

# Healthcare Professionals' Perspectives on HIV disclosure of a Parent's and a Child's Illness in Kenya

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# Conflicts of Interest

**Grace Gachanja: None to declare**

**Gary J Burkholder: None to declare**

**Aimee Ferraro: None to declare**

# HIV Statistics

- In Kenya, there are 1.4 million adults living with the disease with a prevalence of 5.6% among adults aged 15-64 years (National AIDS and STI Control Programme, 2014)
- There are 200,000 children aged 18 months to 14 years living with the disease with a prevalence of 0.9% (National AIDS and STI Control Programme, 2014)
- Prevalence is expected to keep rising in the decades to come due to increased accessibility to antiretroviral therapy (ART: National AIDS and STI Control Programme, 2014)
- The rising HIV prevalence will lead to an increased need for disclosure within HIV-affected families

# Background

- In Kenya (and elsewhere), parents and healthcare professionals do not always agree on if, when, and how to disclose to children (Gachanja, Burkholder, & Ferraro, 2014a; Gachanja, Burkholder, & Ferraro, 2014b; Klitzman, Marhefka, Mellins, & Wiener, 2008)
- Parents are known to delay disclosure to their HIV-positive and negative children for lengthy periods of time (Gachanja et al., 2014a; Gachanja et al., 2014b; Madiba, 2012)
- On the other hand, healthcare professionals prefer children (especially HIV-positive children) receive timely disclosure (Watermeyer, 2013)
- Additionally, different healthcare professions differ on how disclosure should be approached to children (Watermeyer, 2013)

# Background

- Prior researchers, healthcare professionals, and HIV-positive parents have called for guidelines to ease the challenges of HIV disclosure (Gachanja et al., 2014a; Gachanja et al., 2014b; John-Stewart et al., 2013; Turissini et al., 2013)
- Lack of country-specific or culturally-appropriate HIV disclosure guidelines, as well as poor or nonexistent healthcare professional training on HIV disclosure, impedes disclosure delivery from parents to children (Kallem, Renner, Ghebremichael, & Paintsil, 2011; Madiba & Mokgatle, 2015)
- These factors add to the complexity of HIV disclosure to children
- However, there are generic HIV disclosure guidelines available from WHO (2011). It is unclear if healthcare professionals are aware of or use these guidelines

# Methods: Recruitment

- The study was conducted in Nairobi, Kenya at the Kenyatta National Hospital Comprehensive Care Center
- Healthcare professionals who provide healthcare and disclosure-related services/advice to HIV-positive parents and their children were purposively recruited into the study
- Prospective participants were approached during regular business hours within their working areas at the clinic for participation in the study
- The healthcare professionals included a medical doctor, clinical officer (equivalent of a physician assistant in the US), clinical psychologist, registered nurse, social worker, and a peer educator

# Methods: Data Collection

- Each healthcare professional underwent an individualized semi-structured in-depth interview conducted by the first author; interviews lasted 39-90 minutes
- Interview guide questions explored various aspects of the HIV disclosure process including:
  - Healthcare professionals' role in the HIV disclosure process
  - How disclosure should be approached
  - When should children receive disclosure
  - Who should disclose to children
  - What is the appropriate timing and setting for disclosure
  - Benefits, consequences, emotional, and psychological aspects of disclosure
  - Services/programs available or needed by HIV-affected families going through the disclosure process

# Methods: Data Analysis

- Recorded interviews were transcribed and coded by the first author and two university students assistants
- NVivo 8 qualitative analysis software was utilized for data analysis using the modified Van Kaam method (Moustakas, 1994)
- Codes and themes were cross-checked by the last two authors
- Five themes emerged which included
  - Barriers to disclosure
  - Timing of disclosure
  - Benefits of disclosure
  - Consequences of disclosure
  - Disclosure-related services required by HIV-affected families during the disclosure process



# Results: Barriers for Disclosure

The following parental factors deter disclosure:

- Married/cohabiting parents who disagree on timing of disclosure; Kenya is a patriarchal society
- If infidelity led to infection, or presence of a serodiscordant relationship
- Parents have not accepted their own illnesses
- Parental fear of blame, judgement/losing face, stigma, discrimination, rejection, or fielding questions from the child about the illness
- Parental fears that child will tell others, become depressed, suicidal, or show decline in school performance post-disclosure
- Parental feelings of embarrassment, guilt, and shame for bringing the illness into the home and infecting the child
- Parental avoidance of disclosure due to feelings of discomfort speaking about the illness, or feelings of incapability/inability to disclose

