Integrated Management of Childhood Illness

Complementary course on HIV/AIDS

Module 4 Follow-up and chronic care of HIV exposed and infected children



Department of Child and Adolescent Health and Development (CAH)



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1.0 INTRODUCTION

The diagnosis and management of HIV in children is complex, and certain challenges and considerations are unique to children, as highlighted in the box below.

Box 1.0 Special considerations in children

- 1. Young children have immature immune systems and thus are susceptible to more frequent and severe common as well as opportunistic infections.
- 2. Due to the persistence of maternally-acquired antibodies, a positive rapid HIV test is not definitive to diagnose for children below 18 months. However, a negative test is useful because it usually excludes infection acquired from the mother, so long as the child has not been breastfed for more than 6 weeks.
- 3. Normal CD4 counts are higher in young children than in adults and decrease with age to reach adult levels around the age of 6 years. The absolute CD4 count depends on age and so cannot be used in the same way as for adults to determine progression of infection.
- 4. ARV drugs are handled differently in children's bodies, affecting the doses that are needed. Dosages in children need to be adjusted to weight as the child continues to grow.
- 5. Counselling children for disclosure of their HIV status, to discuss ART, and to support adherence to ART requires special effort and skills in communication.

All children who have been exposed to HIV, whether classified as HIV EXPOSED / POSSIBLE HIV INFECTION or CONFIRMED SYMPTOMATIC HIV / CONFIRMED HIV INFECTION will require regular follow up and reassessment in order to determine their individual care and support needs.

It is important to note that if a child is diagnosed as HIV infected, he or she will not automatically need to be put on ART. The decision to put a child onto ART will depend on the progression of the disease.

Whereas HIV infected adults may be asymptomatic for a period of up to 10 years or more, in children the disease progresses more rapidly and depending on when the infection is acquired. More than 40% of HIV-infected infants will develop severe symptoms and die within the first two years of life if they are not treated with ARVs.

The rate of progression of disease is variable amongst HIV infected children and it is therefore necessary to provide close follow up and constantly re-assess the child's situation. Through regular clinical assessment, and a process known as clinical staging, the HIV infected child can be referred in a timely manner for ARV therapy when it is deemed necessary.

Section 3.0 of this module will teach you how to follow up children under each classification:

- <u>Children classified as HIV/EXPOSED / POSSIBLE HIV INFECTION</u>, should receive regular follow up and reassessment to determine their HIV status.
- <u>Children classified as SUSPECTED SYMPTOMATIC HIV AND CONFIRMED</u> <u>HIV INFECTION</u> should be enrolled into a life-long programme of chronic care. As outlined above, regular follow up and reassessment through a process of clinical staging will determine when they should be put onto ART.

In section 4.0 you will learn the principles of good chronic care. Section 5.0 provides general information on ARVs and section 6.0 teaches you about paediatric clinical staging and assessing eligibility for ART. Once it is decided that a child should be put onto ART, you will need to counsel the mother and child around adherence to ART. This information is provided in section 7.0. Section 8.0 outlines the ARV options for children: recommended ARV regimens, available drug preparations for children, dosages and side effects. The final section is a wrap up exercise designed so that you can practice all the assessment, counselling skills that you have learnt in this course.

Remember to apply the IMCI principles throughout this section: For example, when an HIV positive mother¹ brings her child to the clinic² for a particular problem or symptom or for routine care, you will need to assess the child for the symptoms of common childhood illnesses, based on what you learnt in IMCI and in modules 1 and 2 of this course. In addition to the assessment and treatment of acute conditions, it is necessary to assess the child for possible HIV infection – and this may require a series of follow up visits.

Note that "Follow up" in this course refers to the subsequent re-attendance clinical sessions regarding treatment and/or prevention schedules agreed upon between the mother and the health worker. On the other hand "Chronic care" refers to life-long care.

Note that this module is designed to introduce you to chronic care of the HIV exposed or infected child BUT it does not give you all knowledge and skill needed for chronic HIV care. If you are likely to be more involved with HIV care, it is strongly recommended that you take the IMAI Basic ART Course on chronic HIV care. Conversely, if you have already taken the IMAI training course, then it will not be necessary for you to take Module 4.

¹ Whenever the word mother is used in this module, the comment or statement also refers to other primary caretakers, as applicable and depending on the circumstance of the HIV positive child.

² The mother may have been referred from a PMTCT programme or from other clinical services such as TB.

2.0 LEARNING OBJECTIVES

By the end of this module you should be able to:

- Describe how you would follow up children born to HIV positive women, and be able to differentiate between:
 - Follow up of children classified as POSSIBLE HIV INFECTION / HIV EXPOSED
 - Chronic care for children with SUSPECTED SYMPTOMATIC HIV or CONFIRMED HIV INFECTION
- Understand the principles of good chronic care
- Describe the WHO paediatric clinical staging process
- Describe how to counsel the mother/care giver for adherence to ART and cotrimoxazole prophylaxis
- Describe the recommended ARV regimens for children, the possible side effects of ARV drugs and the management of possible side effects
- Describe the principles of pain management

3.0 FOLLOW-UP OF CHILDREN BORN TO HIV POSITIVE WOMEN

All children born to HIV positive women should be followed up regularly. In doing so, this provides a continuum of care for women who received PMTCT services before and/or during delivery and allows regular reassessment of the child in order to recognize HIV infection early and to determine their HIV status.

The details of this follow-up are outlined in the IMCI chart booklet and summarized in the boxes below. Read through these boxes to learn how to follow-up children born to HIV-positive women. Remember that because HIV is a rapidly changing field, these follow-up recommendations may change from time to time. Make sure that you are using the most up-to-date follow-up information to provide follow-up care.



Note: Children who are POSSIBLE HIV INFECTED / HIV EXPOSED / SUSPECTED SYMPTOMATIC will require regular follow up. If they are then reclassified as CONFIRMED HIV INFECTION, they will need to be enrolled into a life-long treatment plan – referred to here as 'Chronic HIV care'

3.1 FOLLOW-UP OF CHILDREN CLASSIFIED AS POSSIBLE HIV INFECTION / HIV EXPOSED

An infant classified as possible HIV infection or HIV exposed may be a well infant or a sick infant. In both situations, arrangements should be made for a regular follow up in a well-baby clinic or under-five clinic or other appropriate settings. During follow up, all such infants need to receive regular immunization, growth monitoring, counselling on feeding, vitamin A supplementation and opportunistic infections prophylaxis as per national guidelines.

