

Module 3: Comprehensive Care for HIV-Exposed Infants



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Session 3.1: Comprehensive HIV-exposed Infant Care

Session Objectives

After completing this session, participants will be able to:

- Describe the key components of comprehensive care of the HIV-exposed infant
- Provide support to caregivers of HIV-exposed infants to administer infant ARV prophylaxis from birth to 6–12 weeks of age
- Provide support to caregivers of HIV-exposed infants to administer co-trimoxazole prophylaxis
- Recognize the signs and symptoms suggestive of HIV infection in infants
- Understand the importance of the mother's health and HIV care, including good adherence to ART and viral suppression

Overview of HIV-exposed Infant Care

To be successful, initiatives to expand and improve infant HIV testing services need to be part of wider efforts to provide all HIV-exposed infants with a comprehensive package of care starting at birth and continuing through the breastfeeding period and to ensure HIV-infected infants are immediately linked to ART. A comprehensive approach to the care of HIV-exposed infants will maximize the chances of ensuring all HIV-exposed infants are tested by 4–6 weeks of age, receive comprehensive care and testing services throughout breastfeeding, and ultimately have a final HIV status at either 18 months of age or 3 months after breastfeeding (whichever is later).

The comprehensive package of care includes:

1. Identification of HIV-exposed infants and infant HIV testing
 - HIV testing at 4–6 weeks of age, 9 months, and 3 months after cessation of breastfeeding and immediate initiation of ART for those identified as infected. (Note: Some sites/countries may have introduced birth testing in addition to the testing listed above. If birth testing is provided, it is still very important that infants are also tested at 4–6 weeks.)
2. Preventive medical care
 - Infant antiretroviral (ARV) prophylaxis: Daily oral medication to prevent HIV infection from birth to 6–12 weeks of age, depending on risk of infection. Infants considered high risk (see Table 3.1) should receive enhanced postnatal prophylaxis (ePNP). ePNP refers to:
 - First 6 weeks: dual drug prophylaxis (AZT plus NVP)
 - Second 6 weeks (breastfeeding infants only): either AZT plus NVP or NVP alone
 - Healthcare providers should support caregivers to administer infant ARV prophylaxis:
 - Discuss recommendations for ARV prophylaxis based on infant age and risk category, prescribe ARV prophylaxis if indicated.
 - Provide counselling and support.

- Cotrimoxazole prophylaxis: Daily medication (cotrimoxazole) from 4–6 weeks of age until final HIV status is established at least 3 months after stopping breastfeeding, to prevent illness and death due to diarrhoea, malaria and pneumonia among HIV-exposed infants.
 - Tuberculosis (TB) screening and TB preventive therapy for infants in contact with active TB cases. Provide isoniazid preventive therapy (IPT) if the infant does not have active TB disease but has known contact with a person with TB disease.
3. Routine infant care
 - Immunizations: It is particularly important for these children to be immunized completely and on time because of their vulnerability to infection. Provide the same immunizations for HIV-exposed and HIV-infected infants as for those who are not exposed, except infants who are known HIV-infected or have signs/symptoms consistent with HIV should not receive bacillus Calmette–Guérin (BCG) vaccine. This recommendation is based on 1) the risk of disseminated BCG disease in children infected with HIV vaccinated at birth and 2) the vaccine may provide little, if any, protection against tuberculosis in HIV-infected infants because HIV infection appears to impair the BCG-specific T-cell responses[3]. Note: HIV-exposed infants who are not known HIV positive at birth and are not born with signs of HIV should receive BCG vaccine.
 - Growth monitoring and nutritional support
 - Developmental screening
 - Infant feeding counselling to promote exclusive breastfeeding for the first 6 months of life
 4. Family care and support
 - Ensure maternal ART adherence and maternal viral suppression at routine intervals during pregnancy and breastfeeding. Ensure mother’s adherence to lifelong ART.
 - Psychosocial support and caregiver counselling and education on postnatal care and HIV-exposed infant services.
 - Family HIV testing: Sexual partners and other biological children.
 - Male partner engagement in health care services.
 - Family planning.
 5. Community linkages with referrals to support systems and support groups
 6. Tracking of mother-infant pair for missed appointments and loss to follow-up

Additional considerations for comprehensive HIV-exposed infant care include:

- **Integration into child immunization services:** the comprehensive package of care for HIV-exposed infants can occur on the same schedule as immunizations and routine growth monitoring. For example, the first postnatal visit (4–6 weeks) occurs before most HIV-infected infants become ill and offers an ideal opportunity for infant HIV testing and initiation of co-trimoxazole. (For more information on the care of HIV-exposed infants, see Module 3 of Book 2, *Training Curriculum for Healthcare Providers*.)
- **Linking mother and infant care:** The care of the breastfeeding infant should be linked to the care of the mother. The mother-infant pair should receive their care together whenever possible because optimal outcomes for the baby are dependent on the health and viral suppression of the mother. Maternal adherence and retention on lifelong ART can prevent HIV transmission in the current and future pregnancies.

- **Adherence to care and patient tracking:** Given that HIV-exposed infants are at increased risk of malnutrition, illness, and death (even if not HIV-infected) it is important that they attend all clinic visits, are provided with focused examinations at each visit, and are provided with counselling to support safe feeding (discussed in the next session). Mothers and infants who miss appointments should be traced and counselled on the importance of returning to care.

