

Disclosure of HIV Status to Children and Adolescents: When and How?

Introduction

Telling children and adolescents about their HIV infection is a challenging dilemma because children are often asymptomatic in the early stages of HIV yet require daily medications and close monitoring. This contradiction sparks questions and concerns in the minds of children at all ages. As their cognitive and emotional understandings of the world continue to develop with age, children's curiosity only increases. Plus with the advent of ART, children who are HIV positive are living longer into adulthood which allows for more consideration and inquiries about their undefined illness.

Several investigations have been carried out in the United States and Brazil, giving a broad spectrum of results and advice for when and how exactly to disclose an HIV status to a child, while research specific to India is sparse. The following is a brief review of the current medical and sociological literature through which several explanations and recommendations, albeit unique to that country's infrastructure, culture, economics, and religious influences, may be applicable to the current situation in India.

Statistics

- Studies from the United States in 1999 show that between 25% and 90% of HIV-infected school-age children have not been told about their infection (American Academy of Pediatrics)
- This wide range is likely due to the vast differences in family structure and support, cognitive and emotional development of the child, and availability of medical services.

When to Tell?

- Examples from studies of the pediatric cancer population indicate that children are cognizant of the serious nature of their illness and achieve a precocious understanding of their own mortality.
 - o Children may not be able to define exact terms but they remain aware of their surroundings
- Starting in early childhood, developmental models—cognitive, emotional, and psychological—support children's capacity for concepts such as illness, health, treatment, and death
- Some studies indicate that a child's cognitive and emotional understanding of illness and dying will correspond to his or her exposure to death
- One study showed few caregivers are willing to tell children younger than 5 years that their illness or infection is HIV or AIDS
- Another study documented that by age 14 years, most children learned their diagnosis as HIV positive → Many parents consider this age to coincide with maturity
- In 1999, the American Academy of Pediatrics strongly encouraged disclosing HIV positive status to school-aged children
 - o Areas not addressed include: exact age, circumstances for telling, and potential impact of disclosure

- Several studies and developmental specialists advocate the need to consider each child individually, and as such, a definite age or circumstance for disclosure should *not* be outlined

Parental Barriers

- HIV positive parents often feel shame or guilt for passing on their “illness,” the HIV virus with all its social and medical problems, to their children. As a result to decrease their own pain and suffering, they unconsciously or consciously avoid discussing HIV with their children.
- Denial is common, relating to parents’ own infection or the fact that their children are positive themselves
 - Parents feel uncomfortable to approach the topic
 - Children often respond by taking on the responsibility to emotionally support their parents
 - Children stop asking questions about their illness or ignore their illness to take the pressure off of their parents
- Parents want to protect children from social stigma of HIV
- Parents lack confidence in their children’s social filter. They worry young children will discuss their HIV status openly, innocently, regardless of social context. As a result, they will expose themselves to countless repercussions of an ignorant and judgmental society
 - One strategy is to demand that the child keep their HIV status a family secret
 - This often evokes feelings of shame, burden, and guilt within the child
 - Secrecy becomes a barrier to accessing supportive services from health care providers, family, and friends

Factors to Consider Before Disclosure

- CD4 count
 - Children who are more severely ill vs. asymptomatic
- Number of lifetime hospitalizations for the child
- Frequency of treatment and medication doses
- Major life events over the prior year
- Ability for bereavement and past experiences as such
- IQ
- Psychosocial maturity
- Cognitive development
- Transmission route
 - Research shows that different considerations must be taken when discussing perinatal transmission versus transmission through other means (blood transfusion or sexual abuse).
 - One study showed that nearly $\frac{3}{4}$ children were unaware of route of infection
 - Conclusion → It is not a critical part of the discussion for children
- Urban vs. rural setting
 - Children growing up in urban settings are often exposed to issues of sex and disease earlier than those in rural settings.

Age- Related Observations from Brazil Study

Children younger than 6 learn to accept taking medications and repress any questions

- The ominous symbol of some vague disease becomes the medications
- Very little discussion about the disease itself occurred within this age population
- Answers to questions were either:
 - o Authoritarian—"Don't ask and just take them." Or "Because you have to."
 - o Rhetorical—"Because everybody takes medications, don't they?"
 - o Vague—"So that you will feel better." or "So that you will heal."
- Biggest danger noted of withholding information is that eventually, children stopped asking questions

Seven to 9-year olds often had a negative perception of being sick, HIV, or AIDS

- This age group starts to interact with other children via school, where information received from different sources may be inaccurate or unreliable leading to greater confusion

Preadolescents face similar issues but they become more complex as they grasp the stigma-ridden perceptions of HIV of their communities

Adolescents revert and exhibit a poor understanding of the implications of HIV/AIDS for their lives

- They demonstrate an invincibility of adolescents, are irrationally fearless, and therefore may continue risky behaviors if not properly informed about HIV

Still, the final conclusion of study was:

- Disclosure is the wrong approach in perinatally acquired HIV infection.
 - o Such disclosure models are only valid for facing a new diagnosis
 - o Developmental illness (telling children more details as they actually become sick) is more promising for perinatal acquired HIV infection

Benefits of Disclosure ?

