

Disclosing HIV to Children/Adolescents

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Question for polling

- Have you had experience disclosing HIV to a child/adolescent?
 - If so, how many sessions did it take to complete the disclosure?
 - 1
 - 2
 - 3
 - more than 3
 - Show results?

Learning Objectives

1. Learner will be able to define *types* of disclosure of illness status to youth with HIV.
2. Learner will be able to discuss *stages* of disclosure of HIV status to youth.
3. Learner will be able to list *special circumstances* for consideration during process of disclosure of HIV to youth.

Disclosures of Conflicts of Interest

- *The presenters have no conflicts of interest disclosures.*
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Disclosure Definitions

- **Full disclosure:** Use of the words “HIV” or “AIDS” when explaining the diagnosis
- **Partial disclosure:** Providing information about the disease process without using the words “HIV” or “AIDS”
- **Non-disclosure:** No information; avoid explanation of reasons for taking medications and having frequent medical visits
- **Inadvertent disclosure:** Overhearing diagnosis unintentionally during discussions between family members, medical team, etc.; reading about diagnosis after learning name of medication, etc.

American Academy of Pediatrics (1999)

- Consider the child's age, psychosocial maturity, family dynamics, and clinical context
- Encourages the disclosure of HIV status to school-aged children over several visits
- Recommends that adolescents know their HIV status
- Generally consistent with WHO recommendation that youth with HIV know their status by 6-12 years of age (WHO, 2011)

Provider Barriers to Disclosure to Youth

- Fear of negative outcomes
- Lack of resources to disclose
 - Feel unprepared to have discussion
- Caregiver resistance



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Caregiver Concerns

- Child's maturity to manage secrecy due to stigma
 - Fear they may tell others
- Psychological impact on the child (i.e., depression);
fear of stigma
- Parental guilt regarding transmission
- Child may become angry at the parent
- Potential discussion about parent's substance use,
sexual behaviors, etc.



Photo by Ketut Subiyanto: <https://www.pexels.com/photo/photo-of-woman-sitting-on-couch-while-hugging-her-child-4473625/>

Benefits of Disclosure

- Maintain relationship with youth
 - Honest communication
 - Information is youth's right and allows them to protect self/others
- Improved health outcomes:
 - Long-term adherence (Bikaako-Kajura et al., 2006 & Cluver et al, 2015)
 - Viral suppression (Ferris et al, 2007) and
 - Retention in care (Arrive et al, 2012)

Disclosure of Diagnosis: Process vs. Event

Process can incorporate developmental changes over time regarding concepts related to diagnosis and illness

- Build on information already presented
- Allows for follow up with family to monitor response

Event implies a singular, one-time disclosure



Photo by Miguel Á. Padriñán:
<https://www.pexels.com/photo-of-golden-cogwheel-on-black-background-3785926/>

St. Jude Children's Research Hospital Model

- Includes the facilitation of the disclosure process with the assistance of a Child Life Specialist or Social Worker
- Includes education of the caregiver regarding the process, assessment and intervention of parental concerns, and implementation of the process *with* the child in the caregiver's presence

(Cantrell et al., 2013)

Initial Assessment

- Individualized approach
- Establish a timeline and clarify goals with the caregiver
- Discuss caregiver or medical team concerns
- Provide education regarding the process and stages
 - Show materials, give examples
- Encourage reinforcement of education by caregiver



Photo by Antoni Shkraba:
<https://www.pexels.com/photo/woman-in-a-psychotherapy-session-7579190/>

Staged Approach to Disclosure

- Stages of disclosure
- Breaks out topics and groups information together to present to family
- Allows step-by-step process and emphasizes process approach to disclosure

Stage 1: Blood Cells



Child Life, St. Jude Children's Research Hospital

- White blood cells: “fighter cells”
- Red blood cells: “party cells”
- Platelets: “Band-Aid cells”

Stage 2: Germs and Infection

- Bacteria
- Viruses
- Fungi



Child Life, St. Jude Children's Research Hospital

Stage 3: Medications

- Medications that “keep white blood cells strong”
- Name(s) of medication



Photo by Anna Shvets: <https://www.pexels.com/photo/tablets-on-pink-surface-3683044/>