3.1 POSSIBLE HIV INFECTION / HIV EXPOSED

- Follow-up: in 14 days, then monthly for 3 months, then every 3 months or as per immunization schedule
- Do a full re-assessment at each follow-up visit and reclassify for HIV on each follow-up visit
- Counsel about feeding practices (page 25 in chart booklet and according to the recommendations in Module 3)
- Follow OI prophylaxis (co-trimoxazole and/or INH prophylaxis as per national guidelines)
- Follow national immunization schedule
- Follow vitamin A supplements every 6 months beginning at age of 6 months
- Monitor growth and development
- Virological Testing for HIV infection as early as possible from 6 weeks
- Refer for ARVs if child has a positive virological test, suspected symptomatic HIV or any severe classifications suspected to be due to HIV or positive antibody test under the age of 18 months and 2 of the following: oral thrush, severe pneumonia, unexplained severe malnutrition or severe sepsis
- Counsel the mother about her own HIV status and arrange counselling and testing for her if required

3.2 FOLLOW-UP OF CHILDREN CLASSIFIED AS SUSPECTED SYMPTOMATIC /CONFIRMED HIV INFECTED OR UNINFECTED

3.21 SUSPECTED SYMPTOMATIC HIV INFECTION

- Follow up in 14 days, then monthly for 3 months and 3 monthly or as per immunization schedule
- Do a full assessment classify for common childhood illnesses, for malnutrition and feeding, skin and mouth conditions and for HIV on each visit
- Check if HIV test has been done and if not, test for HIV as soon as possible
- Assess feeding and check weight and weight gain
- Encourage breastfeeding- mothers to continue exclusive breastfeeding
- Advise on any new or continuing feeding problems
- Initiate cotrimoxazole prophylaxis according to national guidelines
- Give immunizations according to schedule. Do not give BCG
- Give Vitamin A according to national schedule
- Provide pain relief if needed
- Refer for confirmation of HIV infection and ART initiation

3.22 CHILD IS CONFIRMED HIV INFECTED*

- Follow-up in 14 days, monthly for 3 months and then 3-monthly or as per national guideline
- Continue co-trimoxazole and or INH prophylaxis
- Follow-up on feeding
- Home care:
 - o Counsel the mother about any new or continuing problems
 - If appropriate, put the family in touch with organizations or people who could provide support
 - Advise the mother about hygiene in the home, in particular when preparing food
- Reassess for eligibility for ART or refer
- Check mother's health and advise on safe sexual practices and family planning

* Any child with confirmed HIV infection should be enrolled in chronic HIV care, including assessment for eligibility of ART – refer to subsequent sections of this module.

3.23 CHILD IS CONFIRMED UNINFECTED

- Stop cotrimoxazole
- Counsel mother on preventing HIV infection and about her own health

If HIV testing has not been done:

- Re-discuss the benefits of HIV testing
- Identify where HIV testing including virological testing can be done
- If mother consents arrange HIV testing and follow -up visit

If mother refuses testing

- Provide ongoing care for the child, including routine monthly follow -up
- Discuss and provide cotrimoxazole prophylaxis
- On subsequent visits, re-counsel the mother on preventing HIV and on benefits of HIV testing

When you follow-up a child born to an HIV-positive woman first check for general danger signs, assess and classify this child for common childhood illnesses and then check whether there are any HIV-related signs or signs due to antiretroviral drugs that necessitate referral. The signs that necessitate referral on follow-up are listed in the box below.

You will need to note that some signs require urgent referral, while other signs require non-urgent referral. You will learn about side effects of antiretroviral drugs in section 8.4.

SIGNS DETECTED ON FOLLOW-UP THAT REQUIRE URGENT REFERRAL

- Any child age below 5 years with URGENT (pink) classification of IMCI (refer to chart booklet or Module 1)
- Any child who is on COTRIMOXAZOLE PROPHYLAXIS and who has signs / features of:
 - Steven Johnson syndrome (define) or
 - exfoliative dermatitis or
 - anaemia or
 - recurrent infections
- Any child (any age) who has serious side effects to ANTIRETROVIRAL THERAPY (see section 9.0)



Role Play: Follow of the HIV infected child

In this exercise there will be a role play of follow-up care for an HIV infected child.

At the end of the role play the facilitator will lead a discussion on the problems of providing ongoing follow-up care for HIV infected children and how these problems could be overcome in your clinic

Lungi is 19 months old and was seen one week ago suffering from recurrent episodes of diarrhoea. She also had severe thrush and enlarged lymph nodes in her armpits and groin. You classified her as NO DEHYDRATION, NO ANAEMIA, and SUSPECTED SYMPTOMATIC HIV. She was then referred for HIV testing and found positive.

HEALTH WORKER:

Make a plan with the mother as to how you will manage the ongoing followup of this child. Remember to give her time to ask any questions and to tell her that there is a lot that can be done to keep her child healthy.

MOTHER:

Behave as a real mother would in this situation; imagine how it would feel to find out that your child is infected with HIV and need to be on ART. Ask the questions you think a mother would ask in this situation.

OBSERVERS:

Watch the role play and comment on the advice given, follow up recommended and the difficulties faced by both the mother and the health worker.

4.0 PRINCIPLES OF GOOD CHRONIC CARE

In the management of children with HIV/AIDS, it is important to be able to provide both good acute and good chronic care at health facilities and to link in with home-based care.

Acute care (which you learnt about in the IMCI case management course and in Module 1 of this course) includes the management of common childhood illnesses, such as bacterial infections, malaria, pneumonia, ear infections and skin conditions. In countries with a high prevalence of HIV infection, more and more of these acute problems are due to opportunistic infections that occur because of immunodeficiency caused by the HIV infection.

HIV infection causes a chronic disease and this requires special health care. If we only care for the patient during episodes of acute illness, then we are only providing acute care and not yet providing good chronic care.

Good chronic care for children under the age of 5 years recognises that the mother (or other primary care giver) must understand and learn to help with managing the child's condition. The mother of an HIV infected child thus bears a double burden. Firstly, if she is living with HIV/AIDS she will need to learn to cope with her own illness and secondly she will need to learn to manage and cope with her child's illness if he / she is HIV infected.

