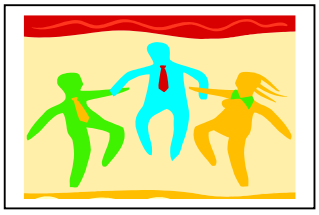
- How has the client adjusted his/her lifestyle? How does he/she remember to take the tablets, and what kind of support is he/she receiving from others?

- What is working with the adherence plan? Does anything need to change? Explore anything that needs to change – develop options and strategies.

- What role has the treatment supporter taken? Is this working?

5. **Monitoring Adherence and Treatment**: In this section, you are finding out how the client monitors his/her adherence, as well as making sure he/she understands when to return to the clinic.

- Do not assume that the monitoring tools the client is using are working. Find out what is and is not working for the client. Help him/her brainstorm other options if the tools are not working for him/her.



Activity 3

Relay Role Play

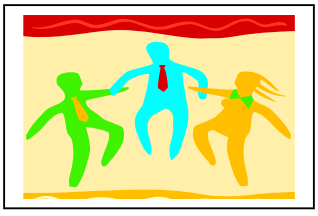
Time: 40 minutes

HIV Treatment Maintenance Counselling

- It is time for another relay role play to practise an HIV Treatment Maintenance Counselling Session.
- *Follow the same format as for previous role plays.*

Suggested Role Play Scenario:
Agatha is a 30-year-old single woman. She started on HIV treatment (ARVs) two months ago. She has experienced a number of side effects, including nausea, diarrhoea and headaches. She is very discouraged because she thought that ARVs would make her feel better, not worse. She has brought her mother, who is her treatment supporter, to the counselling session.

Note to Facilitator: If the participants have demonstrated good basic counselling skills and the ability to ask open, non-judgemental questions during previous role plays, you can replace the relay role play with role plays in triads or groups of four. Try to include the role of the treatment supporter in the role play (this requires groups of four). It is helpful for participants to learn how and practise conducting a counselling session with two people in the room.



Activity 4

Review/Discussion: The Roles We Play

Time: 20 minutes

It is important for counsellors to develop an awareness of the roles that we can play in our counselling relationships. We are discussing this in HIV Treatment Maintenance because it can become an issue when working with clients on maintaining their HIV treatment adherence.

Note to Facilitator:
The concept of the roles we play was introduced in Personal Growth. It is revisited in this section of HIV Treatment Maintenance since there will be a temptation for counsellors to step into the parenting role with clients who are having trouble adhering to their treatment plans.
The same material is included here that was covered in Personal Growth.

- Review the three roles.
- Remind participants of the communication styles for each role.
- Apply this concept to adherence counselling: how might a counsellor behave like a parent during HIV Treatment Maintenance Counselling? etc.

We are going to look at three main types of roles:

1. The Parent
2. The Child
3. The Adult

1. The Parent:

- What do you think this role would be like? *Have participants respond.*
- Key points:
  - This is a role that has authority.
  - Uses frequent statements of what is right and wrong, with a judgement attached.
  - This role expects certain behaviour and can be controlling.

Common words or phrases that represent the **parent**:

Should/should not	Let me help you	Try
Ought	Disobedient	Duty
Don't/do not	Unreasonable	Must
Why? (in criticism)	If I were you	Careless
Sweetheart	Uncooperative	Poor thing
How dare you!	Thoughtless	Now what?

2. The Child:

- What do you think this role would be like? *Have participants respond*.
- Key points:
  - Words and actions are for the purpose of getting satisfaction from pleasant feelings or relief from unpleasant feelings.
  - The child role expresses our basic needs, such as our need to eat, sleep, be warm, and "play" (this includes having sex).

Common words or phrases that represent the **child**:

I can't	I hope	Give me
I want	I hate	I will try
I won't	It is your fault	I wish
I don't care	Do it for me	I am scared
I don't know	Why? (in protest)	

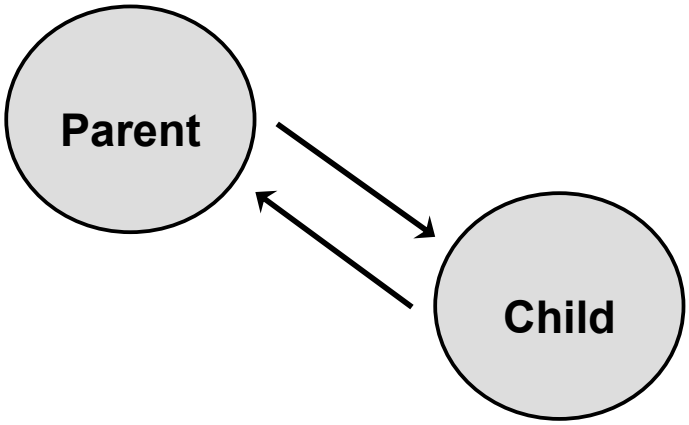
3. **The Adult**:

- What do you think this role would be like? *Have participants respond*.
- Key points:
  - Focussed on and attempts to deal with the present.
  - Does not place values on behaviour, but describes things the way they are.
  - Usually mature, level-headed, responsible and "human."

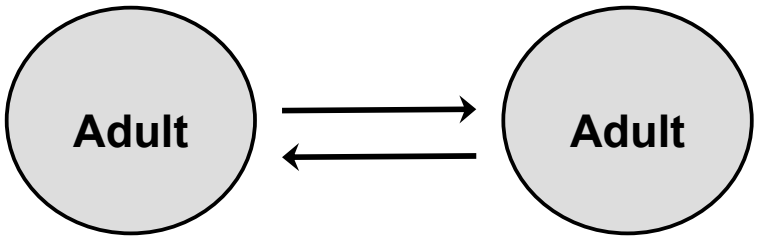
Common words or phrases that represent the **adult**:

Helpful	I see	Rational
Easier	Alternatives	Realistic
Productive	What are the facts?	Responsible
Objective	Why?(for information)	Probability
Authentic	My choice is	No
I choose	I'd rather	Yes
What has been done so far?	Let's take it apart and look at it.	Let's look for the causes.

If you operate primarily in parent role, then people respond to you in their child role. The child role complements the parent role; they fit together like pieces of a puzzle.



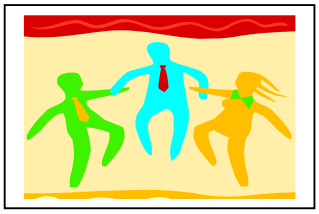
If you operate primarily in your adult role, you are most likely to have others respond to you in their adult mode.



Discussion Questions:

- How can this model apply to HIV Treatment Maintenance Counselling?
- How might a counsellor behave as a parent in Adherence Counselling?
- What do you think the dangers are in counselling?

Key Points:
- The counsellor can tend to behave as the parent, which makes the client take the role of the child. This means that he/she is less likely to take an active, responsible role in his/her treatment adherence.
- Likewise, the client can take the role of the child, which makes the counsellor want to take the role of the parent. You must resist this and respond in the adult role. How do you do this? *Include this in the discussion*.



Activity 5

Role Play

Time: 40 minutes

Note to Facilitator:
- This role play can be done as a relay role play, or you can do a few short role plays to provide more examples.
- Since you are not illustrating a counselling session with stages, it is not necessary to conduct this as one full counselling session.
- Ask processing questions (below) when you switch counsellors and clients.

- We are going to do a role play in front of the group in order to show how these roles can influence the counselling relationship.
- To begin, I am going to be the client. I need a volunteer to play the role of the counsellor.

Suggested Scenario: A 25-year-old young man has been on ART for the part month. He is having trouble remembering to take his tablets, but cannot provide the counsellor with information about when he has missed doses.

Processing Questions:

- Discuss how the counsellor can stay in the adult role. *Refer to the communication table for the adult role.*
- Suggest ways for the counsellor to respond to the client to help him/her behave as an adult.
- Suggest ways that the counsellor can keep from being pulled into playing the parent role.

