THE IMPORTANCE OF DISCLOSURE: TOOLS FOR PROVIDERS

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WHAT IS DISCLOSURE AND WHY DOES IT MATTER?

WHAT IS DISCLOSURE?

Definition of Disclosure:

Disclosure of HIV status is not a one-time event, but rather a process, involving ongoing discussions about the disease as the child or adolescent matures cognitively, socially, emotionally, and sexually.[1] Simply, disclosure refers to the child/adolescent gaining knowledge of their HIV status.[2]

Types of Disclosure:[1]

- Full disclosure – providing full information and knowledge of HIV
- Complete non-disclosure – maintaining secrecy of diagnosis; not providing any information about the diagnosis
- Accidental disclosure – child/adolescent is not prepared and disclosure is done unintentionally
- Deception – attributing diagnosis to a different illness or linking to child's behavior or appearance

Factors associated with HIV Status Disclosure[1,2]

- Age of disclosure – In general, children under age 9 are less likely to know their status
- Child's level of education/cognition
- Parent's/guardian's level of education
- Caregiver and patient readiness
- Child/adolescents adherence to treatment regimen
- Onset of sexual activity and ability to protect themselves and stay healthy

1. Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: weblink provided already. Accessed August 2022.
2. Panel on Antiretroviral Therapy and Medical Management of Children Living with HIV. Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection. Department of Health and Human Services. 2022. http://aidsinfo.nih.gov/contentfiles/lvguidelines/pediatricguidelines.pdf. Accessed August 2022.
3. Hayfron-Benjamin et al. BMC Pediatrics (2018) 18:365 https://doi.org/10.1186/s12887-018-1330-5 .

AT WHAT AGE SHOULD A CHILD KNOW THEIR STATUS AND WHY IS IT IMPORTANT?

WHAT AGE SHOULD DISCLOSURE OCCUR?

- Discussions should begin early in the patient's childhood, from the age of six with age appropriate information. The clinical team and caregivers should aim for full disclosure between the ages of 12-14 years of age.[1]
- WHO guidelines recommend that disclosure should start at age 6 and be completed by age 12[2]
- The process can take a few months when working with caregivers or parents for their child/adolescents developmental stage

Initiation of the disclosure process depends on:

- Caregiver's acknowledgment and acceptance of the child's or adolescent's disease
- Caregiver's readiness to disclose to the child or adolescent.
- Child's cognitive skills and emotional maturity (including ability to maintain confidentiality)
- Among children and adolescents with mild to moderate development delays, it is important to use language the child or adolescent will understand.
- Availability of adherence support
- Individualize plan for each child/adolescent
- Working with caregivers to develop a disclosure plan that meets the individual needs of the family and child/adolescent.
- Ensuring ongoing regular communications with the child or adolescent and their caregiver after disclosure.
- The disclosure process should not be rushed, but the timing of disclosure becomes more urgent closer to adolescence.

1. Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: weblink provided already. Accessed August 2022.
2. Bulali R, et al. International Journal of Pediatrics Volume 2018, Article ID 8058291, 10 pages https://doi.org/10.1155/2018/8058291

BENEFITS OF DISCLOSING TO CHILDREN

BENEFITS OF DISCLOSURE

For children and adolescents

- Feeling more in control of their health and body.
- Open involvement in medical care decisions.
- Allows for access to health education, SRH education, social support, and participation in adolescent peer support groups
- Improves psychosocial well-being and mental health. Improved self-esteem and fewer emotional difficulties.
- Better school focus and performance and less stress
- Improved adherence to ART
    - Significantly fewer missed ART doses compared with undisclosed children

For the Parents and Caregivers

- Relief, no need to maintain secrecy, and reconciliation or acceptance.
- Avoids accidental disclosure from occurring
- Ability to talk openly about the condition with the child or adolescent and others, and to provide support to the child.
- Better able to get treatment support for the child or adolescent at school and during changes in care (e.g., during holidays and with relatives).
- Potentially less behavioral problems with the child or adolescent

Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: weblink provided already. Accessed August 2022.

STEPS ON DISCLOSING TO CHILDREN

STAGES OF DISCLOSURE

- **Pre-disclosure:** HIV status has not been shared with the child
- **Partial disclosure:** Telling the child the truth, but not the entire truth; usually withholding the name of condition, in this case HIV.
- **Full disclosure:** Provides the child or adolescent with the name of the diagnosis and full information and knowledge about HIV.
- **Post-disclosure:** Period of time following disclosure, commonly referred to as early post-disclosure (first three to six months) and late post-disclosure (over six months) periods.
- **Complete non-disclosure:** Maintaining complete lack of knowledge around diagnoses and the child or adolescent are not told the truth about their illness.
- **Deception:** Attributes the child or adolescent's health condition to a different illness or links to their behavior for how they may appear. This is frequently coupled with nondisclosure.

Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: weblink provided already. Accessed August 2022.