Providing chronic care is different from providing acute care. When we provide chronic care for an infant or child we have to take note of and follow several principles. These principles are important and are listed below (check chart booklet p. 21 also):

Box 2.0 General Principles of Good Chronic Care for HIV-infected children

- 1. Develop a treatment partnership with the mother and infant or child
- 2. Focus on the mother or child's concerns and priorities
- 3. Use the counselling skills you learnt in the counsel the mother module and use the '5 As' that you will learn about in section 7.0 of this module
- 4. Support the mother and child's self-management
- 5. Organize proactive follow-up
- 6. Involve "expert patients", peer educators and support staff in your health facility
- 7. Link the mother and child to community-based resources and support
- 8. Use written information registers, Treatment Plan and treatment cards to document, monitor and remind
- 9. Work as a clinical team
- 10. Assure continuity of care

Research has shown that when patients receive this kind of health care, they do better. Five of these principles are explained in detail below:

1. Develop a treatment partnership with the mother and infant or child

What is a partnership? A partnership is an agreement between two or more people to work together in an agreed way toward an agreed goal. For good chronic care, the partnership is between the health worker (or clinical team) and the mother and child. In a partnership both parties share responsibility for the agreement. Each partner knows what role he or she plays in the partnership. Partners treat each other with respect. One partner does not have all the power.

3. Focus on the mothers or child's concerns and priorities

Often we focus only on the obvious signs or symptoms of illness and may miss the real reason that the mother came to the clinic. It is important to find out why the mother has come: Is the child sick? Does he have a cough or diarrhoea or mouth sores or all three? Is the mother afraid or is she having some difficulty or a psychosocial need? If the child is sick you will need to Assess, Classify, Treat, Counsel and Follow-up this child for all the common childhood illnesses (Module 1). In addition, ask or observe any psychosocial needs and make sure that these are addressed.

4. Use the counselling skills you learnt in the counsel the mother module

The counselling skills that you learnt in Module 3 will help you develop a good relationship with the mother and will ensure that good long-term care is provided. For long term care, the mother and the child (depending on age and maturity) will need to agree to the treatment plan. The health worker should assist the caretaker to solve barriers to ensure long term care. There need to be arrangements for definite follow-up dates and scheduling and arranging for the mother to pick up medication such as co-trimoxazole prophylaxis or ART.

• Support the mother and child self-management

Whenever you think and speak about how an HIV positive mother and her HIVinfected child should be managed, you need to realize that the mother should be left as much in charge of her and her child's care as is practically possible and feasible. This self-help approach will give the mother a better sense of control and make her feel better about her situation. It has been shown that this approach makes people more successful in caring for themselves.

Self management recognizes that the mother takes responsibility for the daily treatment of the child's condition.

5. Work as a clinical team

Providing good chronic care (and also good acute care) requires teamwork. To be able to deliver ART, this requires long-term commitment from a clinical team that includes a nurse, clinical officer, an ART aid (for education, psychosocial support, adherence counselling) and a medical officer or doctor. The team may work together differently depending on where they are located.



GROUP DISCUSSION A

The facilitator will now ask participants to discuss the difference between acute and chronic care.

Participants should give examples from their own work situation as to how they can apply the principles of good chronic care.

5.0 ANTIRETROVIRAL THERAPY: GENERAL INFORMATION ABOUT ARVs

HIV is a special kind of virus called a retrovirus. So the drugs against HIV are called antiretroviral drugs:

Anti Retro Viral drugs – shortened to ARV drugs or simply ARVs.

Giving ARVs in the correct way, with adherence support, is called **ARV** Therapy, shortened to **ART**.

In Module 2 you learnt about how the HIV virus replicates by turning CD4 cells into HIV 'factories'. Antiretroviral drugs interfere with the life cycle of the HIV virus, thus preventing it from replication. ART does NOT cure HIV but through preventing replication of the virus it prevents the damage to the immune systems and can improve the quality of life of the patient.

Certain children classified as CONFIRMED HIV INFECTION or SUSPECTED SYMPTOMATIC HIV INFECTION or POSSIBLE HIV INFECTION / HIV EXPOSED who meet specific criteria will be put onto antiretroviral drugs. Their eligibility for the ART is decided through a process of clinical staging which is explained in section 6.0

The table below shows the 3 groups of commonly used antiretroviral drugs. These groups of drugs act at different sites and stop the multiplication of HIV in the body.

For ART to be effective it is important that a combination of 3 drugs is used, rather than using one or two drugs. Combination therapy for HIV is like combination therapy for TB, and makes sense for lots of reasons. Here are the most important ones:

- It takes a lot of force to stop HIV. HIV makes new copies of itself very rapidly. Every day, many new copies of HIV are made. Every day, many infected cells die. One drug, by itself, can slow down this fast rate of infection of cells. Two drugs can slow it down more, and three drugs together have a very powerful effect.
- Antiretroviral drugs from different drug groups attack the virus in different ways. Different anti-HIV drugs attack HIV at different steps of the process of making copies of itself (first when entering the cell, second when making new copies and third when the new copies want to leave the cell). Hitting two targets increases the chance of stopping HIV from making new copies of itself and preventing new immune cells from infection.

• Combinations of anti-HIV drugs may overcome or delay resistance. Resistance is the ability of HIV to change its structure in ways that make drugs less effective. HIV has to make only a single, small change to resist the effects of some drugs such as nevirapine. For other drugs, such as zidovudine, HIV has to make several changes. When one drug is given by itself, sooner or later HIV makes the necessary changes to resist that drug. But if two drugs are given together, it takes longer for HIV to make the changes necessary for resistance. When three drugs are given together, it takes even longer.

Nucleoside reverse transcriptase inhibitors (NsRTI)	Nucleotide reverse transcriptase inhibitors (NtRTI)	Non-nucleoside reverse transcriptase inhibitors (NNRTI)	Protease Inhibitors (PI)
Stavudine (d4T) lamivudine (3TC) zidovudine (ZDV) didanosine (ddI) abacavir (ABC)	tenofovir disoproxil fumarate (TDF)**	nevirapine (NVP) efavirenz (EFV)	lopinavir (LPV) saquinavir (SQV) indinavir (IDV) nelfinavir (NFV) retonavir (RTV)*

COMMONLY USED ANTIRETROVIRAL DRUGS

* ritonavir is used as a 'helper' for another PI to make the effect of the other PI stronger ** not yet available for clinical use



GROUP DISCUSSION B

Discuss possible reasons for the need for 3 drugs when treating HIV positive children and adults. Refer to the basic information on HIV section in Module 2.