Infant ARV Prophylaxis

It is important that HIV-exposed infants receive ARV prophylaxis as protection against exposure to HIV during childbirth and early breastfeeding, even when the mother received ART during pregnancy. Infant prophylaxis is particularly important for PMTCT when the mother received limited, disrupted, or no ARV drugs during pregnancy or when viral suppression has not yet been achieved.

The infant prophylaxis regimens recommended in the 2016 WHO guidelines, which are based on infant’s risk of HIV infection, are listed in Table 3.1, below. [Note: It is most important to understand the national guidelines for your country. Modify the table as needed to reflect national guidelines.]

Table 3.1 ARV prophylaxis for HIV-exposed infants [4]

Scenario	Recommendation
<p>Infants born to women with HIV who:</p> <ul style="list-style-type: none"> • Have received <u>4 or more weeks of ART</u> at the time of delivery <p>OR</p> <ul style="list-style-type: none"> • Have a viral load (VL) ≤ 1000 in the 4 weeks before delivery 	<p>Breastfed: Once daily NVP For 6 weeks</p> <p>Formula fed: Once daily NVP OR Twice daily AZT For 4–6 weeks</p>
<p>High risk infants, i.e., infants born to women with HIV who:</p> <ul style="list-style-type: none"> • Received less than 4 weeks of ART at time of delivery or no ART OR • Have a VL >1000 copies/mL in the 4 weeks before delivery <p>High risk infants also include those:</p> <ul style="list-style-type: none"> • Born to women with incident HIV infection during pregnancy or breastfeeding, OR • Born to women diagnosed with HIV at delivery or postpartum 	<p>Breastfed: Twice daily AZT + once daily NVP for 12 weeks OR Twice daily AZT + once daily NVP for 6 weeks then once daily NVP for total of 12 weeks</p> <p>Formula fed: Twice daily AZT + once daily NVP For the first 6 weeks of life</p>

Table 3.2 Simplified dosing of NVP and AZT for infants [4]

Age	Nevirapine (NVP) (Suspension 20mg/ml) Give <i>once</i> daily	Zidovudine (AZT) (Syrup 10mg/ml) Give <i>twice</i> daily
Birth up to 6 weeks <ul style="list-style-type: none"> • Birth weight 2000–2499g* • Birth weight ≥ 2500g 	10 mg (1ml of syrup) 15 mg (1.5ml of syrup)	10 mg (1ml of syrup) 15 mg (1.5ml of syrup)
6–12 weeks of age	20 mg (2ml of syrup)	No dose established for prophylaxis; use treatment dose: 60 mg twice daily, 6 ml of syrup twice daily, or a 60 mg tablet twice daily)
*For infants weighing <2000 g and older than 35 weeks of gestational age, the suggested doses are: NVP 2 mg/kg per dose once daily and AZT 4 mg/kg per dose twice daily. Premature infants younger than 35 weeks of gestational age should be dosed using expert guidance.		

If a mother has ongoing poor ART adherence and high viral load beyond 12 weeks post-partum, consider continuing infant antiretroviral prophylaxis beyond 12 weeks of age in accordance with national guidelines, while also intensifying efforts to address maternal ART adherence and assessing for treatment failure.

Co-trimoxazole Prophylaxis

Co-trimoxazole prophylaxis is recommended for all infants and children who are HIV-exposed until the child is confirmed HIV-uninfected at least 3 months after the cessation of breastfeeding. Co-trimoxazole is a fixed-dose combination of 2 antimicrobial drugs (sulfamethoxazole and trimethoprim) that can prevent bacterial, fungal and protozoan infections, including malaria. If the infant becomes HIV-infected, co-trimoxazole can also prevent life-threatening illnesses, such as pneumocystis pneumonia (PCP).

Co-trimoxazole is a safe drug that is well-tolerated. Most infants experience minimal or no side effects. **Initiate co-trimoxazole prophylaxis in all HIV-exposed infants at 4–6 weeks of age.**

When initiating co-trimoxazole, counsel mother on:

- Possible side effects. If the infant/child develops any of the following, s/he should be brought back to the clinic for evaluation: skin rash, blistering, peeling, sores around the mouth or eyes and fever. If the child has a severe rash with skin blistering, peeling, or sores in or around the mouth/eyes, the medication should be stopped IMMEDIATELY and child should be brought to a hospital. Cotrimoxazole can rarely cause Stevens-Johnsons syndrome which is a dangerous condition that should be evaluated immediately by a clinician.

Co-trimoxazole prophylaxis in infants/children can be dosed based on age or based on weight. Use the dosing regimen that is recommended in national guidelines. See Table 3.3 for weight-based dosing.

