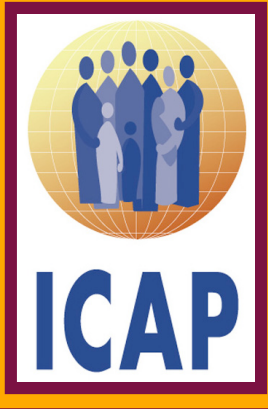


# **Pediatric Disclosure: Talking to Children about HIV**

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

**Columbia University**

**Mailman School of Public Health**



# Learning Objectives

- List important differences between adult disclosure and pediatric disclosure of HIV status
- Describe advantages/disadvantages of disclosing/not disclosing HIV status to a child
- Identify words to use when disclosing HIV status to a child

What does the word  
disclose mean?

# The Word Disclose Means

- To reveal
- To make known
- To make public
- To share

How does telling a child that he or she is HIV infected (disclosing his/her HIV status) differ from an adult disclosing his/her own status?

# Disclosing to Children

- Must consider:
  - Needs, feelings, beliefs of the child **and** needs, feelings, beliefs of the parent(s)/caretaker(s)
    - Pediatric health care providers traditionally advocate for the needs of the child
    - Multidisciplinary teams advocate for the needs of the family
  - Current and evolving developmental and cognitive stage of the child
  - Existing status of family dynamics and communication

# Why are Parents Reluctant to Tell their Child that He/She is HIV- Infected?

# Reasons Parents are Reluctant

- Fear of impact of disclosure on child's psychological status and emotional health
  - Reduce child's will to live
  - Leads to depression in child
- Fear of inadvertent disclosure to others by child
  - Child cannot keep secrets
- Protecting child from social rejection and stigma
- Guilt about transmission
  - Association with sexual taboos

AAP, Pediatrics 1999;103:164

Lipson M, Hasting Ctr Rpt 1993;23:68

# Reasons Parents are Reluctant (cont'd)

- Difficulty coping with their own illness or illness of other loved ones
- Established coping strategies within families
  - Traditional silence around illness and disease
  - Limited communication within families
  - Denial as coping strategy
- Belief that child will not understand
- Children as hope for future
  - Avoid thinking of HIV keeps fatality at bay
- Other

AAP, Pediatrics 1999;103:164  
Lipson M, Hasting Ctr Rpt 1993;23:6

# What are Reasons to Disclose a Child's HIV Status?

# Reasons to Disclose

- Undisclosed children may
  - Develop fantasies about their illness
  - Feel isolated from sources of support
  - Learn HIV status inadvertently
- Children often want and ask to know what is wrong
  - May already know diagnosis but are keeping the secret/ waiting for the parent to tell
- With other chronic and fatal illnesses children who know their status have
  - Higher self-esteem
  - Lower rates of depression
  - Lower rates of parental depression

# Reasons to Disclose (con't)

- Recognition of Autonomy
  - Children achieve mastery over their lives as they age
    - Ongoing and evolving process of involvement with their illness and it's consequences

AAP, Pediatrics 1999;103:164  
Lipson M, Hasting Ctr Rpt 1993;23:6

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# Do You Believe Children Should Be Informed of Their HIV Status?

If yes, why?

If no, why not?

There is general consensus among experienced pediatric HIV providers that children should be informed of their diagnosis.

- Primarily US and European experience
- Emerging experience in Africa and other high prevalence settings
  - Accelerated by the introduction of ARV treatment

# Not “When,” but “How”

- Disclosure is more than revealing HIV status
- Entails an ongoing discussion of health and health-related activities
  - Parents/caregivers should be encouraged to begin and continue a dialogue about health issues with their child beginning at an early age
    - Simple explanation of nature of illness for youngest children
    - Disclosure about nature and consequences for older children
  - When to use the words “HIV/AIDS” will vary with the needs of the child and family

# Not “When,” but “How” (cont’d)

- Let the child be the guide
- Individualize the approach - tailor discussion according to child's:
  1. Age
  2. Cognitive development
    - Use tools and language for different developmental capacities: drawing, storytelling, play, drama
  3. Level of maturity
    - Assess coping skills of the child
  4. Health status
    - Terminally ill child may benefit from discussion about death rather than specific diagnosis

# Assisting Families – Getting Ready for Disclosure

1. Preparation
2. Education
3. Planning
4. Follow-Up

# Preparation

## Preparation

- Why disclose now?
- What do you want to communicate to your child?
- What will be the most difficult questions for you to answer when your child knows his/her HIV status?