# Results: Barriers for Disclosure

The following child factors deter disclosure:

- A recent diagnosis
- Child is the only one infected among his or her siblings, or both parents are HIV-negative
- Child is too young and at an age unsuitable for disclosure or is unable to keep secrets
- Child is immature, has slow development, or is deemed by parents not to have high enough intelligence to understand the illness
- Child is known to have a high temper or is easily emotional
- Child is healthy and faring well; parents do not want to rock the boat

# Results: Barriers for Disclosure

The following family factors deter disclosure:

- Family has many HIV-positive members and parents do not know how to start/proceed with disclosure
- Recent or prior undisclosed deaths in the family; child may be unaware that they live with a stepparent or other relative presumed to be a parent
- Unresolved issues such as family conflicts, domestic abuse, and sexual abuse that may have led to the child's infection
- Poor inter-family relationships and/or parents are not close to their children
- Family members do not currently support each other; disclosure will not go well until issues are resolved

# Results: Timing of Disclosure

The timing of HIV disclosure is multifactorial and is based on:

- Parental consent should be present before disclosure occurs to children
- Additionally, both the parent and child need to be prepared and ready for disclosure to occur
- Disclosure is a gradual process that starts at time of parental and/or child diagnosis.
- The gradual process is challenging for children diagnosed late or those who are not regularly seen by a healthcare provider (e.g., missed clinic visits)
- A gradual process is preferable, because it makes illness acceptance easier, and a gradual disclosure process reduces child-associated shock, denial, and withdrawal
- Preferably start gradual process at 7 years and provide increasing bits of information over time

# Results: Timing of Disclosure

- The information provided (e.g., germs/bacteria, chronic illness, virus, then HIV) is based on the child's age, understanding level (occurs at 10 years), and maturity level (occurs at 14 years)
- Disclosure information provided should preferably correspond to classroom lessons
- The aim is to fully disclose between 10-14 years; one professional provided an age of 16 years. Parents need to stay within timeline and bring their children for counseling as decided upon
- Children asking questions (e.g., health status, ART consumption, clinic attendance) are evaluated for their understanding level and capability to absorb full disclosure
- If child is judged as not being ready for full disclosure, age-appropriate disease-related information is provided

# Results: Timing of Disclosure

- Other considerations for disclosure include parental and child health status; preferably disclose when both are in good health
- Disclosure permissible to oldest children if parent is dying or child's health is deteriorating due to poor ART adherence
- Important life events (e.g., major exams, holidays) and family issues/problems also need to be considered
- The clinical officer, social worker, and registered nurse preferred trained professionals to disclose to children in the presence of the parent at the clinic. The physician, psychologist, and peer educator preferred the parent to disclose to the child at home; the psychologist and peer educator also advised if the parent was unable, then a healthcare professional should disclose to the child
- Consensus is that there is no absolute right time, but healthcare professionals are able to assist parents with selecting the appropriate time and setting for disclosure to the child

# Results: Benefits of Disclosure

To disclose to children in a timely manner, healthcare professionals stated that they advised parents of the following HIV disclosure benefits:

- Disclosure helps stop lies to children about theirs or their parents' health status, especially if it becomes inevitable (e.g., child is asking too many questions, has poor ART adherence, appears depressed/withdrawn, his/her lab results are deteriorating, or the parent's/child's health is deteriorating)
- Family members will be able to morally and physically support each other
- There is increased ART adherence due to ability to take medications and attend clinic visits freely; this is important for infected family members' health statuses
- Disclosure provides an opportunity to teach children about the illness while also providing sex education; children are sexually active at young ages (9 years and up)

# Results: Benefits of Disclosure

- **Specific benefits for children include:**
  - ❖ **HIV-positive children:** avoid spreading the illness to others, protect themselves from re-infection and/or opportunistic infections, and they have increased/improved self-care, independence, and adherence to ART
  - ❖ **HIV-negative children:** protect themselves from infection, provide support to their parents and infected siblings by acting as treatment buddies, and they show reduced or no stigma to others
- **Disclosure frees parents from close supervision of older HIV-positive children's ART consumption and care; older children can assist with adherence**
- **Disclosure encourages acceptance of illness and living positively**
- **Disclosure prepares children who are going to boarding school to be self-independent**