Table 3.3 Co-trimoxazole prophylaxis dosing for infants and children by weight [5]

Drug	Strength of tablet or oral liquid (mg or mg/5ml)	Number of tablets or ml by weight band once daily					
		3.0–5.9 kg	6.0–9.9 kg	10.0–13.9 kg	14.0–19.9 kg	20.0–24.9 kg	25.0–34.9 kg
Co-trimoxazole	Suspension 200/40 mg per 5 ml	2.5 m.	5 ml	5 ml	10 ml	10 m.	-
	Tablets (dispersible) 100/20 mg	1	2	2	4	4	-
	Tablets (scored) 400/80 mg	-	0.5	0.5	1	1	2
	Tablets (scored) 800/160 mg	-	-	-	0.5	0.5	1

Adherence Support

Prepare mothers before initiating their infants on medications

Before initiating HIV-exposed infants on ARV prophylaxis or co-trimoxazole, discuss with their caregivers the following:

- The name of the drug their infant will be starting and dosage
- Why their infant needs to take this medication
- How long the infant will be on the medication
- Side effects and what to do if these side effects are experienced
- Drug storage
- How to get more medication/refills
- How they will remember to administer the medications every day; what to do if a dose is missed
 - For example, will they give the infant medications at the same time when the mother takes her ART, or at a different time?
- What to do if the infant doesn't want to take the drug/spits up the medication
- Ask the caregiver:
 - *What concerns do you have about giving medicine to your baby?*
 - *Who else might be administering these medications?*
 - *What other medications, traditional or from a clinic, is the baby taking?*

See Appendix 3B: Key Adherence Messages for Caregivers, Appendix 3C: Adherence Support Guide for Caregivers of HIV-Exposed Infants and Appendix 3D: Adherence Assessment Guide for Caregivers of HIV-Exposed Infants.

Provide support to mothers who give medications to their infants

Mothers living with HIV will need support at every clinic visit to ensure that they are giving co-trimoxazole and/or infant ARV prophylaxis correctly: at the right dose, every day, without fail. Healthcare providers may initiate discussion by asking: [6] [7]

- Most people have some difficulty taking all of their medications all of the time, can you tell me how many doses of your baby's medicine (ARV prophylaxis or co-trimoxazole)

you gave to her yesterday? How about the day before yesterday? And finally, the day before that?

- Can you show me how you give the medications to your baby?

Consider the social/practical issues that may affect adherence

- Has the mother disclosed her HIV status to her partner or others in the home?
- Do others in the home know that the infant is taking medication and why?
- Who is responsible for giving the medication? (If the primary caregiver is sometimes away from the home or working, who else is responsible for giving the medication?)
- Do other caregivers understand the purpose of the medications?

Provide supportive, respectful counselling to the mother or other caregiver. Offer support for disclosure to partner or others in the home (by yourself if trained or appropriate counselling staff).

Missed doses

If a client forgets to take (or administer) a dose of her (or her child's) medication, advise her as follows for co-trimoxazole, or nevirapine (NVP) or zidovudine (AZT):

- Take the missed dose if within 4 hours of when it was supposed to be given. However, if it has been more than 4 hours, skip the missed dose and continue your regular dosing schedule. Do not take a double dose to make up for a missed one. [8]

Recognizing Signs or Symptoms of HIV Infection

Infants and children with signs or symptoms suggestive of HIV would include those:

- Who are malnourished, underweight, failing to thrive (not gaining weight)
- Who are experiencing poor milestone development (delay in reaching milestones, or losing milestones — for example, the infant that was able to sit but cannot do so any longer)
- Who present with severe, recurrent or unusual infections. See Appendix 3E: Criteria for presumptive diagnosis of severe HIV disease in infants and children.
- Diagnosed with TB

In settings where NAT is not available or the result is delayed, a presumptive diagnosis of HIV can be made in an infant with positive serology (RDT) who presents with signs and symptoms of HIV. Provide (or refer for) further evaluation and treatment as soon as possible. Do not delay referral of a sick baby while waiting for a test result:

- The risks of brief ART in an HIV-uninfected infant are minimal compared to the risks of delaying treatment for an infected infant
- Waiting too long to treat an HIV-infected infant may result in the infant's death

Mother's Health and Family Support

At each follow up visit, ask the mother about her health. This is particularly important for mothers with HIV. A critical part of ensuring good infant health is ensuring good maternal health; mothers who are unwell cannot care for their infants. If a mother is sick on ART, evaluate for treatment failure using VL; infants of mothers with high VL are at high risk of acquiring HIV.

If possible, see the mother and infant together at the same appointment. It is usually convenient for the mother and baby to come together on the same day, and it allows you to evaluate the health of the mother and baby together.

Ask mothers with HIV about:

- Their own health
- Enrolment in care and treatment for their HIV infection. If not yet enrolled in care, initiate care and treatment today! (Or provide referrals and ensure she is accompanied to the referral.)
- Adherence to their ART regimens; if women report missing any doses, provide support to achieve optimal adherence
- Mother's VL (follow national guidelines on VL testing. Take action immediately on VL results.)
- Adherence to their infants' ARV or co-trimoxazole prophylaxis regimens (as discussed above); remind mothers that the infant dose will need to be adjusted as the baby gains weight
- Disclosure: does your partner know your HIV status?
- Their partner's health: Has your partner been tested for HIV? If HIV-infected, is he enrolled in care? Is he taking ART? Where available, offer partner education and HIV testing during home visits.
- Partner involvement: would your partner accompany you to the clinic for the baby's next visit. If not, why not? Does your partner support you in exclusively breastfeeding your baby, providing medicine to your baby, attending regular clinic visits, etc?
- The health of the mother's other children: all children of HIV-positive parents should be tested for HIV. Ask about the HIV testing history of other children in the home. If children have not been tested, make a plan to test the other children (bring them to a health facility or home testing).
- Other community services that are available locally—whether community or health facility-based—such as psychosocial support, food provision, safe water system provision. Provide referrals as needed.

