

Pediatric Adherence

**International Center for AIDS Care
and Treatment Programs**

**Columbia University
Mailman School of Public Health**



Learning Objectives

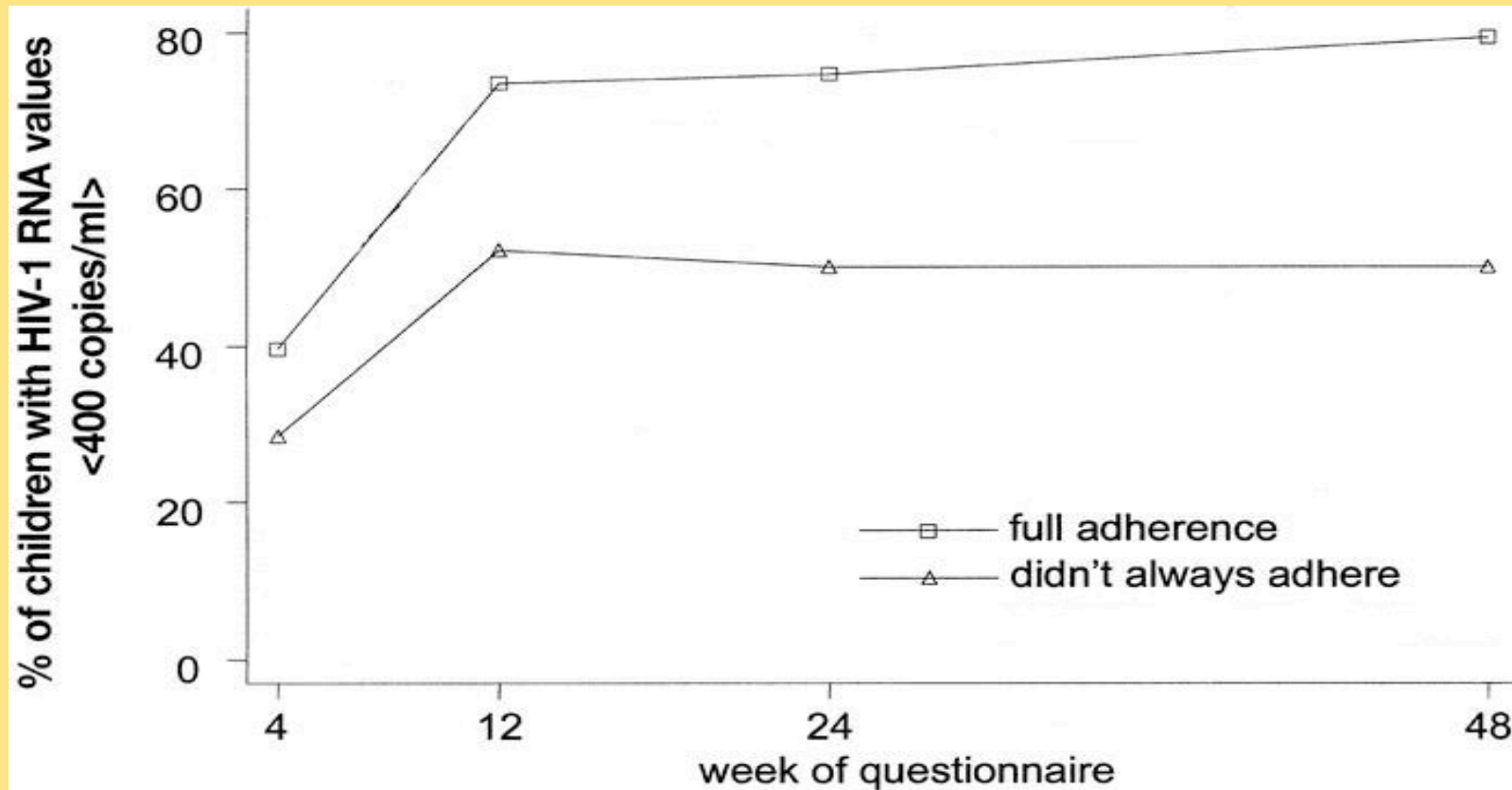
- Identify ways to prepare a family for ARV adherence
- List ways to monitor and support ARV adherence
- Describe ways to assess adherence