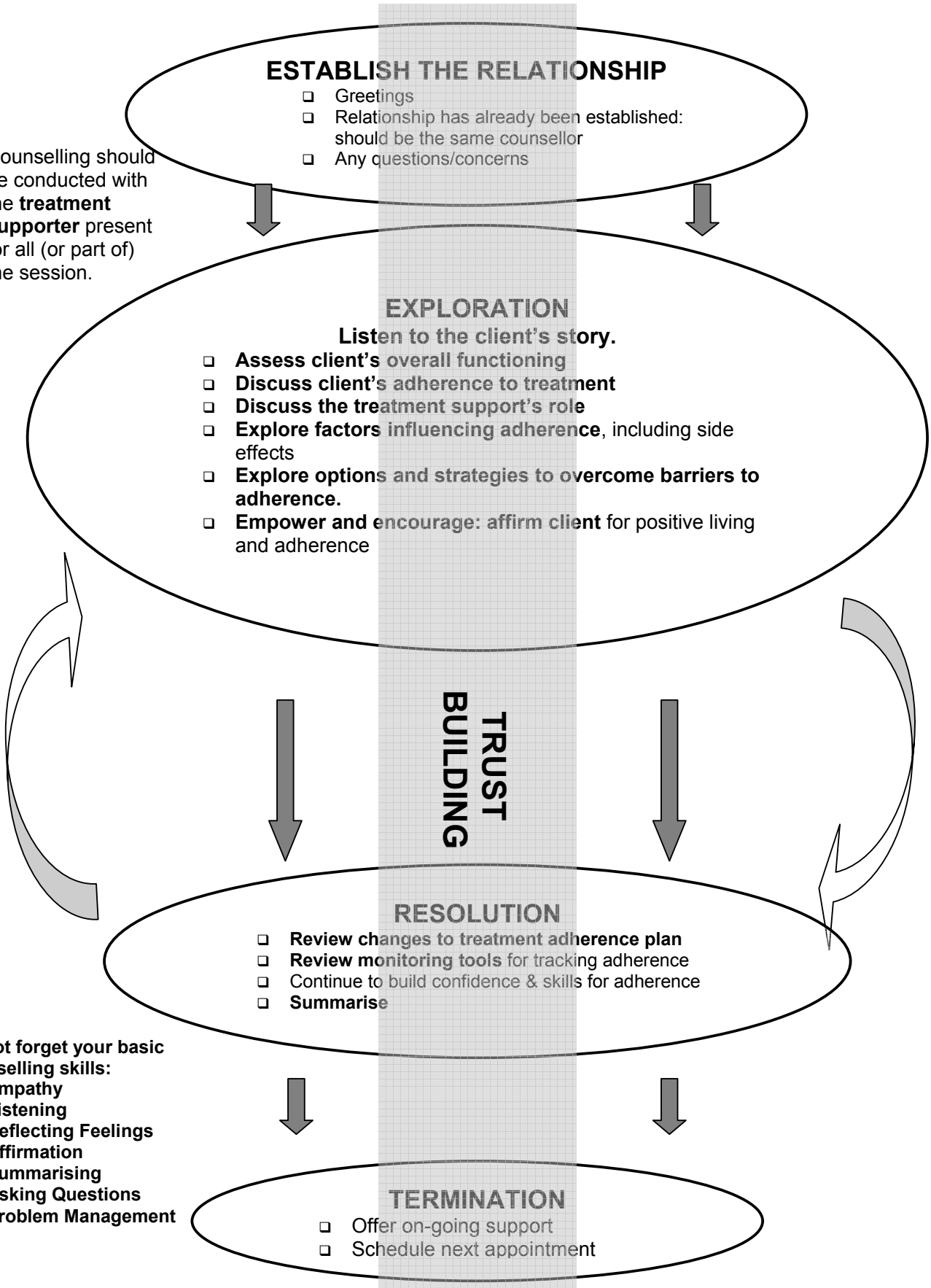
Stage 3: HIV Treatment Maintenance Counselling Checklist*

1.	**Overall Functioning** ❑ **Emotional Responses**: Explore how the client feels and how he/she is doing. o How are you feeling? How are you doing? ❑ **Expectations**: o What is different/the same about treatment than what you expected? ❑ **Concerns**: Listen to concerns. o Do you have any concerns about your treatment so far? ❑ **Encourage and support** the client.
2.	**Regimen Adherence** ❑ **ART Regimen**: Determine how the client has been taking HIV treatment. o Tell me how you have been taking your tablets. o What times have you been taking them in the morning and evening? o Many people find it difficult taking the medication. Do you ever have trouble taking the tablets? o What kinds of problems make it hard to take your tablets? ❑ **Late and Missed Doses**: o It is difficult to take medication every day, and many people miss a dose now and then. When was the last time you missed a dose? o When is it most difficult to remember your medication?

3.	**Factors Influencing Client's Adherence**: personalise it. ❑ **Side Effects**: o Have you experienced any side effects from your HIV treatment? o If so, how have you dealt with them? ❑ **Personal Adherence Concerns**: Explore any and all adherence concerns and help client think of solutions. o What sorts of things have affected your adherence? o How do you think you can solve these adherence problems? (Problem-solving with client) ❑ **Identify Personal Positive Adherence Factors**: Help the client identify characteristics about him/herself, lifestyle or past experiences that help the client adhere to HIV treatment. o Can you identify anything about yourself that helps you stick to your HIV treatment? o Offer encouragement for areas where the client has adhered to his/her treatment plan.
4.	**Personalised Adherence Plan:** Make changes to the plan based on adherence difficulties. ❑ **Lifestyle Adjustments**: o How has HIV treatment fit into your lifestyle? What has been easy? What has been challenging? ❑ **Memory Aids**: o How have you remembered to take your tablets? o What things help you remember to take your tablets? ❑ **Support:** o Whom have you gotten support from during the process of starting on HIV treatment? ❑ **Treatment Supporter:** *The treatment supporter should be part of the counselling session.* o Has your treatment supporter been involved in your adherence? o What role has he/she taken? Has this worked?
5.	**Monitoring Adherence and Treatment** ❑ **Personal Monitoring Tools**: suggest pill diaries, charts o How have you kept track of your adherence? o What has worked? What has not worked? ❑ **Hospital/Clinic Monitoring**: o When are you supposed to return to the clinic? o When will you collect your next set of tablets?

* Counselling should be conducted with the treatment supporter if possible.

STAGE 3: HIV TREATMENT MAINTENANCE



Counselling should be conducted with the **treatment supporter** present for all (or part of) the session.

Do not forget your basic counselling skills:

- **Empathy**
- **Listening**
- **Reflecting Feelings**
- **Affirmation**
- **Summarising**
- **Asking Questions**
- **Problem Management**

SESSION 22: REVIEWING A COUNSELLING EPISODE

Objectives:

1. Identify basic counselling skills in counselling episodes.
2. Evaluate counsellor responses and formulate empathic and supportive counsellor responses.

Time: 45 minutes

Session Overview

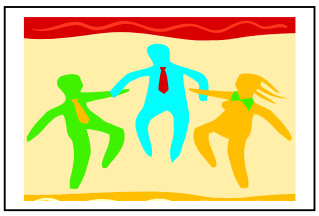
Activity/Method	Time	Materials Needed
Introduction: Read Adherence Counselling episodes	10 minutes	Adherence Counselling Episodes
Small Group Discussions	20 minutes	
Large Group Processing	15 minutes	

Activity 1

Introduction

Time: 10 minutes

Read the two Adherence Counselling episodes. Point out that there are two different counsellor responses in the episodes: counsellor 1 and counsellor 2. Each shows an alternative response. Have three volunteers read the episodes: client, counsellor 1 and counsellor 2.



Activity 2

Small Group Discussions

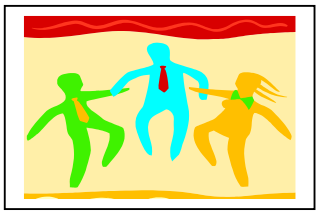
Time: 20 minutes

Please divide into groups of 4 – 5 participants. In your groups, discuss the following:

- What is your overall view of these counselling sessions?
- Comment on each of the responses made by the first counsellor. What type of skill is being used? Why is this effective or ineffective?
- Comment on the responses made by the second counsellor. What is this counsellor doing? How is this effective or ineffective?

- According to “The Role You Play,” what type of roles do you think each of the counsellors is playing? Remember the “adult”, “child” and “parent” roles.

You will have 20 minutes to discuss these issues.



Activity 3

Large Group Processing

Time: 15 minutes

- What is your overall view of these two counselling sessions?
- What skill was the first counsellor using? What it effective? Why or why not?
- What about the second counsellor? What it effective? Why or why not?
- What roles were being played by each of the counsellors?
- What could either of the counsellors have done to improve the session?
- Provide some alternative questions or responses for the counsellors.

Adherence Counselling Episode # 1

Client: Good Morning. I've come for my monthly visit.

Counsellor 1: Good morning, Maria. It's two months now since you began HIV treatment. How are you doing?

Client: Fine, thanks. It's not easy, but I am managing.

Counsellor 1: Do you want to tell me a bit about how it has been going?

Client: Well, I've been taking my medication as I'm supposed to. I just feel very tired all the time and then I want to sleep. I can't cook and clean like before. I'm so tired when I wake up that I'm scared that I'll sleep through my morning dose.

Counsellor 1: It sounds like treatment has been difficult for you. Do you think your tiredness could be a side effect of the medication?

Client: Yes, I think it is. The doctor told me that I might feel like this. He also said that I might get diarrhoea from the AZT/3TC.

Counsellor 1: Has knowing this made it any easier for you to cope, knowing that what you're experiencing is common?

Client: (Laughs) Yes, but some days I'm tempted not to take my medication. I don't like the way it's making me feel.

Counsellor 1: Perhaps you have days when you wonder if this is worth it. Maybe the side effects make you feel worse than the HIV was making you feel before you started treatment?

Client: Yes. (Starts crying) I know that it is really important for me to take the drugs every day. But, I'm scared that I'll forget and then the drugs won't work anymore and I'll get sick and die. There will be nothing left for me.

Counsellor 1: I can see that you realise how important it is to be adherent to your medication, but it seems like you are putting a lot of pressure on yourself too. Would you like to spend some time looking at how you can manage these side effects more easily?

Client: Yes, please. I really need to see if there are things that will help me to get through this.

Adherence Counselling Episode # 2

Client: Good Morning. I've come for my monthly visit.

Counsellor 2: Good morning, Maria. It's two months now since you began HIV treatment. How are you doing?

Client: Fine thanks. It is not easy, but I'm managing.

Counsellor 2: Have you been taking your medication all the time?

Client: Well, I think I've been taking my medication as I'm supposed to, but I'm not really sure.

Counsellor 2: It is very important that you do not miss any doses. You know that you have to take your medication at the same time every day!

Client: Yes, I know that I'm supposed to, but sometimes I forget and lately I think my medicine has been making me feel sicker. I just feel very tired all the time and then I want to sleep. I can't cook and clean like before. I'm so tired when I wake up that I'm scared that I'll sleep through my morning dose.

Counsellor 2: You cannot miss your doses. You know that you have to keep taking your medication.

Client: (Laughs) Yes, but some days I'm tempted not to take my medication. I don't like the way it's making me feel.

Counsellor 2: You know that it's really important to keep persisting. Everyone feels that way.

Client: Yes. (Starts crying) I know that it is really important for me to take the drugs every day. But, I'm scared that I will forget and then the drugs won't work anymore and I'll get sick and die. There will be nothing left for me.

Counsellor 2: You have to pull yourself together; otherwise you will make yourself sicker than you are now. Do you want that?