Stage 4: White Blood Cells

- Types of WBCs (emphasizing lymphocytes)
- Role of CD4 cells



Photo by roberto carrafa: <https://www.pexels.com/photo/purple-and-white-plastic-bottle-3908178/>

Interim Assessment (with Caregiver)

- Review the timeline for full disclosure
- Discuss caregiver concerns & relevant legal issues if applicable
- Review the positive impact of disclosure for children



Photo by Polina Tankilevitch: <https://www.pexels.com/photo/a-woman-having-a-therapy-session-with-a-psychologist-5234573/>

Stage 5: Unhealthy Part

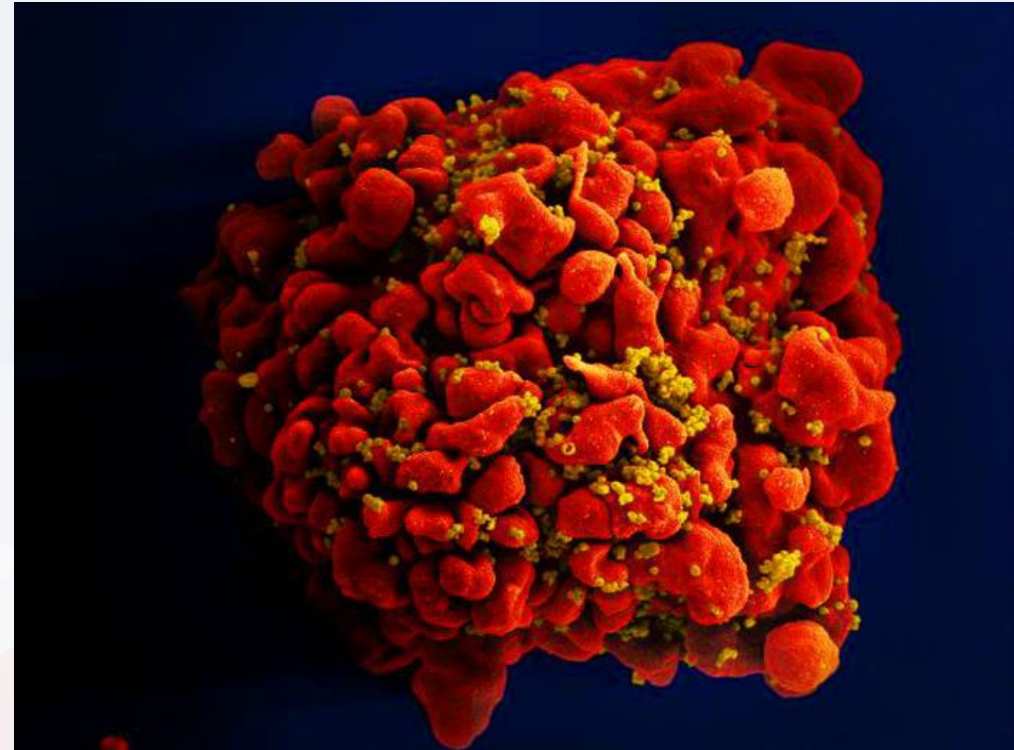
- Introduction of child's blood as unhealthy
- Need for medications to help WBCs function better
- Similar to “partial disclosure”
- Allows for assessment of child's reaction



Photo by Gustavo Fring: <https://www.pexels.com/photo/photo-of-a-girl-looking-at-a-card-with-her-parents-7447259/>

Stage 6: Virus

- Unhealthy part that impacts WBCs is a *virus*
- Review past concepts regarding blood cells and germs; how virus fits in
- Introduce the concepts of viral load (amount of virus) and CD4 count
 - Teaching examples