# Education

- Acknowledge difficulty of disclosure and affirm motivation to begin process
- How to explain HIV transmission to child
- Anticipate questions and responses from child
- Post disclosure event expectations

# Planning

## Planning

- When and where?
- Who will be there?
- What will you say?
- Plans after disclosure?

# Follow-Up

## Follow-up

- School and family functioning
- Monitor medical treatment adherence
- Disclosure to peers and others
- Support groups, counseling

# Counseling Children

- Help children cope with emotions and challenges they experience when they discover they have HIV/AIDS
- Help children with HIV to make choices and decisions that will prolong their life and improve their quality of life

# Counseling Children

- Establish a helping relationship
- Help children tell their story
- Listen attentively to children
- Give children correct and appropriate information
- Help children make informed decisions
- Help children recognize and build on their strengths
- Help children develop a positive attitude towards life.

# Perspective on Disclosure and Multidisciplinary Teams

- Members of multidisciplinary teams may find themselves in conflict around disclosure to children
  - Some team members may advocate for pediatric disclosure
  - Others, particularly those working with adult caregivers, may resist disclosure
- Multidisciplinary teams may hold/mirror conflicts occurring in families.
  - Needs of the child vs. needs of the adult
  - Different opinions of different adults

# Pediatric Disclosure and Multidisciplinary Teams

- Importance of self-reflection
  - Understand how work affects individual members and team as a whole
  - Consider the issue from different points of view (child, parent, health professional)
- Importance of retaining family-focus and considering decisions in best interest of the child and the family

# Destia: Disclosure of HIV Diagnosis

# Desta

- Desta is an 11 year old girl. Her mother died five years ago and she has since lived with her aunt Amsale, uncle Yared and maternal grandmother Bogalech.
- Amsale was enrolled in the clinic during her pregnancy last year. Desta and Yared both tested HIV positive and were enrolled as well.

# Desta Starting Treatment

- Desta was eligible for ARV treatment based on a history of recurrent varicella zoster, chronic thrush and low CD4%.
- She began ZDV + 3TC + NVP but developed a Grade III rash. NVP was changed to Kaletra (LPV/r).
- She has done well on treatment.

# Desta Resisting Medications

- Grandmother Bogalech brings Desta for her monthly visit. She reports that everything is fine.
- When asked about missed doses Bogalech reports that Desta gets all of her medication. She reluctantly mentions that Desta is fighting with her about taking her medications.

# What Do You Want to Ask Bogalech?

# Assessing Incomplete Adherence

- Review current regimen
- Inquire about problems administering medications – obtain a **descriptive** assessment
- Review **WHO, WHAT, WHEN, HOW**

# Desta Refuses Medications

- Bogalech states that Desta no longer wants to take her medications. She was a good girl in the past and took them without complaint though the orange pills always made her choke. Now she doesn't want them any more.
- Desta keeps asking why she has to take these pills. She wants to know when she will finish taking them.

## Desta Refuses Medications (cont'd)

- When you ask Bogalech what Desta knows about her health she becomes quiet. You notice a few tears. She doesn't want to discuss Desta's problem. She says that the child is taking medications now and will be fine.

# What Should You Do?

# Desta Refuses Medications

- Desta and Bogalech return home. You discuss the case at next team meeting and decide to approach aunt Amsale when she comes for her monthly visit.
- When asked about Desta's medication adherence Amsale notes that she has been resisting taking her medications.

# Desta

## Family Tension

- Amsale feels that Desta should know about her illness. She and grandmother Bogalech have fought about it several times. They both take care of Desta, but Amsale also has her babies to raise. She doesn't want to fight with her own mother.

Why Do You Think Grandmother  
Bogalech Doesn't Want to  
Discuss HIV with Desta?

