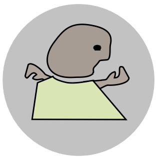





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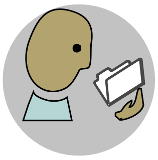


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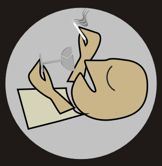
Guide for Trainers



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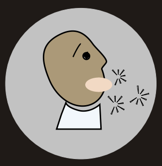

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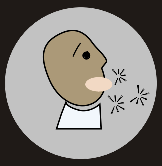

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Children's ART Adherence Resource Pack

Children's Art Adherence Resource Pack

Guide for Trainers

Equipping people involved in antiretroviral treatment
(ART) for children with the relevant attitudes, knowledge
and skills to provide effective adherence counselling for
children and their caregivers

An initiative of the
Adherence Networking Group
2006

Acknowledgements

Development of Guide for Trainers

This Guide for Trainers draws on the Children's ART Adherence Resource Pack also developed by the Adherence Networking Group (see below). Those directly involved in developing the Guide for Trainers were:

- Saranne Meyersfeld (AIDSTEC) who conceptualised and developed the materials for the Guide
- Robin Hamilton (Aurum Institute) who edited the Guide
- Ray Lazarus (PHRU) who provided comment.

The Adherence Networking Group

The Adherence Networking Group (ANG) is a loose alliance of individuals with an interest in ensuring that psychosocial issues related to adherence to anti-retroviral medication are taken into account in programmes targeting HIV/AIDS. ANG members work in a range of organisations involved in programmes related to the HIV/AIDS epidemic. Currently the group comprises: Pierre Brouard (Centre for the Study of AIDS); Robin Hamilton (Aurum Institute); Lauren Jankelowitz (Community AIDS Response); Ray Lazarus (Perinatal HIV Research Unit); Saranne Meyersfeld (AIDSTEC); Helen Struthers (Perinatal HIV Research Unit) and Tumi Tshabalala (Perinatal HIV Research Unit).

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Contents

Appendices

Introduction

Training materials for a 4-day training course on counselling to support children's adherence to ART

Note *that materials in this section are primarily for the use of trainers who will be training lay counsellors in ART adherence for children.*

Course aims and objectives

Aim

- To equip people involved in the planning, provision and support of antiretroviral treatment (ART) interventions for children with the relevant knowledge, attitudes and skills in order to provide counselling that facilitates adherence to the relevant ART regimen.

Objectives

- To revisit the concept of ART, the critical value of adherence and related concepts in relation to children
- To develop understanding of the wide range of factors that affect children's adherence to ART
- To develop the knowledge, skills and confidence needed for counselling with regards to ART adherence in children
- To develop the knowledge, skills and confidence necessary to support the caregiver and family in promoting adherence in children
- To encourage an approach to ART adherence counselling as being a partnership between the caregiver and child and the health care team
- To encourage a child-centered approach, which emphasises the best interests of the child and encourages children to be active participants in their own treatment
- To develop an understanding of the need to make counselling relevant to the developmental level of the child and for changes as the child matures
- To develop familiarity with the 3-stage model of ART adherence counselling as it applies to children and their caregivers
- To develop knowledge of the various enablers of, and obstacles to, ART adherence in children
- To develop knowledge of the wide range of ART side-effects and how to manage their impact on adherence in children

- To develop participants' insight into their own personal beliefs about children and caregivers and how these might impact on ART adherence counselling

Selecting a course trainer

The person selected to take on the task of facilitating training in ART adherence counselling for children should meet the following criteria:

- He/she should have experience in facilitating small groups for the purpose of learning new skills.
- He/she should have a background in a field related to psychosocial functioning, such as psychology, social work, sociology, psychiatric nursing or any other behavioural science.
- He/she should be familiar with the content of, and the rationale behind, adherence counselling.
- He/she should have a strong knowledge base with regards to HIV/AIDS, its progression, treatment and other related issues.

As preparation for this training, he/she should carefully read and understand the content of the Adherence Resource Pack (dealing primarily with adults) and the Adherence Resource Pack for Children.

Note to the trainer

This section is aimed at assisting the trainer to impart the required information and help the trainees develop the necessary skills. There are 27 activities that are offered for use in the training programme. Some activities have information sheets for participants to use – these follow each activity.

Each activity is described in the following format:

- Course module title
- Activity: specifies the type of activity, e.g. a role-play, lecture, small group discussion, etc.
- Outcomes: specify the outcomes of the activity
- Duration: an estimation of how long the activity would take to carry out
- Suggested method: step-by-step suggestions for how to conduct the activity
- *Trainer's notes*: tips that may be helpful for the trainer to know or keep in mind

- Trainer's materials: information for the trainer to use, and in some cases to use as handouts
- Information sheets: numbered and linked to activities

In addition to the activities, four different tools for evaluation of the training course and, at a later stage, how the counsellors implement the training, are provided as appendices.

Criteria for selection of course participants

Remember that this is an advanced and specialised counselling course. Participants should begin the course with an existing foundation upon which the course can build. Participants will need ongoing training and supervision in order to become fully competent.

Pre-requisite areas of competence include:

- the knowledge, skills and values required for basic counselling
- foundation knowledge regarding various models, theories and approaches to counselling
- basic HIV/AIDS knowledge
- knowledge and skills regarding pre- and post-test HIV counselling, VCT and PMTCT
- introductory skills and knowledge with regards to counselling of particular client groups such as couples, children, families and clients abusing substances
- understanding of the role and necessity of regular supervision / mentorship / debriefing.

Entry into this course assumes that participants have undergone a minimum (or the equivalent) of the following:

- a 3-day HIV/AIDS information course
- a 10-day counselling course
- a 3-month period of supervised / monitored HIV/AIDS counselling interventions.

It is recommended that participants have completed a five-day ART adherence counselling course.

Note

In reality some trainers will be faced with a group of participants who do not meet all these entry requirements. At the discretion of the trainer, it is then essential to re-visit basic facts and basic counselling skills before starting training on adherence counselling for children.

On the other hand, if a group of participants meets the above requirements and has experience in adherence counselling with adults, then time allocated to dealing with general information on HIV can be reduced and more time spent on information specific to children or to additional role-plays in counselling.

Four-day introductory course on ART adherence for children and their caregivers

The structure, content and activities of this course are presented as a guide to use in a way that best suits the participants, the trainer and the setting. We believe that approximately four days is needed to develop sound adherence counselling skills. However in your setting, this may be influenced by other constraints such as the amount of time available for training and the level of knowledge, skills and experience of the participants.

Participants should receive the appropriate certification on completion of the course. For example, the certificate could say “XXX has attended a four-day introductory course on adherence counselling for children and their caregivers”.

The course uses a participatory learning approach because we remember:

- about 20% of what we hear
- about 40% of what we hear and see
- about 80% of what we discover and experience ourselves.

Suggested programme for training:

		Day One	
08h30:	1.	Welcome and introductions	30 mins
09h00:	2.	Ground rules	15 mins
09h15:	3.	Self-awareness exercise	45 mins
10h00:	4.	Adherence versus compliance	15 mins
10h15:		Tea	15 mins
10h30:	5.	River of Health	1½ hrs
12h00:	6.	Mock ART exercise (part 1)	30 mins
12h30:		Lunch	45 mins
13h15:	7.	The facts about ART and children	2 hrs
15h15:	8.	Passing on the facts about ART for children	45 mins
16h00:		Feedback and closure	
		Day Two	
08h30:		Welcome and recap	15 mins
08h45:	9.	Adherence and the health care team	1½ hrs
10h15:		Tea	15 mins
10h30:	10.	Using a health care team approach	45 mins
11h15:	11.	Child development and counselling	1 hr 15 mins
12h30:		Lunch	45 mins
13h15:	12.	Caregiver challenges in ART for children	1½ hrs
14h45:	13.	Children's rights	1 hr
15h45:		Evaluation and closure	15 mins

Day Three

08h30:		Welcome and recap of day 2	15 mins
08h45:	14.	Disclosure: case study	1 hr
09h45:	15.	Disclosure and child development: Scripted role-plays	30 mins
10h15:		Tea	15 mins
10h30:	15.	Scripted role plays (continued)	1 hr
11h30:	16.	Age appropriate information/disclosure: Role-play	1 hr
12h30:		Lunch	45 mins
13h15:	17.	The three stages of adherence counselling	15 mins
13h30:	18.	Revisiting contracting	30 mins
14h00:	19.	Stage 1: Pre ART-Readiness assessment	1 hr
14h45:	20.	Factors in ART readiness: Case study	45 mins
15h45:		Evaluation and closure	

Day Four

08h30:		Welcome and recap of day 3	15 mins
08h45:	21.	Stage 1: Pre ART-Preparation and treatment plan	1 hr 15 mins
10h00:		Tea	15 mins
10h15:	22.	Mock ART exercise feedback (part 2)	30 mins
10h45:	23.	Side-effects and children	1 hr
11h45:	24.	Stage 2: ART initiation and maintenance	1 hr
12h45:		Lunch	45 mins
13h30:	25.	Strategies to maintain adherence	45 mins
14h15:	26.	Stage 3: Re-motivation / treatment change	75 mins
15h30:	27.	Assessment: Multiple choice Q&A	15 mins
15h45:		Evaluation and closure	15 mins

Activities

Activity 1

Course module title:	Introductions
Activity:	Round-robin introductions

Duration:

20 minutes

Outcomes:

- Participants are better acquainted with each other.
- The trainer knows more about the members of the group.

Suggested method:

1. The trainer should introduce her/himself first by providing the group with some information about her/his career background, how s/he came to be involved in this course, and what her/his role will be over the next four days.

2. Then ask participants to introduce themselves by answering the following questions (which can be written up on flipchart paper):

- What is your name?
- What does it mean?
- Why do you think it was given to you?
- Where do you work and what is your current work role there?
- How did you come to be on this course?
- What is the course's relevance to your work?

3. Going around the group in a round robin, allow each participant a few minutes to answer these questions.

Trainers Notes:

Trainer's notes:

- Encourage participants to describe their work background as this should help you to contextualise their role and, therefore, the specific area of skills and knowledge that they will need to develop.
- Highlight the strengths which participants bring to the group as a result of their already-acquired experience. Ask them to share their experiences with the group during the course of the programme.

Activity 2

Course module title:	Ground rules
Activity:	Group discussion

Duration:

10 minutes

Outcomes:

- Basic ground rules are agreed between participants and trainer to enable the training to proceed smoothly.
- Participants understand the link between ground rules and contracting in counselling sessions.

Suggested method:

1. Ask the group what ground rules or agreements they think will make the training easier to run. Write these up on flipchart paper.

2. Make sure that the following are included. If they are not mentioned by the participants, add them to the list:
    - Keep confidentiality.
    - Attend all of course.
    - Be punctual so that sessions start on time.
    - Turn cell-phones off.
    - Take responsibility - you are responsible for your own learning on this course.
    - Give yourself permission to risk, to "not know", to experiment.
    - Give yourself permission to do what you need to do to help you get as much as possible out of the course (e.g. ask for clarification, take a break).

- Use direct communication - say what you feel. Speak for yourself and not on behalf of others.
- Say only as much or as little about yourself as you feel comfortable with.
- You are free to stop the process at any time if you are feeling uncomfortable with what is happening.
- The primary language of the course is English. If you feel you do not understand what is being said, you are responsible for asking for clarity.
- This course is a training event and not intended to be a therapeutic experience, although it may provide a growth opportunity for participants. Both trainers and participants share the responsibility of maintaining the boundary between training and therapy.

3. Clarify any ground rules which are not clear to everyone.

4. Ask the participants if they are willing to agree to the list of ground rules. Discuss any with which participants have difficulties.

5. Then stick the list up on a wall, where the list is visible to everyone. Refer to the list through the training, if ground rules are broken.

6. Remind participants that in counselling, the counsellor similarly sets up a contract with the client at the start of the process, which is comparable to a set of ground rules. If there is sufficient time, ask participants to recall the content of the counselling contract.

Trainers Notes:

Helpful processes to encourage in the group

- Be aware of both thoughts and feelings - they are not the same thing.
- Speak in the first person only (avoiding "one", "you", "us", etc).
- Speak directly to another person in the group, instead of speaking about "him/her".
- Listen actively to everyone.
- Avoid theorising, generalising and anecdotes. These tend to obscure and avoid self-disclosure.
- Learning can be painful. Too much pain or anxiety may block learning, but some tension is motivating.
- Understand that this course may evoke strong feelings in you at times. Be prepared for this. Be gentle with yourself, and talk to the trainer if you need to.
- Counselling is mainly about what happens between people and frequently process is ignored. In this course, both the content and process of training will be focused on the present. Remind participants that they will work in the here and now and deal with the content in relation to themselves as much as possible. Where process and content issues both demand attention and time is limited, the training course will deal with the process issues as a priority. As a result the course may not cover all the content.

Activity 3

Course module title:	Self-awareness
Activity:	Self-awareness exercise

Outcomes:

- Participants show increased self-awareness.
- Participants have increased insight into the perceptions of others.
- Group cohesiveness is improved.

Duration:

45 minutes

Suggested method:

1. Each learner folds over a sheet of A4 paper (and then tears or cuts it into the shape of a T-shirt).
2. Each participant is asked to write on one side what others know about them. On the other side of the T-shirt they should write what others don't know about them.
3. Ask the participants to form small groups and discuss what others know about them.
4. Staying in the same groups, ask them to share now what others don't know about them.
5. In the large group, ask participants to share how this exercise felt for them and why.

Trainers Notes:

Trainer's notes:

- Acknowledge the participants for their willingness to disclose about themselves.
- Link this exercise with the need for ongoing self-awareness in this field. This is important in order to recognise the emotional impact of dealing with children and caregivers infected and affected by HIV and AIDS.
- Stress the importance of supervision and support.

Activity 4

Course module title:	Adherence versus compliance
Activity:	Group discussion

Outcome:

- Participants understand the difference between compliance and adherence and how this may influence one's approach to counselling for children on ART and their caregivers.

Duration:

15 minutes

Suggested method:

1. Explain to participants what the two terms mean (according to the definitions given below).

2. Open up discussion about the differences between the two words in terms of implications, philosophy, attitude and relationships between caregiver/child and health care worker.

3. Check whether the participants agree on using the term adherence from now on.

Trainers Notes:

Trainer's notes:

Compliance: The extent to which the patient's behaviour (taking medication, following diets, or making other lifestyle changes) coincides with medical or health advice. Compliance often has connotations that the health-care worker knows best, with the patient passively following the advice of the health-care worker.

Adherence: The degree to which a patient follows a treatment regimen which has been designed in a consultative partnership between the client (caregiver/child) and the health care worker. It encourages discussion about the treatment regimen.

Collaboration: This is another term that some people like to use as it implies that the patient is part of the health care team. It also indicates that he/she is 'on board' with the treatment programme and working together with the health care personnel involved in his/her care.

Old-style compliance

- Health-care worker is the expert.
- Health-care worker has all the important knowledge.
- Patient is passive and ignorant.
- One-way communication.

Collaboration

- Health-care worker and caregiver/child are all "experts".
- Health-care worker and caregiver/child have different kinds of knowledge.
- Three-way communication.
- Alliance formed between all members of the health-care team and the caregiver/child.

Activity 5

Course module title:	River of health
Activity:	Personal drawings, paired discussion and group discussion

Outcomes:

- Participants recall their own health experiences and medication issues during childhood.
- Participants link their own childhood health issues to an understanding of the issues that children taking ART may face.

Duration:

1½ hours

Suggested method:

1. The trainer hands out pieces of A1 or A2 flipchart paper and pens. The trainer then instructs participants to think of the history of their health from birth to the age of 18 years. Ask them to remember any major or minor illnesses, hospitalisation, treatment for any health problem, medication they may have needed to take, and any other challenges in terms of health.

2. Participants are then asked to draw their childhood history of health using the imagery of a river. Their birth is at the source of the river and the end of the river represents the age of 18 years.

3. In drawing the river, difficult experiences or challenges along the way could be represented as the river getting narrower, waterfalls, and rocks and other obstacles in the river. Allow 15-20 minutes for drawing.

4. Then ask the participants to look at their drawings again and discuss answers to the following questions in pairs:
   - What do you remember about your childhood health?
   - Were you ever sick? What were the illnesses?
   - How did you feel about being sick?
   - How were you treated (with western medicine, traditional medicines or home remedies)?
   - Who gave you the medication?
   - Was it difficult or easy to take medication as a child? If difficult, what was difficult about it?
   - Did anyone explain to you the reason for the medication? How did they explain it?

5. Invite several participants to share their experiences with the larger group.

6. Ask participants how they think their childhood experience can help them to understand the challenges that children on ART might face.

Trainers Notes:

Trainer's notes:

- Encourage the participants to acknowledge feelings about their own experience. Suggest they imagine how this experience could be generalised to other people on chronic medication. They should realise that there are numerous demands in taking medication and that others may have a different, but also challenging experience.
- Encourage the participants to become aware of the complex demands and challenging issues involved in giving children ART.

Activity 6

Course module title:	Mock ART exercise (part 1)
Activity:	Paired discussion to prepare for homework exercise

Outcomes:

- Participants experience the challenges of having to take specific pills at a specific time of day.
- Participants experience being a treatment supporter.
- Participants learn to strategise about how to fit medication into one's lifestyle.
- Participants learn to think about ways to make pills more palatable.

Duration:

30 minutes

Suggested method:

1. Divide the participants into pairs. Try to choose pairs on the basis of participants living in close proximity. If the number in the group is uneven, have an extra caregiver / treatment supporter in one group.

2. One in each pair is designated as the patient, while the other is designated the caregiver or treatment supporter.

3. Each pair should discuss and decide upon:
   - a 12-hourly dosage schedule that will fit into the patient's lifestyle (e.g. 7 am and 7 pm daily)
   - ways to link daily activities with dosage times (e.g. television / radio programmes, meal times, etc.)
   - how the treatment supporter will help the patient remember to take the treatment (e.g. phone or SMS the patient as a reminder, be present to supervise the treatment).

4. Hand out “pills” to each pair. Each participant is given a packet of “pills” (sufficient for a four-day trial = 6 pills). The ”pills” should be large and sour (e.g. cal-c-vita or sourballs).

5. In each pair, the treatment supporter should show the patient the pills, explain that they do not taste good, and discuss ways of making the pill-taking easier

6. In each pair, the treatment supporter should instruct the patient how to take the “pills” according to the prescription details, which are written up on flipchart paper (see below).

7. Also hand out a diary card to each treatment supporter to fill in daily.

8. Ask the participants to follow the regimen, starting today.

9. Tell participants that, there will be time on the last day of training for feedback on this exercise. (For the feedback session, see Activity 22.)

Diary Card

Name: ....

Assistant’s name: ....

Day	Am	Pm
1	☼	★★
2	☼	★★
3	☼	★★
4	☼	★★

Prescription

Day one

1 pill on empty stomach in the evening

Day two

1 pill with food in the morning

1 pill on empty stomach in the evening

Day three

1 pill with food in the morning

1 pill on empty stomach in the evening

Day four

1 pill with food in the morning.

Activity 7

Course module title:	The facts about ART and children
Activity:	Interactive lecture

Duration:

2 hours

Outcome:

- Participants understand the medical facts about ART and children.

Suggested method:

1. If possible, give copies of information sheets ***(ART: The facts*** and ***ART: Abbreviations)*** to all participants a day or two before the training begins. Ask the participants to read through the handout and bring any questions they may have to this session. You may then use this time to answer questions. This should take no longer than 1 hour.

2. Alternately, present the facts to the participants in the form of a talk. This should take about 1 hour. Again, allow time for questions. Provide participants with copies of ***ART: the facts*** and ***ART: Abbreviations*** handouts.

3. Remember to adapt the information provided to fit the previous knowledge and needs of your group. If participants' understanding of facts about HIV/AIDS and ART in adults is good, you could move faster through this part of the information and spend more time on information relating to children.

4. End the training session with a quiz, in which you divide the group into two teams, and ask each team in turn questions based on the handout. The team that gets the most answers right can then be given a small prize.

ART – the facts

Q: **What is HIV?**

A: HIV stands for human immune deficiency virus. HIV is a retrovirus. This means that HIV is constantly mutating or changing.

Q: **How does HIV replicate?**

A: HIV replicates by changing its genetic RNA into DNA using the host's cells.

HIV targets (mostly) the CD4+ T-Lymphocyte cells in the body. Once it has attached to the host cell (intracellular viral replication), HIV uses three key viral enzymes which it brings with it. These three enzymes are:

- the reverse transcriptase enzyme (RTE)
- the integrase enzyme (IE)
- the protease enzyme (PE).

The enzymes are essential for infecting the body with HIV, further replicating HIV and developing more infectious HIV.

Q: **What measures are used to assess the extent of HIV infection?**

A: *Two measures are used:*

- The **CD4 cell count** measures the number of CD4 cells in a sample of blood. The fewer cells there are, the more serious is the level of immune suppression.
- The **viral load** is a measure of the number of viral particles or 'copies' of HIV per ml of blood. A rising viral load indicates active HIV disease.

Q: **What is antiretroviral therapy or ART?**

A: This involves the use of antiretroviral drugs to suppress (reduce the frequency of) replication of HIV in the body and its destruction of the immune system. At the same time, the body's immune system is allowed to function normally.

ART is also sometimes referred to as anti-retroviral treatment, anti-retrovirals (ARVs); HIV therapy; or anti-HIV drugs.

Q: **What are the primary goals of ART?**

A: *The primary goals of antiretroviral therapy are:*

- to suppress the viral load as much as (and as long as) possible;
- to restore and/or preserve immunological function;
- to improve quality of life; and
- to reduce HIV-related morbidity and mortality.

Note: Successful long-term ART will possibly result in viral load tests indicating an undetectable viral load because there is so little virus in the body. However, the person is still HIV positive and CAN infect another person - although the level of risk is lower.

Q: **What is triple therapy, combination therapy or HAART?**

A: Triple therapy, as it states, involves the use of three types of drugs for treating (not curing) HIV. In the early days of the epidemic (1988), mono-therapy (one drug) in the form of AZT was used to delay the onset of AIDS. Later on, dual therapy (two drugs) was seen to be better than mono-therapy, until triple-therapy or combination drugs were produced.

In order to maintain ongoing viral suppression as long as possible, combinations of ART are highly recommended. Triple/combination therapy is also known as Highly Active Anti-Retroviral Therapy (HAART). Combination therapy for HIV infection has led to decreased mortality rates and more effective long-term control of the disease.

Q: **How does triple therapy ART suppress viral replication?**

A: Triple therapy ART acts on two of the three different enzymes of HIV in order to reduce viral replication and to prevent the development of resistant strains of the virus. The drugs that are currently available can only inhibit the reverse transcriptase enzyme (RTE) or the protease enzyme (PE). There are no drugs available to inhibit the integrase enzyme (IE).

Q: **Does a patient take ART for life?**

A: ART is not a cure and, based on our current understanding, anyone on ART will need to take the drugs for life, as long as they are working.

Q: **What is adherence?**

A: *Adherence means that medication is taken according to a treatment plan designed in consultation with the patient and involves taking:*

- the recommended dose
- at the recommended time and
- in the recommended way.

Studies have shown that in order for one to be adherent, on average this should entail taking at least 19 out of 20 doses (i.e. missing less than 3 doses in a month). This means that an adherence rate of more than 95% must be sustained in order to maintain control over viral load, build the immune system and prevent the development of resistance to the drug (see below).

