Challenges and achievements in HIV Disclosure for children in MSF France Mathare program in Kenya

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Background


- In the paediatric HIV positive population, only 2% of caregivers tell their children of his/her HIV status.

- We explore the attitudes of caregivers towards HIV disclosure.
Methods

- Between Septembers to December 2008, caregivers that had not disclosed HIV diagnosis to their children were flagged and were reminded and assisted by the counsellors to do so.

- The patients’ files of the children coming to the HIV clinic in that period of time were reviewed.
In this case, disclosure of HIV status
Why is disclosure Important

• Issues regarding when and how to tell pediatrics patients of their diagnoses in cases of serious chronic or terminal illness can present many challenges to health professional and parents/guardians alike.

• Literature in the field of pediatrics oncology suggest that disclosing illness status can have positive effects such as reduction of anxiety in both the child and parent/guardian.
Continues

- Improves family functioning and long term gains in psychosocial adjustment

- Greater ability to cope and provide support to each other especially as the disease progresses

- Adolescent 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
Key findings

- Of the 357 active children in the program, 73 (20%) are children between the ages of 1 to 5 years.

- 145 (41%) are children between 6 to 10 years.

- 122 (34%) are children between 11 to 15 years.

- 17 (5%) children were at the age of 16 to 17 years.
Continues

• Sixty-two (43%) children of the ages of 6 to 10 years with the assistance of the counsellors were started on partial disclosure.

• 18 (15%) of ages 11 to 15 were started on the same.

• A total number of 136 (38%) children out of 357 had been assisted to fully be aware of their HIV Status.
Case studies

• Disclosure of HIV status to children
Accidental Disclosure: Case 1

**Kaingu**

13 year old male, mother not tested

**Disclosure**

at the Pharmacy

**Reaction**

anger, refused to take drugs, wept bitterly

**Feelings**

betrayed by mother
Accidental Disclosure: Case 2

- **Angle**: 13 year old female, mother died
- **Disclosure**: Doctor's room
- **Reaction**: painfully sobbing
Planned Disclosure: Case 1

- **M.K** 10 year old male, mother died of AIDS, Suspicious but in fear & denial
- **Counselling** M.K taken through pre-test counselling, tested and post-test counselling & disclosure
- **Reaction** M.K delayed expression of feelings, act strongly to protect mother
- **Post Disclosure** seeing trained child counsellor.
Planned Disclosure: Case 2

- **Betty** 13 year old female, mother died
- **Counselling** Betty introduced to issues of her illness, requested to think about them. Went for pre-test counselling after 3 weeks
- **Reactions** Betty wept a lot, bitter with aunties but very grateful to the counsellor
- **Post Disclosure** Well adjusted
Reasons Why parents did not disclose to children

• Fear that the child will not keep secret

• Fear that the child and the family will suffer from discrimination and possible physical harm if the child indiscriminately discloses

• Fear that the Child will ask difficult questions

• Concerns that the stress of diagnosis will have ill effects on the child’s health
Observed Impact in non-disclosure Children

- Children that were not disclosed of their HIV status suffered from confusion, isolation, depression and mistrust.

- Non-disclosure can also deprive HIV Positive Children of supportive care services available to their counterparts who know their sero-status e.g. participation in youth and Peer support groups.
Recommendations

- There is a need to help and train caregivers especially counsellors, parents and children prepare for HIV disclosure.

- Parents intended to disclose HIV diagnosis to their children but have poor preparation and knowledge on the issue.
Acknowledgements

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Thank you for listening