# Results: Benefits of Disclosure

- Disclosure followed by regular education on the illness encourages children that they or their parents can live for a long time
- Disclosure helps prepare children (especially older ones) for parental death, property inheritance, and future eventualities; there's an opportunity to tell children who will care for them in case parents die
- Disclosure frees parents from the burden of keeping theirs and/or their children's illnesses a secret
- It is possible for healthcare professionals to inadvertently disclose to children. Therefore, disclosure frees healthcare professionals to provide appropriate care and advice to children, and answer their questions with the correct age-appropriate answers

# Results: Effects/Consequences of Disclosure

Healthcare professionals stated that they advised or had seen the following disclosure consequences occur for parents:

- Loss of face and hatred from children
- Having to deal with rebellious, disrespectful, disobedient behavior from children especially if the child is able to guess which parent brought the infection into the home
- Increased worry and anxiety about the child's psychological health and school performance post disclosure, especially if the child did not receive disclosure well
- Increased worry and anxiety that child will tell others outside the home about the illness and expose the family to stigma
- Discomfort from persistent child questions about the illness, its origin, length of medication consumption, and possible cure or death
- Family separations, divorce, some children run away from home

# Results: Effects/Consequences of Disclosure

**The consequences of disclosure for HIV-positive children include:**

- Impact of disclosure is more profound with increasing child age
- Increased thoughts of death and the illness
- Blame, hate, and anger at parents for not being told sooner or being lied to, rebellion, acting out behaviors, disobedience, poor adherence, some run away
- Self-stigma/isolation, depression, withdrawal, poor school performance or failure of examinations

**Consequences for HIV-negative children include:**

- Increased thoughts of parental death and the illness
- Fear of infection from parent or infecting parent with an opportunistic infection
- Adoption of more responsibility around the house

# Results: Disclosure-related Services

Healthcare professionals stated they provide the following services to HIV-affected families:

- Parents need disclosure-related advice and counseling to be able to navigate the disclosure process. It doesn't get easier with subsequent siblings, each child is treated individually
- As such, healthcare professionals provide regular counseling to parents and children during clinic visits
- When a child is identified as being ready, a disclosure plan is created by the psychologists. Parents and children then attend individualized sessions with trained counselors
- Support groups are also available for parents and HIV-positive children; the children are divided based on age and disclosure levels
- Home visits are provided as appropriate or needed by social workers and/or peer educators

# Results: Disclosure-related Services

- Healthcare professionals were adamant that disclosure-related services be continued pre, during, and post-disclosure. These services included:
  - ❖ Regular counseling
  - ❖ Support groups
  - ❖ Continuous education on the illness
  - ❖ Empowerment training and adoption of positive living
  - ❖ Various forms of support (adherence, social, moral, psychological, physical)
  - ❖ Family therapy and counseling
  - ❖ Referral to other support organizations as needed (e.g., mental health services, nutritional counseling, assistance with non ART prescriptions, etc.)
- Healthcare professionals also advised that other organizations should be involved with disclosure as appropriate and needed. These included religious organizations, AIDS service organizations, schools/teachers, and international non-profit organizations

# Policy Implications

- HIV disclosure is challenging, but guidelines are available from WHO (2011). Healthcare professionals need to be made aware of their existence
- These guidelines should be used to train healthcare professionals working with HIV-affected families
- Disclosure-related training should also be provided to healthcare professionals on a regular basis
- Unless action is taken, disclosure to children will continue to occur at an untimely pace that exposes them to adverse outcomes
- Studies are needed that help find innovative ways to increase HIV-positive parents' desire and capability to disclose to their children in a timely manner
- These studies should be discussed with and planned with HIV-affected family members and peer educators

# Conclusion

- **Disclosure is challenging even for trained and experienced HIV counselors**
- **There is no perfect way on how to do it, and timing is based on the parent's consent and ability to proceed with disclosure**
- **Healthcare professionals are unable to intervene until parental consent is obtained**
- **Uncertainty about the process is sure to continue for years to come and there is no clear solution on how to assure timely disclosure to children.....**