Client: No, I definitely don't want to get sicker.

Adapted from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. The Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.

SESSION 23: ADHERENCE SCENARIOS: WHAT WOULD YOU DO?

Objectives:

1. Identify key counselling issues in adherence scenarios.
2. Develop creative ways to assist and support adherence.
3. Practise counselling skills through role play of these scenarios.

Time: 2 hours (120 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Small Group Discussion: What Would You Do?	45 minutes	Adherence Scenarios
Role Plays & Discussion: Role Play Scenarios	75 minutes	

Activity 1

Small Group Discussion:

Time: 45 minutes

What Would You Do?

We are going to divide into seven groups. Each group is going to be given a scenario. In your groups, I would like you to discuss the following:

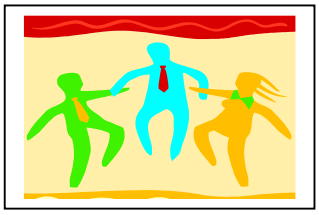
- What are the primary issues in the scenario?
- Provide at least two alternative ways of handling this scenario. You can come up with more options as well.
- Which do you think is the best approach? Is your whole group in agreement?

After you have discussed the scenario, develop a short five minute role play to demonstrate the recommended way to handle this situation in a counselling setting.

- When presenting your role play to the large group, one person should introduce the setting, another should play the role of the client, and another the role of the counsellor.
- Focus on the counsellor's role when presenting your role plays to the large group.
- Remember: when you are presenting your role plays, you should be demonstrating counselling skills like reflection skills, active listening and appropriate body language.

Assign each group a different scenario. Facilitators should circulate amongst the groups in order to help groups explore the issues and practise a quality role play. Refer participants to the checklists and remind them of the basic counselling skills.

Note to Facilitator:
- If you do not have enough time, you can have larger groups and discuss only two or three of the scenarios.
- You can also have several groups discuss the same scenario to shorten the discussion time.



Activity 2

Role Plays & Discussion

Time: 75 minutes

Note to Facilitator:
- As with all role plays, make sure that you provide feedback, allowing the counsellor to evaluate his/her own performance first, before you or anyone in the group offers their comments. You can do this simply by asking the counsellor, "What did you do well?"
- Make sure that the feedback is given in a sandwich format, and offers specific strengths and weaknesses; avoid generalisations.
- Spend some time on the role plays, as they serve two purposes: first, they allow the participants another chance to practise counselling skills. Secondly, they help participants explore ways to handle possible counselling situations.
- If you have the time, it would be beneficial to spend more time on the role plays. You could easily spend 15 minutes on each group's role play.

Scenario Role Plays

Processing Questions:
These can be asked after providing feedback to the counsellor in each role play.

- What option did this group choose to take?
- What was the outcome of that choice?
- What are some other options and possible outcomes?
- If the client had responded in a different way, what could the counsellor have done next?

Note to Facilitator: Adaptation
In the interest of time, you could assign the scenarios as homework. Ask groups to prepare their responses and role plays in the evening, then you can simply focus on the role plays the following morning.

Another possibility is to have the groups present their alternatives instead of role playing them. While this would reduce the amount of time taken for presentations, it takes away an opportunity to practise these skills.

Adherence Scenarios: What Would You Do?

1. A client has not disclosed his status to anyone at work. He is on HIV treatment and is afraid to take his medication at work. How would you use the problem-solving model to brainstorm possible options?

2. George is on HIV treatment and committed to adherence. His job entails shift work, and this interferes with his medication regimen. How would you approach this problem together with George?

3. Sheena has been on HIV treatment for a few months. She is responding well and is feeling physically and emotionally stronger. She has met a man and feels that a serious relationship could develop, but she is anxious and unsure if she should disclose her status to him and when the right time would be. What would you say to her?

4. Randeera has gone through Pre-HIV treatment Initiation Counselling and feels ready and committed to the programme. The health care worker is unsure whether he should begin treatment because he has not disclosed to anyone. What would you do?

5. Your client has completed the Pre-HIV Treatment Initiation Counselling. Some of her friends are on HIV treatment. She is confused as to whether she should go onto the treatment because she has heard so many different opinions about the side effects, how difficult it is to keep the routine and the success of the treatment. How can you assist her in making a decision about whether she should go onto treatment?

6. Peter has been your client for 6 months. He presents as being committed to adhering to the programme. However, you have been told that he frequently goes to the shebeen and drinks a lot. You begin to notice a change in his attitude and physical and emotional wellbeing. What do you do?

7. You client has been on HIV treatment for a few months. The side effects have not decreased. He is feeling despondent and considering stopping the treatment. What would you say to him?

Taken from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. The Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.

SESSION 24: STAGE 4: RE-MOTIVATION OR TREATMENT CHANGE

Objectives:

1. Identify and discuss psychological themes in HIV treatment maintenance and support.
2. Discuss issues related to treatment change.

Time: 2 hours 15 minutes (135 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Presentation/Discussion: Psychological Themes	10 minutes	
Small Group Discussion: Psychological Themes in HIV Treatment	40 minutes	Flipchart paper Markers
Presentation: Treatment Change	20 minutes	
Discussion: Values and Adherence Counselling	15 minutes	
Role Play: Re-Motivation & Treatment Change	50 minutes	

Activity 1

Introduction

Time: 10 minutes

Remember that HIV treatment is treatment for life. As a result, there will be many things that happen in a person's life while he/she is on treatment. Many of these events will directly impact the person's treatment and ability to adhere to his/her treatment regimen. We are going to take a look at the psychological themes that may come up in HIV Treatment Maintenance Counselling.

Psychological Themes in HIV Treatment Maintenance (Supportive) Counselling:

- Empowerment and control
- Survivor guilt: guilt that he/she is alive and loved ones have died
- Grief and loss: client's own and others
- Treatment failure
- Pain management
- Existential struggles: a philosophical search for meaning in life

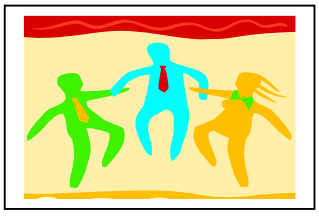
Make sure participants understand these themes before moving on to the small group discussions.

Activity 2

Small Group Discussion

Time: 40 minutes

- Divide into groups of 5. Each group will discuss a different psychological theme in HIV Treatment Maintenance and Supportive Counselling.
- In your groups, I would like you to discuss the following points:
  - How might this theme come up?
  - What could be some of the emotions associated with this issue?
  - How might a person deal with this issue in his/her life?
  - How would you address this issue in counselling?



Activity 3

Presentation/Discussion: Treatment Change

Time: 20 minutes

There are a few options for adjusting a client's ART regimen. Of course, this would be done by the doctor, in consultation with the client, the Health Care Team, and other professionals.

The reasons for changing anti-retroviral treatment are:

- Client intolerance of a medication
- Significant adverse effects
- Treatment failure

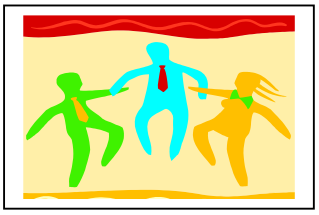
HIV treatment can also be interrupted for many different reasons. However, when HIV treatment is interrupted, it is best to stop ALL of the HIV treatment medications at the same time.

Treatment Change and Counselling

If a client changes treatment regimens, he/she will need to be re-counselled from Stage 1: Pre-HIV Treatment Initiation.

- Do not assume that the client has any former knowledge.
- Treatment change may have psychological effects, including feelings of failure, shame, guilt, embarrassment or fear of failure. Explore those feelings with the client.
- Be careful not to judge the client for failing on his/her previous treatment plan.

- Reflect on the client's previous experience on HIV treatment: what worked and what did not work? Adjust the new treatment plan to take these issues into account.
- Return to the client's original reason for taking HIV treatment. Re-motivate from time to time.
- Encourage your client to celebrate successful perseverance on treatment, i.e. celebrate HIV treatment initiation anniversaries.



Activity 4

Discussion: **Values & Adherence Counselling**

Time: 15 minutes

Remember discussing values in Personal Growth? We have talked before about how values can influence our views of others, and we need to be careful of this, especially in the counselling setting. Let's talk for a few minutes about how our client's values might influence HIV treatment adherence.

- What client values might influence a client's adherence positively? *For example, if a client values health or family.*
- What are values that might influence a client's adherence negatively? *For example, if he/she values spending time with friends and those friends spend time together drinking and getting drunk.*
- How do our values influence our motivation?
- How might you use a client's values to re-motivate him/her in adherence counselling?
- What issues do you think you need to keep in mind as counsellors when doing adherence counselling?

Activity 5

Role Play: Re-Motivation & Treatment Change

Time: 50 minutes

Note to Facilitator: It is always helpful to give participants the opportunity to practise their counselling skills. This role play can be conducted in triads, as a relay role play in the front of the group, or as a demonstration role play. It may be helpful to use the case scenarios provided in order to practise counselling skills related to issues discussed in this session.

Suggested Role Play Scenarios:

1. The client is a 42-year-old man whose wife recently died from AIDS-related illnesses. He has been on HIV treatment for 3 years and is doing well on treatment. He has followed his treatment regimen and rarely misses doses. However, in the last couple of months he has been depressed and finding it difficult to stick to treatment. He feels guilty for doing well on treatment after his wife so recently passed away.

2. A 21-year-old woman has been on treatment for 4 years. For years, she adhered to treatment and besides some side effects in the beginning, she has felt good until recently. She was admitted to the hospital with TB a month ago and the doctor has suggested a change in treatment. The new regimen has will be harder to adhere to, with more dosing requirements.

3. A 32-year-old man has been on treatment for 5 years. However, his health has started to decline and he has been sick a lot and in and out of the hospital. He recently lost his job because he had been sick so much and missed so much work.