6.0 WHO PAEDIATRIC CLINICAL STAGING FOR ASSESSING ELIGIBILITY FOR ART

Starting ART is not an emergency. Before starting ART, the child must be treated for any acute illness and / or opportunistic infections she or he may have.

Once a child is confirmed to be HIV infected it is important to perform a task called CLINICAL STAGING when you ASSESS the infant or child. If the child does not have confirmed HIV infection but you suspect they have severe HIV disease, they will need referral to assess whether ART is indicated.

Clinical staging will help you estimate the degree of immune deficiency the infant or child has.

Staging uses a combination of signs and symptoms to determine the degree of immune deficiency; hence when you STAGE an HIV-infected infant or child you will need to LOOK, LISTEN AND FEEL and also conduct laboratory tests, if possible. You should be aware of some of the staging criteria so that you can identify when a child is in need of referral.

According to the WHO REVISED PAEDIATRIC CLINICAL STAGING developed in 2005, a child with confirmed HIV infection can fall into one of four clinical stages. A stage I and II clinical status indicates that the immune system is not yet seriously affected. Stage III and IV indicates advanced immune deficiency. You will note that most conditions in stage 4 and 3 need URGENT REFERRAL and what is expected from a first level facility is to recognize that. Most conditions in stage 2 can be managed at first level facility.

Open the photo booklet section 6 to practice identifying the signs/conditions used for clinical staging of a child. Your facilitator will help you describe the photographs for each of the clinical stages.

WHO Paediatric Clinical Staging for HIV³

Determine the clinical stage by assessing the child's signs and symptoms. Look at the classification for each stage and decide which is the highest stage applicable to the child - where one or more of the child's symptoms are represented.

	WHO Paediatric Clinical - Stage 1 - Asymptomatic	WHO Paediatric Clinical - Stage 2 - Mild Disease
Growth	-	-
Symptoms/ signs	No symptoms or only: Persistent generalized lymphadenopathy (PGL) 	 Unexplained persistent enlarged liver and/or spleen Unexplained persistent enlarged parotid Skin conditions (prurigo, seborrhoeic dermatitis, extensive molluscum contagiosum or warts, fungal nail infections, herpes zoster) Mouth conditions (recurrent mouth ulcerations, lineal gingival Erythema) Recurrent or chronic RTI (sinusitis, ear infections, tonsilitis, otorrhoea)
ARV Therapy	 Indicated only if CD4 is available: ≤11 mo and CD4 ≤25% (or ≤1500 cells) 12-35 mo and CD4 ≤20% (or ≤750 cells) 36-59 mo and CD4 ≤15% (or ≤350) 5 yrs and CD4 ≤15% (<200 cells/mm3) 	 Indicated only if CD4 or TLC⁴ is available: Same as stage I OR <11 mo and TLC<4000 cells/mm3 12-35 mo and TLC < 3000 cells 36-59 mo and TLC < 2500 cells > 5- 8 years and TLC < 2000 cells* *There is not adequate data for children older than 8 years.

 ³ Note that these are interim recommendations and may be subject to change
 ⁴ Total lymphocyte count (TLC) has been proposed as a surrogate marker or an alternative to CD4 cell counts or CD4% in resource-constrained settings.

WHO Paediatric Clinical - Stage 3 - Moderate Disease	WHO Paediatric Clinical - Stage 4 - Severe Disease (AIDS)
Moderate unexplained malnutrition not responding to standard therapy	Severe unexplained wasting/stunting/ severe malnutrition not responding to standard therapy
 Oral thrush (outside neonatal period) Oral hairy leukoplakia Unexplained and unresponsive to standard therapy: Diarrhoea >14 days Fever >1 month Thrombocytopenia* (<50,000/mm3 for > 1 mo) Neutropenia* (<500/mm3 for 1 month) Anaemia for >1 month (aemoglobin < 8 gm)* Recurrent severe bacterial pneumonia Pulmonary TB Lymph node TB Symptomatic LIP* Acute necrotizing ulcerative gingivitis/periodontitis 	 Oesophageal thrush More than one month of herpes simplex ulcerations Severe multiple or recurrent bacterial infections ≥ 2episodes in a year (not including pneumonia) <i>Pneumocystis</i> pneumonia (PCP)* Kaposi's sarcoma Extrapulmonary tuberculosis Toxoplasma brain abscess* Cryptococcal meningitis* Chronic cryptosporidiosis Chronic isosporiasis Acquired HIV-associated rectal fistula HIV encephalopathy* Cerebral B cell non-Hodgkins lymphoma* Symptomatic HIV associated cardiomyopathy/nephropathy*
Start ART: In all children less than 12 months irrespective of CD4 or TLC; with TB, LIP or oral hairy leukoplakia or low thrombocytopenia, ART initiation may be delayed if CD4 is above age related threshold for immunodeficiency.	Start ART irrespective of CD4 count: Start ART as soon as possible. Also for infants with *Presumptive severe HIV infection defined as HIV antibody positive infants < 18 mo, without confirmed HIV infection but having an AIDS-indicator condition OR any two of: severe sepsis, severe pneumonia or oral thrush.

* conditions requiring diagnosis by a doctor or medical officer – should be referred for appropriate diagnosis and treatment

+ in a child with presumptive diagnosis of severe HIV disease, where it is not possible to confirm HIV infection, ART may be initiated.



WRITTEN EXERCISE A

Using the revised WHO paediatric clinical staging, in which clinical stage do these HIV infected children with the following presentation but no other signs belong?

- 1) 4 years old with many lymph nodes more than 0.5 cm in diameter in the axilla, groin and neck without underlying cause
- 2) 6 months old not feeding well and severe wasting which is refractory to treatment
- 3) 9 months old with persistent diarrhoea and herpes zoster
- 4) 3 years old with persistent lymphadenopathy and recurrent severe pneumonia
- 5) 9 years old with Kaposi's sarcoma, otherwise well
- 6) 12 months old baby doing very well but whose mother is HIV positive

7.0 COUNSELLING FOR ADHERENCE TO ART

Certain groups of children classified as CONFIRMED HIV INFECTION will be placed on antiretroviral therapy, based on their clinical staging and assessment of readiness for ART. You will need to provide mothers or the child depending on age and maturity, with counselling and support so that they adhere to their treatment continuously.