# Conclusion

**“Disclosure is a controversy in our house between I and my wife. I know I have much information on HIV and I would really want my children to be tested but when I bring this discussion in the family, my wife is not free herself yet. That is why we have not even disclosed to them. As much as I would want to disclose, the mother would not want to disclose, and at a given time we have even gone for counseling so that we could discuss this. She was like I am not ready to disclose to my children my status... As much as I have educated people and some I have disclosed to but uh, it is a, it is a difficult story. This is why at a given time we always tell even our colleagues, counselors, and other people that who are caring for us? We also need counseling services.” Peer educator**



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# Questions



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# Quotes From the Five Themes

# Quotes From the Barriers for Disclosure Theme

**“If the child is too ill, they don’t need to be told, if there have just gone through a traumatic experience they don’t need to be told, if they are suicidal, they have other conditions, if there is history of depression in the family, or they don’t have support then we can wait. If both parents are negative, or the child has gone through some molestation or some abuse or some violent experience, we need to wait.”** Psychologist

**“I think it is more of the fear, fear of rejection, the fear of stigmatization by the child, they feel embarrassed, they feel ashamed. Coz so far most people relate HIV to a promiscuous life. So they are thinking if I tell my child, my child will think of me this way and that way and those are the sort of things they are trying to avoid.”**  
Physician

# Quotes From the Timing of Disclosure Theme

**“We have six months or even more coz it still depends. Once you want to disclose to a child you know you really depend on the parent’s consent, so if the parent has not consented yet, you don’t want to push. You don’t want to just tell the child, that is infringing onto their rights also. For a child also you want to gauge, what do they understand, what is their developmental status at that particular moment, are they ready for that information or not.”**

**Psychologist**

**“I would say by 12 you can tell them everything involved but you can start at 10. You see I tend to believe that taking them through the gradual process is not disclosing the information directly but taking the children through information on HIV. If you start from the information then gradually you take them until you will disclose your status and that's the gradual process I would recommend. Tell them what HIV does and how HIV is transmitted, how people get HIV, how to look at that information, that kind of process until it will come a time at 12 years you can now tell the child all the stories I have been telling you all along is, you now disclose the status.”** Peer educator

# Quotes From the Benefits of Disclosure Theme

**“It is better for them to know so that they can take care of themselves. So that they don’t have, or start those risky behaviors which will endanger the others who don’t have HIV. They will know at that early age to take care of themselves and to avoid any risky behavior which will expose them in getting other opportunistic infections like STIs or infecting others.” Registered nurse**

**“I think it is important for children to know their parents have the disease. When they are mature enough is when they can be told so that they should be aware that mummy and daddy maybe one day or time they will not be there, so that they can cope by themselves and take care of themselves.” Social worker**



# Quotes From the Effects/Consequences of Disclosure Theme

“The consequences are being arrogant or even being unruly. Boys tends to be more unruly, girls it’s like they kind of do it in hiding, they don’t show it, but boys openly do it. This is a kid who was very obedient to the parent, he was good in class, you get? That goes out of the way now, he can’t listen to the parents anymore. I don’t know if it is because of the hatred they have, now they start associating themselves with the bad group, what’s called the bad group in the society, those who want to do the bad things. They may even try smoking.” Clinical officer

“The consequences that I have seen is about stigma because when they have understood what HIV is and how it is contracted, they associate it with risky behavior for contracting HIV. If we go to where they stay, it is mostly related to stigmatization, they think if they share or they come closer they will also get HIV, even if it's not the right route for getting HIV.” Peer educator

# Quotes From the Disclosure-related Services Theme

**“They need counseling services, that is one. Two, we have support groups and these support groups we need to refer some of these children or some of these families into support groups where we will build their coping mechanisms into terms. Three we need some more home visits, conduct more home visits to build the relationships between the children and their ailing parents because now they have known yeah bring them up in that kind of family so that they can be able to understand more of their parents and this will also build up their coping mechanisms and how to understand their parents further yes. Finally is to give that family support, what I mean by family support is to give the maximum support into that family, all support we can be able to necessarily give them maybe financial, maybe moral, maybe spiritual, all that kind of support we need to give them so that they can be able to cope to come into terms.” Peer educator**