Q: **What is non-adherence?**

A: *Non-adherence means not following the treatment plan. In other words, any one of the above three criteria is not met - for whatever reason, the client is:*

- NOT taking the recommended dose OR
- NOT taking it at the recommended time OR
- NOT taking it in the recommended way.

Some examples of non-adherence are:

- incorrect doses (e.g. too little/too much medication, taken in the wrong way)
- missed doses (e.g. due to changes in routine, travel, forgetfulness)
- delayed doses (i.e. not taking the dose on time)
- failing to follow guidelines (e.g. social pressures, misinformation)
- experimenting with dosing (e.g. trying unapproved once-daily regimens)
- drug holidays (e.g. transient aversion to taking pills).

Periods of no treatment or sub-optimal treatment can result in the replication of the virus, increasing the risk of mutation and the development of drug-resistant strains.

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

Strictly speaking, taking anything less than 100% reflects non-adherent behaviour. Even with 90-95% adherence, there is a significant increase in viral load for most patients.

Almost all patients will be non-adherent at some stage. Adherence tends to decline over time.

Q: **What is drug resistance?**

A: HIV is a retrovirus and, therefore, mutates (changes its genetic structure) at an extraordinary rate on a daily basis. The result is that some strains of HIV develop that are naturally resistant to the presence of one or more drugs. HIV drug resistance refers to a reduction in the ability of a drug to block replication of HIV.

Resistance can apply to a particular drug or to a class of drugs or to a combination of drugs. For example, patients who develop resistance from taking one non-nucleoside reverse transcriptase inhibitor (NNRTI) are likely to be cross-resistant to other drugs in the same class. The development of resistance thus significantly reduces treatment options.

Q: **What are the signs that a patient is drug resistant?**

A: Viral load tests can determine from a blood sample how much virus is replicating in the body. If viral load increases substantially while a person is on a combination of ART, the most likely culprit is drug resistance. Unfortunately, viral load tests cannot tell which particular drug the HIV is resistant to.

Q: **When does or can the doctor change ART?**

A: There are a few options available for adjusting or altering an ART regimen when necessary. Of course, this is always done in close consultation with the health-care team.

Q: **What is adherence counselling?**

A: This is counselling provided to a person either starting ART, or on ART, to assist them to make choices that support their treatment and enable them to adhere to the medication. This counselling is ideally provided by a person who has been trained in HIV/AIDS counselling skills and in adherence counselling.

Q: **What is adherence support?**

A: This is support in the form of information, discussion, encouragement and motivation, provided by anyone in the patient's life who plays a supportive role. This could include a doctor, a nurse, a dietician, a pharmacist, a treatment assistant, a family member, a partner or a friend.

Q: **What are the different categories of ART drugs?**

A: There are three drug categories. *They are:*

Classification of antiretroviral agent	Abbreviation	Enzyme inhibited
Nucleoside reverse transcriptase inhibitors	NRTIs	Reverse transcriptase
Non-nucleoside reverse transcriptase inhibitors	NNRTIs	Reverse transcriptase
Protease inhibitors	PIs	Protease

Q: **When should one start ART in adults?**

A: It is primarily a doctor's role to assess the patient's physiological stage of readiness for beginning ART. Laboratory staging tests, such as CD4 tests, must be conducted before a decision about treatment is made.

Characteristics	Procedure
CD4 > 200 cells/mm^3 Asymptomatic WHO I and II[1]	Refer to the wellness clinic and/or support groups
CD4+ count < 200 Irrespective of the WHO stages	Treatment recommended
WHO stage IV* Irrespective of CD4 count	Treatment recommended

Q: **Why is there a need to be cautious in diagnosing HIV infection of children?**

A: Not all babies born to HIV-infected women become infected. Even when there is no intervention to prevent infection, only about 30% of babies become infected. With single dose nevirapine to mother and baby to prevent infection, this is usually reduced to about 12-15% of babies becoming infected. It is important to avoid labelling babies born to infected mothers as HIV positive. Rather, until a definitive diagnosis can be made, they are called HIV **exposed**.

Making a diagnosis is complicated by the fact that antibodies to many infections can be passed on to babies from their mothers. HIV antibodies are no exception and can remain in the child's system for up to 18 months, although they are usually gone by 15 months.

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* Refer to WHO Adults HIV/AIDS Staging System

Q: **What HIV test should be used?**

A: The HIV Elisa test tests for **antibodies**. If an Elisa test is positive, this may show either the baby's or mother's antibodies - we cannot tell the difference.

The (DNA) PCR test tests for the **HIV virus** itself. This test is effective from 6 weeks[†].

If a child is under 18 months:

- If mother is HIV positive and the child is 6 weeks or older, the child needs to have a PCR test.
  - If the PCR is positive, the child is HIV positive.
  - If the PCR is negative you need to check when the child last breastfed – if it is more than 6 weeks ago, then you can regard the child as HIV negative. If the child is still breastfeeding, you have to repeat the PCR 6 weeks after she stops feeding.
- If the mother's status is unknown, and the child has features of HIV (described below), counsel and test mother with Elisa test, or child with Elisa if mother not available.
  - If Elisa test is negative, the child is negative (except if still being breast fed, when test needs to be repeated at least 6 weeks after cessation of breast feeding).
  - If Elisa test is positive, do a PCR test if over 6 weeks.
- If the child is over 18 months, do an Elisa test:
  - If positive, the child is HIV infected.
  - If negative the child is not infected unless still breastfeeding. If still breastfeeding, do Elisa test 6 weeks after stopping breastfeeding.

[†] The PCR test may not be available at all centres – if it is not available do an Elisa test at 12 months and if positive at 18 months again.

Q: **What other signs could suggest HIV infection in children?**

A: Testing of children whose mother's HIV status is known should be done as early as possible (with PCR if possible), but in children whose mother's status is not known the following may be the presenting features:

Failure to thrive

- Not growing according to the road to health card.
- Not keeping up with developmental milestones.

Some developmental milestones

1 month	Raises head, alert to sound
2 months	Holds head up, smiles socially, lift chest off floor
4 months	Rolls front to back, laughs
6 months	Sits unsupported, babbles
9 months	Pulls to stand, says "mama"
12 months	Walks alone uses 2 words together

Other common symptoms of HIV-related illness in children are:

persistent ear discharge, enlarged lymph nodes, persistent diarrhoea, enlarged liver and spleen, severe nappy rash. If any of these are seen, HIV testing should be considered.

Q: **How does HIV disease progress in HIV-positive children not on treatment?**

A: Without treatment, there seem to be three categories of children in relation to HIV infection:

- Rapid progressors: these children progress to AIDS very quickly, get many opportunistic infections and, without treatment, usually die within the first year. Almost 40% of children fit in this category and half of infected children never reach their 2nd birthday.
- Medium progressors: Features of infection appear early in life but disease progresses more slowly and death occurs within 3-5 years without treatment. About 50-60% of children fit in this category.

- Slow progressors: these children live beyond 8 years without treatment. Between 5% and 25% of children fit in this category.

With babies, deterioration of health can be very rapid. It is very important that the caregiver understands this and brings the baby for a check-up at the first sign of illness.

Q: **How long can children live once on treatment?**

A: On treatment children can live to at least early adulthood.

The well-being of the mother has an effect on the child's prognosis – if the mother is very ill or dies, or has a high viral count and a low CD4 count at birth, the prognosis is worse.

Q: **What other treatments may be necessary for children with HIV infection?**

A:
- Children should be immunised as for all children.
- Oral vitamin A supplementation is important.
- Routine worm treatment should be given.
- Co-trimoxazole (Bactrim) prophylaxis should be provided for opportunistic infections / TB.
- Nutritional advice should be given.

Q: **What if the child has TB?**

A: Complete TB treatment before starting ART or if not possible delay ART for at least 2 months.

Q: **What are the treatment regimens for children?**

A: *The treatment regimens are:*

Regimen	*6 months to 3 years*	*Over 3 years and >10kg*
First line	stavudine (d4T) lamivudine(3TC) Kaletra	stavudine (d4T) lamivudine(3TC) efavirenz (EFV)
Second line	zidovudine (AZT) didanosine(ddI) nevirapine/ efavirenz	zidovudine (AZT) didanosine(ddI) Kaletra

Special considerations:

- Adherence needs to be at least 95%
- Stavudine solution needs refrigeration (if there is no fridge the capsules can be opened and dissolved.)

Q: **When should one start ART in children?**

A: **CD4%:** In children up to the age of about 7 years, the CD4% is used as a measure of the strength of the immune system. In older children and adolescents, the CD4 count is generally used (as for adults).

The medical criteria to start ART for children are:

- Confirmation of HIV-infection
- Repeated hospitalisations (more than 2) or prolonged hospitalisation (more than 4 weeks)
- WHO stage III or IV
- If the child is relatively well, CD4% <20% if under 18 months or <15% if over 18 months.

Q: **Do children get the same side-effects as adults?**

A: Side-effects (e.g. nausea, abdominal pain, vomiting) are those reactions to drugs that are known to occur. Side effects are thought to be less common among children than adults

Mild side-effects:

- Nausea, vomiting and diarrhoea
- Dizziness
- General tiredness
- Nail discoloration
- Pins and needles and pains in hands, legs and feet.

It is recommended that children remain on treatment if the side effects are mild.

Serious side-effects include:

- Persistent generalised fatigue, weakness
- Persistent nausea, vomiting, diarrhoea
- Abdominal pain
- Sudden unexplained weight loss
- Respiratory difficulties
- Neurological problems, including motor weakness

Longer term side effects (more likely to be seen in older children):

- Fat loss from limbs, buttocks and face
- Increased fat around abdomen, buffalo hump and breast

Q: **Should health care workers discuss side-effects with caregivers/children?**

A: HCWs sometimes worry that talking about side-effects will frighten caregivers / children and put them off agreeing to ART, or that talking about side-effects will bring them on. However, failing to inform caregivers / children can compromise trust and credibility and, in the case of serious adverse events, put the child's life at risk. Adherence is increased when caregivers/children know what to expect.

Q: **What should one do in the case of mild side-effects?**

A: *For nausea and vomiting:*

- Give bland plain food.
- Give small amounts at a time.
- Get child to drink ginger tea or fresh ginger.

For diarrhoea

- Mix 8 teaspoons sugar with ½ teaspoon salt in 1 litre of boiled water. Cool and let the child sip frequently.
- Give fruit juice / rooibos tea.
- Do not worry about the child not eating proper food.
- A doctor or nurse could give Buscopan for cramps.
- The child should NOT take Immodium.

For dizziness:

- Adjust the child's medication time to just before bedtime.

General tiredness and not feeling well:

- The child can be given Panado or Brufen.
- The child should get lots of fluids.
- Bed rest may help.

Nail discolouration:

- See the doctor for a special tablet (griseofulvin).
- Sometimes the nail discloration cannot be treated.

Pins and needles or pains in hands, legs and feet (difficult to diagnose in children):

- Keep feet clean.
- Check feet for wounds or sores.
- Massage may help.
- Rooibos tea may help.
- Antioxidants may help.
- Doctor can prescribe Vitamins B, C and Pyridoxine.
- Panado, Brufen, Tryptanol can be given to the child for pain.

Q: **What should one do in the case of serious side-effects?**

A: Get medical evaluation as soon as possible.

Q: **Do children develop immune reconstitution inflammatory syndrome (IRIS)?**

A: Immune reconstitution inflammatory syndrome (IRIS) is a deterioration of the patient's health after starting ART. It can occur in both adults and children. It happens because of the improved immune system interacting with an organism in the body (like TB). This usually happens in the first 6 weeks after starting treatment. If a child becomes ill with temperature, headache, cough, respiratory distress, severe diarrhoea or vomiting or any other worrying symptoms, especially within the first few months of starting therapy, he/she should be evaluated by medical staff at the nearest referral facility urgently.

Abbreviations

AIDS	acquired immune deficiency syndrome
ART	anti-retroviral treatment
AZT	Zidovudine
ddi	Didanosine
DoH	Department of Health
d4T	Stavudine
EFV	Efavirenz
FBC	full blood count
HAART	highly active anti-retroviral therapy
HCW	health care worker
HIV	human immunodeficiency virus
IE	integrase enzyme
IRS	immune reconstitution syndrome
LFT	liver function test
NNRTI	non-nucleoside reverse transcriptase inhibitor
NRTI	nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OI	opportunistic infection
PEP	post-exposure prophylaxis
PI	protease inhibitor
RNA	ribonucleic acid
TA	treatment assistant
VL	viral load
WHO	World Health Organisation
3TC	Lamivudine

Activity 8

Course module title:	Passing on the facts about ART for children
Activity:	Fishbowl role-play, role-play

Outcomes:

- Participants consolidate their knowledge of ART for children.
- Participants gain experience in counselling a caregiver about the facts of ART for children.

Duration:

45 minutes

Suggested method:

1. The trainer should start the activity by conducting a fishbowl role-play with a volunteer participant. The trainer plays a counsellor conducting an adherence counselling session and the volunteer plays a caregiver of a child who is about to start ART. The trainer should focus on clarifying what the caregiver understands about ART for children and providing input where necessary. The other participants are asked to observe the counselling session.

2. Then divide the group into pairs.

3. Ask each pair to role-play a counselling session, imparting the basic facts they have learnt about in the previous activity, and seen modelled by the trainer. One participant plays the counsellor, the other the caregiver of the child about to start on ART. Remind the participants to begin by finding out what the caregiver already knows.

4. Repeat the role-play, with each pair exchanging roles.

5. Provide the group with general feedback on their role-plays.

Trainers Notes:

Trainer's notes:

- Observe that all of the basic counselling skills are integrated into this information-giving session.

Activity 9

Course module title:	The health care team and adherence for children
Activity:	Brainstorming, followed by group work and feedback

Outcomes:

- Participants understand the nature of the counselling relationship between the health-care worker, the caregiver and the child.
- Participants can identify the various members of the health care team.
- Participants understand the roles of the various health care team members in facilitating adherence.

Duration:

1½ hours

Suggested method:

1. The trainer should introduce the activity by presenting an illustration of the triangle of care shown below (see *Trainer's notes*). This could be on a flipchart, overhead projector or Powerpoint presentation.

2. The trainer should then give some input on the counselling relationship:

- The relationship between health-care worker, caregiver and child is complex.
- The child is the index patient, i.e. the person who is the focus of care and whose interests come first.
- There needs to be a positive working relationship between the health-care worker and the primary caregiver in order to promote the best interests of the child.
- Other members of the family group, school personnel and other members of the health care team (HCT) may also play important roles in the life and health care of the child. Their potential contribution – positive or negative

– needs to be considered. If appropriate, they may be drawn into counselling (with the permission of the primary clients, i.e. the caregiver and child).

- This complex set of relationships can be thought of as a triangle (see 1. above).
- Adherence counselling often focuses largely on the primary caregiver. However, the child should not be forgotten.
- The age and developmental level of the child should determine the balance in the triangular counselling relationship:
  - how much the child should be told
  - the kind of responsibility s/he can be given.
  - The health-care worker will need to decide to what extent to involve one or both (of caregiver and child), together or separately.

3. The trainer should read the following statement to participants:

> “Adherence is more readily achieved when a trusting relationship exists between the child and the health care team (HCT), recognising and accommodating the role of the caregiver.”

4. Ask the participants to identify who they think the various members of the health care team might be. Write the answers given on flipchart paper. Add any listed in the *Trainer's notes*, and not mentioned by the group.

5. Now divide the participants up into six groups, and allocate one of the following categories to each group:

- doctor, nurse
- counsellor
- pharmacist, pharmacy assistant
- social worker, psychologist, dietician
- alternative health practitioner, traditional health practitioner, homeopath, herbalist
- treatment supporter, home-based carer (in a palliative care situation)

6. Ask each group to brainstorm:

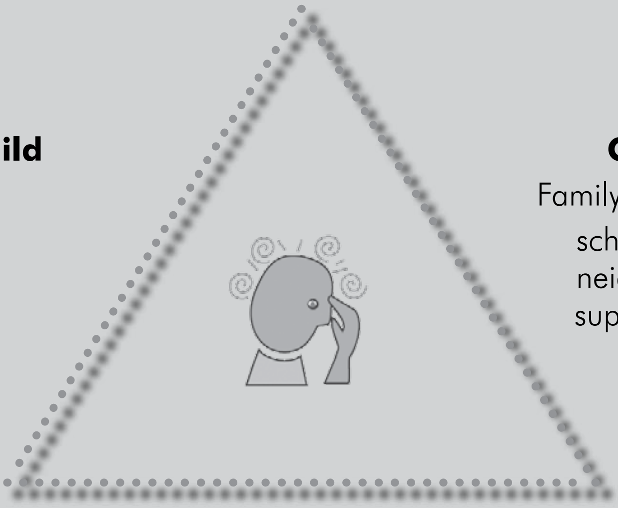
- their role in the adherence process
- their value
- possible interventions they can make
- how they can communicate with other team members.

7. Then ask each group to give feedback in a plenary session. Fill in any gaps.

Trainers Notes:

Trainer's notes:

The counselling relationship



Child

Caregivers
Family group members,
school personnel,
neighbours, other
support personnel

Health care team
Counsellor, doctor,
nurse, pharmacist, etc.

Trainers Notes:

Reinforce the idea that each member of the HCT contributes to adherence based on their unique skills. In addition, all members play a crucial role in maintaining trust, continuously monitoring adherence and supporting the child and caregiver through the various stages of ART.

- The various members of the HCT need to respect and support each other in providing care.
- In most ART settings the HCT will include:
  - doctor
  - nurse
  - counsellor
  - pharmacist and assistant
  - social worker.
- Other important members of the HCT who are often only available in more specialised settings or by referral are:
  - dietician
  - psychologist.
- Important supporting members of the HCT are:
  - treatment supporter
  - alternative health practitioner
  - home-based carer (in palliative care situation)
  - support organisations.
- Here are some examples of the different roles of different members of the health-care team:
  - The doctor identifies a rash when conducting a clinical/physical examination.
  - The nurse identifies signs of an opportunistic infection while checking vital signs (e.g. chest problems).
  - The pharmacist finds out that the caregiver did not collect medication due to transport problems.

- The counsellor learns that the caregiver has lost her part-time job and is feeling so desperate that she has missed some doses of the child's medication.
- The social worker learns that an HIV-positive caregiver is missing doses of her ART to try to keep her CD4 count less than 200, so as to keep her disability grant.
- The dietician learns that the caregiver has difficulty ensuring that the child has a nutritious diet.
- The psychologist identifies that depression could be responsible for a child's lack of co-operation with treatment.
- The treatment supporter becomes aware that the caregiver is missing doses as she is not convinced that ART is safe.
- The alternative health practitioner is aware of possible drug interactions with herbs prescribed for the child.
- The home-based carer is aware of a deterioration in the condition of a family group member who has AIDS.

Trainers Notes:

Activity 10

Course module title:	Using a health care team approach
Activity:	Lecture and group discussion

Duration:

45 minutes

Outcomes:

- Participants are more aware of health care provider issues
- Participants understand the need for a collaborative approach and the appropriate relationship between the HCT and the caregiver/child
- Participants understand the need for developing and maintaining trust
- Participants are aware of ways to work with the care-giving system
- Participants are aware of ways to expand the support system.

Suggested method:

1. Write up the following questions on flipchart paper:

- What are the ideal attributes of health-care providers?
- Why should we see caregivers and children as collaborators, rather than as objects of treatment?
- How can the health-care worker develop and reinforce trust?
- What is a treatment supporter, and what role can he/she play?
- How can we help caregivers support their children on treatment?
- How can we help and support the child on treatment?
- How can we expand the support system?

2. Divide the participants into groups of 4-5 participants, and allocate one or two questions to each group. Allow the groups about 10 minutes to brainstorm possible answers to their questions.

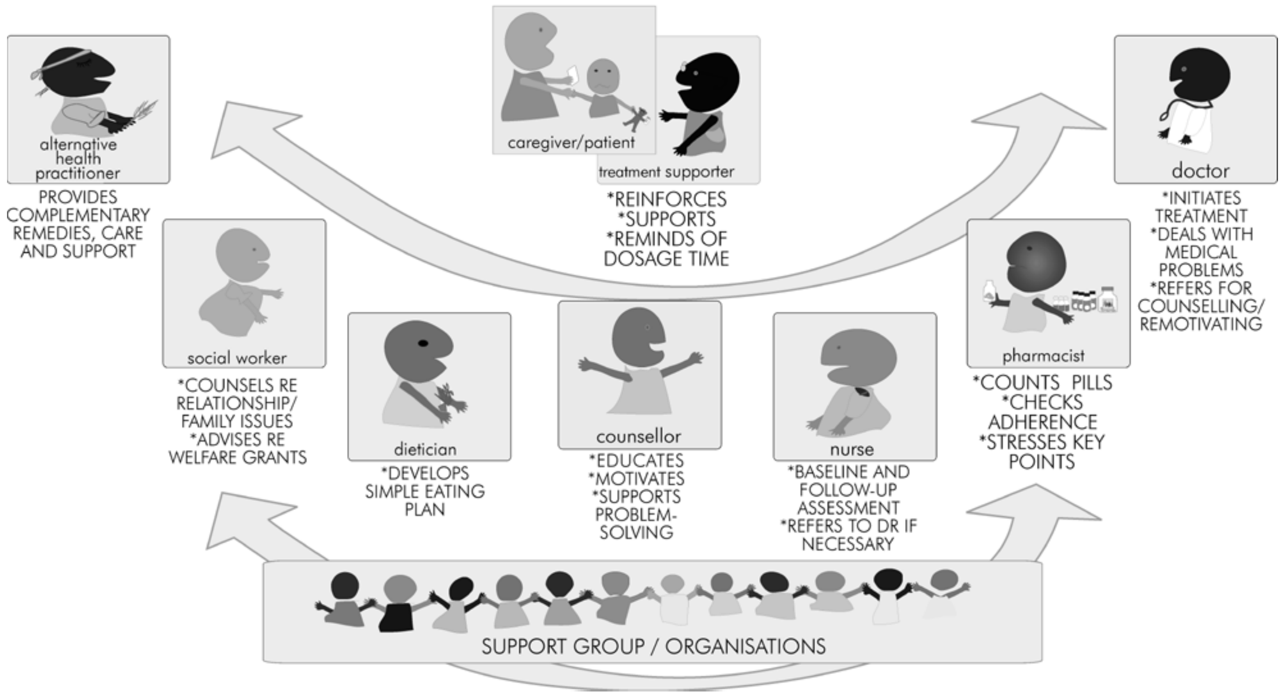
3. Then ask the groups to give feedback in a plenary session. Fill in any gaps using the *Trainer's notes* below.

Information sheets

Give participants copies of the information sheet:

- Sharing information amongst the health care team

SHARING INFORMATION AMONGST THE HEALTH CARE TEAM



Trainers Notes:

Trainer's notes:

Adherence is a complex behaviour.

Key predictors of adherence include:

- the nature of the relationship between the HCT and the caregiver
- caregiver and child factors
- the disclosure situation of caregiver and child
- the regimen
- the system of care.

In order to promote adherence, the HCT needs to adopt a common approach on these kinds of issues.

What are the ideal attributes of health-care providers?

- culturally sensitive
- interested and empathic
- able to assess the situation holistically
- able to communicate flexibly in ways appropriate to the particular individual.