NIAID: <https://phil.cdc.gov/Details.aspx?pid=18143>

Stage 7: More Virus

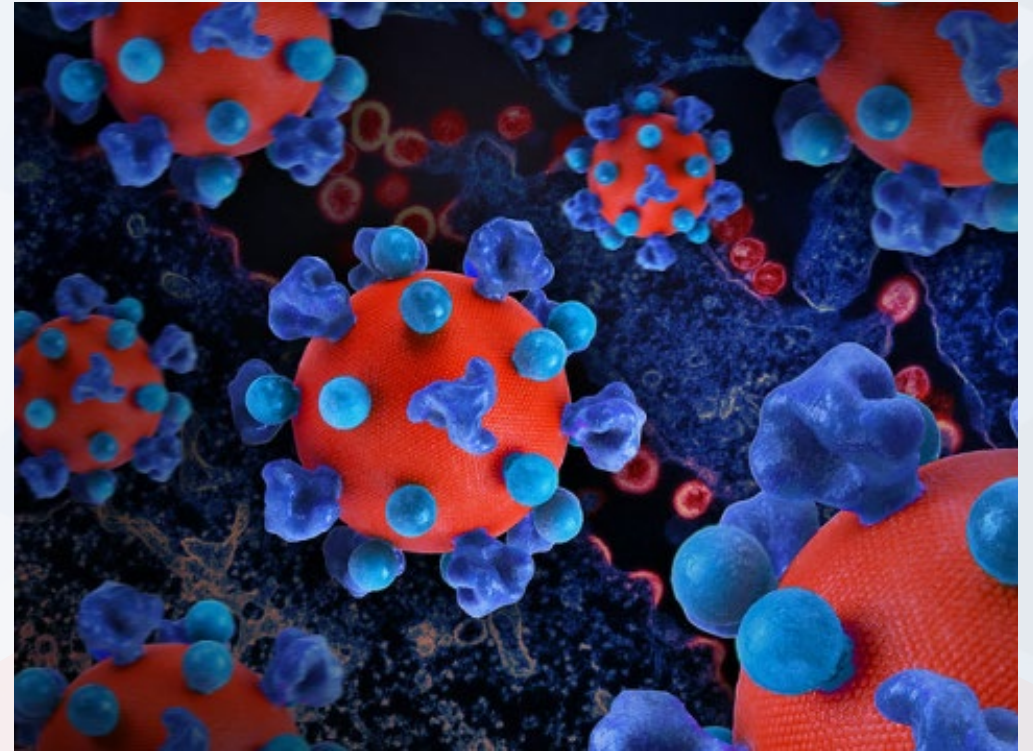
- Stages 7- 9 completed at a single visit
- Born with a virus
- Parent's HIV infection



Photo by Daniel Reche: <https://www.pexels.com/photo/person-s-tummy-and-hand-1556671/>

Stage 8: HIV

- Review of past concepts
- Inquire about the child's awareness of the name of the virus
- Name of the diagnosis is "HIV"



<https://www.flickr.com/photos/niaid/52536527476/>

Stage 9: Privacy and Confidentiality

- People who are HIV aware; people who are HIV unaware
- Negative response by those who are unaware/uneducated
- Identification of people with whom the child can discuss HIV
 - “inner circle”



Photo by Yaroslav Shuraev: <https://www.pexels.com/photo/person-whispering-near-the-woman-s-ear-5085562/>

Reassessment

- Follow up regarding acquired knowledge
- Explore emotional reaction; provide support and referrals as needed
 - Parent and child/adolescent
- Reassessment should occur routinely over time



Stage 10: Transmission

- Modes of transmission
- Prepares for future prevention of sexual transmission



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<https://www.pexels.com/photo/handing-out-blue-condom-6473745/>

Summary

- Disclosure should be a process, not a single event
- Coping with provider and caregiver hesitation
- Staged approach; led by caregiver input
- Preparation is key
 - Resources to support

Resources

Research developed comic for educational purposes (publicly available):

https://phacsstudy.org/cms_uploads/Health%20Education%20and%20Communication%20Documents/What_is_HIV.pdf