Several studies show that increased knowledge and understanding about HIV helps to:

- Facilitate children's adjustment
 - o Within the family
 - o To the illness itself
 - o Within society and its views
 - o To treatment regimens
- Boost self-esteem
- Increase adherence to medications, treatment regimens, doctor visits, and hospitalizations
- Decrease risky behaviors—sex without a condom, multiple partners, and intravenous drug use
- Builds stronger family ties to tackle more challenging issues in the future

Negative Consequences of Disclosure?

(Children learning their HIV Positive Status)

- Children must face their disease and its implications within society → They quickly learn the meaning of stigma
 - o "If the girl stays in school we're leaving [with our children]." Interview results from one study to highlight the academic and work pressures exerted on HIV positive families
 - o "Felt stigma" captures the subjective sense of sadness and judgment felt by the child due to societal misconceptions
 - o "Enacted stigma" explains the visible and apparent violation of human rights relating specifically to HIV positive individuals
- In one study, most children (26 of 35) reported stressful experiences due to learning their HIV status regardless of the disclosure patterns (how they were told)

Negative Consequences of withholding HIV Positive status from the youth?

(Children aware of some illness that remains undefined)

- Impaired understanding of HIV → Increases ignorance of HIV
- Poor health maintenance—personal hygiene, attending to doctor visits or hospitalizations
- Less participation in treatment
- Increased psychological and behavioral problems
- Decreased desire to access support services
- More complicated bereavement, difficulty dealing emotionally with illness, dying, and death
- Continuation of risky behaviors
 - o Most concerning!
- Lack of participation with community HIV prevention programs
- Children can concoct inaccurate and hurtful fantasies about their illness if not properly informed
- Silence about their illness isolate the child
 - o He or she stops asking questions
 - o Tries to access information from other sources that may be inaccurate or unsafe
- One study suggested that older children or developmentally advanced children can have answers to their questions of low self-esteem
 - o For example, HIV positive children often suffer from short stature as compared to their negative peers → This medical explanation may soften the impact of their negative body image
- Inadvertent disclosure, where children find out by overhearing conversations, from other individuals already privy to the information, or through self-discovery, can undermine the child's sense of trust in adults.
- Parents often use strategies of deception and lies (to protect their children from the truth about HIV). This may lead again to a lack of trust by children causing greater fear and anxiety.
 - o Negative consequences for healthcare providers—doctors, nurses, psychologists and social workers—who are already often feared by young children
 - o An untrusting atmosphere develops

- Another strategy by parents of treating HIV status as a family secret may confuse the child and bring about feelings of guilt or burden

Recommendations

To determine the proper time to disclose, one must assess:

- Caretakers' readiness to deal with situation
- Cognitive and emotional status of the child
- Family's communication style
- Community relationship
- Additional potential stressors

- Individualized approach
- Disclosure over time to allow slow processing and understanding, but be complete and answer all questions with each informational session
- Children's understanding of their illness does not start at a particular age but becomes *more sophisticated* with age
- Use simple explanations about the illness and their role (in the family, disease process, therapy regimens, etc.)
 - o They do not need to understand the specifics of the diagnosis, but its affect on their life and the illness manifestations
 - o One study emphasized that no child could accurately explained the mechanism of the HIV virus yet they knew they were sick in some way
 - o HIV+ children may be asymptomatic for many years, immediate full disclosure may not be necessary → partial disclosure as a KEY starting ground
- Emphasize how they can participate → Empower each child

As of 1999: American Academy of Pediatrics Recommendations

1. Counseling for parents and guardians by a knowledgeable health care professional about disclosure to the child of their infection status.
2. Disclosure should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances.
3. Younger children, if symptomatic with illness, discuss more immediate future. Do not need be informed of diagnosis, but the illness should be discussed.
4. The American Academy of Pediatrics strongly encourages disclosure of HIV infection status to school-age children. Symptomatic children, particularly those requiring hospitalization, should be informed of their HIV status.
5. Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behavior.
6. Adolescents also should be informed of their HIV status to make appropriate decisions about treatment and participation in clinical treatment trials. Physicians should also encourage adolescents to involve their parents in their care.

Program Model in Brooklyn, New York

- KATT (Kids and Teens Talk) support group started as a forum for children and adolescents to talk about their HIV status, concerns, struggles, and coping strategies

- KATT holds meetings for every member of the family—caregivers and children (between ages 9 and 12) meet separately but simultaneously for 1 hour. There is another special group for HIV negative siblings
- They use a multidisciplinary approach with psychologists, community counselor or social worker, and physicians if necessary

Cautions when Engaging the Youth

- Example of what **not** to say
 - o “You are responsible for your illness because you were not eating enough”
 - o “You are sick because you were bad”
 - o “You have HIV because you did not do your homework”
 - o “Got sick drinking cold milk," "by eating candies," "by scratching myself,"
 - These tactics are often used for secondary gains of pushing the child to eat more, behave properly, or participate in school or house work
 - Negative statements results in guilt, shame, and more confusion regarding HIV
- Examples of good explanations
 - o "I take pills so that my soldiers that are in my blood can be more efficient to fight microbes [bugs]."
 - o "I come to the hospital for regular visits to have my blood checked, to look at the good and the bad ones so that I don't get sick"

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