Adherence is the cornerstone of successful ART, but may be difficult to achieve in children due to a number of reasons:

- Young children are heavily reliant on their parents/caretakers to ensure adherence.
- There may be a poor understanding of the need to take the medication both for parent and the child.
- Many parents may not wish to disclose the HIV status to the child or to others involved in care, and this may create problems in administering doses whilst the parent is at work or the child is at school
- Lack of suitable easy to use paediatric fixed dose combinations means complicated mixtures of pills/syrups need to be taken.
- Often the medicines are often not palatable to children, resulting in difficulty in their administration
- Intolerability due to toxicity and adverse effects
- Costs of ARVs and cost of monitoring may be prohibitive

Given these constraints, adherence can be supported by involving both parents as well as the child (depending on the child's age and maturity) and through several preparatory counselling sessions involving the mother.

Health workers should use the '5As' to prepare patients for ART adherence:

Assess Advise Agree Assist Arrange

Examples of each are as follows:

> ASSESS

o Assess the mother's and or child's goals for today's visit

"Is there anything special about HIV/AIDS or ART you would like to address in today's session?"

• Assess the mother's and or child's understanding of ARV therapy (ART)

Assessing whether the mother (and or child) understands ART should include **specific questions**. Asking general questions like: "Do you understand everything concerning antiretroviral therapy?" is not very useful. Most mothers will answer "yes" to this question, even if they do not understand all of it. The best way is to ask questions that require more then a 'yes' or a 'no' from the mother. **Questions that make the mother explain in her own words what she knows are good to assess her understanding.** It is important to **make her feel comfortable**, not as if she is taking a test! If the mother has misunderstood or forgotten some information, reassure her that this is normal, and explain once more.

Questions that can be asked to assess the mother's understanding are:

"What do you know about HIV/AIDS and ART?"

If necessary, more specific questions can be used, because **big** questions such as "what do you know about HIV/AIDS and ART?" can sometimes overwhelm the mother. In that case she would say "nothing", while she might know a lot when you ask **smaller but specific** questions:

- ✓ What are the benefits of ART?
- ✓ Does ART cure patients from HIV?
- ✓ How long do you have to take ART?
- ✓ What is the effect of ART on the body's defence?
- ✓ Why is it important to come regularly to the health centre when you are taking ART?
- ✓ What do you know about side effects of ART?
- ✓ Why is it important not to miss a dose when you take ART?
- ✓ What happens if you do not take ART correctly?
- ✓ Why is it not good to combine ART with other drugs without consulting the health centre staff first?

• Assess interest in receiving therapy

Not all mothers are interested in their child receiving ART, even if the child is medically eligible for ART. Mothers may have other urgent preoccupations in their life that make them want to postpone starting ART.

That is why it is necessary to assess (in depth) to be sure that the mother and or the child is interested in the child receiving ART.

> ADVISE

"I have some information about HIV/AIDS and ART. Would you like to hear it?"

Give the mother advice on the following topics (use the flipchart when this is helpful):

- HIV illness and expected progression (locally adapted, using language your patient can understand).
- Explain that in children the progression of disease is often rapid. Whilst they may be initially asymptomatic, children will become vulnerable to opportunistic infections that gradually become more serious because HIV is attacking the body's defence.

ARV therapy (ART)

- Advise the mother that ARVs are life-saving drugs. Her child's life depends on taking the correct dose twice daily and at the right time.
- The pills do not cure HIV— they just control it. It is therefore important that the infant or child does NOT stop taking the drugs. If they stop taking the drugs they will become ill again, as the body's defence system is attacked and their immunity drops again.
- Drugs must NOT be shared with family or friends the child must take the full dose.
- ARVs are very strong medicines. Discuss the possibility of drug interactions and side effects such as nausea and vomiting, which will need to be managed.
- Advise the mother on what additional steps should be taken to improve adherence:
 - Involve all caregivers and both parents and child depending on age and maturity through several counselling sessions.Careful disclosure to the child can help them understand why adherence is important.
 - Involve school nurses or orphanage staff, if and where applicable.
 - Adjust dosage according to changing body weight during follow up visits.
 - Select appropriate drug formulations considering such factors such as taste and pill burden.
 - Choose regimens similar to parents where it is appropriate.

NOTE: do not overwhelm the mother with too much information at once. She will need time to think about and digest some information before being able to concentrate on further information. That is why it is good to split the advice over several visits, and indicate on the education side of the child's treatment card the information that has been given already.

> AGREE

It is important to establish that the mother is willing and motivated and agrees to treatment or the child in older children before initiating ARV therapy for the child. The mother is the one that must take the responsibility for the child taking the medication twice every day and must be very motivated to make the necessary life adjustments to do this. As children get older it is important that the child knows about the ART and understands the need for 100% adherence.

Start by asking:

"After hearing all the explanation and advice, how do you think your child will be able to take this kind of treatment?"

In addition to considering the response to this question, use some other measures to check the motivation of the mother (since in practice the health worker's impression does not always correspond with the real situation). You can check, for example:

- Has the mother demonstrated ability to keep appointments for her child and to adhere to other medications?
- Does the mother want treatment for her child and understand what treatment is for?
- Is the mother willing to bring the child to the clinic for the required follow-up?
- Is the mother taking her treatment or does she need it?

> ASSIST

Explore what is needed to assist the mother with ART for her child:

"What problems might arise when you follow this plan?"

"What questions do you have about this treatment or how to follow this plan?"

Help the mother develop the resources/support/arrangements needed for adherence:

- Ability to bring the child for required schedule of follow- up
- Home and work situation of mother that permits her giving medications regularly to the child without stigma
 - o Regular supply of free or affordable medication
 - Supportive family or friends
 - o Disclosure to child and or family
 - o ART adherence support group

> ARRANGE

When the mother and child are ready for ARV therapy for the child, discuss this at the next clinical team meeting then make a plan.

Note that it will not be possible to prepare the mother and child for adherence on the same visit that you decide the child is medically eligible for ART. It usually takes at least 2 to 3 visits and the involvement of others on the clinical team and a treatment supporter.

If the mother needs another adherence preparation session, arrange a follow-up to reinforce key messages.

Arrange an appointment with the ART support group if the mother wishes so.

The adoption of ART requires long-term commitment on the side of both the clinical team and the mother (and child, depending on his/her age). Both will need support and help from treatment supporters and others in the community.