4. A 27-year-old woman found out her positive HIV status when she was pregnant. She missed her follow-up visits at the clinic and had her child at home. The child was a girl, and she got sick not long after she was born. The child died three months ago when she was 14 months old. Your client started on HIV treatment 4 months ago and her health has improved greatly. However, she has been feeling guilty about her child's death and has been very depressed lately.

SESSION 25: ADHERENCE REVIEW: ROLLER COASTER OF HIV

Objective:

1. Identify the potential highs and lows of life with HIV.

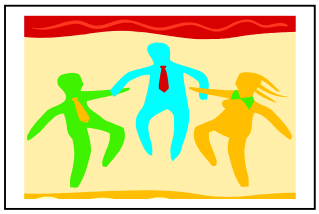
Time: 1 hour (60 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Introduction: The Lifeline/Roller coaster of HIV	10 minutes	
Small Group Project: The Roller coaster of HIV	50 minutes	Flipchart paper, markers, crayons

Activity 1

Introduction: The



Lifeline/Roller Coaster of HIV

Time: 10 minutes

Remember our lifelines from Personal Growth: we drew the highs and lows of our lives and then shared them with each other in our small groups. In this session, we are going to look at the highs and lows of a person living with HIV.

An HIV-positive diagnosis can be the beginning of an often unexpected journey of new highs and lows. The challenges and benefits of HIV treatment will also be triggers for ups and down in clients' lives. Our role as counsellors and supporters is to help prepare clients for the emotions that the various stages might bring, and also to support clients through the highs and lows they experience.

We can call these highs and lows a Lifeline, as we did in Personal Growth. We can also call them a roller coaster. Can anyone tell me what a roller coaster is?

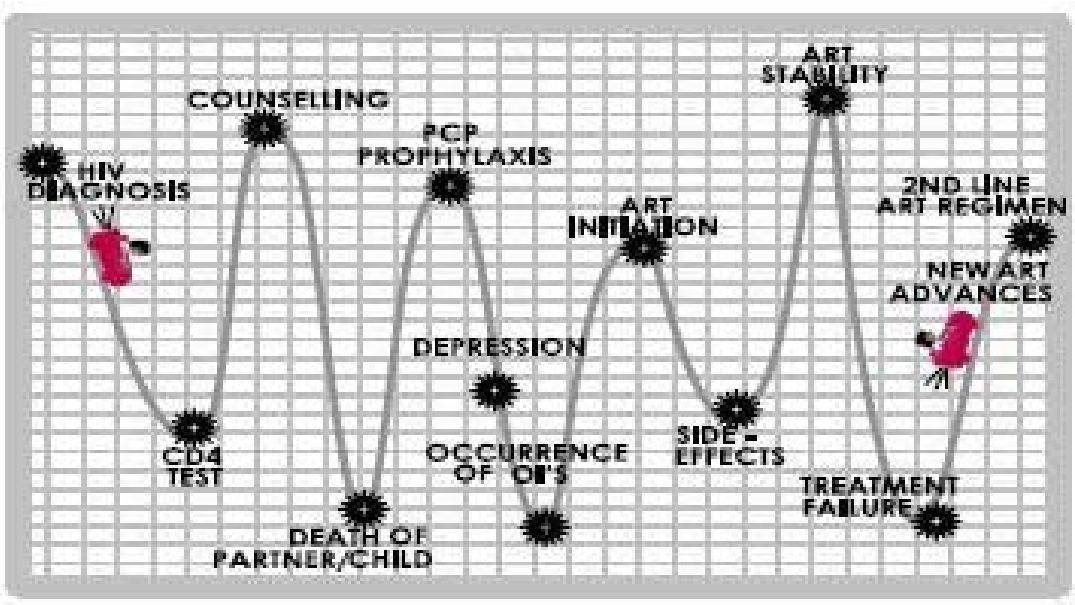
How could a roller coaster be used to illustrate what happens in a person's life, beginning with an HIV-positive diagnosis?

The diagram shows some possible high and low points of living with HIV and being on HIV treatment.

Key points about roller coasters:

- They are a ride on which you do not have control.
- Full of highs and lows.
- Full of surprises: moves in ways you are not expecting.

Diagram taken from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. The Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.



Activity 2

Small Group Project: **The Roller Coaster of HIV**

Time: 50 minutes

- Please divide into groups of three. In your groups, you are going to draw your own roller coaster of HIV.
- Please include some potential thoughts and feelings that a person with HIV may experience; do not just write the events themselves.
- Some of the highs and lows might include aspects of the four stages of HIV treatment. Remember that HIV treatment is treatment for life, so it will continue over the course of many years.
- Try to put yourselves in the shoes of someone who is living with HIV. What might you think and feel? What might your fears and concerns be?
- Be creative with your roller coaster; include pictures and lots of colours.
- *Give the groups about 30 minutes to draw their roller coasters. Then have each group share their project with the large group.*

Processing Questions:

- Why did we do this activity? What was the purpose?
    - *Potential responses: to develop empathy, to illustrate that there are many different emotions and responses to different events, but there are some themes for people living with HIV.*
- How can you use what you have learned here in counselling?

SESSION 26: SELF CARE

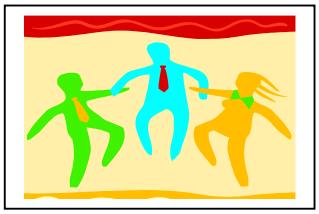
Objectives:

1. Identify stress related to HIV counselling, including internal and external demands.
2. Use circles of concern and influence for counselling and stress management.

Time: 1 hour 40 minutes (100 minutes)

Session Overview

Activity/Method	Time	Materials Needed
Introduction: Review Stress Definition and Model	15 minutes	
Small Group Activity: Internal/External Demands & Resources	40 minutes	Flipchart paper Markers
Written Exercise: Circles of Concern & Influence	15 minutes	
Small Group Discussion: Pro-active vs. Re-active	30 minutes	



Activity 1

Introduction

Time: 15 minutes

We need to refer back to the stress model that we first looked at in Basic Counselling Skills. Do you remember what the definition of stress was?

Stress: when our perceived demands (both internal and external) are greater than our perceived coping ability (both internal and external coping ability).

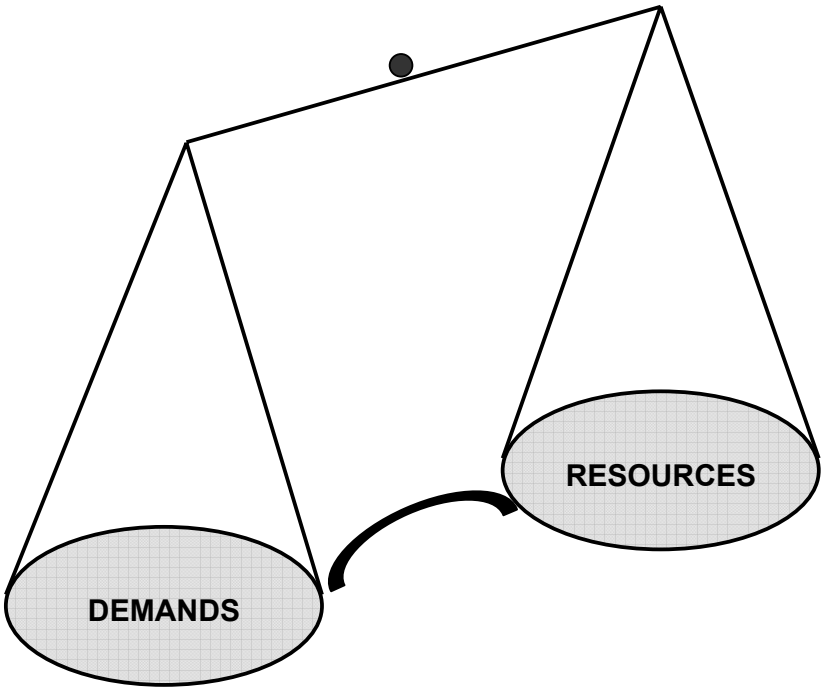
- Is stress only caused by negative things, or can stress also be caused by positive things? *Make it clear that stress comes from both positive and negative demands. Positive things can include marriage, the birth of a child, a move, a new job, etc.*

Why do we keep talking about stress in counselling training?
Let participants respond. Possible responses include:

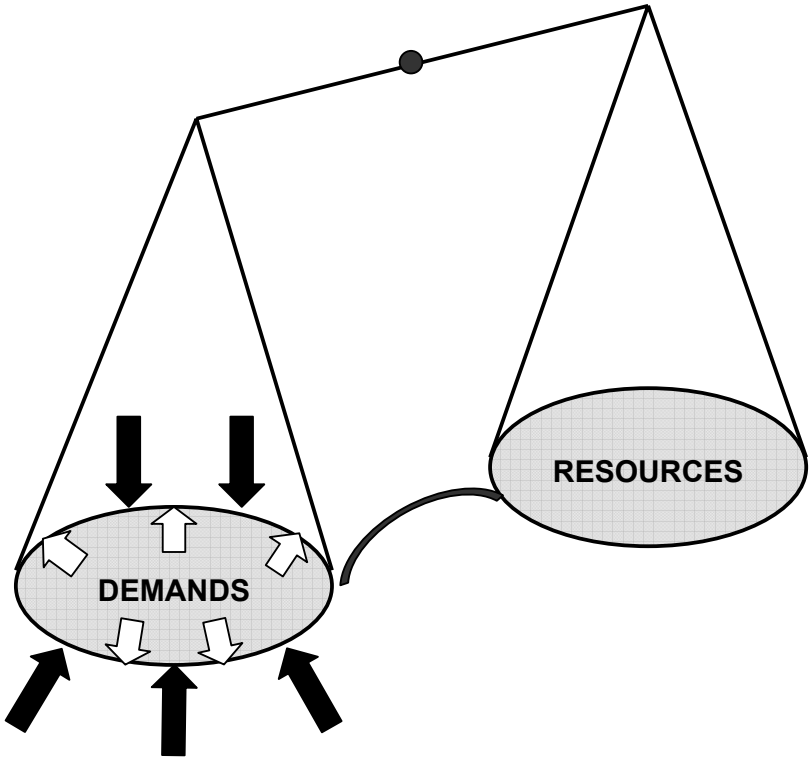
- Stress is part of life, and there are some common stresses for counsellors.
- We have to learn how to handle the stress in our lives, as stress influences our counselling ability.

