



DISCLOSURE TO CHILDREN



Session of objectives



- Why is disclosure important?
- What are the advantages of disclosure?
- What are disadvantages of non-disclosure?
- What should be considered before disclosing HIV status to a child?
- What support can we give to families as they disclose to their children?





Counseling & Disclosure Case Study 1



Anthony, a 12-year old HIV+ boy, attending the specialty clinic at UBTH Hospital, became eligible to obtain ARVs through the PEPFAR programme due to his repeated illnesses and his low CD4 cell count. Anthony's mother died before disclosing her own and Anthony's HIV+ sero-status to him.

Anthony now stays with his 16-year old brother James who does not accompany him to clinic, as he is in school himself. James is not aware of the cause of his mother's death nor of Anthony's HIV sero-status.



Case Study 1 (continued)



EXERCISE

1. How would you go about starting Anthony on treatment?
2. Describe an appropriate follow-up programme for these boys.



Case Study 2



A mother who has been bringing her vertically infected, 13-year-old daughter to your clinic for the last 2 years requests that you start her daughter on antiretroviral therapy. She consistently supports her daughter with proper nutrition, medication adherence support, and regular medical visits.





Case Study 2 (continued)



The mother does not want to disclose to her daughter the daughter's HIV status for fear of her daughter's judgment and possible anger towards her.

- What are some of the mother's fears about disclosing to her daughter?
- What would you do to help the mother gain confidence in disclosing?



Case Study 3



- The mother also fears that the daughter will tell other people in the community about her HIV status which will cause shame and ridicule to her daughter and their family.
- The mother says that she loves her daughter very much and would do anything to get her daughter on life-extending ARV treatment.



Case 3 (continued)



- What skills would you apply during the session?
- What are some of the important things that you as a counselor would discuss with the mother?





Why disclosure is important



- Data from several centres indicated 25% to 90% of school age children with HIV/AIDS are not disclosed to.
- Adolescents need to be informed about their illness to assist in their own care and reduce the risk of transmitting the infection to others through unprotected sex or drug abuse.



- Disclosure of chronic or terminal illness to paediatric patients can present many challenges to health professionals and parents/guardians alike.
- Pediatric oncology literature suggests that disclosing illness status can have *positive effects*, such as reduction of anxiety in both the child and parent/guardian, improved family functioning and long term gains in psychosocial adjustment.





- Disclosure of illness status to HIV infected children is somewhat different as *HIV/AIDS carries stigmas* that are not associated with cancer and other chronic diseases.





What keeps parents/caregivers from disclosing?



- Parent wants to protect child about illness and death
- Parent feels guilt and self-blame for transmitting disease to child
- Parent has low self-esteem and sense of competence
- Parent afraid of loss of privacy





Reasons why parents do not disclose to children



- Fear that the child will not be able to ‘keep the secret’
- Fear of stigma and discrimination if the child indiscriminately discloses his or her sero-status to the wrong people:
 - Possible loss of family/friends
 - Possible physical harm
- Concerns that the stress of diagnosis will have ill effects on the child’s health



Reasons for non-disclosure



- Fear that the child will be angry or 'hate' in cases of vertical transmission
- Fear that the child will ask difficult questions about transmission, death of their parents and their own
- Fear that it will affect the children's emotions.
- Fear that child may not cope



What happens if the child has been disclosed to by someone else?



- Failure to confide in the parents/care givers.
- Bitterness, anger, resentment.