Why see caregivers and children as collaborators in care rather than objects of care?

- The HCT has expert medical and technical knowledge.
- Caregivers and children have expert knowledge about their own lives – its possibilities and limitations.
- Together they can develop workable solutions and times for dosing.

How can the health-care worker develop and reinforce trust as a basis for collaboration?

- The HCT needs to have an open-door approach.
- Reinforce the trusting relationship with child/caregiver.

Trainers Notes:

- Maintaining a safe, non-judgmental space to discuss any problems.
- Give ongoing encouragement and re-motivation.

What is a treatment supporter, and what role could he/she play?

The treatment supporter:

- is anyone close to the caregiver and child who can provide effective support to take medication (e.g. a family member, neighbour, friend, teacher)
- should be identified at an early stage
- should be involved at all stages of the adherence process.
- needs to be someone who is aware of the child's status
- is someone the child knows and feels comfortable with
- is prepared to be involved in counselling / helping to manage adherence
- should preferably be living in the same household.

The role she / he should play is:

- backup to the primary caregiver if the caregiver is unavailable
- support for the caregiver, child and the whole family.

How to help caregivers in supporting their children:

- help them develop critical skills like observation, listening and reflection
- draw on their innate care-giving impulses and aptitudes.

How can we support the child on treatment?

- Tailor the approach to the age/developmental level/emotional state of the child.
- Helping the child understand the illness and disclosure is particularly relevant.
- Explore school performance, leisure interests, friendships.
- Once on ART continue to engage with the care-giving system as a source of support for maintaining adherence.

How can we expand the support system?

Some options outside of the immediate care-giving system are:

- Caregiver-caregiver support: Many caregivers are very willing to share their experiences with others, especially those just starting on ART. Caregivers new to ART may find it easier to share uncertainties and anxieties with another caregiver rather than with a HCW.
- Buddy system can provide emotional support:
    - friend or family member, or someone else affected by HIV (e.g. another caregiver or child), who agrees to offer support to the caregiver or child
    - supporter may or may not be HIV infected and may only know that the child has a chronic illness
    - may be particularly helpful for adolescents, especially if the buddy is able to draw on experience similar to that of the target person.
- Directly observed therapy (DOT), which involves individuals taking one or more of their daily doses under supervision of another person, usually someone who has been trained for the task. This may be essential for children living in difficult circumstances, e.g. in care.
- Support groups can provide both caregivers and children with emotional, practical and problem-solving support from others who face similar challenges.
- Community projects: involvement in community projects may offer opportunities for informal support, as well as more tangible benefits e.g. income generation, for caregivers.

The health-care team may need to assist in facilitating these kinds of support.

Trainers Notes:

Activity 11

Course module title:	Child development and counselling
Activity:	Small group discussion, feedback and interactive discussion

Duration:

1 hour 15 minutes

Outcomes:

- Participants understand that children of different ages differ in their ability to understand and co-operate with treatment
- Participants understand factors that need to be taken into account in counselling children of different ages.

Suggested method:

1. Divide the participants into four small groups.

2. Explain that the task is to look at differences in children's capacities at different ages, i.e. infants/babies, toddlers and preschoolers, primary school children, and adolescents.

3. Give each group one of the topics below. The group should brainstorm differences at the different ages for their topic (e.g. differences in the way that babies, toddlers, primary school age children and adolescents use language).

The topics are:

- how they use language (understand what is said to them and express themselves)
- how they experience and express feelings
- how they relate to others (e.g. dependent / independent, range of relationships)
- what they can do in terms of self-care (seeing to their own needs, taking care of themselves).

4. Allow discussion in small groups and then take feedback from each group. Encourage comment and discussion. Correct obviously incorrect statements.

The detail is less important than emphasising the following points:

- Children change and develop with age.
- Different children develop at different rates.
- Children have different needs at different ages.
- Development can be promoted or held back by circumstances affecting the child.
- Children are resilient and have the ability to survive difficult circumstances.

5. Encourage interactive discussion focussed on the two questions given below (and try to include the points noted below):

Question 1 : *"What can help a child to develop or hold back development?"*

What may help:

- feeling safe and protected, having a sense of trust
- having stable, caring relationships
- caregivers who are sensitive and responsive to needs
- expectations and responses are consistent and age-appropriate.

What may hold the child back:

- illness that affects brain or limits opportunities for play and learning
- illness or depression in a caregiver that interferes with the relationship with the child
- difficult circumstances (e.g. poverty, abuse)
- expectations and responses that are inappropriate to the child's developmental level or emotional well-being.

Note: *Children are resilient and have the ability to survive difficult circumstances, but always need support to build their capacity to do so.*

Question 2: *"What does this mean for counselling caregivers and children?"*

- Be aware of circumstances that could affect the child's development and well-being.
- Children need to be involved in ways and to the extent possible in line with their developing capacities.
- The child's emotional well-being, relationships with others and developmental level (including level of understanding and capacity to express him/herself, as well as capacity for self-care) need to be assessed at every visit. This will help to ensure that expectations of the child are appropriate and take account of changes over time.
- With very young children, the focus of counselling is generally on the caregiver. However, even then, this particular child and his/her specific and changing capacities need to be kept in mind.
- The older the child, the better the child's understanding and ability to express him/herself. However, because of differences between children, counselling must always be adapted to the needs of the particular child.
- Communicate with the child in a manner and at a level that s/he can understand.
- Find out what the child knows. Be guided by the questions s/he asks.
- Use short, simple sentences.
- Younger children understand concrete things that they can touch and see. A doll or teddy bear can be used to make information more concrete.
- Use drawings and demonstration to help a primary school child understand.
- Encourage questions to check understanding.
- Be aware of the child's attention span. (A younger child will lose interest more quickly than an older child.)
- Watch the child's body language to determine whether s/he is taking in the information. (The trainer can ask the group to give or demonstrate examples of attentiveness and lack of attentiveness, e.g. fidgeting, slumping, whining, crying, singing, changing the subject, falling asleep.)
- If the child is inattentive, stop and try again at a later stage.

Trainers Notes:

Trainer's notes: child development

Development can be promoted or held back by circumstances affecting a child

There is an interaction between physical and mental/emotional health and development.

A key factor affecting a child's development is how much circumstances allow him/her to feel safe and protected. This sense of trust in the world starts from a very early age. It develops out of having stable, caring relationships with caregivers who are sensitive and responsive to their needs and whose expectations and responses are consistent and age-appropriate.

- Children's development is enhanced when circumstances allow them to explore and to experiment in ways appropriate to their current phase of development.
- Children who are exposed to difficult circumstances, including those that arise from HIV infection, sometimes cope well. Children are often extremely resilient, surviving extreme circumstances with little or no obvious ill effects. However, no matter how strong a child may seem, every child still needs support to build her/his resilience.

Linking ART to child development

Knowing about child development can help HCWs to promote adherence and promote holistic care:

- Regular assessment can help to identify any possible delay and allow for intervention to try to prevent or limit longer-term disability.
- Treatment needs to be tailored to the needs of the particular child and adapted as the child develops. What works for one child, will not necessarily work for another. What works for a particular child at a young age may not be appropriate for the same child when older.
- A child who is anxious or depressed, may be less co-operative - perhaps even, less responsive - to treatment. It helps to pay attention to the child's emotional and social well-being.

Trainers Notes:

- Also pay attention to the social and family circumstances of the child. Identifying and helping caregivers to overcome barriers to development can support children's capacity for adherence.
- When caregivers are withdrawn – as may happen when caregivers are burdened or depressed, or see no future for their children - this, too, may hold back development. And more extreme circumstances such as poverty, domestic violence, or having to take on adult roles because of ill or absent caregivers, can all impact on children's development.

> "When dealing with adherence in children, we have to keep talking with them about their treatment and adapting our approach as they develop and grow."

Phases of development

One way of reminding oneself to think about a child's level of development is to make a point of checking the child's age at every visit and relating it to what one would expect of a child in a particular phase of development. In other words, are you dealing with a baby, a toddler, a pre-school child, a primary school child, a child in early adolescence or a late adolescent? Each of these phases has characteristic features, for example, how well co-ordinated the child is in his/her large body movements or finer eye-hand co-ordination, how the child makes sense of his/her world, how well s/he is able to understand and use language, how s/he expresses feelings, how s/he relates to others and how much s/he is able to take care of his/her own daily needs.

Because there are individual differences between children in rates and patterns of development, the descriptions in the following tables of typical patterns at each stage are only rough averages. Only if there are marked delays or changes is there cause for concern. In that case, referral for further assessment would be advisable.

Phase	**Characteristics**
Babies (0-12 months)	
Movement	Limited head control and uncoordinated movements. Later on: standing, first steps. Grasps objects with whole hand. Later on: able to grasp small objects using index finger and thumb (pincer grasp)
Cognitive	Learns through senses; gradually able to make links between bits of sensory information (e.g. sound and source of sound) and to co-ordinate hand movements with what s/he can see. Beginning to recognise a few familiar objects, but not consistently.
Language	Differentiates between different sounds. Communication is non-verbal (smiling, crying, makes and practises sounds). Later recognises own and family members' names, understands simple commands and says first few words (at least 3 words clearly).
Emotional	Mainly in response to physical sensation, nurturing. Begins to develop fear of unfamiliar (unexpected sights, sounds, movements and, later, strangers).
Social / Relationships	Interest in faces, recognises familiar situations, tries to communicate. Develops personal relationships with familiar people, shows anxiety if separated from familiar people, especially in unfamiliar surroundings.
Self-care	Dependent on others for most care. Opens mouth for spoon, drinks from cup with help, feeds self with fingers.

Trainers Notes:

Trainers Notes:

Phase	Characteristics
Toddlers (1-2 years)	
Movement	Begins to walk, later on: walks without falling, able to run. Uses hands to do things with objects (e.g. build a tower using 3-4 blocks). Later, scribbles with crayon (lines and circular scribbles).
Cognitive	Begins to group and classify objects (things that go together, things that are different). Begins to be use imagination (pretending) and symbols (understanding that one thing, e.g. picture of apple, can stand for another, e.g. real apple)
Language	Expands vocabulary (20 or more words), puts words together (phrases). Follows simple instructions. Later can speak in sentences of 4 short words. Can listen to short stories. Can express what s/he wants, e.g. *"Mommy stay"*.
Emotional	Feelings expressed directly; easily frustrated, may have temper tantrums; mood often affected by physical state (hunger, cold, illness. May show intense fear and distress in unfamiliar situations, relieved by presence of familiar person.
Social / Relationships	Wanting to become more independent, may resist control. Capable of close, trusting relationships with one or more familiar people; uses secure relationship as a base for exploring and coming back for reassurance. Initially plays alone with toys, later begins to play co-operatively (takes turns).
Self-care	Still dependent on others in many areas. Feeds self with spoon, helps in washing hands. At first only being able to take off clothes, later able to put arms in sleeves with help.

Phase	Characteristics
Preschool (3–5 years)	
Movement	Increasing control of large muscles, can competently run and climb stairs, balance. Finer movements still clumsy, but fine motor co-ordination beginning to develop, e.g. learning to use pencil, scissors.
Cognitive	Thinking is concrete, tied to what the child can see and manipulate; tends to focus on one aspect of situation, cannot easily keep many factors in mind. Tends to relate events to self ("this happened because of what I thought/did"). Difficulty separating make-believe and reality – afraid of monsters, witches, tokoloshes, etc. Lots of *"how"*, *"why"* questions. Beginning to understand/use basic concepts, e.g. size, weight, number, colour, time. Learns through doing and playing (a child's "work").
Language	Talks in sentences, simple conversations. Asks and answers simple questions, can understand concrete explanations (especially with demonstrations/symbols/pictures). Uses words to share interest in something, e.g. *"look, look – this is my car"*.
Emotional	Greater range of emotions, more control over how feelings are expressed, but still impulsive at times. Starting to be able to label feelings in simple ways, e.g. sad, cross, happy. More able to tolerate frustration. Sensitive about making mistakes - needs to be reassured that mistakes are an opportunity to learn, not something to be ashamed of.
Social / Relationships	Wants to be independent, do things for self, but sensitive to adult reactions. Being able to say *"No"* gives a sense of control. Relates everything to the self (egocentric), but developing ability to see another's point of view. Starting to learn what is socially acceptable. Gender identity (seeing self as girl/boy) established. Plays with other children, learning to share. May have imaginary friends (useful and normal). Parent figures still very important as source of support, recognition and praise. Able to separate from parent/caregiver for short periods, if sure that parent/caregiver will return (has not abandoned child).
Self-care	Feeds self, washes and dries hands on own, can undress completely and dress self with help, uses toilet with help and later independently.

Trainers Notes:

Trainers Notes:

Phase	Characteristics
Primary school age (6-11 years)	
Movement	Muscle co-ordination and control uneven at first, but almost as co-ordinated as adults later; increased fine motor and eye-hand co-ordination. Able to use pens, pencils, scissors. Learning and becoming skilled in ball games.
Cognitive	Concrete reasoning allows understanding of cause-and-effect relationships. Memory for past events begins to extend over longer periods of time, begins to develop expectations (looking ahead to the future). More able to organise self and do things on own. Enjoys activities that give a chance to control, organise and order things.
Language	**6-9yrs:** Child's vocabulary grows dramatically but may struggle to express their ideas and feelings in words. May also struggle to understand abstract ideas and need to have them explained in a concrete way with clear examples. **9-11yrs:** Improved command of language enables child to express ideas and engage in conversation. Language used as tool to connect with and influence others. Can improve group relationships by exploring ideas and opinions of others through language.
Emotional	Gaining a sense of mastery and achievement, finding something that child is good at, builds self-esteem. Failure at school or not being able to experience pleasure in schoolwork or other activities or not being able to persevere with a task can affect child's confidence and feeling of personal value.
Social / Relationships	Becoming less egocentric (centred on self), more able to take others' point of view. Growing interest in the outside world. Able to play and engage well. Starts to understand rules and why they are important. May stick rigidly to ideas of right and wrong. Develops labels for self and others, e.g. fat, clever, left-handed, always sick, etc.Can be mean and cruel at times. Peer relationships vital, mainly same sex friends. Clear sense of gender differences and views these as important.
Self-care	Increasingly able to organise self and function relatively independently. Able to competently take care of all cleanliness and dressing. May regress and want help from adults if feeling insecure or unsure due to external circumstances (including illness).

Trainers Notes:

Phase	Characteristics
Early adolescence (12-14 years)	
Movement	Control of gross and fine motor co-ordination similar to adults, but may go through uncoordinated patches due to rapid growth spurts.
Cognitive	Developing ability to think beyond the concrete, here and now, and think in abstract terms. Able to think in more complex ways about alternative ideas and challenges. May become interested in abstract concepts like religion and politics or concerned with what is ethical, "right".
Language	Language used as a tool to express identity - may become verbally challenging in defining own point of view. Less likely to accept statements or instructions at face value - logical, well thought out arguments become important.
Emotional	Mood swings as hormonal and bodily changes create feelings of insecurity. May feel discomfort/anxiety about physical appearance, e.g. too tall/ short/fat/thin. Any unresolved emotional issues from earlier phases may be re-aroused, giving an opportunity to rework and resolve issues during teenage years.
Social / Relationships	Forming sense of personal identity (*"who am I?"*) a central task - often defined by being part of peer group with its own norms. Identity may also be defined in opposition to parents, e.g. questioning their knowledge/authority in comparison with others/self. Peer group approval crucial - being understood, trusted and accepted by peers. Very anxious about what is considered socially acceptable by others. May become preoccupied with own image *("how do I look, how I come across?")* compared with peers. Can be easily led and influenced by peers in attempts to "fit in". Increasing interest in sexual, intimate relationships - may struggle to communicate/assert own needs re whether to engage in sex, practise safe sex. Despite reliance on peers and emphasis on independence, wants to feel trusted and relied upon by adults.
Self-care	Able to take care of self adequately and predominantly wants to do things for self. If feeling emotionally vulnerable, may seek or accept help from parents or caregivers as source of comfort.

Trainers Notes:

Phase	Characteristics
	Late adolescence (15–18 years)
Movement	Once growth has stabilised, gross motor co-ordination stabilises at adult level.
Cognitive	Has broad knowledge base. Capable of thinking about ideas and problems in the abstract. Able to look at both sides of an argument. May still tend to be somewhat impulsive and lack capacity to realistically plan into the future (only finally matures in late 20’s).
Language	Enjoys verbally debating issues that affect self (e.g. sex, friends, lifestyle) and challenges established positions. May take a position for sake of argument, sometimes the opposite of own personal beliefs and views.
Emotional	Mood swings related to physical changes much reduced. Capable of greater depth of feeling, more able to handle emotions through applying logical skills. Builds sense of self-esteem through experiences that allow for feeling competent and capable. Wants total independence but, if feeling overwhelmed, may at times want to abandon difficult decision-making to authority figures. May become lethargic and preoccupied when dealing with issues, particularly if feeling unable to cope with challenges of growing independence.
Social / Relationships	Still working out sense of identity - process will extend into early 20’s, affected by opportunities available to be productive, independent member of society versus continued dependence on family/parents. Relationship with caregivers/parents may remain strained or conflicting, but should start to improve near end of this phase. Peers remain vital, but capable of greater independence (e.g. ideas, lifestyle). Usually have boyfriends/girlfriends – with support, more able to handle relationships that may become sexual and ways to negotiate sexual relationship and safe sex.
Self-care	Totally independent.

Activity 12

Course module title:	Caregiver challenges in ART for children
Activity:	Small group brainstorming, feedback and plenary discussion

Outcomes:

- Participants are aware of the phases of children's development and appropriate ways to encourage adherence in the context of the health care team
- Participants understand the differing needs and capacities of children depending on age and maturity.

Duration:

1 hour 30 minutes

Suggested method:

1. Divide the participants into four groups. Give each group one of the following age groups:

- infants
- toddlers and preschoolers
- primary school age children
- adolescents

2. Ask each group to brainstorm:

- the kinds of challenges caregivers might face in managing ART with a child of that age
- what factors might affect adherence
- suggestions on how to manage the ART

3. In a plenary session, ask each group to present the phase they have discussed. Record on flipchart the challenges relating to each of the four developmental phases. The other groups can then add their input.

Trainers Notes:

Trainer's notes:

See the *Trainer's notes* for the previous activity. These can be photocopied and used as a handout for trainees.

Remind participants: To remind yourself to think about a child's level of development, make a point of **checking the child's age at every visit** and relating it to what one would expect of a child in a particular phase of development.

Activity 13

Course module title:	Children's rights
Activity:	Powerpoint / overhead projector presentation, group discussion

Outcomes:

- Participants gain insight into children's rights
- Participants understand that children have the right to appropriate health care
- Participants understand children's legal rights and age constraints on consenting to voluntary counselling and testing and treatment
- Participants understand children's rights to certain government grants
- Participants demonstrate awareness of children's rights and protection under the law.

Duration:

1 hour

Suggested method:

1. Present the main points about children and legal rights in relation to ART to the group by means of a Powerpoint presentation, overhead projector presentations, diagram or use of other visuals. The key points are given in the first box in the *Trainer's notes*, and the trainer can expand on the points using the *Trainer's notes*.

2. Encourage the group to discuss the points presented. Ask participants how they think these legal guidelines could be useful in relation to children on ART. Specifically discuss the age of consent to HIV testing and treatment and explore participants' views. Highlight that health care workers may not agree with every aspect of the law, but are still required to follow it.

3. Divide participants into groups. Ask the groups to discuss ways to assess informed consent and how to deal with the question of involvement or non-involvement of caregivers in the process. Ask the groups to consider first a 14-year-old and then to think about anything that they would need to do differently if the child was 12 years old (as if the new Act was in operation). Have different groups focus on:

- a child wanting to be tested for HIV
- a child who has tested HIV+ and needs to start ART

Use the following questions to guide the group

- "If the child asked to be tested for HIV and/or to go on treatment, how would you assess whether s/he understood the implications? How would you explore the child's wishes and feelings about involving caregivers? If the child asked you to help in involving the caregivers, how could you do this? If the child refused to involve the caregivers, how would you deal with this?"

Take feedback from the groups in a plenary session. Discuss any difficulties (including participant attitudes) and comment on approaches suggested.

4. If you wish, hand out copies of the *Trainer's notes* to the participants.

Trainers Notes:

Trainers Notes:

Key Points

1. The Constitution says that a child is any person under 18 years of age.
2. No child can be refused access to educational or health services because of being HIV positive.
3. The law says that a child of 14 years or older can consent to medical treatment (including HIV testing and ART) without the parent or legally appointed guardian having to give consent.
4. The age of consent for medical treatment will change to 12 years when the new Children’s Act comes into operation.
5. When the new Children’s Act comes into operation, even if a child is not able to give consent for medical treatment, caregivers who are not legally appointed guardians will be able to give consent.
6. Children infected or affected by HIV may be entitled to various social grants, including the child support grant, the child dependency grant, and the foster care grant.

Introduction

Children with HIV/AIDS and their caregivers are affected by a range of laws. (Caregivers include parents, legally appointed guardians and unofficial caregivers.) These laws relate to who may consent to HIV testing and medical treatment (including access to ART), access to government grants and protection from discrimination.

At the time of writing, the law related to children was changing. In December 2005, the Children’s Bill was passed by Parliament. Amongst other matters, it regulates HIV testing and the provision of medical care to children. However, it is unlikely to come into operation for some time, possibly not until 2008.

Meanwhile, consent to HIV testing and medical treatment continues to be governed by the Child Care Act of 1983. The systems sets out in this act were meant to protect children, but have become barriers to health care. In particular, the law does not cater for the large numbers of children requiring

Trainers Notes:

access to medical treatment, including testing and ART, but who do not have parents or legally appointed guardians to give consent.

This section will refer to both pieces of legislation – the Child Care Act and the Children's Act, which will eventually replace it.

There is some confusion about what legislation is currently applicable. However, health care workers (HCWs) need to remember that section 28 of the Constitution states that in all decisions regarding children, "their best interests are paramount". This means that HCWs must ensure that all decisions that they make are taken after careful consideration of what is in the best interests of the individual child.

Definition of a child

The Children's Act defines a child as any person below the age of 18 years. Although 18 years is the age at which the law will now recognise the right of a young person to act as an adult. However, there are instances where children below this age should be, and are permitted to, make decisions on their own, without the assistance of an adult:

- Young women can access legal abortions without the consent of their parents if they are mature enough to give their informed consent to the procedure.
- Children of 14 years or older can consent to medical treatment and HIV testing, provided that they are mature enough to understand the consequences of their decision. However, the age of consent for surgery is 18 years.
- A child of 12 years or older can obtain contraceptives without the assistance of a parent or guardian.

The new Children's Act will change this.

Access to medical treatment and HIV testing

The law requires a HCW to obtain informed consent before administering any medical treatment to a child. The same principle applies to HIV testing.

Child Care Act

At present, the consent of a parent or legal guardian is required for medical treatment or HIV testing.

Certain exceptions to this rule are:

- Children above the age of 14 years are permitted to consent to medical treatment* without the assistance of their parents or legal guardians.
- In urgent cases, the medical superintendent of a hospital is permitted to authorise medical treatment of children without the consent of a parent or guardian, if the child's life is in danger or the child is at risk of serious or lasting injury.
- Where children have been lawfully removed from the custody of their parents, the person in whose custody they have been placed, may consent to medical treatment.
- Where it is not possible to obtain the consent of a parent or legal guardian (e.g. where consent has been unreasonably withheld by a parent or caregiver or where the caregiver or parent has died or cannot be found), the Minister of Social Development is empowered to substitute his or her consent for that of the child's parents, or the High Court may be approached to give consent.