ONGOING COUNSELLING FOR AN HIV POSITIVE MOTHER

Remember that it is important to provide ongoing support and counselling to an HIV positive mother:

- > Encourage early testing of the baby with the best available test
- Support the mother's infant feeding choice
- Provide regular follow up
- Prescribe cotrimoxazole according to the guidelines in Module 2
- Refer to a support group with other mothers

ROLE PLAY: PREPARATION FOR ADHERENCE TO ART

Mary is 2 years old. At the age of 18 months Mary had an HIV antibody test which was positive and she has been classified as CONFIRMED SYMPTOMATIC HIV INFECTION.

She was brought to the clinic today for a follow-up and was classified as having: Oral thrush, and VERY LOW WEIGHT. The health clinical team has decided that she needs ART.

The health worker should counsel the mother on preparation for adherence to ART, using the 5 As.

The mother should try to behave as a real mother would in this situation.

The rest of the group should watch the role play and comment on the advice given and any difficulties faced by both the mother and the health worker during the consultation.



GROUP DISCUSSION C: PREPARATION FOR ADHERENCE TO ART

- 1. Participants provide examples of reasons why adherence to ART can be difficult in children.
- 2. The facilitator will write all examples on the flipchart
- 3. Assisted by the facilitator, you will see which of the examples provided could be solved by the 5As.

8.0 ARV OPTIONS FOR CHILDREN

This section outlines the recommended first line ARV regimens for children and the dosages that they should be given at, together with some of the issues around availability and suitability of ARV preparations currently available for children.

8.1 RECOMMENDED FIRST LINE ARV REGIMENS FOR CHILDREN

The following regimens are recommended by WHO as first line ART for children. The choice of regimen at the country level will be determined by the National ART guidelines.

AZT or d4T + 3TC + NVP or EFV^1 :

 $\begin{array}{l} AZT + 3TC + NVP \\ AZT + 3TC + EFV \\ d4T + 3TC + NVP \\ d4T + 3TC + EFV \end{array}$

ABC +**3TC** + **NVP** or \mathbf{EFV}^1 :

ABC + 3TC + NVP ABC + 3TC + EFV

* If <3 years or <10 kg, use NVP. EFV cannot be used in these children.

8.2 ARV DRUG PREPARATIONS FOR CHILDREN

The range of commercially available paediatric ARV formulations is narrow and most drugs do not have solid formulations in doses appropriate for paediatric use. Liquid formulations may not be easily available, and even when they are, they are often impractical to use in resource poor settings as they may require refrigeration, are bulky to store and transport and have short shelf lives. They may also be more expensive than solid formulations. Liquid formulations may need to be taken in large volumes to achieve optimal dosage, and are often unpalatable to children, may require clean water for mixing solutions. Some of the liquid formulations are mixed with alcohol which is not good for the child.

Some tablets and capsules come in low enough doses to enable accurate dosing for children of most ages (e.g., d4T capsules come in 15, 20, and 30 mg strength, and NFV (nelfinavir) has scored tablets that can be halved). Where ARV drugs do not come in doses suitable for children, WHO currently advises that drugs used in adults may have to be used, this is usually only possible in children who are above 10kg. The best possible dose can usually only be obtained by breaking tablets. In this instance, health providers and caregivers should be aware of the issues associated with cutting up tablets developed for adult doses:

- Under-dosing of drugs is possible, which can lead to increased risk of resistance;
- Over-dosing of drugs is possible, which can lead to increased risk of toxicity;
- The doses cannot be easily adjusted as the child grows; and
- Some drug combination tablets (e.g., fixed dose ZDV/3TC) do not have the ZDV and 3TC components evenly distributed through the tablet and therefore cutting them could result in wrong dose of either component.
- Current adult fixed dose combinations may not contain the appropriate doses of each of the component drugs for children on a weight basis (example: NVP).



WRITTEN EXERCISE B

Since accurate calculation of dosage based upon weight is the preferred method, use the following example to practice calculating the dosage needed to treat children of different weights. Use dosage table in annex B in the chart booklet.

Example:

A 10 kg child is put on d4T/3TC/NVP. Look at the table for dose per kg in your chart booklet on page 49-51 for dosages of ARV's. For a child weighing less than 30 kg, the dose of d4T is: 1 mg/kg/dose twice daily. Total dose is 1 mg x 10 Kg = 10 mg of d4T twice daily.

Practice the dosages for all first-line ARV's and a fixed combination of d4T/3TC/NVP for the following weight groups:

- 1) 12 month old 10 kg child
- 2) 10 month old 8 kg child
- 3) 13 month old 12 kg child
- 4) 2 year old 10 kg child
- 5) 3 year old 15 kg child

8.3 SIDE EFFECTS OF ART

Most drugs have side-effects of some sorts, although in the majority of cases they are mild, and not all people taking drugs will experience the same effects and to the same extent. Less than 5% of patients taking ART will have serious clinical side effects.

Many more will have non-serious but annoying side effects, especially at the beginning of their therapy. If children and their caregivers know about possible side effects it is easier to deal.

Many mothers and children are worried about possible side effects can be a when they start ART for the first time. It is important that you warn mothers about the very common side effects and suggest ways in which the mother can manage these side effects.

Mothers of children with a higher number of side effects may be concerned and may stop giving the child the drug correctly because of this. Similarly children who have side effects may refuse to take the medication. We have already discussed the need to take all the doses to make sure the therapy works properly, and this should be emphasized at each visit.

If mothers or children do complain about side effects, you should take their complaints seriously; if not, they might start to 'forget' taking pills.

There are three types of side effects. The table below describes commonly experienced side effects of ARV drugs.

SIDE EFFECTS OF ARV DRUGS

	Very common side-effects: warn patients and suggest ways patients can manage; also be prepared to manage when patients seek care	Potentially serious side effects: <i>warn patients and tell</i> <i>them to seek care</i>	Side effects occurring later during treatment: discuss with patients
d4T stavudine	Nausea Diarrhoea	Seek care urgently: Severe abdominal pain Fatigue AND shortness of breath Seek advice soon: Tingling, numb or painful feet or legs or hands	Changes in fat distribution: Arms, legs, buttocks, cheeks become THIN Breasts, belly, back of neck become FAT
3TC lamivudine	Nausea Diarrhoea		
NVP nevirapine	Nausea Diarrhoea	Seek care urgently: Yellow eyes Severe Skin rash Fatigue AND shortness of breath Fever	
ZDV zidovudine (also known as AZT)	Nausea Diarrhoea Headache Fatigue Muscle pain	Seek care urgently: Pallor (anaemia)	
EFV efavirenz	Nausea Diarrhoea Strange dreams Difficulty sleeping Memory problems Headache Dizziness	Seek care urgently: Yellow eyes Psychosis or confusion Severe Skin rash	

For all combination treatments, it is important to advise the mother about the regimen as a whole and not on each specific drug. The mother should never stop giving the child just one drug or giving him a lower dose. If the mother thinks that the child has a side effect from one drug, which is so bad that she wants to stop or change the treatment, she should go with the child as soon as possible to the clinic. Consult with the clinician or, if not available, STOP ALL THREE DRUGS. Never just stop one or two drugs.