Key Point: Our goal is to learn how to better manage stress and to use it a positive force in our lives.

Stress: Perceived demands are greater, or heavier, than perceived resources.



Stress/Distress: Perceived internal and external demands are greater, or heavier, than perceived resources, both internal and external.

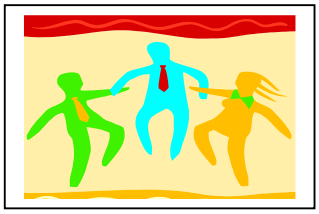


Let's look at our perceived **demands** as counsellors. Remember that these demands can be both internal and external.

- Can you think of an example of an external demand placed on counsellors? *Possible responses: demands to see many clients daily, requests from clients for help. Have participants list one or two examples to make sure they understand.*
- Can you give me an example of an internal demand? *Possible responses: pressure on yourself to help clients or to be a good counsellor.*

Now we should look at a counsellor's **resources**. Remember, these resources can also be both internal and external.

- What is an example of an external resource that a counsellor has? *Examples: colleagues, supervisor, local organisation. Again, only ask for one or two resources, as they will be doing this activity in small groups.*
- Can you give me an example of an internal resource that a counsellor has? *Examples: counselling skills, i.e. listening, reflecting, etc., maturity.*



Activity 2

Small Group Project: Internal/External Demands

Time: 40 minutes

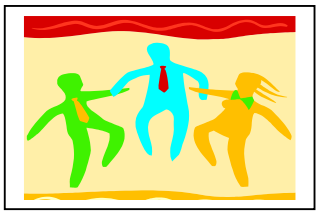
Counsellor's Internal & External Demands & Resources

- We are going to break into 4 groups, so please count off by four's.
- Groups 1 and 2 are going to discuss the demands placed on counsellors. You should divide your demands into two columns: one of internal demands and the other lists external demands. Write down as many demands as you can think of.
- Groups 3 and 4 are going to discuss resources that counsellors have. Again, you should have two columns, one for internal resources and another for external resources. Write down as many resources as you can think of.
- Record your lists on flipchart paper.
- *Give the groups about 20 minutes to make their lists. Wander among the groups and encourage them to imagine what it is like as a counsellor and to use the experience they have had so for at the hospitals or clinics where they have been working.*

- *Gather the large group together and have each group present their lists. During this, encourage the participants to think of other ideas or to discuss items as they come up.*

Processing Questions:

- ❖ What is it like to look at all of these demands and resources?
- ❖ What does it feel like to be looking at the demands of being a counsellor when you are just now in training to become a community counsellor?
- ❖ Which demands do you think will be the hardest for you to deal with? *OR* Will the internal or external demands be most challenging for you?
- ❖ What do you think will help you cope with all these demands? *OR* Do you think the resources listed here will help you cope with all of the demands?

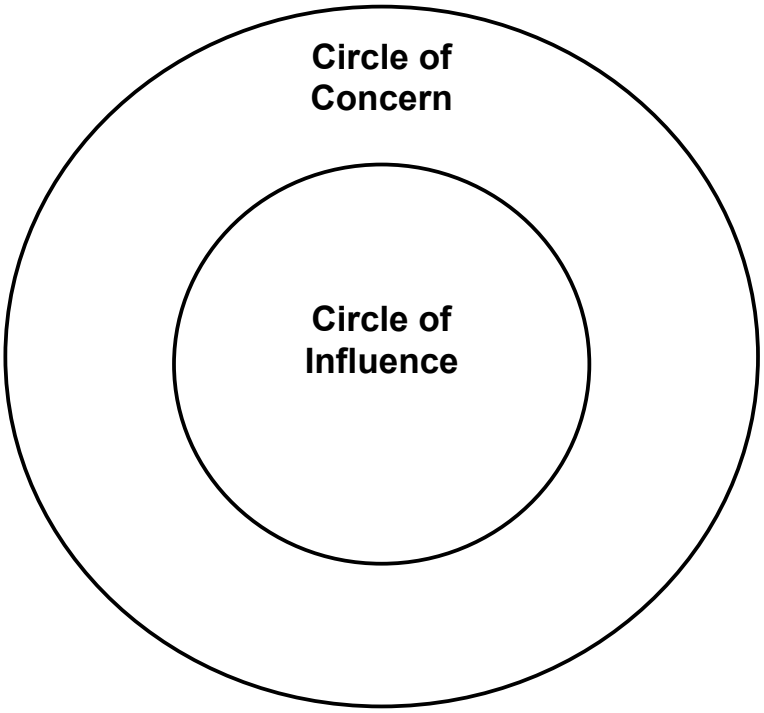


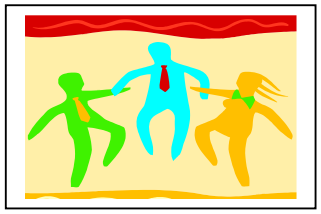
Activity 3

Written Exercise

Time: 15 minutes

- Write down all of your concerns about being an HIV counsellor. What are your concerns related to counselling? Write them all down.
- Now, I want you to think back to Personal Growth. Do you remember our circles of influence and circles of concern? Remember that the circle of concern is the bigger circle: these are all the things that we are concerned about. The smaller circle on the inside is the circle of influence. There are all the things that we have some influence, or control, over.
- I want you to divide up all of your concerns on your list into the circles of influence and circles of control. What do you have some control or influence over and what is out of your control or influence? Make sure that you are realistic about what you can change.


Circle of
Concern
Circle of
Influence



Activity 4

Small Group Project: Circles of Influence and Concern as Counsellors

Time: 50 minutes

- Discuss your circles of influence and concern in your small groups.
- Help each other distinguish between what belongs in the different circles and to focus on the circle of influence in order to be pro-active instead of re-active.
    - **Re-active People**: focus on their circle of concern. They focus on the weaknesses of other people, the problems in their life and environment, and circumstances over which they have no control. Their focus results in blaming and accusing attitudes, reactive language and increased feelings of victimisation. The negative energy generated by this causes their Circle of Influence to shrink.
    - **Pro-active People:** work on things they can do something about. They focus on the circle of influence and try to make changes to things in their life that they have some control over. The nature of their energy is positive, enlarging and magnifying, causing their Circle of Influence to grow/expand.
- Discuss how to reduce the intensity of emotional reactions; this is within the circle of influence:
    - Are you viewing your stressors in exaggerated terms and/or taking a difficult situation and making it worse?
    - Do you expect to please everyone: clients, supervisors, colleagues, and family members?
    - Do you put pressure on yourself to do a perfect job? Is perfection possible in HIV counselling?
    - Do you ever feel that situations are more serious than they later turn out to be?
    - Try to view stress as something you can cope with rather than something that overpowers you.
    - Put the situation into perspective.
    - Do not focus on the negative aspects of your job. Find ways to celebrate your accomplishments and those of your clients, even if they seem small, i.e. showing up for HIV test results or going a week without missing a dose of ARVs.

Note to Facilitator: If you have more than two facilitators, it would be best if you could have one facilitator per group. If not, rotate between the groups in order to facilitate meaningful and helpful discussion around stress and the circles of influence and concern.

Large Group Processing:

- What was it like in your small groups? Was it difficult to focus on being pro-active?
- How can these circles help you reduce your stress as a counsellor?

SESSION 27: COUNSELLING SKILLS ASSESSMENT

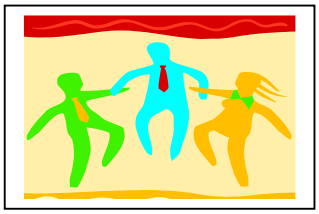
Objectives:

1. Assess personal counselling skills.
2. Share counselling skills and areas for improvement with others.
3. Receive feedback on counselling skills from others.

Time: 1 hour (60 minutes)

Session Overview:

Activity/Method	Time	Materials Needed
Written Exercise: Self-Assessment and Improvement Worksheet	15 minutes	
Small Group Sharing: Share Counselling Skills Assessment	30 minutes	



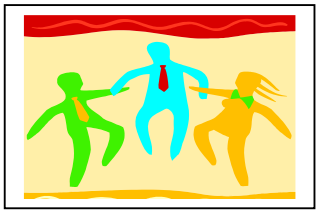
Activity 1

Written Exercise: Self-Assessment and Improvement

Time: 15 minutes

Note to Facilitator: It is best if you can give this worksheet as homework for the participants. If it is given as homework, they can spend more time filling it out and it does not take time during the session. Assign the homework the night before (on Thursday) so that it is completed for today's (Friday) session.

- Please fill out the "Self-Assessment and Improvement Worksheet" in your manuals. *You may need to review each of the questions on the worksheet to make sure that participants understand it.*
- You are welcome to write in your local language or in any language that you feel comfortable using.



Activity 2

Small Group Sharing: Counselling Skills Assessment

Time: 30 minutes

- We are going to break into small groups of three or four people. In your groups, you are going to share your skills and areas for improvement.
- After each person has shared his/her own self-assessment, I would encourage all of you to comment on each of your group members' counselling skills. Remember back to Basic Counselling: note how they have improved since then, what they do really well, and what you think they need to improve on.
- Remember to give your feedback gently and respectfully.
- *Give groups 20-25 minutes, then bring them back for the processing questions.*

Note to Facilitator: You may want to have participants go into the small groups they formed during Personal Growth. This may enable them to share more personally and give honest feedback.