Adherence to Treatment: Issues for Children

- ARV treatment for children requires:
 - Collaboration between the child and caregiver(s)
 - Commitment of the caregiver(s)
 - Cooperation of the child
- ARV treatment for children is complicated by:
 - Developmental stage/age of the child
 - Parent-child interaction
 - Psychosocial milieu
 - Relatively poor palatability of many pediatric formulations
 - Caregiver factors

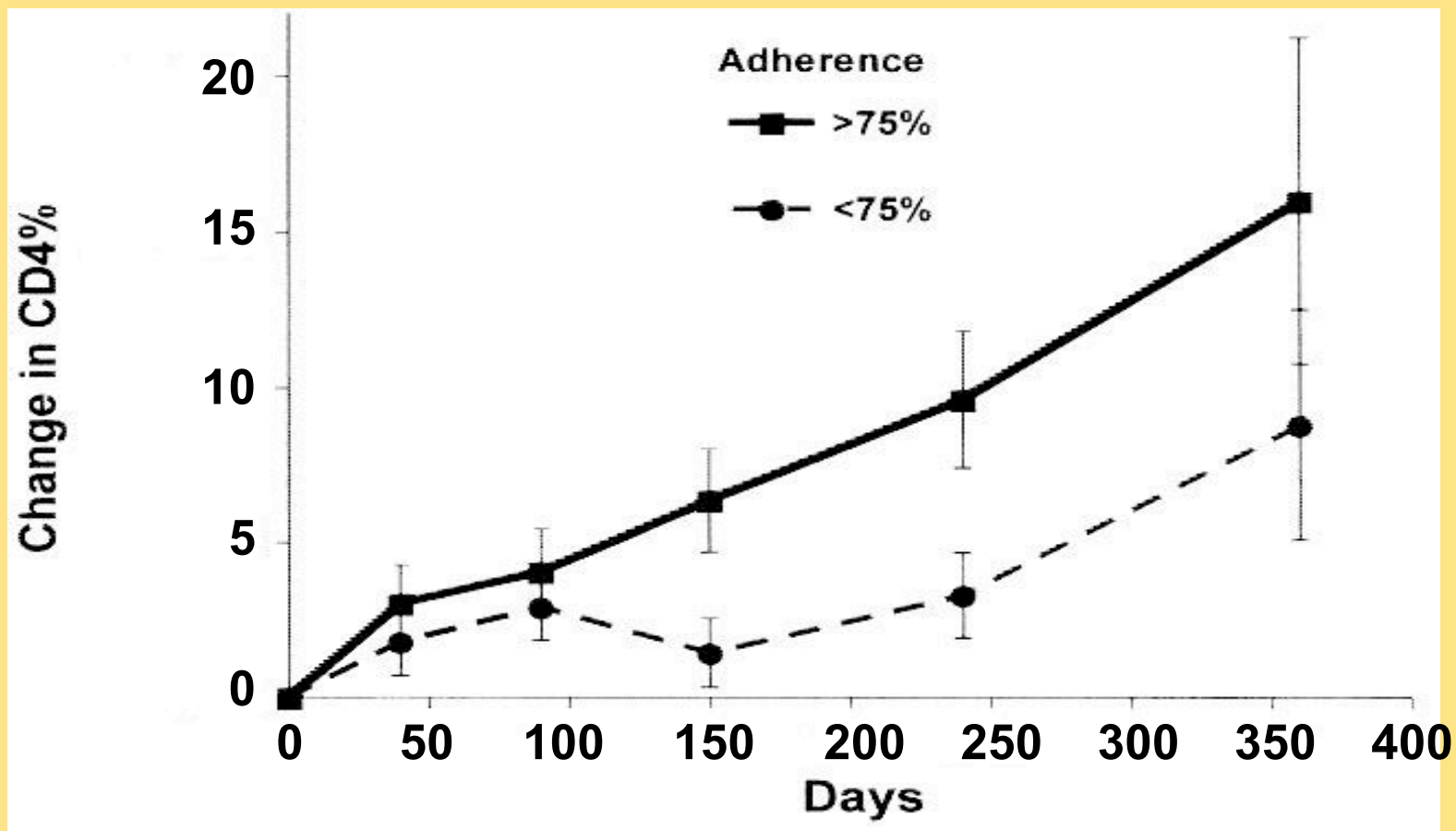
Adherence and Suppression of HIV-1

PENTA 5



Gibb D et al, *Pediatr Infect Dis J* 2003;22:56

Adherence and CD4 Response, U.S.



