What is HIV?

He’s crying because of AIDS. He went to the hospital and the doctor says he can’t treat. He’s crying and…

10-year-old boy

10-year-old girl
SOME QUOTES OF HIV+ CHILDREN

- “Mum tells me to take my medicines, if not I will die. She also tells me not to talk about it with anyone. If she says not to talk about it, it’s because it is AIDS” (Isabelle, 8)

- “When the doctor gave the test results to my mum, I’ve seen her face...I understood” (Adama, 12)

- “Mum’s gonna ask me how I got it.”

- “Because of my skin problems, someone at school said I have AIDS.” (Dieudonné, 14)

- “If I say I have HIV, the others will not play with me anymore.”
LEARNING OBJECTIVES

By the end of this session, participants will able to:

- Describe the concepts of disclosure & progressive disclosure
- List the benefits of child disclosure
- Identify why care-takers are reluctant to disclose the HIV status to their child
LEARNING OBJECTIVES (CONTD.)

- Describe the importance of communicating with the child about health and illness & disclosing the status to the child
- Describe what and how to communicate and/or disclose the status to a child
- Perform child disclosure sessions
WHAT IS HIV DISCLOSURE TO A CHILD?

It is an ongoing process where a child learns about health, (unnamed) infection, treatment, and finally is told about his HIV status.

**Progressive Disclosure = Partial Disclosure → Full Disclosure**

**Partial:** Fragmented information on what is happening in child’s body, illness and need of treatment without mentioning the term HIV.

**Full disclosure:** detailed and complete information using the terms HIV and AIDS.
WHY DISCLOSE?

- Gives appropriate and accurate information to child in a way they can understand → Child feels secret and creates his own explanation (which can be worse than reality)
- Engages children in their care, increased responsibility
- **Improves treatment adherence**
- Fewer psychological issues, confusion, fear, anxiety and depression
- No risk of learning the truth from other sources
WHY DISCLOSE? (CONTD.)

- Healthier relationships in the family
- Promoting children’s sense of self control and self-esteem
- Assists children to make choices and decisions about issues which affect them and improve their quality of life
- Helping both the child and family adopt a positive attitude
WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Educational reasons:

- Not seeing the need, especially when child has few symptoms
- Belief that the child is too young and won’t understand
- Belief that if the child doesn’t ask questions, he doesn’t realize what is going on
- Cultural habits (of little communication with child, of not seeing child as person that can take on responsibility)
- Not knowing how and what to communicate with child
WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Emotional reasons:

- Fear about immediate / long term reactions of child – wanting to protect the child of negative feelings, depression,…
- Fear child will reject caretaker
- Isolation or lack of support to help caretaker to take the decision to disclose
- Difficulty to cope own illness (HIV+ care-taker)
WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Emotional reasons:

- Fear of having to disclose own status (HIV+ care-taker)
- Feeling a shame and guilt of having transmitted the disease (HIV+ care-taker)
- Don’t want to frighten child with possible future death of caretaker (HIV+ care-taker)
- Child represents hope, non-disclosure keeps illness away
WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Family related and social reasons:

- Familial or cultural taboo (sex, death,...)
- Fear of sensitive or embarrassing / difficult questions of the child (on family history,...)
- Beliefs about origin of HIV/AIDS (witchcraft, punishment)
- Fear that the child won’t keep the secret and will disclose to other people

→ Health staff can be reluctant for the same reasons!
DISCLOSURE CAN BE CHALLENGING

- Not rare to see children expressing sadness, anger, depression, isolation: adaptive process also for children
- When disclosed to early or in a bad manner, a child can disclose to others, without being aware of the consequences
- Disclosure to adolescents can provoke intense emotional reactions such as anger, rebellion, denial,…

→ but... keeping a secret for a long time brings a lot of difficulties and are more important than the temporary difficulties of telling them
WHEN AND WHO?

When:
- Partial disclosure can start as early as ~ 5 years old
- Full disclosure should be done before adolescence

Who:
- Parent/caregiver, a person the child trusts at the clinic (health worker)
PREPARING FOR DISCLOSURE

- Is child ready for disclosure?
  - Age alone is an unreliable indicator for “right” time to choose

- Is parent/guardian ready for disclosure?
  - If not ready: counselling should continue at each contact with the family
  - If ready: discuss and confirm with caregiver exactly what will be said to the child
WHEN?

PARTIAL DISCLOSURE (5 to 9 years):

- Start as soon as possible
- Follow child’s rhythm: at latest when child starts asking questions (do not lie!)
- Follow caretakers rhythm
- Verify what the child has understood
- Do not use words as HIV/AIDS in front of uninformed children
WHEN?