Session 3.2: Growth Monitoring and Infant Feeding

Session Objectives

After completing this session, participants will be able to:

- Understand the importance of monitoring growth, development and immunizations for HIV-exposed infants
- Understand the HIV-exposed infant and young child feeding recommendations

Introduction to Growth Monitoring and Infant Feeding

This session provides an overview of routine growth monitoring and outlines the infant feeding counselling session. Both of these activities are key components of the routine child visit.

Poor growth can be one of the first indications that a child is HIV-infected and can also indicate problems with infant feeding. Growth monitoring is the same process whether measuring an HIV-exposed, HIV-infected, or an HIV-uninfected child. Accurate measurements of weight and length/height are essential parts of the health evaluation of any growing child. If the child is less than 24 months of age, measure the head circumference as well to screen for potential developmental and health problems. Mid-upper arm circumference (MUAC) can also be used to assess nutritional status for infants >6 months of age. This module is an overview of the process, a reminder of good practice, under the assumption that most learners are familiar with key concepts. This is not a full training on growth monitoring and nutritional screening, so if you are new to this subject, you will need further training to become competent in this area.

Growth Monitoring

Growth monitoring is a course unto itself, the following information is by no means complete, and the assumption is that the trainee is already familiar with techniques used to weigh and measure. It is particularly important with HIV-exposed children to ensure that their growth is assessed at every routine and sick child visit, as it warns the health provider that there is an issue. As for any infant, the key steps in growth monitoring are as follows:

- Record/confirm the child's name, sex and date of birth
- Determine the child's age as of today's date
- Remove all clothing and make a visual assessment of the child (e.g. does the child appear thin, fat, active, lethargic, anaemic) and evaluate for oedema. If the child has oedema in both feet, make note of this. Complete the growth assessment of the child (weight and height), then refer immediately to a clinician since this child may have severe malnutrition
- Weigh the child
- Measure the child's length (for children < 2 years) or height (children > 2 years)
- Measure the child's head circumference
- If the child is between 6–60 months of age, measure MUAC

Use the child's growth standard (also referred to as growth chart) to plot his/her weight and length/height (as per national recommendations) at every visit and assess if child is growing normally. Follow national guidelines for measuring growth, as head circumference and MUAC may be recommended as well.

Weight gain should consistently follow one of the growth lines (with minor ups and downs for periodic growth spurts and minor illnesses). If weight is not increasing or increasing but falling below the growth line, intervene immediately.

- Ask questions about feeding and recent illness to determine why the infant's growth has slowed.
- Provide infant feeding counselling: remind the parent of the infant and young child feeding messages provided during antenatal care and provide support to follow that advice.
- If child meets criteria for acute malnutrition (moderate or severe), refer for nutritional support according to national guidelines.

Additional resources on growth monitoring can be found at:

- WHO Child Growth Standards. Available at: <http://www.who.int/childgrowth/standards/en/>
- WHO Child Growth Standards, Training Course and Other Tools. Available at: <http://www.who.int/childgrowth/training/en/>
- WHO Combined Course on Growth Assessment and IYCF Counselling. Available at: <http://www.who.int/nutrition/publications/infantfeeding/9789241504812/en/>
- The WHO IMCI Chart Booklet, March 2014, provides guidance for screening for low weight for age and counselling parents of sick children on feeding. Available at: http://www.who.int/maternal_child_adolescent/documents/IMCI_chartbooklet/en/

Infant and Young Child Feeding

Provide infant and young child feeding counselling and support at every visit, even if the child is growing normally. Infant and young child feeding counselling and support is particularly important for infants who are HIV-exposed, as these children are at higher risk of malnutrition, even if they are not HIV-infected.

Global recommendations

Whether HIV-exposed, infected or uninfected, WHO recommends that infants are breastfeed exclusively for the first 6 months of life, with the introduction of appropriate complementary foods at 6 months of age.

Mothers with HIV should continue breastfeeding for at least 12 months and can continue breastfeeding for up to 24 months or longer (similar to the general population) while being fully supported for ART adherence.

It is important to note that the recommendation to breastfeed to 24 months or longer, assumes that women with HIV will have:

- Lifelong ART, including adherence counselling

- Infant feeding counselling and support

For situations where women do not meet these conditions (women not on ART or with poor ART adherence), health care providers should discuss the feeding options and HIV transmission risk with women to make an individualized decision about infant feeding plan. Breastfeeding should stop only once a nutritionally adequate and safe diet without breast-milk can be provided.

Infants who are HIV infected will benefit from extended breastfeeding and should continue breastfeeding for as long as feasible and desired, 24 months or longer.

ART lowers the risk of HIV transmission through breast milk. Breastfeeding women who follow national guidelines on infant feeding and who are taking ART every day as recommended by their healthcare providers have a very low risk of transmitting HIV to their infants through breast milk. In many settings, for HIV-exposed infants the risks associated with not breastfeeding (i.e., diarrhoea, pneumonia and malnutrition) are much greater than the risks associated with breastfeeding (i.e., risk of acquiring HIV from breastmilk), especially when the mother is on ART and virally suppressed.