WRITTEN EXERCISE C

The table below lists common and potentially serious side effects to common ARV drugs. For each side effect listed, fill in the name of the drug, or drugs which cause it:

Side effect (* requires urgent care)	Drug which causes the side effect
Changes in fat Major side effect occurring later with long term treatment	
Severe belly pain *potentially serious, because could be pancreatitis	
Tingling or numbness in feet or hands * this is neuropathy, should seek advice soon	
Yellow eyes * needs urgent referral-this is likely liver toxicity	
Skin rash * It could be a severe reaction to the drug and may require urgent referral.	
Nausea, vomiting, diarrhoea Common patients will need to be prepared to cope with these side effects	

8.3.1 GOOD MANAGEMENT OF SIDE EFFECTS

Good management of side effects should include the following:

- Discuss common possible side effects before the child starts the medication
- Give advice on how to manage these side effects. Use the Patient Treatment Card for the regimen.
- Warn mothers and children about potentially serious side effects and tell them to seek care urgently if they occur.
- Give immediate attention to side effects: access to the clinic or by phone
- Initiate a discussion about side effects, even if the mother or child does not mention them spontaneously
- Refer the patient to peer-educators.

The table below outlines common side effects experienced in patients on ART, together with the appropriate response required / advice to give to the mother:

SIGNS/SYMPTOMS	RESPONSE
Nausea	Advise that the drug should be given with food (except for DDI or IDV). If on zidovudine, reassure that this is a common, usually self-limiting side effect. Treat symptomatically. If persists for more than 2 weeks or worsens, call for advice or refer
Headache	Give paracetamol. Assess for meningitis. (See chart booklet) If on zidovudine or EFV, reassure that this is common and usually self-limited. If persists more than 2 weeks or worsens, call for advice or refer
Diarrhoea	Hydrate. Follow diarrhoea guidelines in your chart booklet Reassure mother that if due to ARV, it will improve in a few weeks. Follow-up in 2 weeks. If not improved, call for advice or refer
Fatigue	Consider anaemia especially if on ZDV. Check haemoglobin.
Anxiety, nightmares, psychosis, depression	This may be due to efavirenz. Give at night; counsel and support (usually lasts < 3 weeks). Call for advice or refer if severe depression or suicidal or psychosis. Initial difficult time can be managed with amitriptyline at bedtime

SIGNS/SYMPTOMS	RESPONSE	
Blue /black nails	Reassure the mother - it's common with zidovudine	
Rash	If on nevirapine or abacavir, assess carefully. Is it a dry or wet lesion? Call for advice. If severe generalized or peeling, stop drugs and refer to hospital	
Fever	Check for common causes of fever (as per Module 1). Call for advice or refer. (This could be a side effect, an opportunistic or other new infection, or immune reconstitution syndrome)	
Yellow eyes (jaundice)	Stop drugs. Call for advice or refer. (Abdominal pain may	
Abdominal or flank pain	tenderness, send for ALT test* and stop ART. (Nevirapine is most common cause.) Call for advice or refer	
Pallor: anaemia	If possible, measure haemoglobin. Refer/consult (and stop ZDV/substitute d4T) if severe pallor or symptoms of anaemia or very low haemoglobin (<8 grams)	
Tingling, numb or painful feet/legs	If new or worse on treatment, call for advice or refer. Patient on d4T-3TC-NVP should have the d4T discontinued— substitute ZDV if no anaemia. (Check haemoglobin)	
Cough or difficult breathing	This could be immune reconstitution syndrome. Call for advice.	
Changes in fat distribution	Discuss carefully with the mother and child $-$ can they accept this for the child?	

*Amino alanine transferase

9.0 PAIN RELIEF

9.1 SPECIAL CONSIDERATIONS IN ASSESSING AND CONTROLLING PAIN IN CHILDREN:

Children infected with HIV often experience pain due to many common causes such as mouth sores / ulcers and nappy rash. It is important to relieve pain so that the child is made as comfortable as possible. Children need adults to recognize and respond to their pain. Children often do not complain, therefore adults need to look for signs suggesting pain in children. Some of these are listed below:

- Brief pain—crying and distressed facial expression.
- Persistent pain—look for behavioural signs of pain:
 - o irritability
 - not wanting to move
 - o lack of interest
 - o decreased ability to concentrate
 - sleeping problems
 - changes in how the child moves
 - o restlessness
 - o increased breathing rate or heart rate

Note the following:

- It is important to differentiate pain from anxiety.
- Parents may under- or over-estimate pain in their child.
- The child's judgment of pain control should be valued.
- When treating the child, never lie to them about painful procedures explain exactly what they are likely to experience and ensure that you take steps to help them cope with the pain.

Older child can grade pain by number of fingers or pointing on a ruler or faces (smiling or frowning). This is illustrated below:



There are a number of non-drug methods to help to relieve pain in children:

- You may use cognitive methods to help relieve pain:
 - Age-appropriate active distraction.
 - Older children can be encouraged to concentrate on a game, a conversation or special story.
 - Music or song can be used.
- Other non-drug methods:
 - Swaddling or carrying an infant, providing warmth, breastfeeding or feeding.
 - Stroking, rocking, massage.

Special considerations for pain relating to the skin in children:

- HIV-infected children are prone to rashes, some of which are itchy. Clean and cover moist areas with a dressing, or expose and apply GV solution if there are not too many flies around. Keep finger nails short and clean to help reduce scratched areas from getting infected. Give an antihistamine for sleep at night if sleep is disturbed by scratching. Sometimes an oil-based cream or a short course of a weak steroid cream is helpful.
- Nappy area: Diarrhoea may cause a nappy rash or sores near the anus. Encourage careful washing with soap and clean water, and the application of a protective ointment (e.g. vaseline). Avoid the constant use of plastic pants over nappies. Change wet pants or nappies often.