FULL DISCLOSURE (10 to 15 years)

- Ideally happens between 6 and 12 years
- Do not judge or force caretakers
- When disclosure is not done at 10, we need to work with caretaker on their reluctance and advantages of progressive disclosure, so disclosure is done before 12
DISCLOSURE FLOWCHART

**ART REFILL DAY**
- Identify all children available
- Ask age and cross check with MC
- Assess disclosure status from the guardian and seek consent
- Assess the level of information from the child
- Identify the level of disclosure session

**1ST PARTIAL DISCLOSURE SESSION**
- Book an appointment –next refill

**2ND PARTIAL DISCLOSURE SESSION**
- Book an appointment –next refill

**FULL DISCLOSURE SESSION**
- Book an appointment –next refill

**FULLY DISCLOSED CHILD JOIN TEEN CLUB**
(if available at health facility)
Disclosure decision tree for children > 5 years old

If child is not or partially disclosed

What age is the child?

- 5-8 years old
- 9-12 years old
- 13-15 years old

Plan partial disclosure (PD), with caregiver’s consent. =2 PD sessions in group or individual during the usual refill days. (Booking children on the same day can facilitate group sessions).

Assess if child is disclosed

- If child is not or partially disclosed

Is caregiver present in the session?

- yes
- no

Send invitation slip with child for caregiver to attend in next refill* session (or within 1 m). Do 1st PD session with child

Does the adolescent come alone at HF?

- yes
- no

Inform the caregiver about disclosure importance and do PD session 1 & 2 for ado

Before the child reaches 12 years, do full disclosure (FD)

- no
- yes

Plan full disclosure (FD) as follows: Combine PD 1 & 2 in one session. Give appointment 2 weeks to 1 month after for FD

For YP > 15 years old see next slide
Disclosure
decision tree for
YP>15 years old

Assess young person’s (YP) level of disclosure

- YP is partially disclosed
  - Do one FD session, by going through all disclosure cards.

- YP is totally unaware of HIV status
  - Plan full disclosure (FD):
    - Combine PD 1 & 2 in one session.
    - Give appointment 1 week to 1 month after for FD
DISCLOSURE PLAN

Provide information about:

- Being healthy, taking care of the body
- Visit to clinic
- The human body
- Our defenses (immune system)
- Germs and getting sick
- The immune system needing assistance from drugs
- The specific virus the child has (name the virus and the illness: HIV)
- The CD4 count and viral load
- Transmission and non-transmission of HIV, sexual relations and condoms use
DISCLOSURE SESSION 1: PARTIAL DISCLOSURE

- Card 6: My visit to the hospital
- Card 7: Human body
- (Card 5: Taking care of the body)
- Card 10: Protection by green soldiers

Use explanations about partial disclosure; do not name HIV, CD4 etc.
DISCLOSURE SESSION 2: PARTIAL DISCLOSURE

- Review card 10: Protection from green soldiers
- Card 11: Infection with red germ
- Card 14: Yellow germs entering the body
- Card 15: Taking treatment
- Card 16: Taking treatment – Inside the body
- Card 17: Effect of treatment

*Use explanations about partial disclosure; do not name HIV, CD4, ARV etc.*
DISCLOSURE SESSION 3: FULL DISCLOSURE

- Card (7), 8: (Human body from outside), Blood circulation (inside human body)
- Review Card 9 using full disclosure explanations: Blood and green soldiers as CD4s
- Review Card 10 using full disclosure explanations: Protection by green soldiers as CD4s
- HIV Cards 11, 12, 13, 14: Red germs as HIV
- ARV cards 15, 16, 17: drugs as ARVs
- (Cards 22, 24: Ways of transmission and non-transmission)

_Name HIV, CD4s, ARVs, (explain modes of transmission)_
FOLLOW UP COUNSELING POST-DISCLOSURE

- Provide opportunities for child and family to:
  - gather more information and understanding
  - express difficulties they are facing

- Help child to know who he/she can talk to

- Regularly assess:
  - child’s understanding of condition
  - potential coping difficulties (e.g. behaviour change)
KEY MESSAGES

- Disclosure is a process, starting from partial disclosure to full disclosure
- Disclosure has many benefits, including helping to improve adherence
- Child’s readiness for disclosure depends on:
  - Family wishes and available support post-disclosure
  - Age and developmental stage
  - Child’s current needs and experiences