The Child Care Act was developed before the advent of a large-scale HIV/AIDS epidemic. It does not cater for the many children orphaned by AIDS who often have no legally appointed guardians and who live in informal care settings with extended family members. Because they have not been legally appointed as guardians, the law does not recognize the right of these caregivers to consent to HIV testing and medical treatment on behalf of children below the age of 14 years. Nor do children under 14 years living in child-headed households have the right to consent to HIV testing and medical treatment.

The new Children's Act

The new Children's Act allows a much wider range of persons to consent to the provision of HIV testing and medical treatment of young children.

Trainers Notes:

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* The act does not define medical treatment to include HIV testing but a legal opinion obtained from the State Law Advisers indicated that it should be interpreted to include testing. This section has been used to allow children of 14 years and older to consent to HIV testing.

Trainers Notes:

They include:

- the child him/herself, if s/he is above 12 years
- a child below the age of 12 years, if the child is mature enough to understand the benefits, risks and social implications of the test
- the parent or caregiver taking responsibility for the child (even if not a legally appointed guardian), if the child is under 12 years of age, or not mature enough to understand the consequences of the decision
- a designated child protection organisation that is arranging the placement of the child, if the child is below the age of 12 years and is not mature
- a children's court or child and family court if consent is being unreasonably withheld or the parent or caregiver is not capable of giving consent
- the head of a hospital if the child is below the age of 12 years and not mature enough to understand the implications of the decision and there are no parents or caregivers to consent and no child protection agency arranging placement.

Important legal requirements

- Until the new Children's Act comes into force, the age of consent for HIV testing and medical treatment remains 14 years. However, the changes to the age of consent in the new Children's Act were adopted after an extensive public consultation process. A legal opinion is that this means that, even before the new Act comes into force, a HCW could obtain consent for HIV testing and medical treatment from a child aged 12 years or more, where there is no parent or legal guardian to give consent. The HCW would need to document carefully the reasons for doing so and ensure that the child is sufficiently mature to understand the implication of the test and the medical treatment. Withholding essential and life saving medical treatment solely on the basis that there was no adult able to consent could expose the HCW to potential legal action and will also violate the constitutional rights of the child.
- As is the case for adults, HIV testing should only be conducted if there is proper informed consent for the test. This means that pre- and post-test counselling must be given by an appropriately trained person.
- A child of an age to consent must be involved in the decision to have an HIV test. They should be counselled in ways appropriate to their age. If the child lives with an adult caregiver, as long as the child agrees, it is

generally advisable to involve the caregiver to facilitate later support to the child. HCWs need to think about how to consult the child and his/her caregivers about these matters. Caregivers who are involved in the consent process, must also receive counselling. (See *Children's ART Adherence Resource Pack* Part D: *VCT for children* for suggested approaches.)

- The law does not say how to assess whether a child of an age to consent to an HIV test and/or anti-retroviral treatment, actually has the capacity to make an informed decision. HCWs have to use their discretion and assess each case individually. (See *Children's ART Adherence Resource Pack* Part A: *Child development* for some general pointers.)
- Testing should only be undertaken if it is in the best interests of the child. This principle is laid down in the new Children's Act, together with strict procedures to be followed for specified exceptions (e.g. for adoption, or where HIV transmission may have occurred as a result of someone coming into contact with the child's bodily fluids).

The right to confidentiality

An adult has the right to keep personal medical information private. This right extends to information about a child. The Constitution also gives everyone, including children, the right to privacy.

No person may disclose the HIV status of the child without consent either from the child, or a person who has the right to consent on behalf of the child.

Access to contraception

The new Children's Act will allow children above the age of 12 years to have access to contraceptives other than condoms, without the consent of their parents. This is as long as the child has received proper medical advice and there is no medical reason why the child should not receive these contraceptives. No one will be able to refuse to sell condoms to a child or refuse to distribute free condoms to a child.

Again, because of the widespread support for lowering the age of consent for access to relevant health services, children under the age of 16 years should have access to contraception. The same cautions about medical advice and contra-indications would apply.

Trainers Notes:

Trainers Notes:

Consent to sexual activity

In terms of the Sexual Offences Act, girls under the age of 16 years and boys under the age of 19 years do not have the capacity to give consent to sexual activity. If someone does have sex with a child under these ages, this is regarded as rape. The only exception is where the other person involved reasonably believed that the child was over the relevant age at the time of the sexual activity.

Changes to the age of consent are currently under discussion, including whether to raise or lower the age, and whether to treat sex between children of a similar age as not being a criminal matter. The age of consent for girls and boys is likely to be the same.

In existing and new legislation, sexual acts with the child under 12 years are always viewed as rape or sexual abuse.

Where HCWs become aware of a child's involvement in sexual activity that amounts to abuse of the child, the matter should be reported to the Department of Social Services or a relevant child welfare organisation.

Social security available to children

Child-headed households

There is no specific provision for support for children with HIV/AIDS, nor for child-headed households. However, the SA Social Security Agency (SASSA), the organisation that now controls grant applications and payments, makes some allowance for the situation of child-headed households, where the child-head is under 18 years.

Applications may be accepted from child-heads aged 16 years or older on behalf of a maximum of six younger siblings (under 14 years in the case of a child support grant, under 18 years in the case of a care dependency grant), provided they have an ID document. Or an adult or an NGO can be appointed to receive the grant(s) on behalf of the children and to assist in managing the grant(s). In each case, all the other requirements for grant applications (in particular, various documents) still apply.

The nearest Social Security office should be approached to assist the child-head make the relevant application and to obtain any necessary documents.

Alternatively, the Social Security office may assist in identifying a suitable adult person or NGO to administer the grant(s).

Practice may vary from office to office and province to province, so it may be necessary to put pressure on officials to facilitate applications. Consult one of the organisations listed in the **Resource List** at the end of the manual.

Child support grant

The child support grant (CSG) applies to parents and caregivers of children below the age of 14 years and is currently set at R190.00 per month. This amount changes annually.

To qualify for the grant:

- The person applying for the grant must be the primary caregiver of the child.
- The caregiver must be 18 years or older.
- The primary caregiver must be a South African citizen and must live in South Africa.
- There is a means test – for caregivers who are unemployed, this will not apply.

The application for a CSG can be made at any local Welfare Office. The caregiver should have the following documents to support the application:

- the caregiver’s bar-coded ID
- the child’s bar-coded birth certificate
- proof of income where the caregiver is employed
- a marriage certificate if the caregiver is married
- if the caregiver is the parent of the child and is divorced, a copy of the divorce order or agreement of settlement relating to custody of the child
- if the parent of the child is alive, a letter or affidavit from the parent stating the caregiver is taking care of the child
- a copy of the death certificate of the parent of the child, if the parent is deceased

Where these documents are not available, the Department of Social Development must assist the caregiver to obtain them.

Trainers Notes:

Trainers Notes:

Care dependency grant

The care dependency grant is available to caregivers, including biological parents, foster parents and adoptive parents, caring for **very sick and disabled children** under the age of 18 years. The child must need 24-hour home care. It is currently set at R820.00 per month and this amount also changes annually.

The following requirements must be met:

- the caregiver must be a South African citizen, except in the case where the caregiver is a foster parent
- the caregiver and the child must live in South Africa
- a medical practitioner must certify that the child is seriously ill or disabled
- there is a means test
- the child must not live in a state institution.

The application for a care dependency grant can be made at any local Welfare Office. The caregiver should have the following documents to support the application:

- the caregiver's bar-coded ID
- the child's bar-coded birth certificate
- proof of the caregiver's income
- proof of the household income.

Where these documents are not available, the Department of Social Development must assist in obtaining them.

Trainers Notes:

Foster care grant

Children are placed in foster care through an order of the Children's Court. Currently the foster care grant is set at R590.00.

To obtain a foster care grant:

- the child must be properly cared for, and
- the foster parents may only receive the grant while they foster they child – if they do decide to adopt the child, they lose the foster care grant and will only be eligible for the CSG, if the child is below the age of 14 years.

The caregiver should have the following documents to support the application:

- the foster parent's bar-coded ID
- the foster child's bar-coded birth certificate
- proof of the child's income, e.g. if the child receives maintenance from a parent
- proof of the foster parent's household income
- the court order placing the child in foster care.

Discrimination against children living with HIV/AIDS

Section 9 of the Constitution prohibits unfair discrimination on various grounds. Although it does not specifically refer to unfair discrimination on the grounds of HIV status, the Constitutional Court has indicated that it would regard discrimination on the grounds of HIV status as unconstitutional.

Children living with HIV/AIDS may not be denied access to any services on the grounds of their HIV status. Specifically regarding education, the policy of the Education Department is that no child may be unfairly discriminated against directly or indirectly on the grounds of HIV status. Children with HIV have the right to attend any school or institution. No child may be denied admission to or continued attendance at a school or education institution on account of his/her HIV status (or perceived HIV status).

Activity 14

Course module title:	Disclosure
Activity:	Case study on disclosure

Duration:

1 hour

Outcomes:

- Participants are aware of the value of social support and its contribution to adherence
- Participants understand the need to incorporate planning and preparation for disclosure into the counselling process
- Participants demonstrate awareness of the sensitivity and risk involved in disclosure
- Participants are aware of the need to listen to, respect and guide the client towards appropriate forms of action
- Participants understand the influence of social norms and cultural beliefs on disclosure.

Suggested method:

1. Read the material on counselling and disclosure (see *Trainer's notes* and Further *Trainer's notes*). Introduce this issue for discussion with the participants. Use the Further *Trainer's notes* as a handout for participants if you wish.

2. Read out the case study given below, and then hand out the copies of the case study to participants.

3. Divide the participants into small groups. Ask each group to select a scribe and a rapporteur. Let the groups discuss the following:

- What are some of the potential negative consequences of disclosure to Dudu (i.e. what are the risks as possibly perceived by Mary and Ophelia)?
- What are some of the potential positive consequences of disclosure to Dudu (i.e. the advantages)?

4. Discuss the answers to these questions in the plenary session.

5. Ask participants to share how this exercise felt for them and why.

Disclosure case study: Dudu and Ophelia

Dudu (8) lives with her mother Mary, and her grandmother, Ophelia, in Dube. Her aunt and uncle and two cousins spend weekends with them. Dudu's father died two years ago. Mary discovered her HIV-positive status when she was pregnant with Dudu. There was no nevirapine option at that stage. Ophelia was a part-time nurse and was completely supportive. Mary has been on ART for one year and is responding well. She is adherent and her CD4 count has risen from 146 to 290 with an undetectable viral load. Mary has not disclosed her status to any else, apart from her mother and one close friend.

Dudu has been ill recently, and has often needed extensive medication. She has been taking cotrimoxazole (bactrim) for five months. The doctor has advised Mary that Dudu needs to start on ART. Mary and Ophelia both believe that Dudu is too young to be told of her status but are ready to enter stage one of the ART process.

Trainers Notes:

Trainer's notes:

Encourage participants to try to identify with Mary / Ophelia's experiences:

- What might they be going through?
- What kind of community life are they likely to have?
- How might the decision about disclosure possibly impact on their lives?
- Who are the people that it might be easiest or most difficult for caregivers to disclose to?

Help the participants to see that counsellors have to individualise each client's situation and needs. The plan for disclosure is unique for everyone. We cannot dictate what clients should do with regard to disclosure.

Ask participants to consider too:

- How can you support them through this decision-making?
- How can you help to prepare them?
- What factors do you think would help a caregiver to disclose their HIV status to a child? Why?

Counsellors need to be willing to trust client's feelings and decisions, which may be the right ones for them in their situation and at that time. But, whilst not forcing them to do anything against their will, counsellors can still explore the situation with the client to gain a better understanding of it. This process can also help clients to review and re-confirm or, perhaps, reconsider their position.

Trainers Notes:

Further Trainer's notes on disclosure

Six tips on disclosure

1 Disclosure is a process that takes place over time. It is not a once-off event.

2 Most caregivers find it difficult to disclose the child's status to the child, but they can be helped through the process.

3 Disclosure needs to taken into account the needs, wishes and views of caregivers, and allow them to feel a sense of control over the process.

4 Disclosure needs to take into account the developmental stage of the child and her or his individuality.

5 Children often react badly at first to disclosure, but with support come to terms with their diagnosis.

6 The caregiver is the person who is most suited to disclose, but in exceptional circumstances a health care worker may need to undertake disclosure.

Introduction

Disclosure of a child's HIV-positive status is one of the most sensitive issues for caregivers. It is particularly difficult for caregivers who are themselves HIV positive, especially where the child's status is a result of mother-to-child transmission.

Children have the right to participate in decision making about their own health care. Knowledge of their status may also help to promote adherence to treatment, while not knowing or having a confused understanding may cause difficulties with adherence. Keeping HIV-positive children ignorant of their status may also further complicate the psychosocial challenges that they face, such as how to deal with stigma and sexuality.

Trainers Notes:

Helping a child to understand his/her illness:

- is an essential part of good health care
- communicates respect for a child
- recognises a child's individual rights
- empowers a child to participate in health care
- allows for making choices, and protecting oneself and others
- is a process that takes place over time
- needs to be done in ways appropriate to the child's developmental level
- requires ongoing and effective communication within families.

In all cases of disclosure of children's HIV status, it is essential that the process takes into account family needs, wishes and opinions, as well as community norms and pressure. Caregivers should as far as possible feel a sense of control over how disclosure happens. Respect for the position of families means that HCWs cannot impose their views on families. But, that does not mean that HCWs should not explore with caregivers the implications of disclosure or non-disclosure and help them plan for disclosure.

> "I never told my grandchild about her illness, but one evening as we were praying, my grandchild asked God to remove the HIV from her body. I was taken by surprise and couldn't think of what to say."

Process of disclosure

Disclosure should be seen as a **process** of telling a child that they have HIV disease and helping the child to understand what this means. It is a **two-way conversation** that involves:

Trainers Notes:

- speaking with the child over time about his/her illness
- disclosing the specific diagnosis at a time appropriate to the child's needs (e.g. as shown by questions in the course of conversations with the child, or other comments the child makes, or at important moments in treatment)
- continuing after disclosure to help the child understand and cope with knowing the diagnosis.

Through the process, the child should come to know about:

- the diagnosis, the infection and disease process, and health changes that could occur
- strategies to prolong a healthy life (including adherence to ART), risk factors, responsibilities now and in the future
- how to cope with possible negative reactions of others.

Ways not to disclose

- Accidentally (e.g. child overhears, or reads something left lying about)
- Carelessly (without really thinking about how to disclose)
- In anger (e.g. in reaction to something child has done or said)
- Unplanned response to child confronting adult caregiver or HCW
- After child has already worked things out for him/herself
- When child is dying (then needs reassurance, comfort, saying goodbyes).

Caregivers often go through phases in moving towards disclosure to their children:

Secret phase

Immediately following diagnosis of the child's status, most caregivers want to keep the information to themselves (and perhaps a close family member or partner). The only other people who know are the HCWs involved in the care of the child and, perhaps, their own. The thought of disclosure to the child, even at some time in the future, causes anxiety and is pushed to the back of the mind.

Trainers Notes:

Exploratory phase

Caregivers may risk disclosure to one person close to them to test their reaction. For others, questions (e.g. about clinic visits) are met with vague replies or false explanations (e.g. that the child has another illness). Caregivers are more likely to try to give their children a plausible explanation for clinic visits, without making specific disclosure of HIV status. The need for eventual disclosure may be more readily acknowledged, but is usually set at some vague or distant time in the future.

Preparatory phase

Caregivers may now be prepared to disclose to a wider group of people and be interested in hearing about the experience of other caregivers and children. They begin to think more concretely about ways to disclose to the child, but without making a definite decision to do so.

Disclosure phase

Caregivers take steps to disclose to their child, or, if confronted by the child, no longer avoid answering or give only vague answers, but try their best to give clear answers.

Disclosure strategies for different developmental stages

At all ages

- Always keep in mind the particular child (and caregivers and family group).
- Create a climate where the child will feel free to ask questions. Try not to avoid questions the child may ask.
- Anticipate and plan how to respond to possible responses (verbal and non-verbal) of the child.
- Anticipate and plan for the impact on family members, friends, school and community members.

- What is said will vary according to the need and circumstances at a particular time.
- Be led by the child (their questions, reactions) about the amount of information given at a particular time.
- Use language appropriate to the child's developmental level, level of education and emotional readiness.
- Keep what is said simple, clear and honest.
- Remember that children often believe that illness is their fault and may need reassurance that it is not because of something wrong that they have done.
- Post-disclosure, monitor the child's behaviour (sleeping, eating, emotional reactions, school performance) and follow-up if any negative changes persist for longer than a few weeks.

Preschool children

Understanding is closely tied to their own experiences (me, here and now), language is mainly used to communicate wants; the child is emotionally dependent on the primary caregiver.

In the case of young children (preschool children, under the age of about 5-6 years), the emphasis will be on the child's health and illness, and disclosure specifically of HIV status will generally be delayed till later.

- Give information in response to the child's questions (*"Why does the doctor take my blood?"*) or reactions (e.g. refusing to co-operate with procedures).
- Give explanations that answer what was asked – don't add unnecessary detail.
- Use play activities (e.g. doctor-doctor) to allow child to communicate any concerns or express feelings indirectly.

Some examples

You have to see the doctor so he can check your blood.

The doctor takes your blood to make sure you stay well.

You need to take medicine because there's a germ in your blood that can make you sick.

Trainers Notes:

Trainers Notes:

A germ is something very small that can get in your body and make you sick, like when you have a cold.

You (and Mommy) take this medicine to keep us strong.

Primary school children

This age group may be optimal for disclosure.

Understanding takes place through everyday life experiences, learning basic concepts (cause and effect, right and wrong, fairness), and getting information from a variety of sources; increasingly children compare themselves to peers, rely on familiar people for support, and may regress to earlier behaviour under stress.

- Give detailed information with concrete examples.
- If a child asks for more information (e.g. *"What's the germ called?", "How did the germ get in my body?"*), give short, clear answers. Stop when the child seems satisfied. S/he can always ask for more information later when s/he's ready.
- Help the child deal with possible stigma.
- Reassure the child that s/he can ask further questions or share any concerns now or later.

Some examples

Germs are very small organisms (things) that carry disease. Germs can get into the body in various ways (e.g. through a cut). They are carried in the blood. Germ fighters in the blood (called CD4 cells) defend the body against germs.

There are different kinds of germs. Some are called viruses. You have a virus (called HIV) in your blood. It attacks and kills (destroys) the germ fighters (called CD4 cells). This makes it easier for germs that carry other diseases to attack your body and make you sick.

HIV stands for human immuno-deficiency virus. That means it affects people's immune system – the system of germ fighters that defend the body. That means you get sick easily.

You have to take medicine to kill the HIV virus in your body, so the germ fighters can work again and you won't get sick so easily.

You and I both have this infection in our bodies. You were born with HIV – it passed from my (your mommy's blood) to yours before you were born.

HIV is nothing to be ashamed of, but not everyone understands about HIV. Having HIV is something private. You don't have to tell other people if you don't want to.

Maybe we should keep this in the family for now. Who (in the family) should we tell?

Trainers Notes:

Adolescents

Adolescents begin to be able to think beyond what's immediately present and can be felt and touched, and to think about ideas and possibilities. Friends and peers are important. Adolescents develop their own identity, have strong feelings (often judgemental), and can be impulsive.

- Accurate and more detailed information can be given in response to questions or to expand information given earlier.
- Realistic information about health status should be given.
- Ways to live meaningfully with HIV are often a more important concern than mode of transmission.
- Anxiety about being different and fear of rejection is strong. Being assured that their status and that what they say is confidential is very important.
- Normal teenage striving for independence may complicate the response to disclosure (e.g. decrease in adherence).
- Issues of possible disclosure to others should be discussed, but the adolescent should make his/her own decisions on this matter.
- Assurance of support and willingness to help should be given, but adults need to avoid seeming intrusive.

Some examples

You have the HIV virus. A virus is something that gets into your blood and can make you sick. But having the virus does not mean that you are sick all the time. You can control the virus by taking your medication every day.

Knowing that you have HIV gives you a special responsibility not to pass it on to other people. You can avoid giving it to others by taking care to put a plaster on any cuts you happen to get, or by using a condom if you have sex. Doing this also helps to protect you against getting the virus again.

Having HIV does not mean that you can't have relationships. It does mean that you need to plan carefully about your future with others so that you make good decisions about your safety and others.

You could have a baby, but there are risks of passing the virus on to your partner or (for a girl) to the baby. It is possible to reduce the risks of passing on the virus to a baby, but it is still a serious decision that needs careful thought.

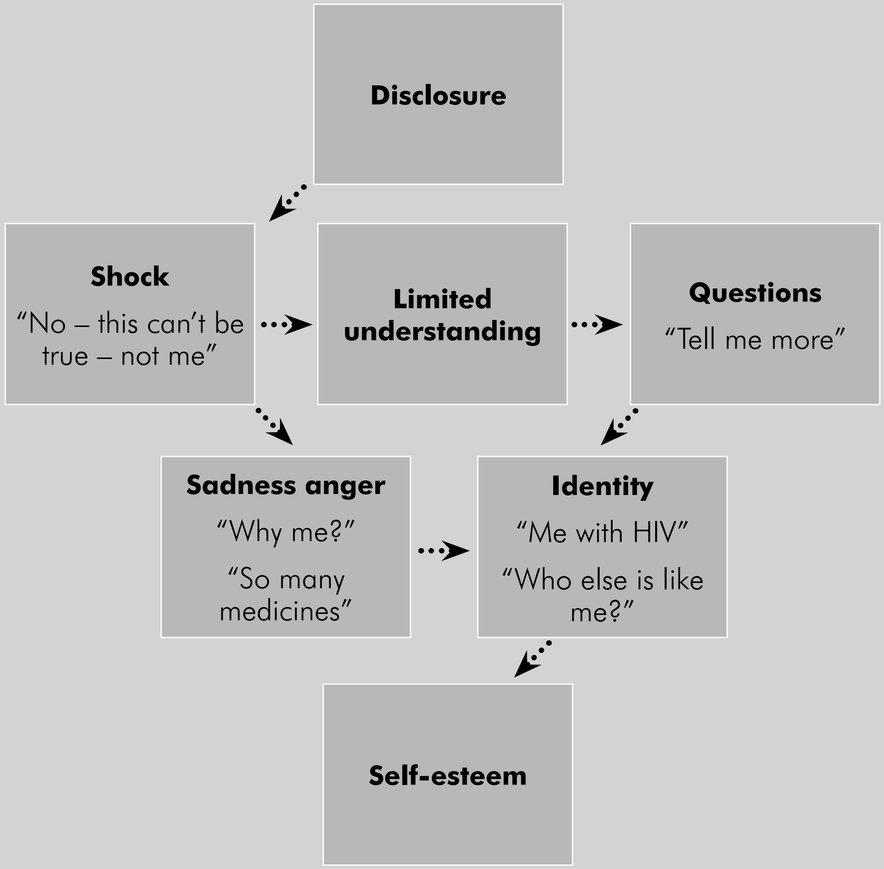
Trainers Notes:

Special circumstances

In the case of children with severe developmental delay or intellectual disability, disclosure is likely to be limited to simple information about the child's illness, rather than his/her status. A child with severe emotional or psychiatric disturbance may also be assessed as not having the emotional resources to cope with disclosure of his/her HIV status. However, such children should be periodically re-assessed to see whether specific disclosure is now appropriate.