CONSIDERATIONS FOR DISCLOSURE TO CHILDREN

- Do not rush the process. May involve several conversations.
- Gather as much information to support the child
- Support families decisions with timing and expectations
- Relax and create a positive conversation.
- Clear and age appropriate explanations of the disease and diagnosis
- Find a time that is free from interruptions
- Disclosure date should not coincide with other important life events such as birthdays, holidays, graduation, etc.
- Encourage questions and discuss feelings
- Use age appropriate educational materials

Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: weblink provided already. Accessed August 2022.

Talking with Your Children about Your HIV Status or Your Children's Status | The Well Project

CHALLENGES OF DISCLOSING TO CHILDREN

CHALLENGES AND BARRIERS TO DISCLOSURE

- Disclosure may lead to stigma and discrimination as well as rejection and in some instances violence against those living with HIV
- Negative impacts of disclosure include:
  - Emotional difficulty coping with diagnosis (sadness, anger, etc.)
  - Blame toward parents
  - Fear and worry about stigma both externally and internally
  - Withdrawal
  - Fear of death or shortened future
  - For adolescents with behaviorally acquired HIV, fear of revealing sexuality and rejection by peers and family

Health Facility Barriers	Community Barriers
• **No requirement of documentation of disclosure** • **Provider discomfort with handling disclosure** • **Lack of standardization and tools for disclosure** • **Need for individualized approach** • **Time constraints** • **Confidentiality** • **Limited support and resources**	• **Caregiver/family discomfort with disclosing** • **Belief that child is not ready or too young** • **Concern for child emotional/physical well being** • **Fear of consequences of disclosure including rejection** • **Stigma** • **Confidentiality concerns within community**

Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: weblink provided already. Accessed August 2022.

DISCLOSURE TO ADOLESCENTS

CONSIDERATIONS FOR DISCLOSURE TO ADOLESCENTS

- Adolescents living with HIV fall into two groups:
  - those who acquired HIV at birth and may be highly treatment experienced or
  - those who acquired HIV behaviorally in their teenage years
- Adolescence can be a time of social, biological, and physical change and a time at which young people start to take on adult roles and behaviors.
- All adolescents should know their status as a right given to them
- Ownership of own sexual and reproductive health
  - State specific laws related to partner notification
  - Prevention of HIV transmission

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THE 5 Cs AS PERTAINS TO ADOLESCENTS

Consent

- Parental or caregiver consent to disclose HIV status to their child or adolescent until they reach an age of maturity
- A behaviorally infected adolescent can give consent when relevant to disclose to family and friends

Confidentiality

- Ensure that this is a safe space and nothing discussed between the adolescent and provider should be shared without consent

Counseling

- Have a support system in place

Correct

- High quality testing services to ensure accurate test results

Care

- Linkage to care and follow up services including support and prevention services for HIV negative sexual partners

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ADOLESCENTS

ADOLESCENT DISCLOSURE TO SEXUAL PARTNERS

- Over 3 million youth (age 15-24) live with HIV globally[1]
- Disclosure to adolescent has shown to increase social support as well as improve adherence and overall outcomes.
- Disclosure of diagnosis to sexual partners remains a challenge, with reports from 33-43% having had disclosed[1,2]
  - Speaking to a provider about disclosure increased the odds of sharing status to partners among youth in South Africa[1]
  - Most common reasons for non-disclosure include not wanting partner to worry and fear of rejection
- Disclosure to partner does not correlate to increase condom use[1]
- In a US Study, among 98 perinatally infected youth in NYC, over half reported not disclosing to partners regardless of condom use[2]
  - Increased disclosure was associated with female sex, older age, earlier age of learning of diagnosis, STI knowledge, parent and child communication and disclosure intentions.

1.Kidman, R and Violari, A. AIDS Care. 2020 December ; 32(12): 1565–1572. doi:10.1080/09540121.2020.1736260.

2. Weintraub A, et al. AIDS Behav. 2017 January ; 21(1): 129–140. doi:10.1007/s10461-016-1337-6.

DISCLOSING STATUS TO OTHERS

HELPFUL RESOURCES

1. Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018. Available at: new_horizons_disclosure_toolkit.pdf (newhorizonshiv.com). Accessed August 2022.
2. Talking with Your Children about Your HIV Status or Your Children's Status | The Well Project
3. Mkumba et al. Reprod Health (2021) 18:219 https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-021-01269-7
4. Weintraub, et al. AIDS Behav. 2017 January ; 21(1): 129–140. https://link.springer.com/article/10.1007/s10461-016-1337-6
5. Kidman, R and Violari, A. AIDS Care. 2020 December ; 32(12): 1565–1572. https://doi.org/10.1080/09540121.2020.1736260
6. Bulali, R, Kibusi S, and Mpondo, B. International Journal of Pediatrics Volume 2018, Article ID 8058291, 10 pages https://doi.org/10.1155/2018/8058291
7. Hayfron-Benjamin et al. BMC Pediatrics (2018) 18:365. https://doi.org/10.1155/2018/8058291

Note: This is not an exhaustive list of all available resources.