Chapter 28

Integration of Palliative Care With ART in Children

Authors
Paul Roux

Vanessa Adams

Henry Barigye

At a Glance

Overview

Although most children in sub-Saharan Africa do not currently have access to antiretroviral therapy (ART), the numbers are increasing. Palliative care should be integrated into paediatric medical care at all stages of HIV disease and for all levels of care including those in which ART is available. Palliative care can enhance symptom management, adherence, and quality of life for children undergoing ART. Moreover, ART is the most potent form of palliative care for HIV disease.

The goals of ART for children are to (ANECCA, 2004):

Prolong life

Promote optimal growth and development

Preserve, enhance or reconstitute the immune system and therefore reduce opportunistic infections

Suppress HIV replication and therefore prevent disease progression

Reduce HIV-related illness and improve quality of life

The purpose of including this chapter in a book about palliative care is to provide palliative and primary care health workers with a basic understanding of their young patients who may be on ART. For more information, see also the adult chapter on ART, Chapter 12: Integration of Palliative Care with Antiretroviral Therapy. ART is best administered and monitored by prescribers who have been trained and have experience in HIV management.

See Chapter 26: Clinical Assessment of Children for diagnosis and staging of HIV disease and for prophylaxis for opportunistic infections.

Published 2006

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Table of Contents

Published 2006

Criteria for Commencing ART

Prerequisite criteria for commencing ART are important both because of the adverse effects of the drugs themselves and because supplies are limited. The drugs pose significant health risks to the child if not taken correctly, so they must be prescribed only in appropriate cases. In areas where antiretroviral drugs (ARVs) are scarce, it is important that they be given to those who will benefit the most. To assure children are appropriate candidates for ART, they need to meet both medical and social criteria before starting therapy. The following criteria are provided only as a guide (ANECCA, 2004). Refer to national guidelines for specific criteria for commencing ART as well as for information about specific drugs that will be used.

Medical Criteria:

- Confirmed HIV diagnosis by laboratory test (see section on laboratory diagnosis of HIV in Chapter 26)
- WHO recommends ART in all children with Stage 3 or 4 disease (for staging, see Table 26.2 in Chapter 26)
- WHO recommends ART in children with Stage 2 disease if:
  <18 mos of age: CD4 <20%
  >18 mos of age: CD4 <15%
- Where CD4 testing is not available, WHO recommends ART in children with Stage 2 disease if:
  <18 mos of age: TLC <3,400/mm^3 or mother has severe symptomatic disease or has died
  >18 mos of age and <6 yrs of age: TLC <2,300/mm^3
  >6 yrs of age: 1,200/mm^3

Social Criteria:

- A clearly identified caregiver who understands the prognosis of HIV infection, side effects of medicines, how to administer and store medicines, implications of non-adherence, and that therapy is life-long. Indicators of reliability may be used, such as history of regular clinic attendance or record of previous adherence to nutritional supplements/other chronic care regimens such as TB drugs.
- Ability to attend the ART centre on a regular basis (transport may need to be arranged for patients in rural areas or for those remote from the treatment site).
- Access to supportive processes, such as counselling services and family support groups.
- Access to nutritional supplements and cotrimoxazole prophylaxis.
- Facilities at home for safe and appropriate storage of medications.

The clinical team at the referral site should make the decision to refer for treatment. The referral team should include medical, nursing, and counseling staff, and the child's mother or other caregiver.

The ART treatment site should have trained personnel and a regular supply of drugs to prevent and to treat opportunistic infections, ARV drugs, laboratory reagents, and the capacity for ongoing monitoring. Treatment of parents and siblings with HIV infection should be considered to preserve the family unit; the health of the caregiver is particularly important for the survival of the child (ANECCA, 2004).

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Process for Commencing and Monitoring ART

Children receiving ART require close monitoring. Caregivers must be able to make frequent trips to clinic. Members of primary care and palliative care health teams need to support the family in assuring that appointments are kept, the child takes medications properly, and symptoms and side effects are managed. Box 28.1 provides tips for assisting caregivers in administering medications.