Processing Questions:

- ❖ What was it like to share your strengths and weaknesses in your group?
- ❖ What was it like to hear the comments from other group members?

Key Point: Remember to work on the counselling skills you have identified as areas where you need improvement. We will be reviewing them again in future trainings.

Self-Assessment and Improvement Worksheet

Strengths:

My strengths as a counsellor or the basic counselling skills I am good at:

Example: I am good at establishing the relationship and making the client feel comfortable in counselling.

How will I use this to build on my skills as a counsellor?

Example: I will expand my ability to make an initial connection with a client to build trust and allow the client to explore very personal things that are often hard to talk about, such as sexual behaviour.

Areas for Improvement:

The areas where I need to improve as a counsellor or the skills I struggle with:

Example: I am uncomfortable when my client is emotional. I try to make her feel better by reassuring her, and then I usually give advice instead of helping the client explore her feelings and options.

How will I work on improving these skills?

Example: I will write in my journal every day about my own feelings to get comfortable with my own emotions. I will role play with my counselling colleagues, focussing on simply validating the feelings and not giving advice.

Date of Assessment_____

SESSION 28: HIV TREATMENT MEDICATION EXERCISE DEBRIEFING

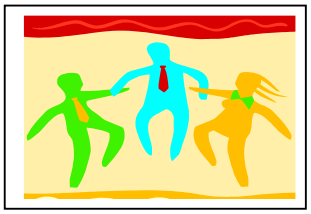
Objectives:

1. Gain an experiential understanding of the challenges of adhering to HIV treatment.
2. Develop empathy for clients' experiences.

Time: 20 minutes

Session Overview

Activity/Method	Time	Materials Needed
HIV Treatment Exercise Debriefing	20 minutes	



Activity 1

HIV Treatment Debriefing

Time: 20 minutes

Note to Facilitator:

- You can ask the participants to bring in their medication on the last morning to do a final pill count. However, this is not necessary.
- The purpose of the debriefing is to find out how the experience was for the participants.

Processing Questions:

- How many of you adhered to your HIV treatment perfectly? This means that you took the recommended dose, at the recommended time and in the recommended way every time. May I have a show of hands?
- How many of you missed a dose or took it late?
- How many of you missed more than one dose?
- Did you get better or worse about adherence as the week progressed?
- Did any of you make any adjustments through the course of the week that improved your adherence?
- Where there any circumstances that made adherence harder or easier?
- Did anything surprise you about this exercise?
- Did you learn anything about yourself by doing this exercise?

- What did you learn through this exercise? Is there anything you could apply to an adherence counselling setting?
- Why do you think we did this medication exercise?

Key Point: Adhering to medication is difficult, even for those of us who know the importance of adherence.

TIPS FOR POSITIVE LIVING

(For reference)

1. **Be Informed**
   - Encourage the client to learn what he/she can about HIV infection. Understanding more about HIV may lessen fears the client has related to HIV, and he/she can learn ways to stay healthy.
   - Knowing more about HIV may help the client be more adherent to any medicines he/she takes to treat HIV or prevent other illnesses.

2. **Medicines**
   - HIV has no cure, but medicines can help a person with HIV be healthier and live longer.
   - Some medicines need to be taken even if the client feels well. These are for opportunistic infection prevention, i.e. cotrimoxazole, or ARVs.
   - Some medicines help manage some side effects, such as pain, vomiting and diarrhoea.
   - Some medicines can be taken to treat opportunistic infections, i.e. antibiotics.
   - Many herbal or traditional medicines can interact with ARVs. Clients should not take them without first consulting their doctor.
   - People with HIV and those on HIV treatment should avoid alcohol, non-prescribed or illegal drugs, and cigarettes.

3. **Work**
   - Those living with HIV should be encouraged to continue working as long as they are well, or to return to work after recovering from illness.
   - Work provides income, stability, routine, friendships and fulfilment to many people that can promote health, both physically and emotionally.

4. **Stress**
   - Avoiding stress and dealing with worries is important to maintaining health.
   - People with HIV need to find positive ways to deal with stress, i.e. talking with friends or family, exercise, etc. and to avoid negative ways of dealing with stress, i.e. taking alcohol or drugs.

5. **Nutrition**
   - There is an interaction between HIV and nutrition that causes poor nutrition and weight loss.
     - Nutrients from food are not absorbed well into the body, often due to diarrhoea, vomiting, etc.
     - Less food is eaten because of nausea, pain, poverty, etc.
     - Because of HIV, the body has a higher need for nutrients.
   - Many HIV-related illnesses cause low appetite or difficulty in eating.
   - Side effects of HIV treatment can include nausea or vomiting.
   - When people have poor nutrition, their immune systems do not function well and they tend to get more infections.
   - Many people do not have resources to buy enough food.

- People with HIV should:
  - Eat a well-balanced diet with regular meals, even if not hungry.
  - Wash vegetables with clean water.
  - Drink plenty of clean water, up to 2 litres a day.
- People with HIV who feel nauseous or have low appetite should:
  - Eat small, frequent meals.
  - Eat bland foods, i.e. rice, porridge, toast
  - Do not eat greasy or spicy foods.
  - Take HIV treatment tablets with food.
  - Ask someone else to cook for them.

6. Prevent Infection

- Since HIV affects the immune system, a person with HIV is more susceptible to infections, or gets infections more easily.
- People with HIV should take steps to prevent infections, including:
  - Drink clean water. Boil water for a few seconds, then let cool.
  - Wash vegetables and fruits with clean water.
  - Eat well-cooked food, i.e. meat is brown and soups are boiled.
  - Wash hands with soap frequently, including after using the toilet.
  - Avoid STIs and HIV re-infection by abstaining from sex or using condoms.
  - Take steps to avoid malaria, such as using bed nets.
  - Avoid contact with others who are sick.
  - Clean and cover any cuts or wounds.

7. Exercise and Rest

- Benefits of regular exercise include:
  - Increased energy levels
  - Increased appetite
  - Decreased nausea
  - Maintenance of muscle tone
- Exercise can range from moderate, i.e. being active around the house, to active, i.e. team sports, jogging, or walking.
- Sufficient rest and sleep help to restore energy.

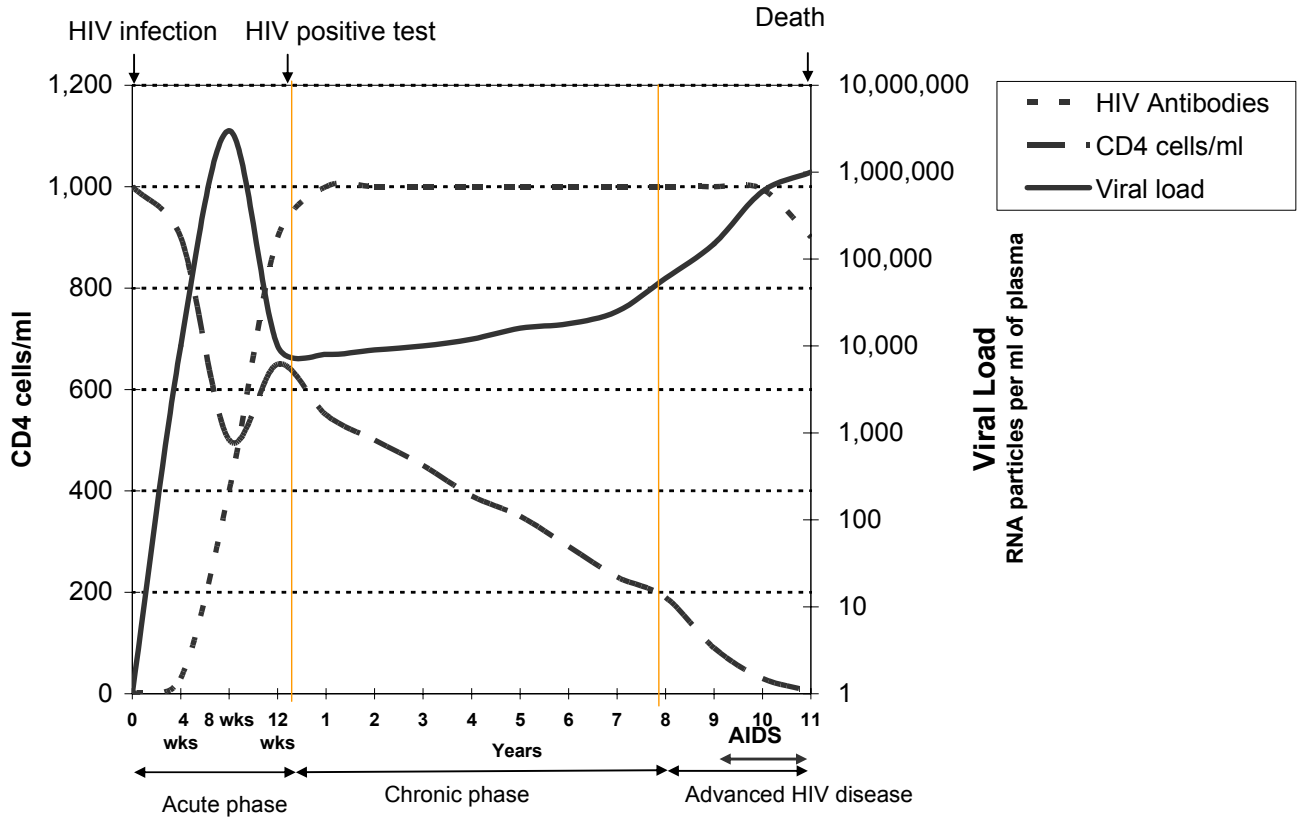
8. Prevention

- HIV can still be spread to others, even if the client is on HIV treatment
- People with HIV should take measures to prevent spreading HIV to others, such as remaining faithful in current relationships, using condoms and abstaining from sex.