Breastfeeding mothers

If **breastfeeding**—observe a feed, check attachment and positioning, provide support.

- Ensure mother is taking ART every day exactly as recommended by the healthcare provider. Advise her on the risk of transmitting HIV to her infant through breastfeeding, but remind her that she can minimize this risk by taking her ART, exactly as prescribed.
- Test mother’s VL when indicated according to national guidelines (routine testing as well as targeted testing if mother is ill) to ensure that ART is effectively suppressing the virus.
- **Support mothers to breastfeed exclusively in the first 6 months of life:** Exclusive breastfeeding in the first 6 months of life reduces the risk of death from diarrhoea, pneumonia and malnutrition among babies. During the first 6 months of life infants should receive no porridge, cow milk, juice, infant formula, or other foods or liquids (feeding foods or liquids other than breastmilk in the first 6 months of life is referred to as “mixed feeding”).

Note: Exclusive breastfeeding pertains only to the first 6 months of life; infants need complementary foods (i.e, foods in addition to milk) after 6 months.

- Mothers should continue breastfeeding even after the introduction of complementary foods and may continue breastfeeding for 24 months or longer while being supported for ART adherence. Breastfeeding should stop only once a nutritionally adequate and safe diet without breast-milk can be provided. [1]

The WHO and UNICEF 2016 Guideline, *Updates on HIV and Infant Feeding* states:

“Mothers living with HIV and health-care workers can be reassured that ART reduces the risk of postnatal HIV transmission in the context of mixed feeding. Although exclusive breastfeeding is recommended, practising mixed feeding is not a reason to stop breastfeeding in the presence of ARV drugs.” [1]

Formula feeding mothers

Refer to national guidelines for recommendations on formula feeding, often called replacement feeding. In most resource-limited settings, formula feeding is not recommended because of challenges in purchasing sufficient quantities of formula and safe preparation may lead to higher rates of severe illness and death among infants taking formula than those who are breastfeeding.

If a caregiver opts for **formula feeding**—ask caregiver to describe how she prepares and stores feeds, step-by-step; ask what she does when she runs out of formula. See national guidelines for guidance on supporting parents who formula feed. If possible, these caregivers should be seen by a nutritionist or nutrition-trained staff member for full counselling and evaluation.

Support formula feeding parents to formula feed exclusively for the first 6 months of life, and then introduce appropriate complementary foods thereafter and continue providing formula for the first 12 months of life.

Complementary feeding

If child is approaching 6 months of age or older, counsel around complementary feeding. See national guidelines for more information on complementary feeding.

Assessing an Infant/Child with Poor Growth

- If feeding is adequate, review overall health assessment. Poor growth may be a sign of HIV infection, TB disease or other health-related issue.
- Conduct HIV testing, even if the last test was administered relatively recently.
- Ask client, in a non-judgmental manner, about family food hygiene practices (hand washing, washing of dishes and food preparation surfaces), food storage (separation of raw and cooked foods, storage at safe temperatures), if food is cooked thoroughly, and use of safe water and foods.
- Assess socioeconomic situation. If food is insufficient, offer services to address these problems, where supplemental foods or other nutritional interventions are available.
- If child is already diagnosed with HIV infection, ensure he/she is on ART and taking it every day as prescribed.
- Consider referrals for further care.
- See infant again soon (timing of follow up depends on clinical condition of the child)

Exercise 1

Exercise 1: HIV-exposed infant care: Case studies in small groups

Purpose	To review clinical care and treatment of HIV-exposed infants according to national guidelines
Instructions	<ol style="list-style-type: none">1. You should use the content in this session as well as “Appendix 3A: Checklist for HIV-exposed Infant Care” to guide your case study discussion.2. After breaking into 3 or 4 small, multidisciplinary groups, the trainer will ask your group to assign a facilitator and notetaker.3. The trainer will assign one of the case studies (in the box that follows) to your group.4. You will have about 20 minutes to read and come up with answers to your case study.

Exercise 1: HIV-exposed infant care: Case studies in small groups and large group discussion

Case study 1:

Baby A ____ is a **6-week-old infant girl** born to a mother living with HIV; the mother has been on ART since her 22nd week of pregnancy with excellent adherence. This is the first time Baby A has come to the maternal-child health clinic. The mother says that Baby A ____ has been doing well and gaining weight. She does not report any problems with the infant. She has been feeding the infant only breastmilk.

- What additional questions do you want to ask the mother?
- What tests and/or medications do you recommend for the infant?
- What education and counselling do you want to provide to the mother?
- What is the recommended infant ARV prophylaxis regimen for this baby?
- What will you do to support adherence?
- What are the key areas to assess for the mother’s health and HIV care?

The mother brings **Baby A** ____ **back to clinic at age 10 weeks**. Again, the mother reports that the infant is doing well, without problems, and is gaining weight. The infant’s HIV PCR test result done at the 6-week visit was negative. Her mother is still breastfeeding.

- What tests and/or medications do you recommend for the infant?
- Is baby still on co-trimoxazole? If so, what will you do to support adherence?
- Should this baby still be taking infant ARV prophylaxis?