Children's responses to disclosure of their HIV status*

Caregivers worry about how their children will react when they are told about their HIV status. Much will depend on what they already know and how their earlier questions have been answered. How the disclosure of the diagnosis is managed is obviously also critical. And, of course, each child has his/her own way of responding. The following model sets out a common pattern.



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* From Mtishizana, S. Disclosure of HIV diagnosis to children. *PACTG Conference, 2004.*

When told about their HIV status, children respond cognitively and emotionally. There is often an initial reaction of shock and denial, which gradually gives way to some understanding of what this means for the child. Then, as more questions arise, linked to the child's own development and experiences, there may be more active searching for information and better understanding.

Sadness, sometimes mixed with anger, is a common early response. Gradually the child begins to integrate HIV into his/her identity, including seeing other HIV-positive people (starting with those in the family) as a reference group. If the process is not managed well, the child's self-esteem may suffer. But, with help and support, a child should come through the process with stronger self-esteem.

Prolonged denial (e.g. denying having the disease or claiming to be cured) is problematic if expressed in refusing or sabotaging medical care and may need intervention by a mental health professional (if available). Similarly, if there are signs of chronic depression (e.g. problems with sleeping, appetite, persistent somatic complaints without a physical basis, fall-off in school performance), referral for professional mental health assessment or intervention is advisable. Expressions of suicidal intention are rare, but if they occur, a mental health professional should be consulted.

Trainers Notes:

Trainers Notes:

Who should disclose?

The primary caregiver should preferably be the person to disclose to the child. Sometimes, caregivers ask for help with the process. A HCW can assist, first by preparing the caregiver and then, if asked, being present when the caregiver makes the disclosure. The HCW's role in this situation is not to take over from or stand in for the caregiver, but rather to support the caregiver and facilitate the conversation between caregiver and child.

Where caregivers refuse to disclose and this is clearly against the best interests of the child (e.g. in the case of a teenager who is not adherent, or is engaging in risky behaviour), HCWs should do everything they can to persuade the caregiver of the necessity to disclose to the child. This is particularly important as the child will need support following disclosure and the caregiver, rather than the HCW, will be the person most likely to be in daily contact with the child and therefore in a position to provide this support.

If the caregiver continues to refuse, the HCW may decide that his/her duty to the child as patient outweighs the rights of the caregiver. This is a decision that should not be taken lightly and should always involve consultation with other members of the health care team. In making the decision, consider the likely consequences for the child of disclosure under these circumstances and sources of support apart from the caregiver. The HCW should inform the caregiver of the intention to disclose and invite their participation or presence during the process. But, if the caregiver continues to refuse to be involved, the HCW will have to undertake the disclosure. The HCW then has a particular duty to monitor the consequences of disclosure and to ensure support.

Activity 15

Course module title:	Disclosure and child development
Activity:	Scripted role-plays: information and disclosure

Outcomes:

- Participants demonstrate skill and sensitivity in providing information and support for disclosure to children of different ages and their caregivers.

Duration:

1 hour 30 mintues

Suggested method:

1. Reiterate the main points made in Activity 14 regarding disclosure of HIV status to the child. Refer back to the Further *Trainer's notes* if necessary. Make reference to the following points:

- Children have a right to appropriate information about their health.
- Helping them to understand their illness is an essential component of good health care.
- Disclosure is a circular process that involves gradually giving more complex or detailed information over time.
- The caregiver is the person most appropriate for undertaking disclosure.
- In exceptional cases, a health-care worker may need to undertake disclosure.
- The process of disclosure should take account of the needs, wishes and views of caregivers.
- Caregivers should feel that they have a sense of control over the process.
- Health-care workers should help caregivers explore the implications of disclosure.
- Health-care workers should help caregivers plan for disclosure.
- Different strategies are appropriate for different ages.
- Paying attention to feelings (often unspoken) of both child and caregiver is as important as giving information.

2. Read through one of the following dialogues, using different participants to take different roles. (You will not have time to read all of them.) Stress that the dialogues are excerpts from longer counselling sessions.

The sets of dialogue are:

  a. a caregiver with the child not present
  b. a pre-school child with a caregiver (without using a doll)
  c. a pre-school child with a caregiver (using a doll)
  d. a primary school child with a caregiver
  e. an adolescent.

3. Then ask the group what they observed in the dialogue.

   Ask: In what ways was it age appropriate? Refer to inputs linked to A, D and E to highlight age appropriate counselling.

4. Follow up by getting participants to split up into pairs. Allocate two of the remaining dialogues per pair. Ask them to use their counselling skills to read through the dialogues. They should swop roles for the second dialogue.

   Again ask: In what ways were the dialogues age appropriate?

5. If there is time, the trainer can model a scenario with the assistance of a participant.

Scenario A:

A caregiver with the child not present

Trainers Notes:

Trainer's notes:

Giving information to preschool children under the age of about 5-6 years

- Emphasis should be on the child's health and illness.
- Disclosure of HIV status will generally be delayed till later.
- Give information in response to the child's questions (*"why does the doctor take my blood?"*) or reactions (e.g. refusing to co-operate with procedures).
- Give explanations that answer questions – don't add unnecessary detail.
- Use play activities (e.g. doctor-doctor or dolls) to allow child to communicate any concerns or express feelings indirectly.

Thembisa and Gladys

Thembisa is 4 years old. She has lived with her grandmother/caregiver Gladys since her mother died three years ago. Thembisa and Gladys have been visiting the clinic since Thembisa started to become symptomatic. The doctor wants her to start ART soon. Gladys is having problems giving Thembisa her Bactrim (cotrimoxazole) and she believes that Thembisa would co-operate better if she understands more about the medication and why she needs it, specially since ART is now about to become part of their lives. The HCT has suggested that Gladys sees the counsellor, first without Thembisa present, to help her to explain to Thembisa why she needs to take her medicine and to support her through the long process of disclosure.

C: Gladys, good morning. *(Welcome and introduction)*

G: Good morning, counsellor.

C: I see from the note that you want to speak to me before you bring your grandchild for the ARV treatment?

G: Counsellor, my grandchild, Thembisa, is getting sick now. She has the HIV and the doctor says she must start drinking more pills to make her strong. She doesn't like to take the Bactrim because her sister doesn't take it. Now with more pills, there will be more trouble and the nurse has told me that she has to drink them every day twice. If she misses, the pills won't work and she will get weak and very sick.

C: You are worried about Thembisa's health and want some help in getting her to take the medicine because it's going to be more difficult now with more pills?

G: Yes, that is right - and I am so worried that she will get very sick.

C: I can see that you understand how important it is for Thembisa to take her pills to keep strong and healthy. It's very hard for a granny or a mother to talk to their child about HIV, so I'm glad that you are here today because we can start looking at ways to make Thembisa understand why she needs to take the medication. This will be the first of many steps in telling her about her illness.

G: I will be glad of that. But I don't want to frighten her – telling her could make her get sick.

C: Yes, Gladys, I understand you're worried, but trying to work things out for herself and getting things wrong, or finding out by accident could also be very scary for her. So that's why it's important that Thembisa learns about her HIV from you - not everything at once, but slowly, just a little bit at a time. She's still a little girl, so you don't have to tell her more than she needs to know now. As she gets older and can understand more, you'll tell her more.

G: But she is too clever - that child. She asks all the time why the doctor takes her blood.

C: And what do you tell her Gladys?

G: No, I tell her it's because she is sick and the doctor needs to look in her blood.

C: That's a good way of starting to explain things, Gladys. You're using words that she can understand. But what if she asks what the doctor is looking for? What would you say then?

G: She already asked that and I didn't know what to say! So I just pretended I didn't hear her and she didn't ask again.

C: It is hard to know what to say. But Thembisa's questions are telling you that she wants to know more – and they're telling you what she wants to know. If she stops asking, it could be because she doesn't want to upset you. Let's think what you could say.

G: I really don't know what to say. If I tell her about viral load and CD4, then I'll have to tell her about HIV and she's too little to have to know that.

C: You're right. She's too young to understand about viral load and CD4. Maybe you could say that the doctor takes her blood to look for the germs that are making her sick. You probably don't need to say more than that – unless she asks and she might – you did say that she is a clever child and she seems to want to understand more.

G: (nods) Then, what would I say?

C: She might want to know what a germ is - you could say to her: A germ is a small thing that makes you sick. If she doesn't ask more, then she is probably satisfied with that explanation for now. She will show you when she's ready to know more.

Try to answer her questions as she asks them. Remember, you don't need to tell her everything in one day. It can take a long time before you get round to talking about HIV. But when she's older and ready to know more, she will already know about germs. Then, you can use the idea of germs to start talking to her about her HIV.

G: How will I know when she is ready to know more?

C: When she asks you, or does something that shows she wants to know. After a while you will understand how to answer her questions. Remember to be open and honest with her. In that way she will trust you more and feel comfortable to ask you questions.

G: So now when I go home, I can tell her about the germs in the blood?

C: If you think she wants to know more…

G: But will knowing about germs make her want to take her Bactrim and the other drugs the doctor wants to give her? I'm not sure about that.

C: It may help – you can explain that taking it will help to stop germs in her blood from making her sick. But getting her to take the drugs probably depends more on how you are with her. Shouting because you are worried won't help. Showing you love and care about her will help. Make her feel that she is being really good and grown-up when she takes her Bactrim and that will help, too.

G: I'm not sure. She gets so cross because Thandi, her sister, is not getting medicine. She says it's not fair and nothing I say seems to help.

C: Can you tell me a little bit about Thandi?

G: Yes, Thandi's eight and has many friends. She doesn't think about Thembisa. She is busy with her homework and her playing. She is also too clever and good at school. Like her mother was.

C: So Thandi reminds you of your daughter. It must be very difficult for you, Gladys, to have lost your daughter.

G: Too difficult. But my church is helping with praying and ... these children are taking my time. I don't think too much.

(Silence for a few moments)

G: But what must I do about Thembisa and the medicine then?

C: Maybe it would help if you can show that you understand it's not nice to have to take the medicine. To make up, if she takes her medicine every day for a week, you two - just the two of you - will do something special together. Talk to her about some things you could do. Some examples might be going to the park together, going shopping together, a small treat that you can afford (e.g. a chocolate) or a special meal that she likes at the end of the week. You could make a calendar showing the days of the week and make a big red cross every time she takes the medicine. Give her lots of praise and hugs at the time. At the end of the week, make sure you give her lots of praise for being such a big girl. Make sure you do what you agreed to do together. Then plan for the next week. How would that work for you?

G: I could try that *(and then gets into discussion of the details)*

C: Now we should talk about giving the new medicines – how many pills, when they should be taken and so on…

Scenario B:

A pre-school child with a caregiver (without using a doll)

C: Hullo Ma, this must be Thembisa? Hullo Thembisa, my name is ____

T: Hullo. (*shyly*)

C: So how have things been since our last session?

G: Like I told you last week, Thembisa doesn't like to take her medicine ____. And now the doctor says she needs to take the other medicines. We talked about that – about things she would like to do if she takes all her medicine like a big girl. She says she'll try to take it, but she's still not happy about it…

C: (*Smiling*) Thembisa, is what your granny is saying right?

T: (Looks down and says nothing)

(Silence for a few moments while Thembisa fidgets.)

C: Thembisa, it's OK not to like taking your medicine. What don't you like about it?

T: I don't like it. My sister doesn't have to take it.

C: Yes it's not nice to have to take medicine ____ But it's very important that you take it.

T: Why do I have to take it?

C: To stop you getting sick.

T: Why will I get sick?

C: Because there's a germ in your blood that makes it easy for you to get sick.

T: What's a germ?

C: A germ is something very small that can get in your body and make you sick, like when you have a cold.

G: Remember last week when you were coughing and coughing all the time?

T: Yes.

G: And after a few days you felt better and could play with Tshepho again?

T: Yes.

G: Well ____ the medicine killed the cough germ and that is why you got better. ____ and you need to take the medicine every day to try and keep the germs from making you sick again.

C: That's right. So, Thembisa, the medicine was too strong for the cough germ. How can you try to make sure that another germ doesn't try to make you sick?

T: Take my medicine every day …

C: Yes, Thembisa, you're right! Granny, you said you talked with Thembisa about what will happen if she takes her medicine every day – what did you decide?

T: Granny said, if I take all my medicine, I can ask my cousin to play on Saturday – and Granny will take me shopping with her on Friday. So I'm going to try.

C: Your granny and I spoke in the last session about the best time to give you the medicine and worked out that 7 in the morning and 7 in the night is a good time. That's when your Granny listens to her church programme on the radio in the morning and you have your supper at night. Will you be a big girl and try to help your granny remember?

T: OK, but I don't want Thandi to be there when I take it. Can we do it in the other room?

G: That's fine, Thembisa.

(Session winds down).

Scenario C:

A pre-school child with a caregiver (using a doll)

Trainers Notes:

Trainer's notes:

Introduce the concept of communicating with children through a doll or a teddy bear. The doll should be perched on the trainer's knee, facing the child and caregiver. The trainer should model the skill of listening to the doll as though it is talking and then report back to the child what the doll has said. Note that this is NOT a puppetry method.

C: Hullo Ma, this must be Thembisa? Hullo Thembisa, my name is ____

T: Hullo. *(shyly)*

C: So how have things been since our last session?

G: Like I told you last week, Thembisa doesn't like to take her medicine… And now the doctor says she needs to take the other medicines. We talked about that – about things she would like to do if she takes all her medicine like a big girl. She says she'll try to take it, but she's still not happy about it …

C: *(Smiling)* Thembisa, is what your granny is saying right?

T: *(Looks down and says nothing)*

(Silence for a few moments while Thembisa fidgets)

C: Thembisa, today I have brought this doll who is called Mpho - Mpho is four years old like you. He's also been sick. He would like to talk with you about being sick. You can touch Mpho if you like.

T: *(Tentatively touches the doll)*

C: Mpho says that it's OK not to like taking your medicine. He also doesn't like taking his medicine. He wants to know what you don't like about it?

T: I don't like it. My sister doesn't have to take it.

C: Yes it's not nice to have to take medicine … but it's very important that you take it.

T: Why do I have to take it?

C: *(Putting her ear close to Mpho)* Hey what do you say about this Mpho? … Mpho says: To stop you getting sick.

T: Why will I get sick?

C: (*Pause while she listens to Mpho*) Mpho says: Because there's a germ in your blood that makes it easy for you to get sick. Mpho says he also has a germ.

T: What's a germ?

C: *(Pause while she listens to Mpho)* Mpho says a germ is something very small that can get in your body and make you sick, like when you have a cold.

G: Remember last week when you were coughing and coughing all the time?

T: Yes.

G: And after a few days you felt better and could play with Tshepho again?

T: Yes.

G: Well - the medicine killed the cough germ and that is why you got better. And you need to take the medicine every day to try and keep the germs from making you sick again.

C: That's right. What are you saying, Mpho? *(Listens for a moment, nodding her head)* Mpho says the medicine was too strong for the cough germ. He is asking you - how can you try to make sure that another germ doesn't try to make you sick?

T: Take my medicine every day… *(Looking at Mpho)*

C: Yes, Thembisa, you're right! She's right, hey Mpho? (*Listens to Mpho*) Mpho says you are a clever girl. (*Turning to Gladys*) Granny, you said you talked with Thembisa about what will happen if she takes her medicine every day – what did you decide?

T: Granny said, if I take all my medicine, I can ask my cousin to play on Saturday – and Granny will take me shopping with her on Friday. So I'm going to try.

C: Your granny and I spoke in the last session about the best time to give you the medicine and worked out that 7 in the morning and 7 in the night is a good time.

Mpho says he also takes his medicine at 7 and 7. That's when your Granny listens to her church programme on the radio in the morning and you have your supper at night. Will you be a big girl and try to help your granny remember?

T: OK, but I don't want Thandi to be there when I take it. Can we do it in the other room?

G: That's fine, Thembisa.

C: Mpho says he is tired now. He wants to have a sleep, but he says he will be here next time to talk to you again. Do you want to say goodbye to Mpho?

T: Bye, Mpho.

Scenario D:

A primary school child with a caregiver

Trainers Notes:

Trainer's notes:

Giving information to primary school children

- Give more detailed information with concrete examples.
- If a child asks for more information (e.g. *"What's the germ called?", "How did the germ get in my body?"*), give short, clear answers.
- Stop when the child seems satisfied. S/he can always ask for more information later when s/he's ready.
- Help the child deal with possible stigma.
- Reassure the child that s/he can ask further questions or share any concerns now or later.

Lucky and Agnes

Lucky is 8 years old. Some time ago, he developed shingles and respiratory problems. His caregiver, Agnes, brought him to the clinic where he was diagnosed as HIV positive, with a very low CD4% and TB. Agnes was shocked as she had had no idea that Lucky was infected. His mother had left Lucky with Agnes (her aunt) when he was 5 years old, saying she would be back once she had found a job. She never returned and has never been traced. Agnes seems to love Lucky very much. Agnes has a good understanding of HIV, but was concerned about whether she should disclose his status to him. She felt that she needed help. She attended three counselling sessions without Lucky, and spoke openly to the counsellor about her fears.

Lucky successfully completed his TB treatment and his ART will start in two weeks. The counsellor has supported Agnes and spoken about the process of disclosure. Agnes felt better prepared after a few weeks. She was firm with Lucky about his TB treatment and has answered all his questions honestly and openly. Lucky appears to have a healthy relationship with Agnes.

Last month, after Lucky asked about HIV for the second time, Agnes gently told him he was infected. Lucky seemed to accept this well. Through counselling, Agnes identified the supervisor at Lucky's school as being someone important to disclose to. The supervisor has been helpful in assisting with monitoring Lucky's health and emotional state. Agnes feels less alone, but is now concerned about having to give Lucky more medication.

C: Hullo. Agnes and Lucky.

A: Hullo ____ Lucky say hullo to ____

L: Hullo ____

C: Lucky, you must be wondering why you are here.

L: No, Agnes told me you are going to talk to me about my new pills

C: And we are going to spend a short time talking more about all the things you have been asking Agnes about. You know that you have a sickness called TB - you have been coughing quite a bit lately and the doctor wanted you to take medicine to help take away the germs that are causing you to cough.

L: Yes.

C: Do you know what germs are, Lucky?

L: Yes, I know some things.

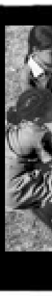
C: Do you want to tell me what they are?

L: OK, germs are things that make you sick.

C: That's right, Lucky. Let's do some drawings to find out more.

(Draws a germ on paper) Germs are very small things that make people sick. This is a drawing of a germ but made bigger. Germs can get into the body in lots of different ways, like through a cut.

(Draws a picture of a person with a cut on the skin and shows how the germ goes into the blood)



L: *(Nods)*

C: Germs are carried in the blood. In the blood we have germ fighters, called CD4 cells, to keep the body safe from germs.

L: Like soldiers?

C: *(Drawing a soldier cell).* Yes. In the blood the CD4 cells are a lot like soldiers. What do soldiers do?

L: I think soldiers defend the people.

C. That's right, Lucky. The same thing happens in the blood. The soldiers are called CD4 cells. We all have them. They fight the germs in our body. How about doing a drawing for Agnes and me.... of the CD4 soldier cells fighting the germs?

L: OK. *(He draws a soldier and a germ on paper)*

C: Wow, that's a really ugly-looking germ! And what a strong-looking soldier cell that is.

L: Yes he is. (Adds to the drawing)

C: And do you know, there are lots and lots of different germs. Ones that make you get colds, coughs, measles ... Some are called viruses. Agnes told you that you have a virus called HIV in your blood?

L: Yes, I have HIV.

C: And can you tell me what you know about HIV?

L: It can make me sick.

C: Well, what HIV does is to kill the germ fighters - the CD4 cells - one by one … until there are hardly any germ-fighters left. This makes it easy for other germs to come in and make you sick. *(Drawing of HIV added to illustration)* See how it attacks the germ fighters? *(Smudging the CD4 germ-fighter cell)* That means you can get sick easily.

That was probably why you got TB. But now, after taking the TB drugs, you are getting better and your body is strong enough to be able to use stronger medicine to kill the HIV virus in your body. Then the germ-fighting soldiers can grow strong again – like the one in your drawing - and you won't get sick so easily.

L: How did I get this HIV? Was I bad?

C: No, Lucky, you were not bad. You were born with HIV – it passed from your mommy's blood to yours before you were born.

A: Eish, people don't understand about HIV. People have much shame.

C: Not everyone understands about HIV. HIV is nothing to be ashamed of, but having HIV sometimes has to be something you don't have to tell other people if you don't want to. Maybe we should keep this with you, Lucky and the teacher for now. Maybe later we can decide if you want to tell other people.

Scenario E:

An adolescent

Trainers Notes:

Trainer's notes:

Giving information to adolescents

- Accurate and more detailed information can be given in response to questions or to expand information given earlier.
- Realistic information about health status should be given.
- Ways to live meaningfully with HIV often a more important concern than mode of transmission.
- Being assured that their status and what they say is confidential is very important.
- Normal teenage striving for independence may complicate the response to disclosure (e.g. result in a decline in adherence).
- Issues of possible disclosure to others should be discussed, but the adolescent should make his/her own decisions on this matter.
- Assurance of support and willingness to help should be given without seeming intrusive.

Romeo

Romeo is a 14-year-old male sex-worker. He has been on the streets for years, using and selling drugs. He recently found a place to stay at a shelter in Berea. The social worker was concerned that Romeo was HIV infected as he had been experiencing severe bouts of diarrhoea as well as ongoing skin infections and swollen glands. Over time she became closer to Romeo, and after he disclosed that he had tested positive at a VCT day at the shelter, she suggested he speak to a counsellor at the ART clinic. Due to his compromised immune system, Romeo's CD4 count is under 200 and the doctor has advised him to start on ART.

C: *(Welcome and introduction and explanation of role)* Romeo, would you like to tell me why you are here today?

R: Yes, I have been sent by Carol, the social worker at Berea House. I am positive, and need the AIDS drugs. But I'm confused. What really is HIV? How did I get it?

C: Romeo, it seems that you have been given a lot of information, but it's not so easy to make sense of it all. Let's talk about things one at a time. I'll answer all your questions. You ask me whatever you want, and remember, whatever we talk about is between you and me - confidential. That means that whatever we talk about will be between us. No-one else will know about anything we say here in this room. How does that sound to you?

R: OK, OK …

C: Do you want to tell me what you know about HIV?

R: All I know is that you get it from sex and drugs and that you get it and die. I got the result and they sent me to the doctor. The doctor says I have to take the drugs.

C: OK … yes Romeo, you have the HIV virus. A virus is something that gets into your blood and can make you sick.

R: But I'm not always sick! It's only the last few weeks that things have been bad …

C: Romeo - having the virus does not mean that you are sick all the time... And once you start taking the drugs, you can control the virus by taking your medication twice a day every day. This will make the virus less and less strong until it won't even show up on a test.

R: Does that mean I will not have HIV any more?

C: No. Maybe one day there will be new and stronger drugs that will be able to do that. With the drugs we have now, the virus still stays in the body - hiding away. That is why it is so important to keep taking the medicine. If you stop taking it, the virus comes out and starts making more and more virus until you get sick again … and the drugs that you are taking will no longer work. But if you go on taking your drugs twice a day every day, then you can stay well for a long time.