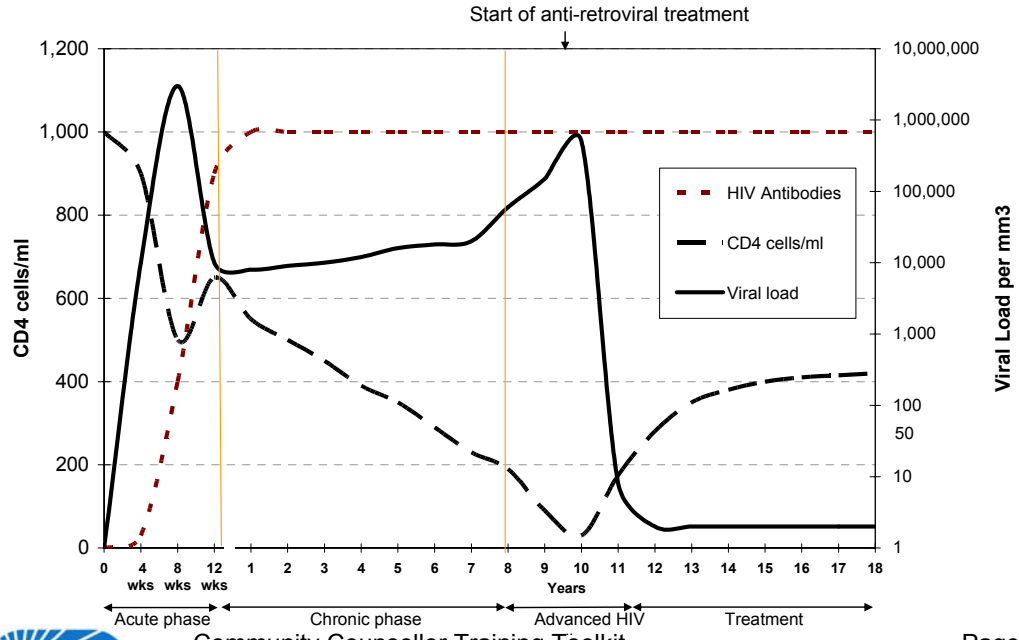
9. Regular Medical Care

- People who are living with HIV should regularly visit the hospital or clinic to monitor their progress.
- If a person is taking ARVs, he/she will be given a regular schedule for visiting the doctor, refilling his/her medicines and counselling. The client should keep all of these appointments.
- Clients should go to the clinic or hospital promptly when they are feeling ill. Early treatment of infection can prevent further illness.

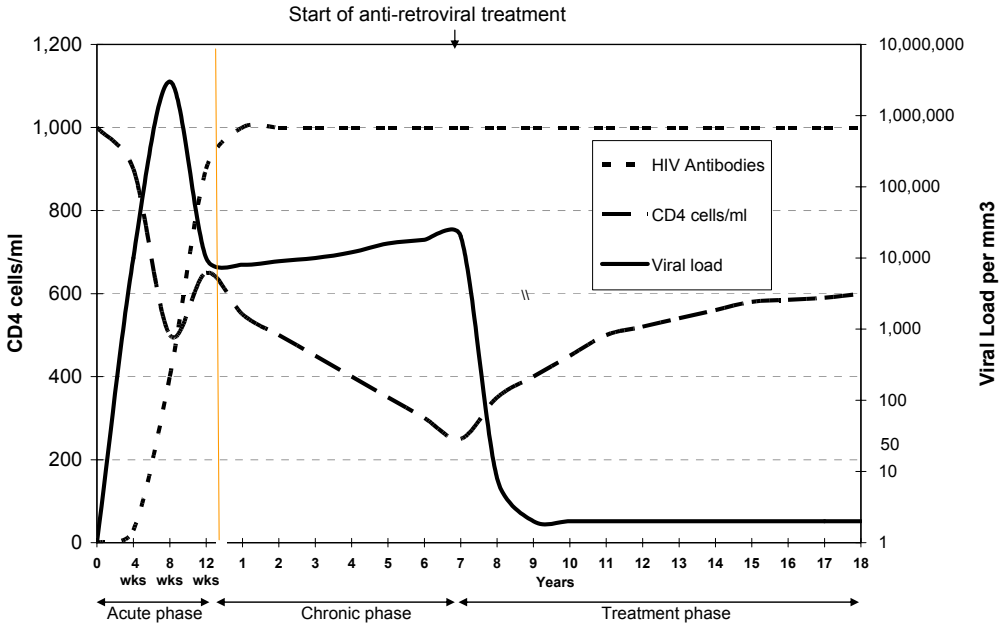
CHARTS
HIV PROGRESSION



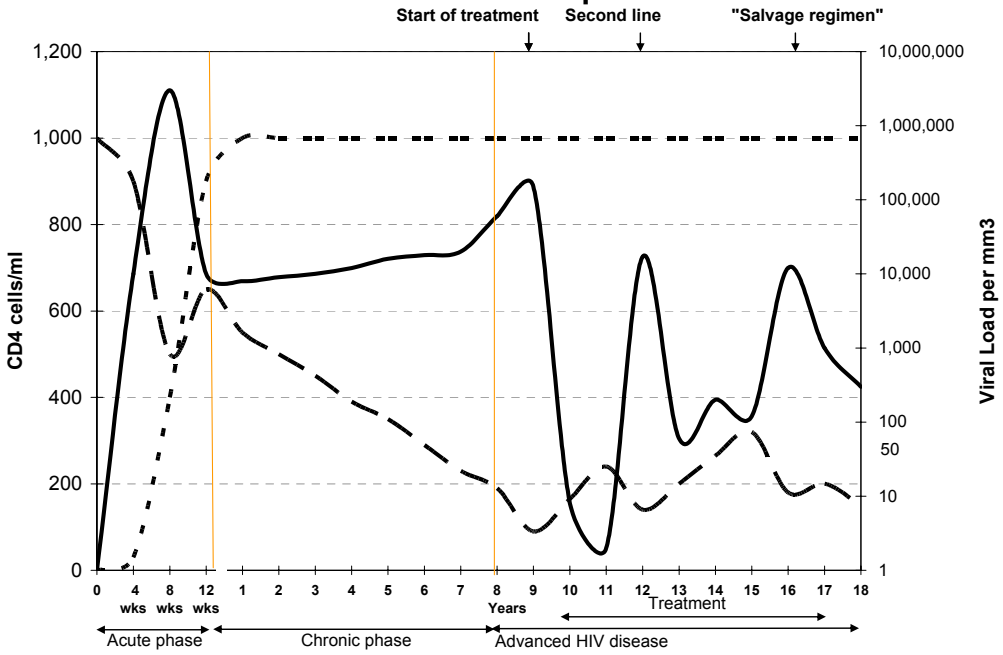
HIV Treatment in advanced disease



HIV Treatment before advanced disease



HIV Treatment and inadequate adherence



GLOSSARY

Abrupt stopping of breastfeeding/abrupt weaning: Completely stopping breastfeeding with a switch to replacement feeding. Mixed feeding should be avoided during this time.

Adherence: The extent to which a person's behaviour (taking medication, following a treatment regimen, making lifestyle choices, etc.) corresponds with recommendations made by the health-care team. ART adherence is taking the correct dose at the correct time and in the correct way.

AIDS (Acquired Immune Deficiency Syndrome): late-stage HIV infection.

Acquired: obtained or contracted; not inherited.

Immune: the body's defence system that provides protection from most diseases.

Deficiency: a defect, weakness or inability to respond; when linked with the immune system, this refers to the inability of that system to perform its functions and combat antigens or germs.

Syndrome: a group of symptoms and diseases that indicate a specific condition; it is not by itself a disease.

ANC: Antenatal clinic or antenatal care.

Antenatal care: Care of a pregnant woman and her unborn child or foetus.

Antibody: the substance that the body makes to fight an antigen (foreign substance in the body such as a germ). Its purpose is to protect the body from disease by countering or identifying the antigen to be destroyed.

Antigen: any foreign substance that gets into the body and causes the immune system to respond. Antigens include bacteria and viruses such as HIV.

Antiretroviral drugs (ARV): drugs that slow the growth and replication of HIV and the progression of HIV disease.

Antiretroviral prophylaxis (HIV prophylaxis): use of antiretroviral drugs to reduce the likelihood (or possibility) of HIV transmission, for example, the use of single-dose Nevirapine for prevention of HIV transmission from mother to child.

Antiretroviral treatment (ART): Use of antiretroviral drugs to treat HIV infection or AIDS.

Asymptomatic: without symptoms of illness or disease. People who are infected but asymptomatic may transmit HIV or other STIs (sexually transmitted infections).

CD4 cell: The white blood cell within the immune system that is targeted and destroyed by HIV.

CD4 count: The number of CD4 cells in the blood, which reflects the state of the immune system. A normal count in a healthy adult is 500-1,200 cells/mL3. When the CD4 count falls below 200 cells/mL3, there is a high risk of opportunistic and serious infection.

Complementary food: Any food used as in addition to breast milk or to a breast milk substitute when feeding an infant.

Cup feeding: Feeding an infant from an open cut without a lid.

Diarrhoea: illness characterised by loose, watery bowel movements more than three times a day, every day.

Disclosure: sharing personal information, thoughts or feelings with others. In the context of HIV, disclosure is usually used to refer to sharing one's HIV status with others.

Discrimination: treating one particular group in society in an unfair way.

Embryo: fertilised egg (egg & sperm) until 2 months of development.

Exclusive breastfeeding: an infant receives only breast milk and NO other liquids or solids, not even water. The only exceptions are drops or syrups that contain vitamins or minerals, or any medicine prescribed by a doctor.