Case study 2:

Baby B ____ is a **4-month-old boy** born to a mother with HIV; **Baby B** ____ has been exclusively breastfed. However, **Baby B** ____’s mother is under pressure from her mother-in-law to introduce porridge. **Baby B** ____’s mother started taking ART just after she delivered **Baby B** _____. She attended **Baby B** ____’s 6 week visit (about 10 weeks ago) but hasn’t been seen in the clinic since. At the 6-week visit **Baby B** ____ was tested for HIV and

started on co-trimoxazole. You see from the Baby Testing Register that he tested HIV-negative at that time.

- How should you advise this mother about infant feeding?
- How long should Baby B___ be on ARV prophylaxis? What drugs should he be receiving for prophylaxis?
- Should Baby B be taking co-trimoxazole? If so, what will you do to support adherence?
- What tests and/or medications do you recommend for the infant?
- What are the key areas to assess for the mother's health and HIV care?
- Do you have any other concerns about the care of this mother & infant?

Case study 3:

Baby D_____ is a **6-month-old infant girl** who tested HIV-negative by NAT at 6 weeks of age. She has been exclusively breastfed. At today's visit her mother reports that Baby D_____ has had diarrhoea, has been losing weight, is feeding poorly, and has lost developmental milestones (is no longer rolling over). Baby D_____'s mother started ART 2 weeks before she gave birth.

- What should you do for this baby?
- Is baby still on co-trimoxazole? If so, what will you do to support adherence?
- Is this baby still on infant ARV prophylaxis?
- What will you ask the mother to ensure she is doing well and taking care of herself?
- When should the baby return?

Module 3: Key Points

- Special care for HIV-exposed infants should include infant HIV testing (discussed in Module 2), infant feeding support, infant ARV prophylaxis, co-trimoxazole prophylaxis. In addition, the health status of the mother should also be closely monitored.
- It is important that HIV-exposed infants receive routine care for growth monitoring and immunizations as they are at increased risk of malnutrition, illness and even death.
- Provide caregivers with respectful care and the education and psychosocial support that they need to administer daily medications to their infants/children.
- At each follow up visit, ask the mother about her own health. Ensure she is on ART, in care, and check that she has had blood drawn for a VL measurement if indicated; provide her with adherence support. Ask to whom she has disclosed her HIV status. Also, ask about her partner's health and screen for other psycho-social or medical needs.
- Growth monitoring that includes weighing, measuring length/height, head circumference and MUAC are core activities for any routine and sick child visit. Poor growth can be a sign of HIV, other illness, or feeding problems.
- WHO recommends that HIV-exposed, infected or uninfected infants be breastfed exclusively for the first 6 months of life, with the introduction of complementary foods at 6 months of age while continuing to breastfeed for at least 12 months and up to 24 months or longer. To minimize risk of transmission through breastmilk, mother should be on ART with good adherence. Breastfeeding should stop only once a nutritionally adequate and safe diet without breast-milk can be provided. [1]

Appendix 3A: Checklist for HIV-exposed Infant Care

At each encounter with the health system, ensure the following are addressed. Note that national guidelines may recommend visits additional to those listed below or recommend different timing of routine visits. Always adapt this table to national guidelines.

Activity	Timing of routine visit							
	Birth	6 wk	10 wk/ 2 mon	14 wk/ 3 mon	4 mon	6 mon	9 mon	18 mo
Mother								
Provide/refer care; ensure viral suppression on ART	✓	✓	✓	✓	✓	✓	✓	✓
Adherence support (ART, IPT, CTX, etc)	✓	✓	✓	✓	✓	✓	✓	✓
Screen for other needs & refer	✓	✓	✓	✓	✓	✓	✓	✓
HIV-exposed infant								
Growth monitoring/plotting	✓	✓	✓	✓	✓	✓	✓	✓
Routine immunizations	✓	✓	✓	✓	✓	✓	✓	✓
Screen for TB symptoms and exposure; start IPT if indicated	✓	✓	✓	✓	✓	✓	✓	✓
Ensure family members are tested; address disclosure issues	✓	✓	✓	✓	✓	✓	✓	✓
Infant feeding support	Exclusive breastfeeding						✓	✓
Introduction of complementary feed						✓	✓	✓
Infant ARV prophylaxis	✓	✓	1					
CTX prophylaxis		Initiate	✓	✓	✓	✓	✓	✓ ²
Focused clinical exam	✓	✓	✓	✓	✓	✓	✓	✓
Virologic testing (NAT)	3	✓	If symptomatic for HIV				✓	
Serologic testing	Only if required, e.g., if HIV-exposure status is unconfirmed and mother not available for testing							✓
<p>1 Extended prophylaxis for high risk infants born to women with HIV who:</p> <ul style="list-style-type: none"> Received less than 4 weeks of ART at time of delivery, OR Have VL >1000 copies/mL in the 4 weeks before delivery, OR Had incident HIV infection during pregnancy or breastfeeding, OR Were identified for the first time during the postpartum period <p>2 May discontinue CTX if infant is confirmed HIV-negative.</p> <p>3 See national guidelines.</p>								

Appendix 3B: Key Adherence Messages for Caregivers

IT IS IMPORTANT TO MAKE AN ADHERENCE PLAN FOR YOUR BABY

- If you are taking medicines, give your child medicines at the same time you take yours.
- Try to schedule your own and your baby's appointments on the same day.
- Get support from someone you trust.