Watson D et al. *Pediat Infect Dis J* 1999;18:682

Reported Difficulties Taking ARV Medications, PENTA 5

- Taste/Palatability/Volume
 - Difficulties with unpleasant flavor and/or smell
 - Nausea
 - Too many pills
- Social Situations – Fear of disclosure
 - Visiting or out with friends
 - Visiting relatives over weekend
 - Visitors in house
 - Had to leave child with a friend for the day

Gibb D et al, *Pediatr Infect Dis J* 2003;22;56

Factors Associated with Adherence

- Demographic Variables: age, sex, caregiver type, caregiver sex, income
- Disclosure to child, to others
- Caregiver-child communication
- Caregiver Self-efficacy
- Caregiver Health Beliefs
- Caregiver Depression
- Stress
- Stigma

An Approach to Adherence: Giving Medications to Infants & Children

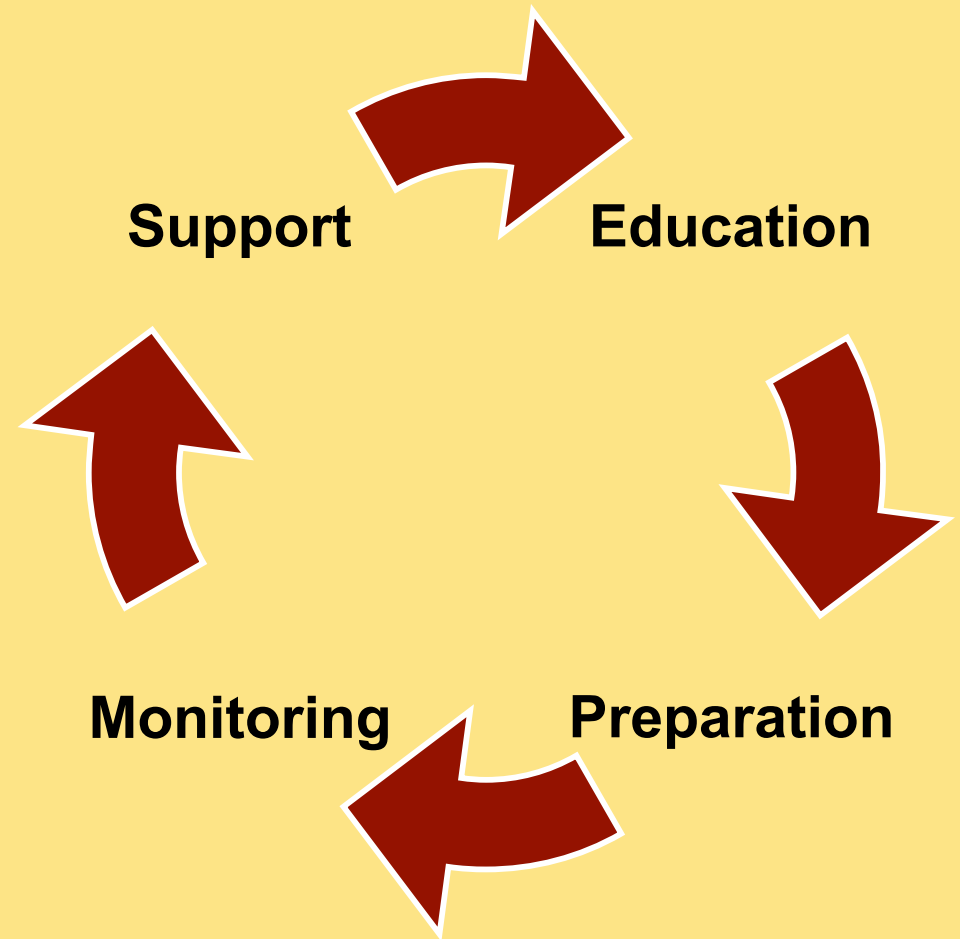
- **Promoting Adherence**
- **Assessing Adherence**

An Approach to Adherence: Giving Medications to Infants & Children

- **Promoting Adherence**
 - Education
 - Preparation
 - Monitoring
 - Support
- **Assessing Adherence**
 - Assessment Methods
 - Addressing Barriers

Promoting Adherence

1. Education
2. Preparation
3. Monitoring
4. Support



1. Adherence Education

- Define adherence
 - Never missing a dose
 - Keeping to specific times of administration
 - Taking it the “right” way
 - Lifelong treatment, even when feeling well
 - Underscore difficulty of task
- Explain importance of strict adherence
 - Use simple terms, visual aids, analogies
- Emphasize need for communication with health care team
 - Trust
 - Partnership
 - Honesty