R: How long?

C: It's not possible to say for sure. But there are many people who have lived for more than 10 or even 15 years taking the drugs …

R: Taking the same drugs all that time?

C: Sometimes, after a while, the drugs don't work so well. If that happens, you have to take different drugs - what is called the 2nd regimen. You have to take them more often, and if you stop taking those as well, there are not many other options left to keep the virus down.

R: I have heard that you get different HIV when you, you know, have sex without condoms?

C: Yes Romeo, it is very important that you use a condom if you have sex. Condoms also help to protect you against getting more of the virus again. Do you know how to use a condom?

R: Yes I know. I will feel bad if I give this virus to anyone.

C: I can see that you are the sort of person who cares about other people. It's true: knowing that you have HIV gives you a special responsibility not to pass it on to other people. Having HIV doesn't mean that you can't have sex. It does mean that you need to plan carefully about your future so that you make good decisions about your safety and others.

If you find a girl who you would want to have a relationship with, she could have a baby. There are risks of passing the virus on to your partner and she could pass it onto the baby.

R: I read in the paper that the new medicine stops the baby from getting the HIV.

C: It is possible to bring down the risks of passing on the virus to a baby, but there is always still a possibility of passing it on. So it is a serious decision that needs careful thought.

Activity 16

Course module title:	Age-appropriate information giving and disclosure
Activity:	Individual role-plays in providing information on ART

Outcomes:

- Participants understand the importance of disclosure being tied to the child's current understanding of his/her illness, with further information being given step-wise over time.
- Participants develop skills and sensitivity in providing information and support to children and their caregivers.

Duration:

1 hour

Suggested method:

1. Before beginning the role-plays, ask the group to brainstorm what an 8-year-old might know about his/her illness and how a caregiver would know/find this out.

2. Get the group to suggest how a caregiver could go about taking the disclosure process a step further, including specific questions, words and descriptions s/he could use.

3. Break the group up into pairs – with each pair playing counsellor and caregiver respectively.

4. Read out the scenario given below to the group. Instruct participants to role-play this situation for approximately 10 minutes.

5. *Ask for feedback in a plenary session:*
    - How did it feel for both of you?
    - What were the obstacles and challenges encountered in the process?

6. Now ask the pairs to exchange counsellor and caregiver roles, and repeat the role-play for about 10 minutes.

7. Again, ask for feedback in a plenary session.

8. Observe the role-plays and give general feedback to the participants.

Scenario for role-play

Gugu is a retired nursing sister. She has brought her 8-year-old grandson Tiny to the clinic. Tiny was infected perinatally and his mother died a few days after giving birth to him. The doctor wants him to start ART and has suggested to Gugu that she sees a counsellor to assist her in preparing Tiny for ART and eventually to disclose his status to him.

Trainers Notes:

Trainer's notes:

See Activity 14: Further *Trainer's notes* for more information on disclosure.

If during Activity 14 you handed out notes on disclosure to the participants, refer to these notes during your discussion.

Activity 17

Course module title:	The three stages of adherence counselling
Activity:	Lecture

Outcome:

- Participants have a broad understanding of the 3-stage model of ART adherence counselling.

Duration:

1 hour

Suggested method:

1. Introduce the three stages of adherence counselling to the participants using a Powerpoint presentation, overhead projector, diagram or other visuals, starting with stage I and working towards stage 3. (See the *Trainer's notes* for details).

2. Encourage participants to ask general questions to obtain clarity on the model. (Hold detailed discussion of the various components of each stage till later.)

3. It is important that participants have a broad understanding of the stages, as this will guide their future ART adherence interventions.

Trainers Notes:

Trainer's notes:

The three-stage adherence counselling model

- Adherence counselling is a process that is ongoing and constantly changing as new issues arise.
- It is preferable to work through each stage over a period of weeks. This gives the caregiver/child time to deal properly with the demands of the particular stage.
- The model should be used flexibly and adapted to the needs of the particular caregiver/child. Although it would be usual to start with and work through the first stage, before moving on to the second, this is not always the case.
- Always adapt the intervention to the level of development of the child, the specific circumstances of the child/caregiver and the needs of the particular case.

Stage 1: Pre-ART assessment and preparation

Starting ART is never an emergency. Ideally adherence assessment and counselling should begin early in HIV care. The period leading up to the initiation of ART for children involves:

- assessment of the capacity and readiness of the caregiver/child to start ART
- a decision to start ART – made by the caregiver, supported by the HCT and, where possible, with the involvement of the child
- preparation for integrating ART into the life of the child and caregiver.

Stage 2: ART initiation and maintenance

The second stage involves the child starting on treatment, and their initial adjustment and ongoing maintenance.

Initial adjustment may involve unexpected or more difficult than anticipated challenges for the caregiver or child. The caregiver or child needs to be supported through these challenges. The crucial need for adherence must be constantly reinforced.

All members of the HCT need to play a role in the above. The counsellor should be available at each visit for any queries, to respond to any fears or other concerns, or simply to recognize and encourage the caregiver's/ child's efforts to maintain adherence.

Stage 3: Re-motivation and/or treatment change

After a certain period, adherence may decrease, or the patient may experience side-effects or develop a toxic reaction, become resistant or suffer treatment failure. Treatment change may be required. The caregiver and child need intensified support in any of these circumstances. Re-motivation is required.

With non-adherence, revisit the original reasons for starting treatment (Stage 1). Long-term benefits need to be stressed. The stresses and monotony of sticking to the treatment plan need to be explored, and efforts made to deal with any problems or to re-motivate. There may be a need for contact with the child and caregiver between clinic visits to help with remembering daily treatment times and administering the drugs.

With treatment change, the caregiver and child need to understand the different requirements of the new (and therefore, at least to start, more complicated) regimen. This would involve using elements of the pre-ART counselling stage adapted to meet the caregiver's and child's needs.

Trainers Notes:

Activity 18

Course module title:	Revisiting contracting
Activity:	Small group discussion and feedback

Duration:

30 mintues

Outcomes:

- Participants understand the importance of contracting in the context of adherence counselling for caregivers and children.

Suggested method:

1. Ask participants to break into small groups of three or four. Each group should appoint a rapporteur and a scribe. In their groups they should discuss the concept of contracting with a client (caregiver or older child):

- What are the components of a contract?
- What are the benefits of contracting?
- How do we include children of different ages in the contracting process?
- How do we create an environment conducive to counselling?

2. Take feedback from the groups and record on flipchart paper.

3. Fill in any missing information and stress the importance of the contract in the context of adherence counselling for caregivers and children (as well the continual use of all key counselling skills).

Trainer's notes:

- Contracting is a joint activity shared between the caregiver, the child and the counsellor.
- We need to contract clearly and precisely.
- Contracting should include: welcoming, explanation of confidentiality, a brief and simple explanation of what counselling is, the length of the counselling session, agreement to this, reiteration of importance of returning for further counselling sessions, using sessions to share how things are going.
- Emphasise to participants that contracting should not only be addressed to the caregiver – the child should be included in ways and in words appropriate to the child's level of development. This can range from:
    - talking only about meeting regularly *"to see how you are"*
    - referring to the need to talk about taking medicines and any problems
    - referring to using the time to talk about problems that the child (more usually with adolescents) faces in dealing with being HIV positive

Trainers Notes:

Activity 19

Course module title:	Stage 1: Pre-art – ART readiness assessment
Activity:	Lecture and fishbowl role-play

Duration:

1 hour

Outcomes:

- Participants understand components of and how to conduct an ART readiness assessment for children about to start ART.

Suggested method:

1. In a large group, ask participants what they think needs to be discussed and explored with caregiver/child to assess readiness for starting ART. Record key points on a flipchart.

2. Give each participant a copy of the checklist given in the *Trainer's notes* for conducting an ART readiness assessment. Note that this process is the first part only of Stage 1 of the ART counselling process.

3. Go through the format with the participants (20 minutes). Comment on similarities and differences with what was discussed under 1.

4. Check understanding and explore questions and issues that are raised.

5. Then model a role-play using a fish-bowl format, with participants volunteering to be the caregiver and the child respectively.

6. After a little while, invite another participant to take over as the counsellor in the fishbowl (with everyone observing). This can continue until most participants who are willing to volunteer have had a chance to role-play as the counsellor and the session has been played out.

7. Follow with a group discussion.

8. Encourage an atmosphere of supportive learning and constructive criticism in which participants feel comfortable to volunteer, knowing that they will not be judged or negatively criticised.

Trainers Notes:

Trainer's notes:

Stage 1:

Pre-ART assessment and preparation

Starting ART is never an emergency. Ideally adherence assessment and counselling should begin early in HIV care. The period leading up to the initiation of ART for children involves:

- assessment of the capacity and readiness of the caregiver/child to start ART
- a decision to start ART – made by the caregiver, supported by the HCT and, where possible, with the involvement of the child
- preparation for integrating ART into the life of the child and caregiver.

This activity involves only steps 1 and 2 of the process.

Trainers Notes:

Checklist	
Preferably there should be at least three pre-ART counselling sessions before initiation of ART. Do not initiate antiretrovirals at first visit.	
Note: At Department of Health sites, proof of citizenship (ID) is required for inclusion in programme	
All staff (at all visits)	• Reinforce trust between caregiver/child and HCT
Adherence counsellor/ doctor/ nurse	• Explore understanding of health and illness • Review existing knowledge on HIV infection and HIV/AIDS disease stages • If necessary, educate/re-educate caregiver (and child, if appropriate) on HIV infection, etc.
Adherence counsellor/ doctor/ nurse	• Introduction to treatment and adherence programme. • Overview - risks and benefits of ART • Understanding that treatment is not a cure • Understanding that treatment is lifelong
	ART Readiness assessment
Doctor/ nurse	**Medical component** • Complete history (incl. immunisation history) • Complete physical examination • Complete blood count, chemistry profile • CD4+ T lymphocyte cell count (children under 7 yrs: CD4%) • Plasma HIV RNA measurement (viral load) • Past illnesses (opportunistic infections, hospitalisation) • Assessment of growth and development (incl. weight, height and, if under 2yrs, head circumference for baseline) • Mental health (e.g. depression, behaviour change) • Other medications (incl. prior ART) • Other routine tests (opportunistic infections) • Information re physical and emotional status of caregiver
Adherence counsellor (or doctor/ nurse)	**Child's HIV history** • Year of diagnosis • Reason for testing • Mode of transmission to child (perinatal/breast/blood/sexual) • Caregiver's story (experience, feelings about child's status) • Child's story (depending on age/disclosure status, refer to either illness or HIV)
Adherence counsellor (or doctor/ nurse/social worker)	**Child's family/social circumstances** • Household composition (incl. primary and any secondary caregivers) and caretaking arrangements • Family history (e.g. HIV infection of others, deaths, relocation, fostering) • School attendance, performance, disclosure • Material circumstances (e.g. housing, finances, grants)

Trainers Notes:

Adherence counsellor (or doctor/ nurse/ social worker)	**Disclosure** (see Part D: *Disclosure*) • Clarify with caregiver and then, if appropriate, with child • How much does child know about own status/status of other family members? • How much do other household members/others know about child's status? • Reactions from child/others to any disclosure • Caregiver's reasons for not disclosing child's status to child/ others if applicable • Caregiver's plans about disclosure to child, household members, others (e.g. school)? • Partner disclosure if child is sexually active (previous, current and future sexual partners) • Test readiness to engage in disclosure process if appropriate
Adherence counsellor (or doctor/ nurse/ social worker)	**Factors influencing adherence** Discuss factors that might facilitate or be barriers to adherence and ways to address latter: • Caregiver's/child's lifestyle and daily routines (eating/sleep patterns, work/crèche/school routines, leisure activities) • Caregiver's/child's capacity to understand treatment plan/ adherence requirements (e.g. intellectual/developmental level, literacy, language) • Caregiver's/child's personal qualities (extent of self-discipline, organisation, responsibility, compliance) • Sources of adherence and social support (treatment supporter, family members, friends, etc.) • HIV status of caregiver and own health status • Prior medication adherence patterns (caregiver and child) • Attitude towards being on ART (or other medication) • Possible use of alternative/complementary meds • Material/financial resources (e.g. food parcels, child support/ foster care grant, disability grant/pension for caregiver) • Access to nearest roll-out site and reliable transport (refer to alternative site if necessary)
Adherence counsellor (or doctor/ nurse/ social worker)	**Caregiver's/child's holistic care** • Caregiver's/child's attitude towards own illness and HIV status • Dietary patterns and nutrition • Rest and stress patterns (current routine, life demands and management thereof) • Treatment and prophylaxis for opportunistic infections • Substance use/abuse by caregiver/child (drugs, alcohol) • Patterns of sexual behaviour and intimate relationships (if child is sexually active)

Trainers Notes:

Adherence counsellor (or doctor/ nurse/social worker) and all team members	**ART "readiness"** • Caregiver's (or child's) motivation for beginning ART • Caregiver's (or child's) views about whether they can commit to the ART regimen and lifelong ART treatment • Caregiver's (or child's) perceived advantages/disadvantages of being on ART, extent of belief in need for/efficacy of ART • Emotional response to possibly starting ART - fears, excitement, hopes (realistic/unrealistic)

Activity 20

Course module title:	Factors in ART readiness
Activity:	Case study

Outcomes:

- Participants understand the various factors contributing to adherence in children
- Participants show awareness of how to apply the ART readiness assessment process to a case study.

Duration:

45 minutes

Suggested method:

1. Divide the participants into groups, with 3-5 participants per group. Each group should appoint a rapporteur and a scribe.

2. Hand out to participants copies of the case study below.

3. Read the case study of Jane, Jabulani and Harriet to the participants.

4. Allow 15-20 minutes for the groups to discuss the case study, with participants guided by the handout provided in Activity 19.

5. In a plenary session afterwards, a rapporteur from each group should present comments and the main points from their group discussion.

Case study

Jane was infected with HIV by her husband. He died of an AIDS-related illness two years ago. He was open about his status. Jane decided to test when she fell pregnant with Jabulani. The results were positive. It took some time but Jane accepted her result and became extremely health-conscious.

Now Jabulani is three years old. Jane has been on ART for 10 months. Her CD4 count has climbed from 187 to 260. Her viral load is undetectable. Jane, whilst knowing the child was HIV exposed, was reluctant to test him as she had believed that the child was negative due to her previously robust health. Jane became alarmed when a bout of severe diarrhoea left the child listless. She decided to have Jabulani tested and was extremely shocked at the positive result. Due to Jabulani's CD4% and other clinical factors, the doctor has decided that Jabulani should start on ART.

Jane works at a bank in the city. She lives with her mother and Jabulani in Diepkloof in a small house with electricity and water. Jane's mother Harriet is supportive and concerned. Harriet works part time as a cashier for a fast-food outlet close to home. Jabulani attends a crèche run by the bank for its employees.

Trainer's notes:

- Encourage the participants to identify with Harriet and Jane's experiences. Suggest they "put themselves into the shoes" of Jane and Harriet and imagine what each of them is experiencing. What impact will this have on their respective lives?
- ***Ask:*** What are some of the challenges facing Jane and Harriet in ensuring good adherence for Jabulani? How could we assist them to overcome these challenges?
- Remind the participants that the HCT has expert medical and technical knowledge, but that caregivers and children have expert knowledge about their own lives – its possibilities and limitations.
- Stress the collaborative approach whilst brainstorming about dosage times.

Trainers Notes:

Activity 21

Course module title:	Stage 1: Pre-art initiation – Preparation and treatment plan
Activity:	Lecture and fishbowl role-play

Duration:

1 hour 15 minutes

Outcomes:

- Participants understand factors to consider and how to assist in preparing and developing a treatment plan for children about to start ART.

Suggested method:

1. Remind the participants that they have already covered the pre-ART readiness assessment process with the caregiver and child (see Activity 19). If necessary, remind the participants what this involved. Tell the participants that they are now involved in the second part of Stage 1 counselling, i.e. preparation of the caregiver and child, and development of a treatment plan.

2. Using the *Trainer's notes* below, go through the components of the preparation and treatment plan process with the participants. You may decide to hand out photocopies of these notes if you wish.

3. Ask the group to recall the case provided in Activity 20.

4. Using the points outlined in the preparation and treatment plan stage, conduct a fishbowl role-play of a counsellor talking to Harriet and Jane. Start by playing the counsellor, with two volunteers playing Harriet and Jane. Then encourage every participant to take a turn in taking the counselling process further. Encourage participants to stick to the points outlined in the preparation and treatment plan stage.

5. Provide feedback to participants as they take turns, focusing on what is useful and constructive in their counselling.

6. After everyone has had a turn (including the two volunteers who played Harriet and Jane), discuss the overall process.

Information sheets

Give participants copies of the following information sheets:

- Giving medicine to babies (together with pictorial information sheet for caregivers)
- Helping school-age children take medication
- Drinking your pills: Tips for adolescents

Trainer's notes:

Trainers Notes:

This is the third step in pre-ART counselling. It follows after:

- assessment of the capacity and readiness of the caregiver/child to start ART
- a decision to start ART - made by the caregiver, supported by the HCT and, where possible, with the involvement of the child.

The third step involves:

- preparation and a specific plan for integrating ART into the life

Trainers Notes:

Trainer's notes:

	Preparation
Doctor/ nurse/ pharmacist/ adherence counsellor	**Caregiver/child preparation** • Expected changes in physical well-being • Possibility of side-effects (usually less in children, generally pass within 1-2 weeks, more serious will need attention) • Possibility of opportunistic infections – what to do in case of symptoms • How and when to take the medication • Importance of adherence and what this involves • Consequences of non-adherence (treatment ineffective, resistance) • Reinforce caregiver (child's) commitment to lifelong treatment • Assist caregiver to obtain necessary supports (e.g. child support grant, disability grant for caregiver if CD4 < 200 and unemployed, food parcels) • Explain treatment site procedures, location of various services
Doctor/ nurse/ pharmacist/ adherence counsellor	**Develop specific treatment plan** • HCT members should collaborate closely in developing a plan • Treatment regimen (specifics of medication, doses, and the intervals at which they should be given) • Possible side-effects, what to do and who to contact in the case of serious side-effects • Integrate treatment into daily routine of caregiver / child, especially the specific times the medication will be given (e.g. 8a.m., 8p.m.) • Individualise strategies by looking at basic needs, regimen, literacy, language • Provide practical aids, supportive handouts • Demonstrate dosage and method of administration • Have caregiver / child demonstrate administration with mock medication • Practice run (1 week) with mock medication (e.g. fluids, sweets). Review, revise plan if necessary
All	**Establish full commitment to therapy before proceeding with ART initiation**

Giving medicine to babies

Babies are hard to give medicine to because they do not understand why they must take it. Sometimes you may have to make your child take medicine, even when he or she doesn't want to. Here are some suggestions for giving medicine to babies more easily:

1. First prepare the medicine: put out bottles, crush and dissolve tablets if necessary.
2. Measure the medicine. Use a syringe or soft plastic dropper.
3. Sit in a firm, comfortable chair with the medicine close by.
4. Have a towel over the baby. Take the baby on your lap.
5. If you are right-handed, hold the baby in your left arm.
   (If left handed, reverse left and right here and in the following.)
6. Put the baby's right arm around your back. Hold the baby's left arm with your left hand.
7. Support the baby's head and right shoulder between your left arm and chest so that the head stays still. Tilt the head back a little.
8. Put the medicine in the corner of the baby's mouth towards the back, along the side of the tongue. This makes it harder for the baby to spit. Give little amounts at a time to prevent choking or spitting.
9. Gently keep the baby's mouth closed by holding under the chin until the baby swallows.
10. Talk to the baby in a soothing way. Never shout or show anger.
11. When the medicine is finished, hold your baby sitting up or over your shoulder for a few minutes and comfort and cuddle him/her.

Try to finish the procedure in one go, as the baby may resist being put in the holding position again if s/he is distressed. But if the baby is very distressed during the process – wriggling and crying so much that it is difficult to continue – stop completely for a few minutes, comfort and talk to the baby, then sit down and continue.

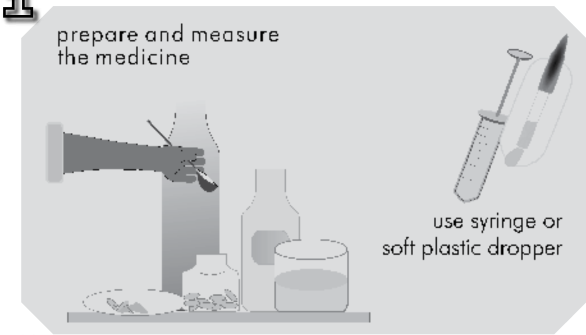
NB: If the baby vomits within 30 minutes of being given medication, give another dose. Give the next dose at the time it is due – don't delay it.

Some more tips:

- Keeping medication in a fridge
    - When you are finished giving the medication, put back in the fridge any medication that needs to be kept cold.
    - Note that norvir must **not** be kept in the fridge.
- With bad-tasting solutions (e.g. kaletra, ritonavir):
    - Chocolate milk can be used to mask the taste, but is expensive. Putting dry Nesquik powder or something similar on the tongue is an alternative.
    - When kaletra is cold, the taste may be better.
- Using syringes:
    - Pour a small amount of the liquid into a small cup to make it easier to draw up the liquid.
    - Syringes should preferably be marked with a permanent marking pen at the level of the dose and covered with sellotape to prevent the markings from rubbing off.
    - The syringe and the medicine for which it is used should be colour coded with the same colour to prevent mixing of medications and doses
    - Ask your health worker to show you how to make accurate measurements – make sure the plunger lines up with the marker on the syringe.
    - When drawing up liquid, ensure that the tip of syringe remains under the top level of the liquid. If there are bubbles, tap the syringe to get rid of them.
    - Pour the remaining medicine back into medicine bottle.
    - If the bottle has a syringe adapter, the above does not apply. Follow the instructions of the health care worker on how to use the adapter.
- Using spoons
    - Use a medicine spoon **(not** a teaspoon) for measuring medication that is prescribed per spoon (1 medicine measure = 5ml).
    - Hold the spoon upright.
    - Put the spoon up to the baby's lips and tilt it.
    - Let the liquid flow in slowly to allow normal swallowing.

