

Pediatric ART 7: The ongoing management of the child on HAART

Unit 14.1

Paediatric Antiretroviral Therapy Workshop

Abuja

24-28 July 2006

Goals

- Understand the concept of the family-friendly clinic
- Describe how to measure adherence
- Be able to formulate an assessment based on information gathered at follow up visit

Ensuring follow up of children receiving HAART

- Interruption in adherence is greatest danger!
- Be sure patient has more than enough drug to last until scheduled follow up: allow for delinquent visits
- Be sure family knows when to return
- Encourage regular attendance but make room for patients who “drop in”

The family-friendly clinic and adherence to follow up

- Assign patients to counselor/nurse/doctor team- so patients & professionals know each other & provide continuity of care
- Greet each family by name
- Child-friendly environment- play space, etc
- Patients and families should *enjoy* coming to clinic: where people with HIV are treated with respect

Assuring adherence to follow up

- Maximize clinic flow efficiency to minimize patient time in clinic
 - Monthly visits, often by more than one family member can be a burden for parents that may lead to nonadherence- especially if visit takes all day
 - Relieves congestion in clinic
- Home visits by counselor to reinforce adherence to meds and visits
- Track clinic attendance/pharmacy activity
- Contact patient if appointment missed

Schedule for follow up

- Every 1-2 weeks initially
 - Dispense another month's worth at 2 weeks- this will ensure an extra 2 weeks of medications in the event clinic visit missed
 - If patient gets off schedule, always ensure that family has at least 2 week supply at time of next follow up
- Then monthly
- More frequent visits as circumstances dictate!

Elements of interval visit

- Chief complaint (if any), systems review
- Developmental/school history
- Interval illnesses
- Medication history
- Adherence review and pill count
- Dosing problems
- Psychosocial issues
- Physical assessment as indicated
- Laboratories as indicated

Most or all of this can be done by trained HIV nurse or counselor!

Physical assessment

- Growth
 - Weight is the most powerful predictor of mortality in children with HIV
 - Height- a measure of long-term well being
- PE
 - Manifestations of disease
 - Adenopathy should slowly improve on treatment (but can also decrease with advancing disease)
 - Lymphoid interstitial pneumonitis, parotitis gradually improves
 - Toxicity
 - Lipoatrophy (with multiple drugs; most associated with D4T; takes years)
 - Rash- usually 3 days-6 weeks: NVP, EFV, ABC
 - Neuropathy is rare in children

Labs to monitor disease

- CD4
- Viral load
- Hgb
- Urine for protein (infrequent)

Labs to monitor toxicity

- Blood count or Hgb
 - ZDV-induced anemia should manifest in first 4 months
 - May occur later if there are other problems- AIDS, malaria, Fe deficiency
- Transaminase
 - All drugs- especially soon after starting
- Cholesterol?
 - Only likely to affect plans if very high

Labs to monitor toxicity

- Blood sugar?
 - Only a problem in adults
- HCO_3^- ?
 - Severe lactic acidosis is extremely rare in children, and in adults emerges suddenly- no established value for screening in *nonsymptomatic* patient
- Amylase?
 - Pancreatitis tends to occur abruptly. No established value for screening in *nonsymptomatic* patient

Suggested paediatric ART monitoring: first 6 months

	2 wk	4 wk	Monthly	3 months	6 months
Adherence	X	X	X	X	X
Weight	X	X	X	X	X
Height				X	X
PE		X		X	X
CBC or Hgb ¹		ZDV	ZDV	ZDV	X
Transaminase ²	NVP	NVP		NVP	NVP
CD4					X
VL				(X) ³	

¹CBC or Hgb at 1,2, 3 months if ZDV used

²Transaminase also at 2 monthly if abnormal and on anti-TB therapy

³VL at 3 months should be very low or non-detectable- if available and there is any question about adherence, do VL at 3 months or anytime thereafter

Suggested paediatric ART monitoring: long term

	Every 1-2 mo	Every 2-4 mo	Every 6 months	Every 12 mo	Per need
Adherence	X				X
Weight	X				X
Height		X			X
PE		X			X
CBC or Hgb			X		X
Transaminase		(NVP)			X
CD4			X	X	X
VL (1)					X
Other (2)					X

(1) VL if there is any question about adherence or response to therapy

(2) E.g. U/A annually if VL not undetectable, amylase if ? pancreatitis, etc.

Medication review

- Get history from family
- What medications is child taking?
- How much?
- When?
- **ALWAYS BRING MEDICATION TO CLINIC**
 - Pill count/liquid volume
 - Clarifies communication
- Do not assume that what you think you prescribed is what child is taking!

Adherence recall

- Who gives the medication?
- Do you watch her take it?
- Which doses have you missed in the past 3 days?
- How many missed in past week?
- How many missed in past month?
- Which medications were missed?
- Tell me what happens when doses are missed- why are they missed?

Dosing problems review

- Families may deny nonadherence, but report dosing difficulties
- Does child initiate medication-taking?
- Does child avoid or refuse dosing?
- If so, why?
- What happens after dosing refused or forgotten?

Formulating assessment and plan

- Establish procedures for review of laboratory data as soon as it is generated (before patient returns)
- Team meetings to review patients
 - Most patients routine- no need to discuss
- Home visit, phone, etc to contact family as needed (poor adherence, disturbing lab value, etc.)

Assessment

- Adherence assessment based on:
 - Adherence to follow up
 - Medication dosing recall
 - Adherence recall
 - Pill count
 - Viral load
 - Other signs of clinical response
- Staging change?
- What is the viral load?
- What is the resistance?
- *How can you know this without lab test?*

Plan: Adherence

- Information should be shared with family in a way they can understand
- Families should share in decision-making
- Adherence
 - Family must come to feel that our goal is to support adherence, not to chastise for nonadherence
 - If adherence problem identified a plan for addressing it must be made!
 - Continuing adherence education and support- regardless if problem identified

Plan: Medication

- Medication
 - Should we continue, stop, or change treatment?
 - Is dosage correct?
 - Are TMP/SMX (Bactrim) or other medications needed or can be stopped?
- Dispensing medication and medication training
 - Pills preferred over liquids generally
 - **USE SYRINGE WITH COLORED TAPE TO MARK AMOUNT TO GIVE. IDENTIFY BOTTLE WITH SAME COLOR TAPE**
 - Have family demonstrate proper dosing
 - Patient should always have buffer- about a week extra medication

Documentation: Flow sheets

- Clinic visits
- Medications
- Adherence
- Growth charts- height and weight
- Laboratory results
- Other data: CXRs, Mantoux