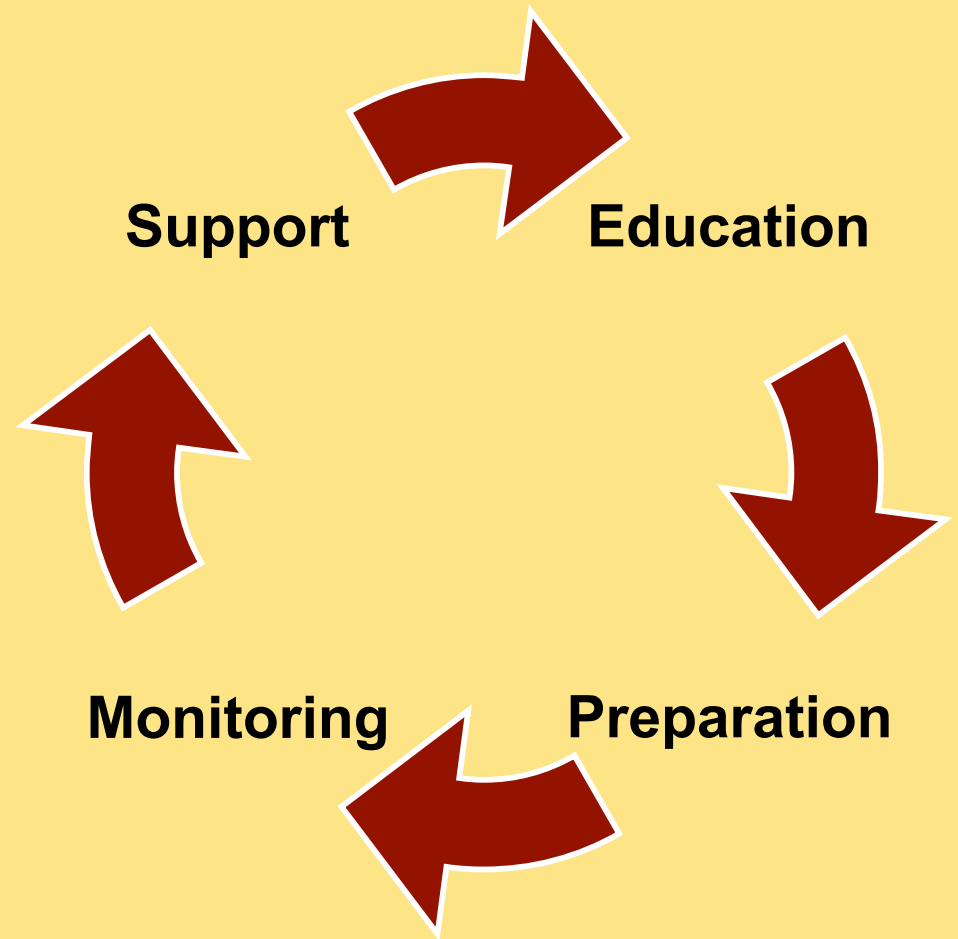
Promoting Adherence

1. Education

2. Preparation

3. Monitoring

4. Support



2. Adherence Preparation

- ARV treatment is rarely an emergency
 - Take time to prepare the child and the caregiver
- Personalize medication administration to match the specific aspects of a child's and family's life
- Address the **WHO**, **WHAT**, **WHEN** and **HOW** of medication administration.

2. Adherence Preparation (cont'd)

- **WHO** will administer the medications?
 - Everyday? Weekdays and weekends?
- **WHAT** medications will be given?
 - Familiarity with medication
- **WHEN** will medications be given?
 - Establish specific times and routines
- **HOW** will medications be given?
 - Details of administration