# What Can the Team Do To Help Desta and Her Family?

# The Disclosure Process

## Beginning a Dialogue

- Meet with family members alone then together
  - Begin a discussion/dialogue about Desta's health and behaviors
  - Address Bogalech's concerns about Desta.
  - Work with family members to enhance communication
- Offer counseling for Desta, other family members
- Follow general counseling guidelines
- Continue to monitor adherence closely

## Beginning a Dialogue (cont'd)

- After several family meetings, Amsale takes the lead and starts to talk with Desta about her health. Bogalech doesn't take part in the conversations, but doesn't prevent them.
- Amsale who is also prescribed ARV treatment begins to take her medicines with Desta. She talks about staying healthy and having strong blood. After several weeks Desta begins to ask questions and stops fighting about her medications. She and Desta become pill buddies and complain to each other about the nasty blue pills.

# Desta Continues to Ask More Questions

- Several months later Amsale brings Desta to her medical appointment. She tells the clinician that she thinks it is time to tell Desta more about her illness. Bogalech doesn't want to take part but has agreed to let Amsale talk with Desta.
- Amsale asks for help.

# What Would You Do To Assist Amsale and Her Family?

# Assisting Families - Ready for HIV Disclosure

1. Preparation
2. Education
3. Planning
4. Follow-Up

# Disclosure of HIV Status to Desta

- The team works with Amsale and Yared in preparation for meeting with Desta. Amsale asks that the nurse and physician help during the session.

How do you feel about talking with  
Desta?

What will you say?

## Destá's Follow-up Care

- Amsale, Yared, the pediatrician, and the nurse meet with Destá to disclose her HIV status. The meeting is very emotional for all participants. Destá and Amsale choose to meet with the counselor on a weekly basis to continue talking about their concerns.

# Family HIV Disclosure

# Nigist

Nigist is a 12-year-old girl who lives at home with her parents and two younger siblings. Her mother, Melkam, and her new 6 month old brother are both HIV infected.

Melkam wants to tell Nigist about her own and the baby's HIV status. Abede, Nigist's father, however, strongly objects.

During a recent clinic visit Abede told Melkam in front of the treatment team that he does not want Nigist to learn anything about HIV.

# Clinical Question

- Why might the parents have different views about disclosing to Nigist?
- What, if anything, is the team to do to bring them together?

# Case Continuation

At a follow-up clinic visit, Melkam reports to her nurse that she relies on Nigist often to give the baby her medicine. Nigist doesn't always remember. When Nigist came to clinic last week to help her mom, she began to ask why the baby has to take so many vitamins?

# Clinical Question

- How should Nigist's questions be answered?
- Can disclosure be done when the parents are not in agreement?

# Disclosure

- During the next visit when Nigist again assists her mother, she starts asking again about the baby's health. Melkam starts to cry and abruptly tells her that she and the baby both have AIDS and need to take medicine. She also tells her not to tell her father that she now knows.

# Clinical Question

- How can the team help Nigist cope with this information?

# HIV Disclosure – Developmental Challenges

# Case Presentation

- Elias is 6 years old and he has a 3-year-old sister, Selam. The children's parents have died, and both children now live with their maternal aunt Mekdes and her family. Mekdes is pregnant and she is being followed at the clinic.
- During a recent visit Mekdes reports that both Selam and Elias have been sick a lot. She requests that both Selam and Elias be tested for HIV/AIDS. She also reports that the children do not eat or sleep well.

# Clinical Questions

- What additional information do you want?
- How will you go about arranging for testing of the children?
- How will you explain the testing to the children?

# Case Continuation

During his blood draw for HIV testing, Elias asks the nurse what happened to his mother and if something bad is going to happen to his sister and he. He seems very worried and frightened.

# Clinical Questions

How will you respond to his questions?

How will you help his aunt in her parenting of Elias and Selam?

What should happen, if anything, while the family is awaiting test results?

# Summary

- Disclosure of HIV status to a child is guided by the needs of the child and their caregivers
- Disclosure should be part of an ongoing dialogue about health and treatment
- Disclosure should be guided by the age, developmental and emotional stages, and health status of the child
- Disclosure is difficult!

# Summary

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