Here are some tips on giving your baby syrups:*

- Look at the coloured tape/markings on the syringe to make sure you are giving the right dose.
- You can reuse syringes until the markings begin to wear off or the plunger is hard to use. Wash the syringes with warm, soapy water, rinse, and let them air dry.
- If the medicine is too sticky, add a little breast milk or formula to the syringe.
- DO NOT add medicines to a baby bottle or cup of milk.



If your baby does not want to take his or her medicine, here are some tips:*

- Wrap your baby in a blanket and hold him or her in the bend of your arm.
- Place the dropper in the corner of the baby's mouth and slowly give the medicine. Aim for the inside of the baby's cheek instead of the back of the tongue.
- Blow gently into your baby's face, which should make him or her swallow.
- Do not give medicine when your baby is crying or by pinching his or her mouth open.



If your baby vomits medicine within 30 minutes of giving it, give the dose again.

* Where possible, the healthcare provider should demonstrate these tips or invite the caregiver to demonstrate.

Adapted from: ICAP. Prevention of Mother-to-Child Transmission (PMTCT) of HIV Resources. [9] <http://icap.columbia.edu/resources/detail/prevention-of-mother-to-child-transmission-pmtct-of-hiv-resources>

Appendix 3C: Adherence Support Guide for Caregivers of HIV-Exposed Infants

The adherence preparation and support guide on the next page was developed to assist a range of providers who work with women living with HIV and their families, as well as caregivers of HIV-exposed and HIV-infected children.

Given the importance of early and timely initiation for PMTCT, it is critical that barriers to immediate ARV/ART initiation are removed for pregnant women and HIV-exposed infants. To avoid delays, initial adherence preparation counselling can be conducted on the same day the client initiates ARV/ART.

Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits. These guides can also be used as job aides to help providers conduct adherence counselling with clients.

Basic information: Write the client's name and file number at the top of the form. Be sure to sign and date the form.

Questions to ask the client/caregiver: The questions in this section allow the health worker to discuss specific care, medication, and adherence issues with the client. The questions should be used to identify areas where the client may need additional information and support, but should not be used to "score" a client's knowledge and readiness to take ARVs. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on effective next steps, important areas for follow-up, and in supporting the client's adherence over the long term.

Client requires more counselling and support in these areas: Write down specific areas in which the client needs ongoing adherence counselling and support. Refer to this section of the form during follow-up counselling appointments and clinic visits. Even if a client has questions about her own or her child's care and medicines, or is facing specific adherence challenges, this is usually not a reason to delay initiation of ARVs/ART. Instead, these issues should be viewed as important areas for ongoing counselling and support.

The following tool is for caregivers of HIV-exposed infants.

Adherence Preparation/Support Guide for Caregivers of HIV-Exposed Infants

Client's Name: _____ Client's File#: _____

1. Can you tell me about the group or one-on-one counselling sessions you have had here at the clinic?	
2. Can you explain why your baby needs to take ARVs?	
3. How long will your baby need to take ARVs?	
4. What concerns do you have about giving your baby ARVs?	
5. Can you explain why your baby needs to take Cotrimoxazole?	
6. How long will your baby need to take Cotrimoxazole?	
7. Who helps you take care of your baby? Do they know your baby has been exposed to HIV? Do they understand how to feed your baby and how to give your baby medicines?	
8. How will you remember to give the baby medicines the right way, at the same time, every day?	
9. How will you remember to come for your baby's clinic appointments?	
10. Can you tell me about the medicines that you will give to your baby and how and when you will give them (how much, how to give syrup or tablets, what times of day)?	
11. What will you do if your baby does not want to take medicine? Or spits up the medicine?	
12. Can you tell me some possible side effects of ARVs and cotrimoxazole? What will you do if your baby has side effects?	
13. Are you giving the baby medicines other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
14. Where will you store the baby's medicines?	
15. What will you do if you are about to run out of medicine(s)? What about if you will be away from home? Or away from the baby?	
16. What will you do if you or your baby misses a dose of medicine?	
17. Can you tell me how you plan to feed your baby in the first 6 months? What will you say if people want to give your baby something other than breast milk (or formula)?	
18. When should your baby get tested for HIV?	
19. <i>For mothers:</i> What medicines are you taking? How many doses did you miss in the last 7 days? What support or reminders do you have to remember your medicines? What was your last viral load result?	
20. <i>For mothers:</i> Can you tell me how you plan to continue your own care and treatment now that you are also taking care of the baby?	
21. Do you have any questions about your own or your baby's care and treatment plan?	

Client requires more counselling and support in these areas (LIST):

Signature of person completing assessment: _____ Date: _____

Adapted from: ICAP. Prevention of Mother-to-Child Transmission (PMTCT) of HIV Resources. [9]
<http://icap.columbia.edu/resources/detail/prevention-of-mother-to-child-transmission-pmtct-of-hiv-resources>

Appendix 3D: Adherence Assessment Guide for Caregivers of HIV-Exposed Infants

How to use the adherence assessment guide

This adherence assessment guide was developed to support providers who work with caregivers of HIV-exposed and HIV-infected children. Routine adherence assessments help identify and solve adherence challenges in a timely manner. Use this form at every follow-up and refill visit to ensure that the client understands the care and medication plan and is giving the child his or her medicines the correct way, every day. Keep completed adherence assessment forms in the client's file and refer to it during follow-up visits. If individual client files are not maintained at the clinic, these guides can be completed when counselling caregivers and then given to clients to keep with their health card.