2. Adherence Preparation (con't)

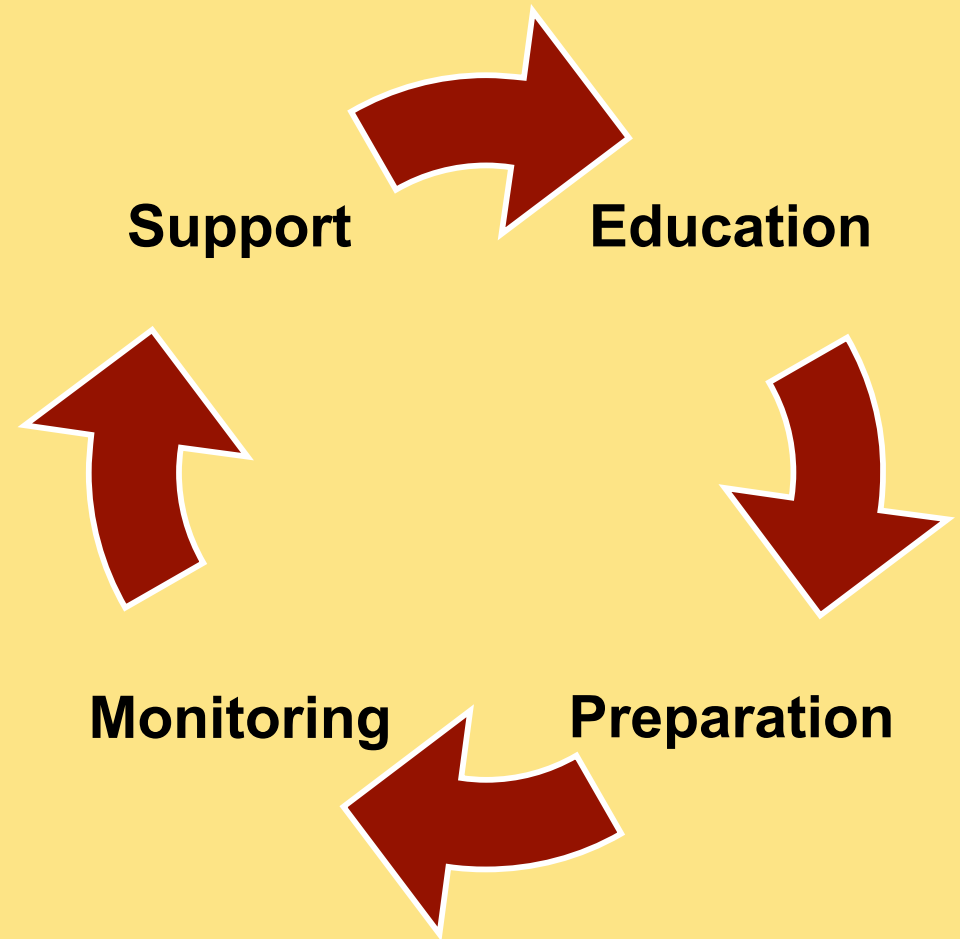
- **HOW** will medication be given?
 - Details of administration
 - Using syringes or measured spoons
 - Cutting and crushing tablets
 - With or without food
 - Mixed with beverage
 - Mixed together
 - Sequencing

2. Adherence Preparation (con't)

- Other preparatory tools for children:
 - Taste testing
 - Observation of dosing
 - Training for pill swallowing
 - Behavioral reward system
 - Role play
 - Anticipating problems
 - Hypothetical scenarios – What would you do if....vomiting, refusal, fever, other?

Promoting Adherence

1. Education
2. Preparation
3. Monitoring
4. Support



3. Adherence Monitoring

- No perfect measures
- Emphasize the importance of honest reporting
- Importance of multidisciplinary approach to monitoring

4. Adherence Support

- Lifelong adherence to complex medication regimens is an extremely difficult task!
- Identify and reinforce effective, successful strategies
- Psychosocial Support
 - Disclosure
 - Adherence Buddy
 - Support Groups
- Adherence Aids
 - Pill Boxes
 - Blister Packs
 - Calendars
 - Pre-pouring
 - Labeling syringes

What Do You Do When Adherence is Incomplete?

1. Assess why adherence is incomplete
2. Address the barriers to adherence

Assessing Incomplete Adherence

1. Review current regimen
2. Inquire about problems administering medications – obtain a **descriptive** assessment
3. Review **WHO, WHAT, WHEN, HOW**
4. Observe administration

Addressing Adherence Barriers: What to do Next

1. Identify specific barriers to adherence
 - Consider stopping current regimen
2. Address specific barriers to adherence
3. Alter current regimen or change to new regimen
 - Formulation or single drug substitution
 - New regimen in the case of treatment failure
4. Begin again
 - Adherence education
 - Adherence preparation
 - Adherence monitoring
 - Adherence support

Adherence Fatigue

- Do not assume “once adherent, always adherent”
- It can be anticipated that with time:
 - Children may tire of taking medications
 - Caretakers may tire of administering/supervising medication
 - Providers may tire of monitoring/supporting adherence
- Beware of adherence fatigue!