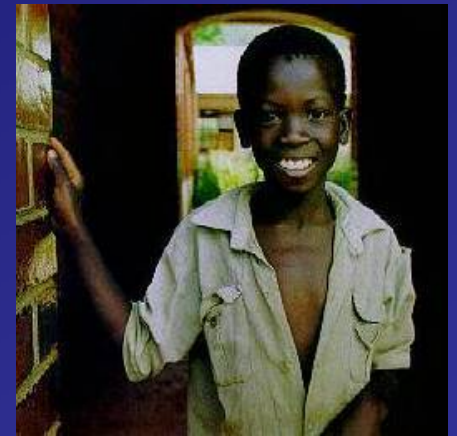




Advantages of disclosing



- Encourages open and honest relationships and teaches child about trust
- Helps child face reality and handle emotions
- Helps child behave more maturely and responsibly
- Instills pride in child that he/she is trusted with information





Advantages of disclosing



- Gives the child “permission” to talk openly about his diagnosis and prognosis
- Helps adolescents make responsible and informed decisions on treatment and risk behaviors
- Prevents accidental disclosures



Advantages of disclosing



- Gives child better coping skills after knowing the consequences of their illness
- Encourages the child/adolescent to participate in his/her own medical care
- Encourages higher self esteem than for those children who are not disclosed to.





Disadvantages of **not** disclosing



- Child isolates him/herself
- Child fails to get support or proper care
- Child loses self-esteem
- Child may transmit unknowingly





Impact of non-disclosure



- Non-disclosure can lead to depression, anxiety, and low self-esteem.
- Children who are not told of their status suffer from confusion, isolation, depression, and mistrust.
- Non-disclosure can deprive children of supportive care services such as participation in youth and/or peer support groups.





“Looking back, I realize that actually *telling* them the diagnosis was not nearly as difficult as having to keep it a secret.”



Things considered before disclosure



- Studies suggest that children who know their HIV status cope better with their illnesses.
- Consider child's age, psychosocial maturity, social circumstance to decide how and when to disclose.



Disclosure process...



- Establish trust and rapport
- Equip the parent with disclosure skills.
- Family is the most important partner in the disclosure process.
- Most of the clinician's work should be directed at working with the family.
- Remember: Parents know their children best.





Talking with the HIV positive child



- Be friendly, simple and direct.
- Try to read their emotions to see if they are aware.
- Ask “Why do you think you’re taking your medications?”
- Ask “Why do you think you come to see us?”





Talking with the HIV positive child



Find out

- What the child knows about HIV /AIDS
- Who disclosed to the child
- What exactly was told to the child

- Check child's understanding of the content
- Dispel any myths the child may have
- Readdress topic over a period of time
- Give continued help and support



Talking with the HIV positive adolescent



- Do you know your HIV status?
- What is it?
- When were you told that you were HIV+?
- Who first told you your blood test result?

Ask about, age, date, events, e.g. death of a loved one, etc. that may have led to the child's suspicion about his/her sero-status



Talking with the HIV positive adolescent



- What led you to suspect that you have HIV infection (e.g. death of a parent)?
- How did you feel when you suspected you had HIV?
- How did you feel when you learned you had HIV?
- What did the person who informed you of HIV infection tell you about how you got the infection?
- Who have you told about your HIV infection?



Talking with the HIV positive adolescent



- If you had a choice, who would you have liked to tell you about your infection?
- Why do you think the person you chose is the best person?



Possible feelings after disclosure



- Shock
- Anger
- Sadness/Depression
- Embarrassment
- Fear
- Confusion
- Loss
- Rejection, Isolation





The feelings a child might experience after disclosure are not different from adults'; they are also human beings.





Helping children cope with disclosure



- Start where the patient is
- Address basic needs first
- Problem-solve with patient
- Empower
- Be creative - use a story





Helping children cope with disclosure



- Give hope to child that they can live a healthy life if they take the medication
- Help patient visualize future success
- Help patient take one step at a time
- Allow silence
- Encourage and comfort



Coping Skills



- Do you ever become afraid since learning your sero-status? If so, what do you do when you feel this way?
- What do you do when you feel very sad because of your illness?
- What do you do when you feel too sick to go out?
- What do you do when you feel too sick to go to school?



SUMMARY.



- Children need to know their status so they can cope with illness, take an active role in treatment, and protect against transmission.
- Children who know their status have more confidence and better self-esteem than children who aren't disclosed to.
- Care providers can work with parents/guardians so they can gain skills to disclose to their children.



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- THANK YOU FOR YOUR ATTENTION