GROUP DISCUSSION D

The facilitator will now lead a group discussion on the following questions on pain in children.

How do children manifest pain? How can you assess the level of pain in children? What methods can you use to relieve pain in children?

9.2 DRUG MANAGEMENT OF PAIN

When treating chronic or severe pain, give regular doses of pain relief. There are three steps in the analgesic ladder:

STEP 1

If the child comes to see you for the first time and he/she is not taking any medicine, you should always start with drugs from step 1: paracetamol or ibuprofen Choose between these based on whether an anti-inflammatory effect is needed and whether there are cautions against use. Ibuprofen is particularly good for pain in the bones.

NOTE:

Do NOT use aspirin in children. Avoid ibuprofen in children under the age of 2 years – use paracetamol instead.

<u>STEP 2</u>

If pain persists or increases, it should be re-assessed and an opioid for mild to moderate pain (such as codeine) should be added to the regular pain relief offered in step 1 (paracetamol).

<u>STEP 3</u>

If pain persists or increases, it should be re-assessed and oral morphine added to the regular pain relief offered in step 1. Do not combine morphine with an opioid.

The table below contains the drugs dosages to relieve pain by age and weight band.

PAIN MEDICATION – DOSING FOR CHILDREN			
	STEP 1	STEP 2	STEP 3
AGE or weight	Paracetamol Give every 4-6 hours 100mg tablet OR Ibuprofen (see doses in footnote ⁵)	Codeine Give every 4 hours 30mg tablet	Oral morphine 5mg/5ml
2 months up to 4 months (4-<6kg)	-	1/4	0.5ml (dose reduced in infants <6 months)
4 months up to 12 months (6-<10kg)	1	1/4	2ml
12 months up to 2 years (10-<12kg)	1 1/2	1/2	3ml
2 years up to 3 years (12-<14 years)	2	1/2	4ml
3 years up to 5 years (14-19kg)	2	3/4	5ml

 $^{^5}$ *Recommended dosages for ibuprofen: 5-10 mg/kg orally, 6-8 hourly to a maximum of 500 mg per day i.e. $^{1}\!\!\!/_4$ of a 200 mg tablet below 15 kg , $^{1}\!\!\!/_2$ tablet for 15 up to 20 kg of body weight.

10.0 FINAL REVISION EXERCISE OF THE VARIOUS COMPONENTS OF THE COMPLEMENTARY COURSE ON HIV/AIDS



WRITTEN EXERCISE D

This exercise is designed to help you use your knowledge gained throughout this course, and combines various assessment and counselling skills, associated with IMCI initial assessment, treatment of acute conditions, infant feeding, adherence, counselling the mother, clinical staging and principles of chronic care.

You will now meet the 4 children, Mishu, Dan, Ebai, and Henri for the last time in this course. Some time has passed since you first met them. To complete this exercise, you will need to use the test results from the 'assess and classify each child for HIV' that you were given in Module 1.

These results are listed below to remind you of them:

Mishu

Mishu's mother was tested for HIV and was positive. However Mishu did not have an HIV test.

When you last met Mishu she was classified as:

- DYSENTERY
- NO DEHYDRATION
- MALARIA
- NOT VERY LOW WEIGHT
- POSSIBLE HIV INFECTION OR HIV EXPOSED

Mishu is now 8 months old. She is well and has no illnesses. She is not classified as VERY LOW WEIGHT on this visit. She has recently been tested negative for HIV using virological tests She has been on cotrimoxazole. Mishu's mother stopped breastfeeding her 3 weeks ago.

How would you manage Mishu?

<u>Dan</u>

When you last met Dan he was 23 months old. Neither Dan nor his mother was tested for HIV. Dan had parotid enlargement but did not have oral thrush or lymphadenopathy.

Dan's classifications were:

- PNEUMONIA
- NO DEHYDRATION
- PERSISTENT DIARRHOEA
- CHRONIC EAR INFECTION
- SEVERE MALNUTRITION
- SUSPECTED SYMPTOMATIC HIV INFECTION

Dan has had an HIV antibody test and it was positive. On this visit Dan is classified as PNEUMONIA (no wheeze), PERSISTENT DIARRHOEA AND VERY LOW WEIGHT. He also has oral thrush. Dan has been coughing for 2 months. His mother is well and is breastfeeding him.

How would you manage Dan?

<u>Ebai</u>

Ebai's mother has been tested for HIV infection and is HIV positive. Ebai was classified as POSSIBLE HIV INFECTION OR HIV EXPOSED.

Ebai is now 6 months old. His mother stopped breastfeeding him 10 weeks ago. He tested HIV negative on virological testing test done 2 weeks ago.

How would you manage Ebai?

<u>Henri</u>

Henri's mother has been tested for HIV infection and is HIV positive. Henri has had an antibody test and the result was positive.

Henri is now 9 months old. His mother is still breastfeeding him. He is well today. There is no feeding problem.

His main reason for coming to the clinic was cough. He is classified as COUGH OR COLD: NO PNEUMONIA and NOT VERY LOW WEIGHT. He does not have a wheeze. He has been coughing for 2 weeks.

How would you manage Henri?

11.0 RECORDING AND REPORTING

Recording information and reporting it to the next level is essential to document and review the experience, and re- planning. It becomes absolutely necessary to improve the way we manage sick infants and children and when dealing with essential supplies and medicines such as antiretroviral medicines.

Follow the national format for patient recording. Transfer key HIV Care/ART Card data to Pre-ART or ART registers. Patient information may be gathered either on paper registers or electronic data entry registers. Summarize data in monthly (or quarterly) report as per national guideline.

12.0 SUMMARY OF MODULE, SUMMARY OF COURSE AND CLOSING

The facilitator will now ask participants to briefly summarize what topics have been covered by Module 4. Participants should call out what this module has taught them and the facilitator will list your responses on a flipchart.

Look back to the learning objectives for the module and provide your feedback as to whether you feel that these objectives have been met.

Participants should highlight any difficult areas, where you need further clarification and ask final questions.

Next the facilitator will ask you to run through the same procedure for the course as a whole. What have you learnt in each module? Have the overall learning objectives been met? Are there any remaining areas where you feel that you need further clarification or further training?

Congratulations! You have now reached the end of this IMCI Complementary Course on HIV/AIDS.

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