Kebede's Adherence to ARV Treatment

Kebede

- Kebede is a 2.5 yr old boy who has been enrolled in the clinic since birth.
- He began ZDV + 3TC + NVP at 6 mo of age when he was diagnosed with pneumonia and failure-to-thrive. He has done very well on this regimen.

How do You Define ARV Treatment Success?

Defining Treatment Success

1. Clinical Improvement

- Appropriate/improved growth for age
- No WHO III or IV category illnesses
- Age-appropriate development/Gaining new milestone
- No hospitalizations

2. Increased/increasing CD4 count

Kebede's Current Medications

- **ZDV** 15cc every 12 hours
- **3TC** 6cc every 12 hours
- **NVP** 10cc every 12 hours
- **Cotrimoxazole** 10cc every morning
- **MVI** 1 cc every morning

Case Presentation

- Alem, Kebede's mother, reports that lately she has been having trouble giving him medication. In the past he has always taken the ARV treatment easily, but over the last several months it hasn't gone well.

What Questions Should You Ask Alem?

Questions for Alem

- Who gives the medicine? All the time?
- Which medications is he getting?
- What happens when Alem tries to give him his medication –what does Kebede do?
- Does he 1) refuse; 2)vomit, spit, choke; 3)run away?
- Does this happen all of the time or some of the time?
- Is it one drug in particular or all of the drugs?
- How long does it take to give him his medication?
- Has he missed any of this doses? All of the medications or just one?
- Has Alem found anything that helps to give his meds?
- Other?

Case Continuation

- Alem reports that he doesn't like the ZDV. He runs from her when she tries to give him his medications. She must capture him, hold him down, force his mouth open to take the ZDV. He then gags and chokes, often vomiting the medicine. He takes the NVP and 3TC, but sometimes she thinks he doesn't keep them down either. Alem, having learned the importance of adherence, is worried.

What do you need to know to begin to determine the cause of Kebede's behavior?

Possible Reasons for Kebede's Behavior Change

- New developmental stage
 - Increasing emotional and physical independence, “terrible twos”
- Changes in household
 - Change in schedule
 - New changes in caretaker
 - New members of household
- Adherence fatigue
- Other

What do you want to do now?

Addressing Incomplete Adherence

What to do Next?

- Identify specific barriers to adherence
 - Observe medication administration
 - Assess parent-child interaction
- **Address specific barriers to adherence**
 - Offer explanation for Kebede's change in behavior
 - Alter current regimen or change to new regimen
 - Formulation or single drug substitution
 - New regimen in the case of treatment failure
- **Begin again with adherence**
 1. Education
 2. Preparation
 3. Monitoring
 4. Support

Case Continuation

- You feel that the problem is probably related only to the ZDV and may require a change or alteration in the regimen.
- Since Alem understands the importance of adherence and is committed to Kebede taking all of his medications, you begin to discuss options with her.

What are some possible solutions?

Other Ways to Give Kebede Medications

- Consider behavioral interventions
 - Reward system
- Explore ways to mask taste
 - Mix with liquids
 - Mix medications together
 - Tasty “chaser”
- Explore other formulations
 - Crushed tablet if dosing appropriate
- Other?

Kebede's Antiretroviral Dosing

- You look at the dosing guidelines brochure for each of Kebede's medications
- Each ZDV capsule = 100mg.
- Together with Alem you decide to change the ZDV to 2 capsules twice daily.

Kebede's Follow-Up

- Alem & Kebede return 2 weeks later. Alem reports success giving Kebede crushed tablets (She crushes and mixes the tab with sweet pudding) and he takes it willingly.

Abede

Case Presentation

- Abede is a 7 year old boy who has been coming to the clinic for the past year. He was enrolled when his mother learned of her HIV status at the ANC during her last pregnancy
- Abede started on ARVs (ZDV+3TC+NVP) 6 months ago after some oral thrush and a third case of pneumonia made him eligible for treatment.
- Mom, who is also on ARVs, administered his medication at the same time as his baby sister (14 mos.) and reports great adherence for both children.

Case Presentation Cont'd

- Abede also lives with his 4 year old sister (HIV negative), his maternal grandmother, and his father, although Dad works away from home 6 months out of the year.
- Mom has a small fruit stand during the days to make extra money, but she is able to administer the morning and night doses because she doesn't start working until later in the morning.
- Mom has not disclosed her or the children's status to her mother because she is afraid it will make things worse between her husband and her mother. She fears her mother will blame her husband for bringing this disease into the household.