Basic information: Write the client's name and file number at the top of the form; record the name of the caregiver attending the clinic visit. Tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session.

Questions to ask the client/caregiver: The questions in this section guide the adherence assessment. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, know important areas for follow-up, and support the clients' adherence over the long term.

Other assessment measures and next steps:

- Depending on standard procedures at the clinic, the health worker may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- **Specific adherence challenges identified by client and health worker:** Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made:** If there is an outside organization or facility-based service—such as a support group, counsellor or a home-based care programme—that could help support the client to overcome challenges to adherence, refer the client to that organization and record the name and service in this part of the form.
- **Next steps and follow-up plan:** Together with the client, identify which solutions and next steps he or she thinks are feasible and manageable. For each solution, list the necessary steps the client or healthcare provider will need to take and a time line for each. Record the date for the follow-up visit on the form. This section of the form can be used as a starting point for the adherence assessment during follow-up visits.

Adapted from: ICAP. Prevention of Mother-to-Child Transmission (PMTCT) of HIV Resources. [9]

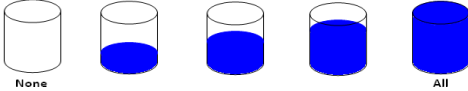
<http://icap.columbia.edu/resources/detail/prevention-of-mother-to-child-transmission-pmtct-of-hiv-resources>

Adherence Assessment for Caregivers of HIV-Exposed and HIV-Infected Infants and Children

Client's Name: _____ Client's File#: _____

Tick one: 2-week follow-up 1-month follow-up monthly refill 3-month refill

Questions to ask the caregiver:

1. Can you tell me more about how you gave your child his or her medicines this past month (or 2 weeks)? (Do you know the names of the medicines? How much medicine do you give? At what time of day do you give them?)	
2. Can you show me how you give your child his or her medicines? <i>(give praise and provide additional training and support, as needed)</i>	
3. I would like you to think about the last 7 days. How many doses did your child take late in the last 7 days? What were the main reasons the doses were late?	
4. How many doses did your child miss in the last 7 days? What were the main reasons the doses were missed?	
5. Which of these pictures best shows how many doses you gave to your child in the last month (or 2 weeks)? <i>(circle one)</i> 	
6. Can you tell me about any changes you noticed (such as in your child's health) or challenges you or your child had with the medicines?	
7. What support or reminders do you have to give your child medicines at the same time, every day?	
8. What questions do you have about your child's care or medicines?	
9. <i>For mothers:</i> I would like you to think about the last 7 days. How many doses of your ART did you miss in the last 7 days? What were the main reasons the doses were missed?	

Other assessment measures and next steps:

Results of pill count, medicine diary, or calendar if applicable:	
Specific adherence challenges identified by client and health worker: <i>(discuss possible solutions to each)</i>	
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment: _____ Date: _____

Appendix 3E. Criteria for Presumptive Diagnosis of Severe HIV Disease in Infants and Children

A presumptive diagnosis of severe HIV disease should be made if:	
<p>1. The child is confirmed as being HIV antibody-positive</p> <p>AND</p>	<p>2a. The infant is symptomatic with two or more of the following:</p> <ul style="list-style-type: none"> • Oral thrush • Severe pneumonia • Severe sepsis <p>OR</p> <p>2b. A diagnosis of any AIDS-indicator condition(s) can be made</p>
<p>Other findings that support the diagnosis of severe HIV disease in an HIV-positive infant include:</p> <ul style="list-style-type: none"> • Recent HIV-related maternal death or advanced HIV disease • Child's CD4+ <20% 	
<p>Confirm the diagnosis of HIV infection as soon as possible.</p>	
<p>a AIDS-indicator conditions include some but not all HIV paediatric clinical stage 4 conditions such as Pneumocystis pneumonia, cryptococcal meningitis, severe wasting or severe malnutrition, Kaposi sarcoma, extrapulmonary TB.</p> <p>As per the IMCI definition:</p> <ul style="list-style-type: none"> • Oral thrush: Creamy white-to-yellow soft small plaques on red or normally coloured mucosa which can often be scraped off (pseudomembranous), or red patches on the tongue, palate or lining of mouth, usually painful or tender. • Severe pneumonia: Cough or difficult breathing in a child with chest indrawing, stridor or any of the IMCI general danger signs; i.e. lethargic or unconscious, not able to drink or breastfeed, vomiting, and presence or history of convulsions during current illness; responding to antibiotics. • Severe sepsis: Fever or low body temperature in a young infant with any severe sign, e.g. fast breathing, chest indrawing, bulging fontanelle, lethargy, reduced movement, not feeding or sucking breast milk, convulsions. <p>It is unclear how often CD4 is lowered in the above conditions in HIV-uninfected children.</p>	

Source: WHO. *Antiretroviral Therapy for HIV infection in Infants and Children: Towards Universal Access*. 2010; Available from: http://apps.who.int/iris/bitstream/10665/164255/1/9789241599801_eng.pdf?ua=1

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