Giving medicine to babies

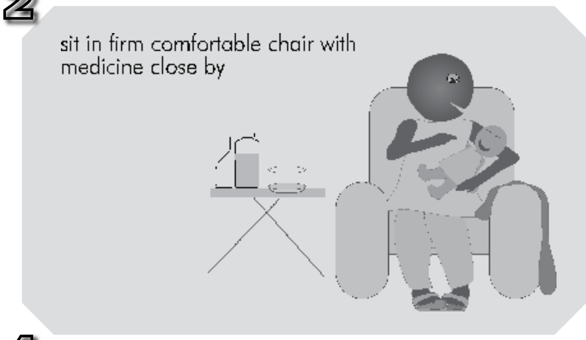
1



prepare and measure
the medicine

use syringe or
soft plastic dropper

2

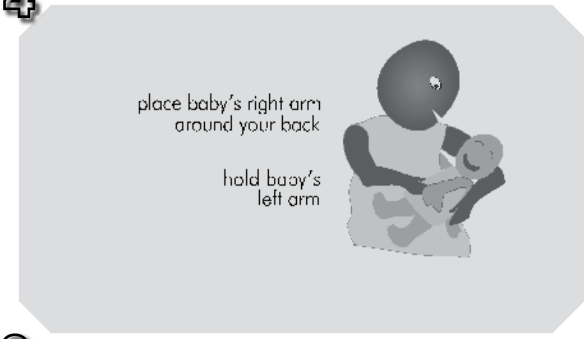


sit in firm comfortable chair with
medicine close by

3

have a towel on the baby
take the baby onto your lap
hold baby in left arm
(right arm if left handed)

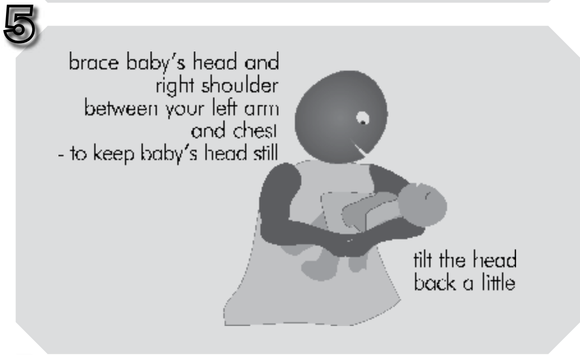
4



place baby's right arm
around your back

hold baby's
left arm

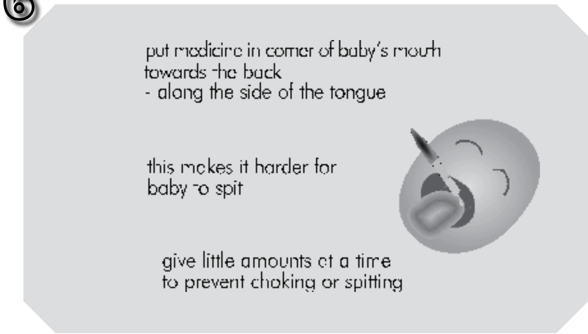
5



brace baby's head and
right shoulder
between your left arm
and chest
- to keep baby's head still

tilt the head
back a little

6

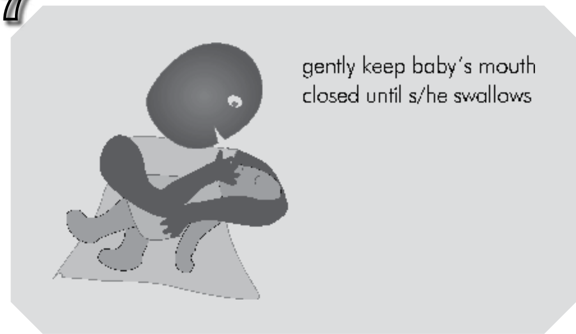


put medicine in corner of baby's mouth
towards the back
- along the side of the tongue

this makes it harder for
baby to spit

give little amounts at a time
to prevent choking or spitting

7

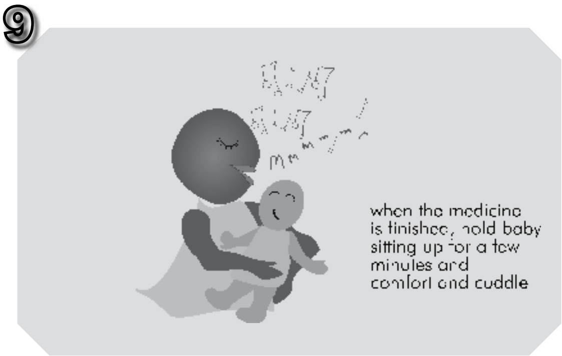


gently keep baby's mouth
closed until s/he swallows

8

speak softly and say kind and
soothing things
never shout or show anger

9



when the medicine
is finished, hold baby
sitting up for a few
minutes and
comfort and cuddle

Helping school-age children take medication

- Always be there to supervise your child taking his/her medicines. Make sure s/he takes them all and that they all go down.
- Remind your child that medicines help to keep from getting sick
- Never ask your child whether s/he wants to take the medicine or whether s/he will take it. Be positive and consistent and matter of fact ("It's time for your meds…"). If necessary, be firm and insist that s/he must take the medicine.
- Always offer as many choices as possible as to **how** to take the medication. Let your child choose what is best for him/her.
    - Let your child choose what kind of food/ drink they want to take to cover a bad taste, or as a follow-up reward.
    - Some children do best when they take a breath and drink the medicine fast. Others take the medicines a step at a time, with a drink in between.
- Always say something positive when your child has taken his/her medication.
- Reward your child with a sticker or star on a record chart or calendar.
- Allow the child to earn special treats for sticking to her/his schedule (e.g. a small weekly treat, a bigger monthly treat).
- Get other people who your child cares about to encourage and reward him/her for taking the medication.

Drinking your pills: Tips for adolescents

PIlls are your friends for life. Like most friends, they can make you feel great, but they can also be a pain! Here are some ways to get along better with your pills

Try to make these your rules for life!

* Wake up and go to sleep in the same place every day, where your pills are.

* Keep your medication in a pill box if you can. Fill your pill box once a week.

* Keep the pill box where you will be sure to see in the morning and the evening.

* Take your pills at the same time every day (e.g. 7a.m. and 7 p.m.).

* Try to link pill-taking times with specific things you do every day, e.g. brushing teeth, eating breakfast or supper, watching a TV programme.

* Always carry some pills with you in case something stops you getting home on time.

* You need to collect a new batch of pills every 28 days. Make plans to collect the next batch of pills when you are down to one week's supply.

Swallowing the pills

- * Keep your head up and look straight ahead, relax and drink until the pills go down.
- * If you are finding it difficult to swallow your pills, ask your nurse or doctor or another health care worker to teach you. (Some pills can be crushed, broken, cut in half, dissolved in water, juice or milk to make them easier to swallow).

Side -effects

- * You may feel side-effects (for example, feeling dizzy or tired or feeling like throwing up). This often happens in the first few weeks after starting the pills. Most side-effects go away after a few weeks.
- * Call your nurse or doctor to tell them about any side-effects you are having. They will help you get through it.
- * Do not stop your pills unless a nurse or doctor tells you to do so.

Using drugs and alcohol

- * Try to use drugs and alcohol as little as possible. Using drugs and alcohol can be very dangerous. They can affect how your pills work and damage your liver.
- * Drugs and alcohol can make your immune system weaker and make it easier for the virus to work.
- * If you are not thinking clearly because of taking drugs or alcohol, you could forget to take your pills or take them incorrectly. You might also do things that are dangerous or risky, such as unsafe sex or driving recklessly.

To fight the virus, you have to keep your life organised. This makes it easier to fit your pills into your lifestyle. If you are running around a lot, staying in different places, not in school, or using drugs or alcohol, it will be difficult to take your pills at the right times. Try to keep to a routine.

Activity

22

Course module title:	Mock ART feedback
Activity:	Group work: feedback on mock ART exercise

Outcome:

- Participants are aware of factors contributing to adherence through their own mock ART experience.

Duration:

30 minutes

Suggested method:

1. Invite feedback from participants about their own "adherence" to the mock ART's they have been taking for the previous three days.

2. Ask them: How adherent were you? What made things easier, or more difficult?

   On a flipchart, in one column list the reasons for participants' successful adherence. In the other column, list reasons for non-adherence.

3. In discussion, ask:

   - What methods did you devise in order to remember?
   - What methods did you find helpful?
   - Did the diary cards assist? How? Would you recommend diary cards as an adherence tool?
   - How effective were the treatment assistants?
   - What difficulties did the treatment assistants experience?

4. Link the participants' experience to actual adherence issues.

Activity 23

Course module title:	Side-effects and children
Activity:	Brief revision, followed by brainstorming and role-play

Duration:

1 hour

Outcomes:

- Revision of knowledge about the possible side-effects that children may experience as a result of ART
- Participants practise counselling caregivers about side-effects
- Participants are aware of what to tell children on treatment about side-effects.

Suggested method:

1. Introduce the topic of ART side-effects, emphasising their potentially serious nature. Remind participants of what was already mentioned about side-effects in Activity 7.

2. Split the participants in two groups, giving each group a piece of flipchart paper. Each group should allocate a rapporteur, who will write up the group's points on flipchart and present the results to the plenary session.

3. Tell them that they have 10 minutes to write down any side-effects that they think a child may experience as a result of ART.

4. They should attempt to distinguish between potentially dangerous side-effects and mild side-effects. For which side-effects should the person return immediately to the clinic or doctor? Which side-effects are considered mild?

5. Together with each side-effect, they should try to think about any simple treatments they know of that could be used to relieve the symptoms.

6. The trainer should then add to or correct the feedback by providing information on ART side-effects in children and how to manage them.

7. Then read out to the participants the case study below.

8. Ask the participants to form pairs and take turns in counselling Rachel about side-effects.

9. After everyone has taken a turn at the roleplay, discuss briefly how best to counsel Simon about side-effects.

Case study

Rachel is a 45-year-old grandmother, looking after Simon, her 8-year-old grandson. Simon has been in Rachel's care since he was 3 years old, when his mother died. Simon is HIV positive and his doctor has decided he is ready to start ART. Rachel has heard many stories about how ART can make children really sick. She is very worried about the side-effects of treatment. Your task is to counsel her about side-effects, giving her sufficient information, but not frightening or discouraging her.

Information sheets

Give participants copies of the following information sheets:

- What to do in case of mild side-effects
- What to do in case of serious side-effects

What to do in the case of mild side-effects

nausea and vomiting

eat plain bland food like dry toast
small amounts at a time
ginger tea or fresh ginger

diarrhoea

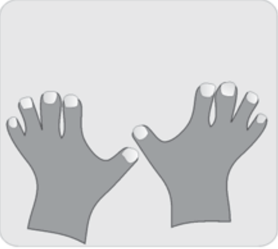
mix 8 tsp sugar with 1/2 tsp salt in 1 litre of boiled water - allow to cool and sip frequently
fruit juice and rooibos tea
do not worry about child not eating proper food
buscopan for cramps (Do Not Give Immodium)

dizziness - usually caused by efavirenz (stocrin)

adjust medicine time
take just before bedtime to be asleep over "dizzy" time
ginger may help

general malaise (feeling unwell)

panado
brufen
lots of fluids
bed rest



nail disclouration due to:

1. HIV
no treatment

2. fungus
see doctor for griseofulvin

peripheral neuropathy (difficult to diagnose in children)

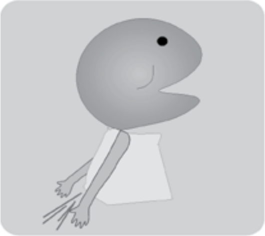
keep feet clean, check for wounds and sores, try massage
rooibos tea / antioxidants from the chemist may help
panado, brufen, tryptanol for pain
doctor can prescribe vitamins b, c and pyridoxine

What to do in the case of serious side-effects

If child develops any of the symptoms below
or any other worrying symptoms,
child should see doctor or nurse urgently

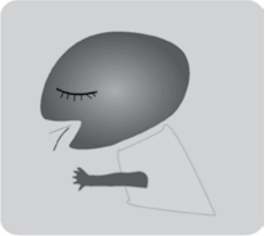
high temperature/ headache

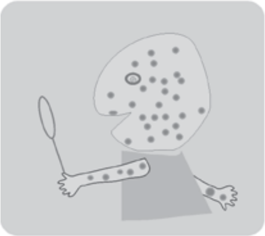
serious vomiting



persistent diarrhoea

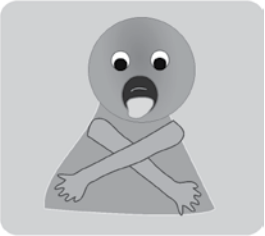
persistent cough





worsening rash

severe breathing or
chest problems



After longer term ART use

sudden unexplained
weight- loss

increased fat around
stomach and upper body
and
fat loss from arms, legs
buttocks and face

Trainers Notes:

Trainer's notes:

- The trainer should try to elicit as much of the information that participants are required to know from the group itself. Do this by using probes or asking linking questions that could lead to the group coming up with the answer. For example, "Correct. Diarrhoea is a common side-effect of ART. What other side-effect do you think this could lead to?" (Answer: weight loss) OR If the child is feeling really nauseous, what might happen?" (Answer: s/he might vomit).

- Discuss how much the counsellor should tell the caregiver/ child.

- There are likely to be (at least some) participants in the group who have some knowledge about traditional African treatments. Caregivers/children might draw on these and, therefore, participants should be aware of what remedies might be used. However, warn participants that the interactions between traditional remedies and ART are not always known, and can in some cases be harmful. Participants need to caution caregivers/children that they should not combine traditional remedies and ART without first speaking to the ART team.

- Also emphasise the need to differentiate between mild and severe side-effects. The same side-effect may be either mild (for example, one or two incidents of diarrhoea) or severe (e.g. diarrhoea which continues for more than a day). In the case of a mild side-effect the caregivers/children can take care of the problem themselves, but with a severe side-effect, the caregivers/children should return to the clinic immediately for treatment. If there is any doubt at all about a side-effect, the caregiver/child should return to the clinic or contact the clinic as soon as possible.

- It is crucial for counsellors to assess the functional impact of any side-effect on an individual's life. For example, if a child is experiencing a bad bout of diarrhoea, it may be necessary to ask quantitative questions, such as *"How often?"* and *"How bad?"*, but also qualitative questions, such as *"How much of a problem is this for you?"* and *"Is it manageable or not?"* These answers will help the counsellor – caregiver/child - health care team to assess whether medication should be suspended, switched or continued.

Trainers should stress to participants:

Caregivers must consult their doctor if they suspect that the child is experiencing drug side-effects. Some of these side-effects may be potentially fatal.

Trainers Notes:

Activity 24

Course module title:	Stage 2: ART initiation and maintenance
Activity:	Lecture and fish-bowl role-play

Duration:

1 hour

Outcome:

- Participants understand and practice the components of counselling about initiation and maintenance of ART.

Suggested method:

1. Present the second stage of adherence counselling by means of a Powerpoint presentation or using an overhead projector (see *Trainer's notes* below). Point out the challenges of this stage of counselling, such as the difficulty initially of getting the medication to become part of daily routine. Later the challenge may lie in maintaining high levels of motivation, and adjusting to changes related to the child's development. Changes in the family may also challenge adherence.

2. Then hand out copies of the *Trainer's notes* to participants.

3. Instruct the group that they will now practise in a fishbowl counselling Rachel and Simon on initiating treatment. They should think carefully about what factors to take into account in deciding how to involve Simon. (Read out to them again the role-play scenario used in Activity 23.)

4. Using the checklist as a guideline, allow participants to take turns role-playing this scenario, paying careful attention to the points that need to be covered. Encourage the rest of the group to observe the role-play carefully.

5. Then conduct a fishbowl role-play of a maintenance counselling session some 9 months after treatment has been started.

6. End the activity with a discussion.

Information sheets

Give participants copies of the following information sheets:

- Tools to help the caregiver and child maintain adherence
- Example of a paediatric adherence record

Trainer's notes:

Stage 2:

ART initiation and maintenance

The second stage involves the child starting on treatment, and their initial adjustment and ongoing maintenance. Adherence support involves a series of interventions linked to routine ART monitoring, or to the occurrence of side-effects or opportunistic infections.

Initial adjustment may involve unexpected or more difficult than anticipated challenges for the caregiver or child. Later there are different kinds of challenges - maintaining motivation, ensuring continued high levels of adherence, adjusting to changes related to the child's development. Unexpected variation in CD4% or viral load, episodes of illness, changes in the daily routines of the household or in household membership (particularly a death in the family) also challenge adherence. The caregiver or child needs to be supported through these challenges. The crucial need for adherence must be constantly reinforced.

All members of the HCT need to play a role in the above. The counsellor should be available at each visit for any queries, to respond to any fears or other concerns, or simply to recognize and encourage the caregiver's/ child's efforts to maintain adherence.

Trainers Notes:

Checklist	
Conduct follow up within 1-2 weeks of starting ART. **Member of HCT should follow up monthly (usually coinciding with collection of medication from pharmacy).** **Follow-up clinical assessments should take place usually every 3-6 months.** **More frequent visits or contacts may be required, especially in early stages of ART or in case of side-effects or opportunistic infections.**	
All (at all visits)	Reinforce trust between caregiver or child and HCT
	Initiation
Doctor/nurse/ pharmacist/ adherence counsellor	**Initiate treatment** HCT members should collaborate closely in the initiation phase • Treatment regimen given to caregiver/child, specifics of medication, doses, and the intervals at which they should be given • Integration of treatment into daily routine of caregiver/child confirmed, especially specific times the medication will be given (e.g. 8 a.m., 8 p.m.) • Remind about practical aids, supporting handouts • Demonstrate dosage and method of administration • Have caregiver/child demonstrate measurement and administration with actual medication • Mention simple remedies for mild side-effects and who to contact in case of serious side-effects • Plan follow up (telephone, clinic visits preferably within 1-2 weeks of starting) • Give contact details for clinic/staff in case of questions/ concerns
	ART monitoring
Doctor/nurse	**Medical component** Height, weight (head circumference if < 2 yrs) Examination directed to: • Accurate notes on prior conditions • Careful history of reported adherence, possible side-effects, recent illnesses • Current clinical situation • Evidence of progression/improvement • Evidence of immune reconstitution disease • Evidence of toxicities

Doctor/nurse/ pharmacist/ adherence counsellor	**Adherence patterns** • Report of caregiver/child (give permission to report missed doses) • Caregiver's/child's identification of medications and demonstration of doses • Pill counts • Review diaries (if used) • Assess implications of CD4%, viral load
Adherence counsellor (or doctor/nurse) and all team members	**Factors influencing adherence** Explore issues that have arisen since starting ART/last visit: • Physical well-being and any illness • Caregiver's/child's attitude towards ART • Process of giving medication (from start to finish) • Ease/difficulty of giving medication (incl. fit with routines) • Use of reminders and tools, e.g. pillboxes, diaries • Child's reactions to taking medication, e.g. taste, swallowing, vomiting • Side-effects and efforts to manage them • Other medications e.g. co-trimoxazole, complementary medicines, over-the-counter remedies • Eating/sleeping patterns • Changes in routine • Changes in disclosure status • Changes in family circumstances • Self-discipline/problems with child's co-operation • Access to site
Adherence counsellor (or doctor/nurse/ social worker)	**Holistic care since starting ART** Explore other concerns, especially factors that have or may become barriers to adherence, discuss ways to deal with them • Treatment and prophylaxis for opportunistic infections • Dietary patterns and nutrition • Rest and stress patterns • Substance use/abuse • Patterns of sexual behaviour and intimate relationships • Need for and sources of emotional and social support

Trainers Notes:

Trainers Notes:

Adherence counsellor (or doctor/nurse/ social worker) and all team members	**Caregiver's/child's experience of ART** • Changes in physical wellbeing, any side-effects, opportunistic infections • Understanding of how and when to take the medication • Expectations of ART vs reality (e.g. pace of change, ease of use) • Emotional reactions (anxiety, depression, disappointment) • Commitment to ART and adherence
	Adherence support
Doctor/nurse	Adjust regimen (dosage/method of administration, specific times) if necessary
Adherence counsellor (or doctor/nurse/ social worker) and all team members	• Find areas to encourage and praise • Stress importance of adherence, consequences of non-adherence (resistance) • Reinforce that treatment is not a cure, is lifelong • Confirm plans to deal with identified areas of difficulty (both those specific to adherence and more general) • Review treatment plan (in case of revised plan, integrate treatment into daily routines) • Review what to do in case of administration difficulties or vomiting • Review what to do if side-effects (particularly if new regimen), opportunistic infections • Plan follow up (at short interval if treatment plan revised)

Tools to help the caregiver and child maintain adherence

There are some simple tools and techniques that can be used to help maintain adherence. They include:

- hints on how to administer medication
- reminders of medication times
- records of medication taken
- ways to recognise good adherence

Not everyone will find these tools useful. Talk with the caregiver/child to see what may be helpful in their circumstances:

- handouts for caregivers (adapted for children or adolescents) to give basic information about ART for reading at home
- syringes/droppers, with the correct measurement for the medication marked and sealed so that it does not rub off
- a list of specific medications, doses, times and any other dosing requirements (with illustrations) to help the caregiver/child remember details of the regimen
- colour coding of bottles or syringes to match a written schedule.
- pill charts that use pictures of pills or bottles and a clock to show which pills to take at particular times
- pillboxes to show doses taken and yet to be taken (they can be built out of egg cartons, perhaps as a support group activity)
- telephone or cell-phone reminders
- alarm clocks or other electronic devices (beepers, alarms)
- a chart or calendar with stickers or stars to record taking a dose
- medication diaries or diary cards (to record dosing)
- certificates of achievement for children (such as “Thabo is a champion medicine taker!”)
- inexpensive treats or special activities to reward good adherence over a period of time (e.g. week, month)
- medications placed where they will be noticed at dosing times, e.g. on the breakfast table, in the bathroom next to a toothbrush
- mood charts (with smiling and frowning faces) which can be marked to record child’s feelings

Example of a paediatric adherence record[1]

Patient: ______________________ Date: ______________________

Caregiver: ______________________ Health worker: ______________________

1. How have things been in the past month? What problems have you had?

____

____

____

2. How do you give the medicines / tablets?

a) Names of medicines

i ______________________

ii ______________________

iii ______________________

b) Technique: (ask to demonstrate in early sessions) good / fair / poor

____

____

____

c) Doses: knows correct doses / unsure / no idea

____

____

____

---

[1] Adapted from the Adherence Counselling form developed by HIVSA

d) Food:

Medication (as above)	Morning	Evening
I With / without food	Before meals / after meals	Before meals / after meals
ii With / without food	Before meals / after meals	Before meals / after meals
iii With / without food	Before meals / after meals	Before meals / after meals

e) What times?

i _________A.M. / _________P.M.

ii _________A.M. / _________P.M.

iii _________A.M. / _________P.M.

3. Which doses were you not able to give in the last 3 days?

(Indicate whether all for a particular time, or the name of specific medicine/s)

	Yesterday (e.g. Wed)	Day before yesterday (e.g. Tues)	Day before that (e.g. Mon)
A.M.			
P.M.			

What was the problem?

____

____

4. What do you do when you miss a dose?

____

____

____

5. What do you do if your child vomits?

____

____

____

6. Who else is giving the medicines? Can they come to be trained, (if not yet trained), or to join you on the next visit?

7. What happens during school holidays?

8. What happens when the caregiver is away, or the child is away from home?

9. If your child needs to come to hospital, what do you do?

10. Do you anticipate any problems with giving medicines in the next month?

Referred for further assessment/support to: (name/contact details of nurse/doctor/other person)

Activity 25

Course module title:	Strategies to maintain adherence
Activity:	Brainstorm and feedback on tools and systems for sustaining adherence

Outcome:

- Participants learn to think creatively about ways of assisting and supporting adherence in caregivers and children
- Participants acquire information about tools and systems that have proven effective in other ART adherence programmes.

Duration:

45 minutes

Suggested method:

1. Introduce the concept of tools and systems for sustaining adherence within the context of Stage 2 of ART adherence counselling for children.

2. Explain the international context of designing and developing multiple measures, systems and tools that act to support and sustain adherence.

3. Tell the participants to form pairs or triads. They should brainstorm tools and systems that could be used to assist and support caregivers and children with ART adherence. Remind them to accommodate the possibility of caregivers being illiterate or innumerate and living in resource-poor settings. Encourage them to brainstorm creatively. This could be facilitated by them drawing pictures of the tools onto a sheet of flipchart paper.