Case Continuation

- After just one week on ARVs, Abede began to feel better. His oral thrush cleared up after a course of Nystatin, and a course of antibiotics helped to clear up his pneumonia.
- Abede began to feel much better, although he never missed a follow-up visit
- 4 months after he began ARVs, his mom decided he was healthy enough to start school.
- Fortunately, there is a primary school only a fifteen minute walk from home, so Abede enrolled there.

School

- Abede really liked school and his teacher said that he was doing really well.
- He started learning to read a few words and to write a little bit.
- He made some really nice friends and was happy to go to school.
- However, about six weeks after school started he began feeling a little bit more tired in the morning.
- Mom reports that it has been harder to get him up in the morning, even though he has been going to bed earlier.
- He has had some diarrhea on and off, not like before, but every once in a while.
- He has missed 2 days of school in the past month because he as feeling too sick to go in the morning

Case Question

- What do you want to ask Mom?
- What do you want to ask Abede?

Case Continuation

- Mom reports that both of Abede's sisters are doing well and have been healthy.
- She feels fine, although a little bit more tired lately.
- She mentions that it has been harder to hide the medications from Grandma lately but that Abede has taken his medications on time.

Time with Abede

- Abede says that he likes school, his teacher, and class mates
- He doesn't like when he misses school and wishes he felt better.
- You spend some time with him and decide to do some drawings
- You ask him to draw his family.
 - He draws a picture of his house. He is with his sisters, his mom, and his grandmother sitting at the kitchen table.
 - When you ask him where Daddy is, he says that he has not been home in a very long time

- What do you need to know now?
- How do you want to follow-up?

The MDT Meeting

- When you discuss Abede at the MDT meeting the home worker reports that it seems like Mom may be working more lately. Each time she has stopped by, she has found Grandma at home with the children alone.
- What else do you need to know?

Case Follow-Up

- The team decided to have Mom bring Abede back in one week.
- Abede has been more tired this week. He already missed one day of school and has had diarrhea every day.

Clinical Question

- What would you like to do now?

Case Continuation

- You decide that Mom should see the counselor. The counselor asks Mom how things are going financially for the family since the outreach worker seems to think she is working more.
- Mom says that the school fees for Abede have been an extra burden on her and since she can't get in touch with her husband, she has been working longer hours to pay the fees and for his books.
- She is really tired and doesn't see the older children as much, although the baby often spends the days with her at the fruit stand.
- Sometimes, she gets home so late that the children are already in bed.

Clinical Question

- Do you want to know anything else?

Case Continuation

- You ask Mom who gives Abede his evening doses?
- Mom admits that sometimes he misses his medicines on the nights that she has to work late, since Grandma still doesn't know about the medications

Case Conclusion

- You begin talking to Mom about disclosing her status and the children's status to Grandma.
- You decide to meet again in one week
- You also decide that Mom could benefit from adherence review, so you schedule extra-long sessions for the first three weeks.
- You make a plan for her to have Abede stop by the fruit stand for his medication on his way home from school. That way he can continue taking it with his baby sister and he will have some time to spend with Mom each day.

Case Conclusion

- Two weeks later, Mom comes to her counseling session with Grandma. She reports that Abede hasn't missed any doses and he is doing much better. He hasn't even missed a day of school. Since she sees how much better he has been feeling she decides it is time to tell Grandma.
- Grandma is at first upset, but admits she suspected it because of Abede's frequent illness and all of the trips to the clinic.
- Grandma begins making sure that Abede takes his medication every night when he is working on his homework.
- He hasn't missed a day of school in 2 months, and proudly tells you that he is in the top 10% of his class!

Summary: Adherence to ARV for Children

- There are multiple barriers to adherence
- Successful adherence requires
 - education and preparation before starting treatment
 - assessment and monitoring during treatment
- Most families will have periods of time when adherence is incomplete
 - Barriers to adherence should be assessed and addressed
- Providers and families may experience **Adherence Fatigue**

Summary

- Adherence for children
 - Involve the child as well as one or more adults
 - Require attention to
 - Age, developmental stage, feelings, health status of the child
 - Beliefs and feelings of the caregivers
 - Family dynamics
- Adherence for children should be viewed as ongoing processes requiring
 - Systematic approach
 - Varied skills held in multidisciplinary teams