



UNIQUE ISSUES IN PAEDIATRIC ADHERENCE



OBJECTIVES



1. Adherence readiness
2. Unique aspects of pediatric adherence
3. Follow-up assessment



Adherence Readiness



BEFORE starting ARVs

- **Starting ARVs is rarely an emergency**
- **Adherence counseling and patient education is necessary to maximize adherence**
- **May require several visits before starting ARVs**



Weighing benefits and risks of HAART



Benefits

- Reduce viral load
- Increase CD4 cells
- Prevent infections & other symptoms
- Prolong life
- Provide hope

Risks

- Drug resistance
- Toxicity
- Side-effects
- Cost: Drugs, labs, staff, family



Assessing adherence potential: psychosocial



- Where does child live?
- Who is in family and who lives at home?
- Who knows the diagnosis?
- What is their attitude to disease and treatment?
- Who will be responsible for dosing?
- What is family's routine schedule and how does it vary?
- Can they be educated and trained?
- Will the child cooperate?



Assessing adherence potential: logistics



- How will drugs be obtained and paid for?
- Where will drugs be stored?
- How will drugs be measured?
- How will dosing be scheduled relative to meals, school, work, sleep?
- How will family remember to give medications?



The unique aspects of adherence with the pediatric population





Parents/caregivers must **GIVE** the medications



- Parents/caregivers must **GIVE** the medications
 - Parents/caregivers may be dealing with their own illness and medications
 - Parents/caregivers may have job obligations
 - Multiple caregivers may give medication without communicating about whether child has received medication
 - Concerns: “Too much medication for a child”



Parents/caregivers must **GIVE** the medications



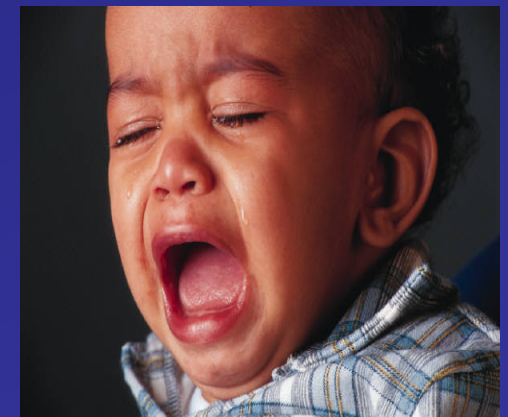
- Lack of resources (psychological, emotional, cognitive, financial, social)
- Myths/ lack of understanding re: HIV
 - Dosing instructions
 - Resistance
- Too much responsibility for children
 - Overburdened
 - Depressed
 - Substance abuse
 - Lack of support



Children must TAKE the medication



- Previous medication history
- Ability to swallow pills
- Taste/texture
- Volume of liquid
- With/without foods
- Refusal, fight...
- Intercurrent illnesses





Issues Affecting Medications in Infancy



- Dependence on caregiver
- Prematurity
- HIV-related feeding difficulties
- Pills vs. Liquid
- Side effects of meds
 - Diarrhea
 - Vomiting
 - Decrease oral intake





Issues Affecting Medications in Preschoolers



- Dependence on caregiver
- Refusal of child
- Taste/texture
- Lack of routine
- Change of caretaker
- School/daycare





Issues Affecting Medications in School-aged Children



- Taste/texture/amount
- Timing
- Hiding the meds
- Lack of control
- Lack of supervision
- Disclosure status
- Understanding HIV





Issues Affecting Medications in Adolescence



- Pill burden
- Responsibility for self
- Side effects on activities
- Peer pressure
- Affective disorders
- Disclosure status
- Teens believe that they are invincible
- Increased insight into HIV disease impact on life
- Increased risk taking behavior





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”



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
- Track clinic attendance
- Contact patient if appointment missed



Elements of interval visit



- Developmental/school history
- Interval illnesses
- Medication history
- Adherence review
- Dosing problems
- Psychosocial issues

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
- Illness
- Side Effects





Medication review



- Get history from family
- What medications is child taking?
- How much?
- When?
- Is the child taking the medication with or without food?
- Have patient 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 non-adherence, 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?



Assessment



- Adherence assessment based on:
 - Adherence to follow up
 - Medication dosing recall
 - Adherence recall
 - Pill count
 - Viral load
 - Other signs of clinical response



Reasons for Non Adherence



The three most common themes for children and families found in one qualitative study were:

- Complexity of regimen
- Side effects
- Forgetting



Pugatch et al., 2002



Plan: Adherence



- Information should be shared with family in a way they can understand
- Families should share in decision-making
- 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