Foetal (also spelled fetal): connected with a foetus, i.e. foetal blood is the blood of the foetus.

Foetus (also spelled fetus): a baby before birth, while the baby is still in the mother's uterus/womb; from 2 months to birth.

Gender: our maleness or femaleness, often including our social roles.

HIV (Human Immuno-deficiency Virus): the virus that causes AIDS.

Human means that it affects only humans and lives only in humans.

Immuno-deficiency means a deficiency or a breakdown of the immune system; a decrease in the body's ability to fight disease.

Virus: A virus is a germ that invades the body and causes diseases. A virus is a type of antigen.

Health care worker (Health care provider): A doctor, nurse or midwife who work with clients in a health care facility, i.e. hospital or clinic.

Immune system: the body's resistance or the body's defence mechanism for fighting off infections. The immune system defends the body against infections; it includes the white blood cells, which include CD4 cells, T cells and B cells.

Infant: a person from birth to 12 months of age; a baby.

Infant formula: a breast milk substitute that contains the nutrients an infant needs. It is a powder sold in tins.

Intercourse: sex that involves one partner entering another's body. Intercourse may refer to oral, anal and vaginal sex.

Intervention: Specific action or strategy to address a particular problem or issue and to accomplish a specific action or outcome.

Maternal: of the mother, or related to being a mother, i.e. maternal blood is mother's blood.

Mixed feeding: feeding both breast milk and other foods or liquids, including water. Mixed feeding increases the risk of transmission of HIV from a positive mother to her child.

Mother-to-child transmission (MTCT): transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery, or breastfeeding.

Nutrients: substances that come from food and are needed by the body, i.e. carbohydrates, proteins, fats, vitamins and minerals.

Opportunistic infection: infections that occur in the presence of immune deficiency (weakened immune system), or HIV-related diseases. Any disease that occurs more frequently in people with HIV.

Oral thrush: a fungal infection of the mouth that looks like white patches or curdled milk.

PCP (Pneumocystic carinii pneumonia): a severe, life-threatening lung infection that causes fever, dry cough and difficulty breathing. It is an opportunistic infection.

PCR (polymerase chain reaction) test: This test detects HIV in the blood and can be done at 6 weeks following possible exposure; it is also may be used to test infants.

PEP (post-exposure prophylaxis): medicine given after someone has been exposed to a virus or disease, such as HIV, in order to prevent infection.

Placenta: organ in the womb that filters the mother's blood and allows oxygen and nutrients to pass through the umbilical cord to nourish the growing foetus.

Postnatal care: care given to mother and baby after the child is born. It includes medical treatment, services on breastfeeding, immunisations, maternal nutrition and support for the mother and her family.

Prevention of mother-to-child transmission (PMTCT): prevention of mother-to-child transmission of HIV.

Replacement feeding: feeding infants who are receiving no breast milk with a diet that provides all the nutrients they need until they can eat family foods. During the first six months of life, replacement feeding should be with a breast milk substitute such as infant formula or modified cow's or goat's milk.

Replicate: to duplicate or make more copies of something.

Resistance (viral resistance): changes in the genetic makeup of HIV that decrease the effectiveness of antiretroviral drugs (ARVs).

Safer sex: Ways to have sex that reduce the danger of acquiring or transmitting HIV or other sexually transmitted infections (STIs).

Sex: sexual activity or behaviour; sexual intercourse.

Sexual orientation: determined by whom a person is physically and emotional attracted to; common divisions are **heterosexual** (attracted to people of the opposite gender), **bisexual** (attracted to people of either gender) or **homosexual** (attracted to people of the same gender).

Sexuality: the experience of being sexual; this is shaped by behavioural, psychological, emotional, social and orientation factors.

Sexually Transmitted Infection (STI): infection that is spread from one person to another through sex or sexual activity. The unprotected sex may include vaginal, oral and anal sex.

Side effect: unintended action or effect of a medication or treatment.

Stigma: mark of shame or discredit; the strong feeling in a society that a type of behaviour is shameful. An attribute of a person that is considered unacceptable.

Symptomatic HIV infection: the stage of HIV infection when a person experiences symptoms. Common symptoms include fever, weight loss and swollen lymph glands.

Transmit (transmitted): to pass on, as in a disease. To transmit HIV is to pass on the virus to another person.

Tuberculosis (TB): A highly contagious (easy to get) bacterial infection that attacks the lungs and other parts of the body.

Umbilical cord: connects the foetus (unborn baby) to the placenta. The umbilical cord carries oxygen and nutrients from the mother to the unborn baby. The umbilical cord is cut after the baby is born and forms the belly button.

Unprotected sex: sexual intercourse without a condom or other barrier to prevent contact with the partner's body fluids. This can be vaginal, anal or oral sex.

Vaginal fluids: liquids produced by the female reproductive system that provide moistness and wetness in the vagina and serve as lubrication during intercourse.

Viral load: The amount of HIV in the blood as measured by a blood test (usually the HIV RNA polymerase chain reaction test, or PCR).

Viral replication: the process by which a virus makes copies of itself, using genetic material in human cells.

Virus: a type of germ that causes infection.

Wasting (syndrome): condition characterised by loss of more that 10% of body weight, and either unexplained chronic diarrhoea lasting more than a month or chronic weakness and unexplained fever lasting more than a month.

WINDOW PERIOD: THE TIME BETWEEN INFECTION WITH HIV AND A DEFINITIVE POSITIVE RESULT ON AN ANTIBODY TEST. FOR HIV, THE WINDOW PERIOD IS USUALLY ABOUT 3 MONTHS.

ADHERENCE COUNSELLING TRAINING SCHEDULE

Day 1

Time	Session	Facilitator
8h00 - 10h30	Welcome and Introduction Adherence Counselling: Expectations & Concerns Personal Experience with Medication HIV Treatment Exercise	
10h30-11h00	*Tea Break*	
11h00-13h00	Natural Course/Progression of HIV Review Opportunistic Infections Understanding HIV Treatment	
13h00-14h00	*Lunch*	
14h00-15h30	Adherence & Resistance Adherence Video	
15h30-15h45	*Tea Break*	
15h45-17h00	Disclosure	

Day 2

Time	Session	Facilitator
8h00 - 10h30	Check-In/Recap Adherence Factors Tools & Systems for Adherence	
10h30-11h00	*Tea Break*	
11h00-13h00	Nutrition Benefits & Limitations of HIV Treatment	
13h00-14h00	*Lunch*	
14h00-15h30	Inter-Disciplinary Team and the Role of the Community Counsellor	
15h30-15h45	*Tea Break*	
15h45-17h00	HIV Treatment Guidelines & Treatment Supporter	

Day 3

Time	Session	Facilitator
8h00 - 10h30	Check-In/Recap Adherence Counselling Overview Stage 1: Pre-HIV Treatment Initiation	
10h30-11h00	*Tea Break*	
11h00-13h00	Stage 1: Pre-HIV Treatment Initiation Role Play (continued) Managing Side Effects	
13h00-14h00	*Lunch*	
14h00-15h30	Stage 2: HIV Treatment Initiation	
15h30-15h45	*Tea Break*	
15h45-17h00	Role Play	

Day 4

Time	Session	Facilitator
8h00 - 10h30	Check-In/Recap Stage 3: HIV Treatment Maintenance	
10h30-11h00	*Tea Break*	
11h00-13h00	Reviewing a Counselling Vignette Adherence Scenarios: What Would You Do?	
13h00-14h00	*Lunch*	
14h00-15h30	Stage 4: Re-Motivation or Treatment Change	
15h30-15h45	*Tea Break*	
15h45-17h00	Stage 4: Re-Motivation or Treatment Change Role Play	

Day 5

Time	Session	Facilitator
8h00 - 10h30	Check-In/Recap Adherence Review: Roller coaster of HIV Self-Care	
10h30-11h00	*Tea Break*	
11h00-13h00	Counselling Skills Assessment HIV Treatment Exercise Debriefing Wrap – up/Evaluation	
13h00-14h00	*Lunch*	

ADHERENCE COUNSELLING COURSE EVALUATION

Please fill out this questionnaire and return it to your course facilitator before you leave. You do not need to write your name on this sheet. It will be used to adapt the training and make it more appropriate for community counsellors.

1. Please complete the following by ticking the column of your choice.

PLEASE RATE THE QUALITY OF THE FOLLOWING…	VERY POOR	POOR	FAIR	GOOD	EXCELLENT
Overall Content of Course					
Participant Manual					
Presentation of Material by Trainers					
Participant / Group Activities					
Facilitation of Activities by Trainers					

2. Think about what you *already knew* and what you *learned during* this training about Adherence Counselling. Then evaluate your knowledge in each of the following topic areas related to Adherence Counselling ***before*** and a***fter*** this training.

1 = No knowledge or skills **3 = Some knowledge or skills** **5 = A lot of knowledge or skills**

BEFORE TRAINING					*SELF-ASSESSMENT OF YOUR KNOWLEDGE AND SKILLS RELATED TO:*	AFTER TRAINING				
1	**2**	**3**	**4**	**5**	Understanding Adherence Factors	**1**	**2**	**3**	**4**	**5**
1	**2**	**3**	**4**	**5**	Pre-HIV Treatment Initiation Counselling	**1**	**2**	**3**	**4**	**5**
1	**2**	**3**	**4**	**5**	HIV Treatment Initiation Counselling	**1**	**2**	**3**	**4**	**5**
1	**2**	**3**	**4**	**5**	HIV Treatment Maintenance Counselling	**1**	**2**	**3**	**4**	**5**
1	**2**	**3**	**4**	**5**	Re-Motivation or Treatment Change	**1**	**2**	**3**	**4**	**5**

3. Any comments or suggestions to improve this course?

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