4. Invite feedback on participants' ideas, as well as sharing of their illustrations.

5. Using the information on the following pages, fill in the gaps and clarify any misconceptions.

Trainers Notes:

Trainer's notes

Contact with caregiver and child

- Follow up 1-2 weeks after starting medication - this is when problems and side-effects are most likely to occur (have daily 'phone calls if possible for first few days, to check on how adherence is going).
- Discuss alternative ways for contact with patients who live far away or do not have access to telephones.
- *Home visits:* If planned around medication time, home visits are a useful tool for assessing and supporting adherence. Caregivers and children are usually more relaxed in their own environment and more easily able to discuss problems and identify possible solutions. Other family group members may also be present and (taking into account the disclosure situation) may be drawn in to problem solving.

Treatment-related strategies - caregivers and children

- Anticipate and talk about possible problems (e.g. difficulties in implementing regimen, side-effects, opportunistic infections) before they arise.
- Be flexible with the treatment plan. Accommodate change (e.g. in the scheduled time of doses) if this would result in better adherence.
- Think of possible simplification of the regimen.
- *Vomiting after taking medication:* make sure the caregiver knows that, if a child vomits within 30 minutes of taking medication, the dose should be repeated. The next dose should be taken at the scheduled time.

  (Note: if a baby burps a small quantity after being given medication linked to a feed, this will not have a major effect on intake and should not be treated as vomiting.)
- Ask about any side-effects, suggest ways to manage less serious side-effects and indicate likelihood of relatively short duration.
- Ask about other medications that the child may be taking in order to avoid possible drug interactions.
- Anticipate possible adherence fall-off during times of increased stress or change in family group. Make time to discuss and find ways to deal with problems and feelings more broadly and as they affect adherence.

Some adherence tools and strategies

- Setting an alarm on an alarm clock
- Setting a cellphone alarm or reminder
- Using a pillbox
- Using a diary card
- Using a wall calendar
- Keeping a treatment diary
- Sending SMS reminders to the caregiver
- Using daily TV or radio programmes as cues
- Having a treatment supporter
- Having a treatment buddy (another child, also on treatment)
- Keeping medication in a familiar place
- Using directly observed treatment support (DOTS), as for TB

Trainers Notes:

Information sheets

- Give participants copies of the starchart.

Name:..

Date:..

Next Clinic Visit: ....

	WEEK 1	WEEK 2	WEEK 3	WEEK 4
M				
T				
W				
TH				
F				
S				
SUN				

Activity 26

Course module title:	Stage 3: Re-motivation / treatment change
Activity:	Lecture, group discussion and fishbowl role-play

Outcomes:

- Participants are sensitive to the difficulties and potential crises that caregivers or children might experience throughout the course of treatment
- Participants are informed about the psychological impact that failure of treatment might have on caregivers or children, and on their role as counsellors.

Duration:

1 hour 15 minutes

Suggested method:

1. Explain to the participants the reality that caregivers and children on ART go through different psychological processes as treatment continues. It is common for motivation to diminish after some weeks or months, and so some caregivers and children will need re-motivation. Explain, too, that some children on treatment may experience treatment failure and may need to change treatment. (This may be because of non-adherence, or may have occurred because the particular combination of drugs does not work for this particular child.) So then the caregiver and child will need counselling for change of regimen.

2. Hand out copies of the notes on Stage 3 counselling. Go through the components of the counselling process with the participants. Encourage discussion.

3. Read out to participants the following scenario:

> *Maria is a 29-year-old unemployed woman who lives in an informal settlement. She has been living alone since her male partner left her 10 years ago when she fell pregnant and discovered she was HIV positive. Maria has no permanent employment, but does find occasional piecework. She has a daughter called Lerato, who has been HIV positive since birth. Lerato is now 9 years old. She has been on treatment for 3 years now, and has generally done well.*
>
> *In the last month, CD4 tests have detected that Lerato's CD4 count has deteriorated. After various tests, it emerges that Lerato may need to be changed to a second-line treatment regimen which has worse side-effects. Both Lerato and Maria feel discouraged about this prospect.*

4. Ask participants to comment on how they would feel if they were the counsellor in this situation and how the mother and child might feel. Assure participants that feelings of anger, disappointment, sadness are normal and it is important to find time in the counselling session to deal with these feelings.

5. Ask for volunteers to play the caregiver and child in a role-play. Then role-play this situation in a fishbowl, with participants taking turns in playing the counsellor. Encourage the rest of the group to observe, and look out for useful and less useful aspects of the counselling process. Offer constructive feedback to participants, focusing on what they do appropriately. Remember to get the participants playing the client and child to swop roles with the other participants, so that they each also get an opportunity to play the counsellor.

6. End the activity with a group discussion.

Trainers Notes:

Trainer's notes:

Stage 3:

Re-motivation and/or treatment change

After a certain period, adherence may decrease, or the patient may experience side-effects or develop a toxic reaction, become resistant or suffer treatment failure. Treatment change may be required. The caregiver and child need intensified support in any of these circumstances. Re-motivation is required.

With non-adherence, revisit the original reasons for starting treatment (Stage 1). Long-term benefits need to be stressed. The stresses and monotony of sticking to the treatment plan need to be explored, and efforts made to deal with any problems or to re-motivate. There may be a need for contact with the child and caregiver between clinic visits to help with remembering daily treatment times and administering the drugs.

With persistent or serious side-effects, or toxic reactions, medical assessment is essential to establish whether there are steps which can be taken to relieve these effects and allow the regimen to be continued. Counselling is needed to help the caregiver and child understand what is happening and what can be done. However, it may be necessary to change to another regimen (see below).

In the case of resistance developing, the caregiver and child will need help to understand what is happening and what the future options are. They may need help to deal with feelings associated with this development (e.g. disappointment, anxiety, despair).

With treatment change, the caregiver and child need to understand the different requirements of the new (and therefore, at least to start with, more complicated) regimen. This would involve using elements of the pre-ART counselling stage adapted to meet the caregiver's and child's needs.

Trainers Notes:

Checklist	
Allow at least one counselling session at the time of any treatment change, and follow-up 1-2 weeks after any treatment change. **Ensure monthly follow-up with a member of the HCT (usually coinciding with collection of medication from pharmacy).** **Clinical assessments usually need to take place 3-6 monthly.** **More frequent visits or contacts may be required, especially in the case of non-adherence, side-effects or toxic reaction, or in early stages of treatment change.**	
All (at all visits)	Reinforce trust between caregiver/child and HCT, maintain supportive role, liaise patiently with caregiver/child Avoid conveying attitude of blame, disappointment or disapproval
	Assessment
All team members	Note and alert team to: • Indications of persistent non-adherence, despite counselling • Persistent or severe side-effects or signs of toxic reaction • Clinical signs of treatment failure, e.g. progressive deterioration in developmental milestones (walking, talking, etc.), failures in physical growth (height, weight, head circumference), disease progression • Laboratory indications of resistance or treatment failure (increase in viral load, decrease in CD4% or CD4 Count)
Doctor	• Clinical assessment • Decision on any regimen change (preferably in consultation with experienced clinician because of limited options)
	Re-motivation
Adherence counsellor (or doctor/ nurse) and all team members	**Re-counsel as for stage 1** (including re-education on HIV/AIDS, ART if necessary) • Assess understanding of ART and that ART is life-long commitment • Reinforce caregiver's/child's understanding of treatment regime and consequences of non-adherence • Revisit original decision to start ART • Explore or clarify caregiver's/child's understanding of why treatment change is necessary • Explore/counsel regarding feelings (caregiver/child) related to need for treatment change (e.g. possible shame, guilt, fear of failure, blame or self-blame) • Revisit issues which may impact on adherence (financial, family, social, school, peers, lack of discipline, fear of side-effects, etc.) • Brainstorm ways of developing a disciplined approach to adherence • Discuss possibility of missing doses, and explore ways to deal with this when it occurs • Explore support • Encourage caregiver to motivate child with empathy

	Treatment change
Doctor/nurse/ pharmacist/ adherence counsellor	**Caregiver/child preparation** • Educate on new regimen • Emphasise any differences in dose quantity, frequency, timing • Discuss possible side-effects • Emphasise importance of adherence and what this involves • Reassure that non-adherence can happen but reinforce consequences (treatment ineffective, resistance) • Reinforce idea that treatment is a lifelong • Reinforce caregiver's (and child's) commitment
Doctor/nurse/ pharmacist/ adherence counsellor	**Develop a new treatment plan** HCT members should collaborate closely in developing the plan • Treatment regimen (specifics of medication, doses, and the intervals at which they should be given and differences from previous regimen) • Possible side-effects and who to contact in the case of serious side-effects • Integrate treatment into daily routine of caregiver/child, especially the specific times the medication will be given (e.g. 8 a.m., 8 p.m.) • Individualise strategies by looking at basic needs, regimen, literacy, language • Provide practical aids, supporting handouts • Demonstrate dosage and method of administration • Have caregiver/child demonstrate measurement and administration with actual medication • Talk about simple remedies for mild side-effects and who to contact in the case of serious side-effects • Plan follow up (telephone, clinic visits preferably within 1-2 weeks of starting) • Support and monitor closely during adjustment period

Trainers Notes:

Activity 27

Course module title:	Assessment
Activity:	Completion of multiple choice questionnaire

Duration:

15 minutes

Outcome:

- Indication of participants' areas of strength and weakness relating to basic information about ART and children

Suggested method:

1. Hand out a copy of the questionnaire (Q & A) to each participant. Explain that it is intended to help them assess their knowledge of some of the key facts about HIV and ART in children and to give the trainer some idea of what participants have understood. Participants need to choose the correct answer or answer in each case. Allow about 5 minutes for completion of the questionnaire.

2. Ask for volunteers to give their responses to the questions and provide the correct answers. Where necessary, explain why a particular answer is or is not correct.

3. Refer participants to the notes from Activity 7 for follow-up reading. Collect completed questionnaires for assessment purposes.

Note: This activity may also be used as a self-assessment exercise.

Q & A

1. Who may at present consent to a child having an HIV test?

a. a child aged 14 years or above

b. a child below the age of 14 years, provided the child is mature enough to understand the benefits, risks and social implications of the test

c. the parent or caregiver, if the child is under 14 years or not mature enough to understand the consequences of the decision

d. the schoolteacher of a child who is continually ill.

2. The Elisa antibody test shows:

a. whether HIV antibodies belong to the mother or the baby

b. if the child was infected perinatally

c. if the child was infected through breastfeeding

d. if the child was sexually infected

e. none of the above.

3. Common indications of HIV in children are:

a. persistent diarrhoea

b. chicken pox

c. persistent ear discharge

d. enlarged lymph nodes

e. severe nappy rash

f. delayed developmental milestones

4. Without ART, HIV-infected children progress towards AIDS as follows:

a. less than 5% live beyond 8 years without ART

b. 50-60% live for 3-5 years without ART

c. in about 40%, progress towards AIDS is rapid

d. about 50% die before their 2nd birthday

5. The decision to start children on ART is based on:

a. CD4 count of under 300

b. CD4% of under 50%

c. repeated hospitalisations (more than 2)

d. prolonged hospitalisation (more than 4 weeks)

e. WHO stage III or IV

f. if the child is relatively well, CD4 % < 20% if under 18 months or < 15% if over 18 months
g. diarrhoea and vomiting.

6. ART dosage in children:
a. is the same as in adults
b. is the same for sisters and brothers
c. changes as the child develops

7. Some common mild side-effects in children are:
a. nausea, vomiting and diarrhoea
b. dizziness
c. general tiredness
d. nail discoloration
e. peripheral neuropathy
f. hair loss
g. ringworm

8. Ideal core members of the health-care team should be:
a. doctor
b. nurse
c. counsellor
d. X-ray technician
e. pharmacist and assistant
f. social worker
g. pathologist.

9. Important supporting members of the health-care team are:
a. the treatment supporter
b. the legal advisor
c. the traditional health practitioner
d. the home-based carer (in a palliative care situation).

10. The correct way to approach disclosure is:

a. recognise that disclosure is a process that should take place over time

b. it should be left up to the caregiver to decide when to tell

c. it involves helping the child to understand what HIV means

d. the doctor or another health worker should tell the child when s/he believes the child is ready

e. all children can be told about their HIV status in the same way

11. The best way to disclose to a child is:

a. leave HIV information lying around for the child to read

b. let the child overhear family members talk about their status

c. when the child is naughty, tell her/him as punishment

d. leave the child to work it out for her/himself

e. wait until the child is really ill

f. none of the above

12. The best age to disclose to child:

a. is under the age of 6 (preschool)

b. is when children are of primary school-age

c. is when children reach adolescence

d. depends on the needs of the individual child.

Correct answers

1.	a, c	*This question will need to change, when the new Children's Act comes into effect – then the age of consent will be 12 years*
2.	e	
3.	a, c, d, e, f	
4.	b, c, d	*5-25% live beyond 8 years*
5.	c, d, e, f	
6.	c	
7.	a, b, c, d, e	
8.	a, b, c, e, f	
9.	a, c, d	
10.	a, c	*The caregiver should be counselled on the advantages and disadvantages of disclosure and encouraged to act in the best interests of the child with regard to when and how to disclose.*
11.	f	
12.	d	*For many children, primary school age is the most appropriate time to begin to explain that their illness is caused by HIV infection.*

Appendices

Evaluative discussion

Post-training verbal evaluation

This is a list of open-ended questions to help facilitate discussion on the effectiveness of the course with the participants and/or the trainer. It can be used by the trainer and the organisation, or fed back to the course developers.

Questionnaire for structuring evaluative discussion with group of participants

1. How did you experience this course?
2. What did you feel was most helpful to you?
3. Which sections did you find to be less helpful?
4. How do you think these sections could have been done differently, if they are necessary?
5. How did you feel about the case scenarios and role-plays?
6. What are your comments about the training materials (*information sheets, Trainer's notes)* that you received?
7. What recommendations do you have for the future running of this training programme?

Questionnaire for evaluative discussion with the trainer

1. How did you experience this course?
2. How effective and useful was the Trainer's Guide as a tool for guiding your facilitation of the course?
3. Do you have any recommendations for changing the Trainer's Guide in any way?
4. As far as content goes, what do you think was most valuable and least valuable for the participants?
5. Do you have ideas for changing the way in which the content was delivered or activities were performed?
6. (If not mentioned): Do you have comments on the amount of time allocated to the various activities?
7. Do you have any other recommendations or comments about the training programme?

Evaluation form

This evaluation form for participants can be used to obtain anonymous feedback from the participants once they have completed the training programme. The feedback can be used to evaluate the benefits of the training programme from the viewpoint of the participants. It can be used by the trainer and the organisation, or fed back to the course developers. See the course evaluation form on the following page.

Course evaluation form

The purpose of this evaluation form is to provide you with an opportunity to anonymously express your views about the training programme that you have just completed. You are not required to write your name on this form or to answer any questions that may identify you. The evaluation form aims to gather feedback that will assist the trainer and the developers of the course to improve it.

Dates of training:

Venue:

Trainer:

1. What was your general view of this course?
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   ....
   ....
   ....

2. Did you feel that this course was worthwhile for you? Please state why.
   ....
   ....
   ....
   ....

3. Please state what was most valuable and least valuable for you.
   Most valuable:..
   ....
   Least valuable: ....
   ....

4. What recommendations would you make for the improvement of this course?
   ....
   ....
   ....

5. Any other comments that you wish to make?
   ....
   ....
   ....
   ....

Evaluation rating

Please rate the value of each area of the training according to a 5-point scale where:

1 = not helpful at all
2 = slightly helpful
3 = helpful
4 = more than helpful
5 = very helpful.

	1	**2**	**3**	**4**	**5**
1. Basic facts about anti-retroviral treatment (ART)					
2. Understanding what ART adherence is and why it is necessary					
3. The three stages of ART counselling					
4. The health care team approach					
5. The phases of childhood development					
6. The process of disclosure					
7. The scripted role-plays					
8. Using a doll to communicate with children					
9. ART readiness assessment					
10. ART side-effects and children					
11. ART preparation and treatment plan					
12. ART initiation and maintenance					
13. Re-motivation/treatment change					
14. Case studies					
15. Multiple choice questionnaire (Q & A)					

Any comments

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Observation schedule

This is an adherence counselling session observation schedule:

- for observing adherence counselling sessions to assess the performance of the counsellor
- to monitor the effectiveness of the service that your facility is providing in terms of adherence counselling
- with careful constructive feedback after the counselling session, this schedule can also be used by the more experienced observer to point out the counsellor's strengths and areas that require improvement.

Assessment form

Name of counsellor:			
Name of observer:			
Date:			
Overall	Poor	Fair	Good
	1	**2**	**3**
Accuracy of information provided 3 Good = Comprehensive, no errors 2 Fair = Minor errors / omissions 1 Poor = Significant errors / omissions			
Counselling skills (Body language, empathy, respect) 3 Good = Positive, personal engagement with client 2 Fair = Generally positive, but some distance / inconsistency 1 Poor = Routine / distant interaction with client			

Any comments

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Observation schedule

For each item, mark yes, no, or not applicable.	Yes	No	Not Appl.
Introduction			
Helps caregiver feel relaxed and willing to accept counselling (Greets caregiver, smiles, asks to sit, uses icebreaker) Helps child feel relaxed and willing to accept counselling (Greets child, smiles, asks to sit, uses icebreaker)			
Explains confidentiality to caregiver			
Explains confidentiality to child			
Clarifies caregiver's understanding of reason for session			
Clarifies caregiver's understanding of reason for session			
Clarifies child's understanding of reason for session			
Uses collaborative approach with caregiver			
Uses collaborative approach with child			
Assesses with caregiver understanding / provides basic information / corrects misconceptions re ART and adherence			
Basic facts about ART			
Adherence and why it is important			
Common ART side-effects and likely course			
Assesses ART readiness			
Assesses level of commitment to ART adherence			
Assesses awareness of what is involved in ART			
Establishes belief in the need for treatment			
Caregiver's perceived advantages and disadvantages of being on ART			

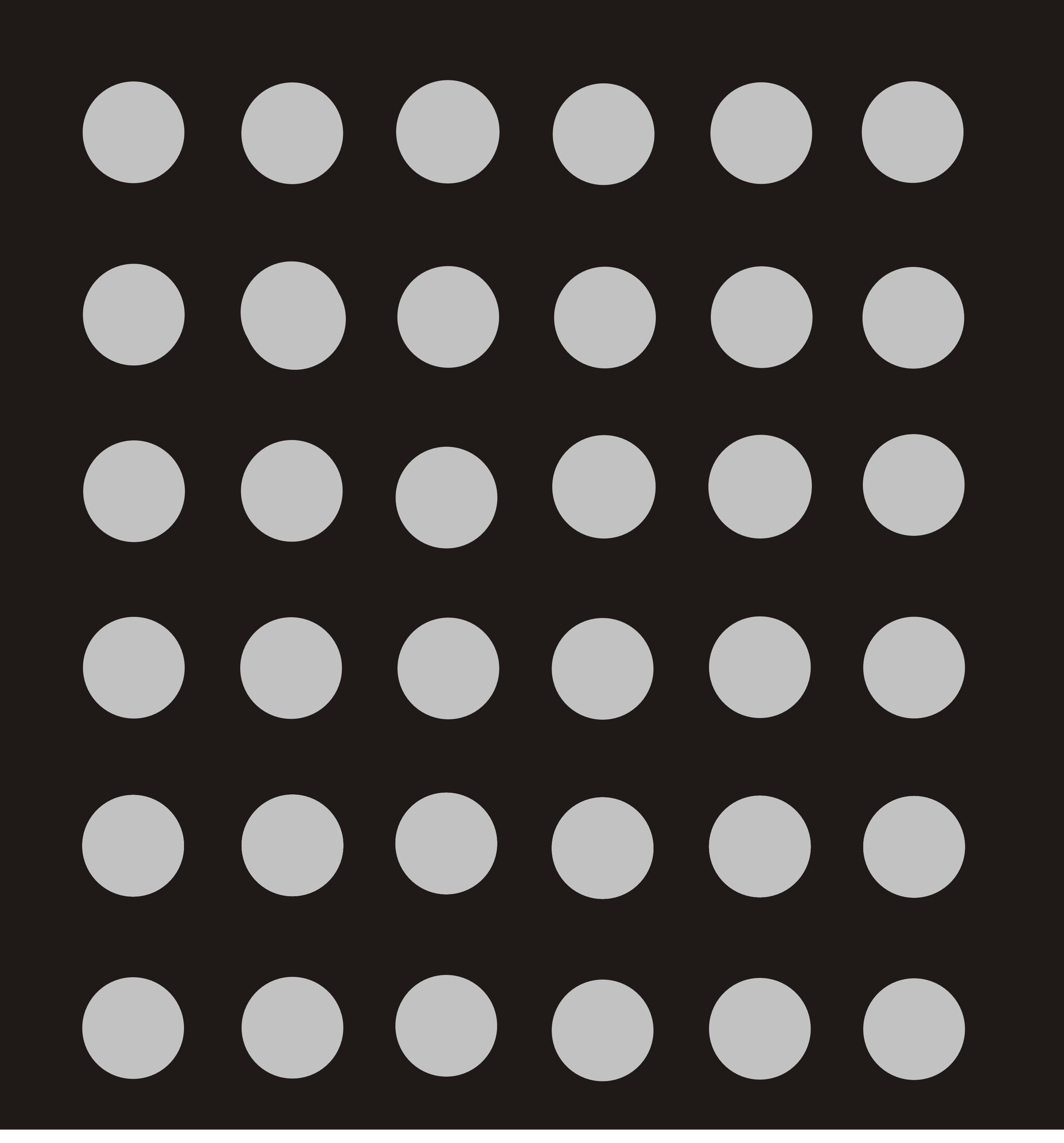
	Yes	No	Not Appl.
Where age appropriate: Assesses with child understanding / provides basic information / corrects misconceptions re ART and adherence			
Basic facts about ART			
Adherence and why it is important			
Common ART side-effects and likely course			
Assesses ART readiness			
Assesses level of commitment to ART adherence			
Assesses awareness of what is involved in ART			
Establishes belief in the need for treatment			
Child's perceived advantages and disadvantages of being on ART			
Assesses child's psychosocial situation:			
Discusses child's lifestyle (e.g. school, daily routine, sleep)			
Explores child's personality traits (e.g. intellectual understanding, emotional readiness, ability to take responsibility for treatment)			

	Yes	No	Not Appl.
Assesses caregiver’s psychosocial situation:			
Discusses caregiver’s lifestyle (e.g. work, daily routine, other demands, stressors)			
Explores caregiver’s personality traits (e.g. sense of organisation, self-discipline, responsibility)			
Caregiver’s use of alcohol and drugs			
Caregiver’s own HIV status			
Caregiver’s health			
Caregiver’s financial and material resources			
Explores barriers/sources of support:			
Shows sensitivity towards risks involved in disclosure			
Respectfully guides the caregiver towards appropriate forms of disclosure to child			
Discusses possible future disclosure			
Discusses current or potential sources of support			
Develops adherence plan with caregiver (and with child, where appropriate):			
Reviews options			
Identifies sources of support and ways to approach them			
Problem-solving regarding barriers			
Collaboratively develops specific adherence plan			

KIDS COUNT

Guide for Trainers

Children's
ART Adherence
Resource
Pack



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