[Wright et al., 2017](#) – includes list of resources – peer-reviewed and not

Example Resource

VERY YOUNG 0 - 4 Years	YOUNG CHILD (Pre-school) 5 – 7 Years	SCHOOL CHILD 8 – 11 Years	SCHOOL CHILD 11 – 14 Years
<p style="text-align: center;">NO DISCLOSURE YET</p> <p>DEVELOPMENTAL LEVEL</p> <ul style="list-style-type: none"> Depends on adult for all needs and information Child needs comfort, support and most of all security <p>WHAT DO YOU EXPLAIN:</p> <ul style="list-style-type: none"> Carry on consultation with child present Child too young for direct information about HIV but explanations to caregiver about how HIV can affect the child remain important Provide ideas to help caregiver support child taking medicine Congratulate child on taking medicines well Address caregiver anxieties Build relationship with the child through play/singing Provide a safe and welcoming clinic <p>AIM BUILD UP CONFIDENCE of CHILD in HEALTH WORKERS and MEDICINE TAKING</p> <p><small>Compiled by Kinosh Naidoo (Department of Paediatrics - University of KwaZulu Natal), Diane Mhloni (Department of Psychology - Great Ormond Street Hospital for Sick Children) and Janet Houghton (Programme Director Child South Africa) Contact telephone: 031 260-4111/031 309 2217</small></p>	<p style="text-align: center;">EARLY DISCLOSURE</p> <p>DEVELOPMENTAL LEVEL</p> <ul style="list-style-type: none"> Can understand concrete based ideas e.g. real events in the present and past Thinking is based in the present Take the lead from confidence of caregiver interactions with health workers Beginning to link medicines and health <p>WHAT DO YOU EXPLAIN: Child needs to learn about illness but not HIV by name yet</p> <ul style="list-style-type: none"> Introduce ideas of good and bad health by eating healthy food, keeping clean, exercising, looking after teeth etc. Medicines help to keep a body healthy and strong Introduce infections as 'germs' that can hurt or damage the body/make you sick or hurt Introduce (white) blood cells as the part of the body that look for and kill infections or germs Some germs hide and you need to take medicines to help fight the germs <p>AIM UNDERSTANDING that MEDICINES SUPPORT the BODY to KEEP WELL</p>	<p style="text-align: center;">PARTIAL DISCLOSURE</p> <p>DEVELOPMENTAL LEVEL</p> <ul style="list-style-type: none"> Able to hold onto ideas and apply them to new situations Can understand past, present and future Has social and moral awareness about right & wrong behaviour Beginning to be more curious and take some control over their lives <p>WHAT DO YOU EXPLAIN:</p> <ul style="list-style-type: none"> Explain that the germ concerned is a virus Viruses are 'clever germs' which can damage white blood cells If medicines are not taken correctly, the virus can get stronger and stop the medicines working (resistance) Naming of virus as HIV may occur but not essential Need to explain that information is private and should only be shared with those agreed with the caregiver(s) Help the child identify who they can talk with about their health or HIV with Disclosure to symptomatic school age children is strongly encouraged <p>AIM NAMING of INFECTION as HIV VIRUS</p>	<p style="text-align: center;">FULL DISCLOSURE</p> <p>DEVELOPMENTAL LEVEL</p> <ul style="list-style-type: none"> More abstract thinking (understands future consequences of actions) Increasingly making decisions on their own regarding identity, independence, school, career Puberty/sexual development Dependence on caregivers decreases Importance of relationships with friends increases <p>WHAT DO YOU EXPLAIN:</p> <ul style="list-style-type: none"> Check understanding of health, medicines, sexual development and HIV infection Directly address young person during clinic consultations Need to understand responsibility for not transmitting HIV i.e. safer sex, and their rights i.e. family planning, confidentiality Preparation for future, encourage direct involvement in discussions and decisions Promote the benefits of attendance at adolescent support group <p>AIM FULL UNDERSTANDING and RIGHTS and RESPONSIBILITIES ABILITY to NEGOTIATE own HEALTH CARE</p>

<https://www0.sun.ac.za/southtosouth/toolkits/peads/Paediatric%20HIV%20Care%20and%20Treatment%20Toolkit.pdf>

Thank You! Questions?



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AETC Program National Centers and HIV Curriculum

- **National Coordinating Resource Center** – serves as the central web –based repository for AETC Program training and capacity building resources; its website includes a free virtual library with training and technical assistance materials, a program directory, and a calendar of trainings and other events. Learn more: <https://aidsetc.org/>
- **National Clinical Consultation Center** – provides free, peer-to-peer, expert advice for health professionals on HIV prevention, care, and treatment and related topics. Learn more: <https://nccc/ucsf.edu>
- **National HIV Curriculum** – provides ongoing, up –to-date HIV training and information for health professionals through a free, web –based curriculum; also provides free CME credits, CNE contact hours, CE contact hours, and maintenance of certification credits. Learn more: www.hiv.uw.edu