Because availability of drugs varies throughout Africa, health care workers are advised to refer to the guidelines for ART therapy in their own regions and countries. See Chapter 11 for adverse effects of specific drugs. The process for commencing and monitoring ART is listed below.

Assessment Visit Prior to Starting ART

- Conduct complete history and clinical evaluation including weight, length/height, and head circumference.
- Update growth chart.
- Conduct a developmental assessment for a baseline and repeat yearly.
- Ensure that TB is adequately excluded (see Box 28.1):
  - History of TB contact
  - Chest radiograph
  - Gastric aspirates or induced sputum if abnormal chest X ray
  - Mantoux test
  - *If available and clinically indicated,* abdominal ultrasound for lymphadenopathy.
- Obtain blood tests (see Laboratory Monitoring below):
  - Full blood count (FBC) and differential count, including total lymphocyte count (TLC)
  - Alanine aminotransferase (ALT)
  - *If available:* CD4 count and viral load
  - Baseline tests as needed to monitor specific ARVs (e.g., fasting cholesterol and fasting glucose if on protease inhibitors — refer to national guidelines).
- Identify and name the caregiver responsible for medication and make sure that this person can be present during all discussion regarding ART.
- Explain the importance of adherence to the caregiver. Give tips for administering medicines (see Box 28.1).
- Explain the side effects of ARV drugs with emphasis on problems associated with the chosen drug regimen.
- Explain exact drug schedule to the caregiver and, if appropriate, to the child.

Visit to Initiate Treatment:

- Complete history and clinical evaluation including weight, length/height, and head circumference.
- Update growth chart.
- Calculate body surface area for dosing.
- Check baseline blood results (taken at first screening visit).
- Explain the importance of adherence and review medicine tips.
- Explain possible side effects of ARVs with emphasis on the problems associated with the chosen drug regimen.
- Explain drug schedule for the child to the caregiver and child, as appropriate, using the diary card.
- Commence ART.
- Prescribe medication for 2 weeks, calculating total volume of medicine and number of units required. Request that all empty containers and unused drugs be brought back for all follow up visits.
- Issue pillboxes, syringes, and diary cards.
- Arrange adherence contact or phone call in 1 week (if possible).
- Arrange followup visit after 2 weeks.

Monitoring Visits (2 weeks, then monthly for 3 months, then 3-monthly):

- Complete history and clinical evaluation including weight, length/height, and head circumference.
- Update growth chart.
- Calculate surface area for dosing.
- Conduct adherence assessment (3-day recall).

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- Reconcile returned empty containers with volume of medication prescribed for prior interval.
- Issue pillboxes, syringes, and diary cards where needed.
- Look for signs of toxicity (e.g., right upper quadrant tenderness, pallor, rash) and ask about adverse effects.
- Check results of laboratory tests from previous visit and obtain blood tests as appropriate (see laboratory monitoring below).
- Address ongoing medical problems, including skin and dental problems and organ-specific complications of HIV infection.
- Treat intercurrent infections if present.
- Check the doses, adjust the dosing schedule, and review the drug schedule with the child's caregiver, using the diary card.
- Issue medication for 4 weeks, calculating total volume of medicine and number of units required.

At subsequent 3-monthly monitoring visits:

- Repeat measures from monitoring visits above.
- When 3-monthly visits are initiated, make sure the caregiver understands what it means to collect repeat medicines at monthly intervals until the next visit.
- At each visit, enquire about surplus units of medication at home and include these in the calculation of volumes to be issued.

Box 28.1:

Tips for Medicine Use

When using liquid medicine, switch to tablets as soon as possible.

When prescribing medicines requiring refrigeration to children in homes without refrigeration, teach caregivers to put the bottle inside a pottery bowl or jug that is placed in a container of water. The moisture evaporating from the clay pot will cool the medicine. See Figure 28.1.

Teach caregivers to:

Train children to swallow pills.

Give food or drink after medicines to settle stomach and wash away bad taste except when medicines should be given on an empty stomach.

Identify measuring devices for liquid medicine.

Establish a consistent time, place, and sequence of events so child knows what to expect.

Link medicine time with ADLs to establish as part of daily routine.

Watch for side effects.

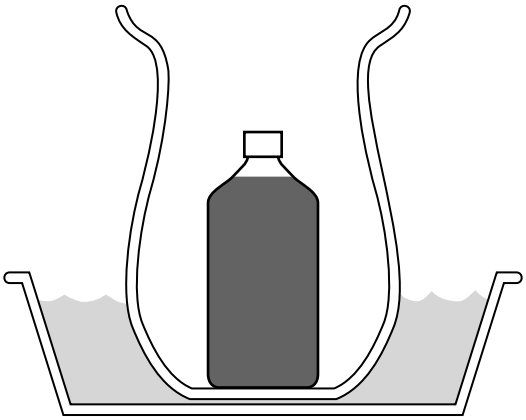
Praise child for taking medicine.

Store medicines in a secure place, where other children will not have access to them.

Laboratory Monitoring

- Full blood count (FBC) and differential count, including total lymphocyte count (TLC): at baseline, then according to drugs being used.
- If available, CD4 count and CD4 %: at baseline and 6-monthly.
- FBC and ALT: at baseline and after 1 month of treatment. If normal, repeat 6-monthly. If on protease inhibitor, test fasting lipid profiles (cholesterol and triglycerides) at baseline and then annually.
- If available, viral load tests: at baseline and 6-monthly. If viral load tests not available, monitor clinically and with CD4 count and % or total lymphocyte counts.

Figure 28.1: Keeping Medicines Cool at Home Without Refrigeration



Water evaporating off a pottery jug keeps the medicine cool inside.

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Box 28.2:

Treat Active TB Before Commencing ART

For children with active TB, commence treatment two months prior to starting ART, to avoid the immune reactivation syndrome which results in an exacerbation of the clinical features of tuberculous co-infection

Paradoxical reactions to ART are defined as transient worsening of signs and symptoms or the appearance of new signs, symptoms, or radiographic features of TB that occur after the initiation of treatment. They are not a sign of treatment failure, but are thought to be a manifestation of an immune reaction to tubercle bacilli, previously inert because of immune suppression. Such paradoxical reactions are reported in up to 36% of patients starting treatment.

Immune reconstitution symptoms occur within days to weeks after starting ART. Initiation of ART within the first two months of starting antituberculous therapy is associated with an increased risk of a paradoxical reaction.

Common presenting signs include fever, enhanced adenopathy, serositis, cutaneous lesions, and new or expanding central nervous system lesions. Most patients with paradoxical reactions have advanced HIV infection with CD4 counts <50 cells/mm^3 and very high viral loads. Treatment includes non-steroidal anti-inflammatory agents and reassurance. High dose corticosteroids (prednisone 2 mg/kg for 7 to 10 days) are indicated in the case of lymphadenopathy with life-threatening airway compression.

Deciding When to Stop ART

If a child on ART appears to be failing therapy, at some point the child may lose all potential for recovery from the present infection or complication. At this time, further survival may only mean further suffering and proper care will entail the curtailment of curative interventions and just the continuation of comfort care (see Chapter 32: End-of-Life Care of Children). It is very difficult to know when a particular child has reached this 'point of no return', the more so if the care of the child has been discontinuous. It is particularly difficult to know how to achieve the proper balance of care when a previously unknown child is admitted in extremis. Because ART is potentially the most effective palliative care in HIV disease, and can reverse the course of very advanced HIV disease, it should be considered if it is available. If prior care was inadequate, the child will have progressed to the terminal state prematurely and palliative care, in that it has not optimized health and limited symptoms as far as possible, may be said to have failed.

References

African Network for the Care of Children Affected by AIDS (ANECCA). 2004. Tindyebwa D, Kayita J, Musoke P, et al, eds. *Handbook on Paediatric AIDS in Africa. Uganda: African Network for the Care of Children Affected by AIDS.* Available at: http://www.fhi.org/en/HIVAIDS/pub/index.htm.

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