HIV disclosure perspectives from HIV-positive parents, HIV-positive children, and HIV-negative children

Grace Gachanja, Gary J Burkholder, Aimee Ferraro

The aim of this research brief is to describe a study that examined the lived experiences of HIV-positive parents and their biological HIV-positive and negative children before, during, and after the HIV disclosure process in Kenya. This is the first study from Sub-Saharan Africa (SSA) that provides perspectives on HIV disclosure of a parent's and a child's illness from the viewpoints of HIV-positive parents, HIV-positive children, and HIV-negative children. Prior studies in SSA have mostly centered on disclosure to HIV-positive children (of their own illnesses) and others have reported on parents disclosing their illnesses to their children. Key Aspects of HIV Disclosure to Children: 1. Disclosure should be performed as a process. 2. It is a parent's decision on when to disclose but also a child's right to be told about his/her own, a parent's, and other family member's illnesses and deaths. 3. Healthcare professionals should help parents prepare for and disclose family member's illnesses and prior deaths to their children. 4. Disclosure should preferably be performed when both the parent and child are in good health. 5. Disclosure should be performed when a child shows understanding of the illness and/or maturity. 6. Disclosure planning should include a determination of who is the most suitable person to disclose to a child. 7. Disclosure should be postponed until animportant life event (e.g., taking a national school examination) has occurred. The original research article is located at: https://peerj.com/articles/486.pdf

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Walden University

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Research Brief

Grace Gachanja,
Gary Burkholder,
Aimee Ferraro.
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Grace Gachanja,[1,2] PhD, MPH, RN

Gary J. Burkholder,[2,3,4] PhD

Aimee Ferraro,[2] PhD, MPH

1. g_gachanja@hotmail.com

2. College of Health Sciences, Walden University, Minneapolis, MN, USA

3. College of Social and Behavioral Sciences, Walden University, Minneapolis, MN, USA

4. Laureate Education, Inc., Baltimore, MD, USA

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AIM

The aim of this research brief is to describe a study that examined the lived experiences of HIV-positive parents and their HIV-positive and negative children before, during, and after the HIV disclosure process in Kenya. This is the first study from Sub-Saharan Africa (SSA) that provides perspectives on HIV disclosure from the viewpoint of HIV-positive parents, HIV-positive children, and HIV-negative children. Prior studies in SSA have mostly centered on disclosure to HIV-positive children (of their own illnesses) and others have reported on parents disclosing their illnesses to their children.

Key Aspects of HIV Disclosure to Children:

1. ***Disclosure should be performed as a process.***
2. ***It is a parent's decision on when to disclose but also a child's right to be told about his/her own and other family member's illnesses.***
3. ***Healthcare professionals should help parents prepare for and disclose family member's illnesses and prior deaths to their children.***
4. ***Disclosure should preferably be performed when both the parent and child are in good health.***
5. ***Disclosure should be performed when a child understanding of the illness and/or maturity.***
6. ***Disclosure planning should include a determination of who is the most suitable person to disclose to a child.***
7. ***Disclosure should be postponed until an important life event (e.g., taking a national school examination) has occurred.***

BACKGROUND

As of 2012, 35 million persons were infected with human immunodeficiency virus (HIV) globally (UNAIDS, 2013); 90% lived in SSA. Kenya has 1.4 million adults and 200,000 children living with the illness (NACC and NASCOP, 2012). HIV prevalence is expected to increase as infected persons live longer due to increased availability of antiretroviral therapy (ART: NACC and NASCOP, 2012). Self-disclosure of illness benefits the HIV-positive person by improving physical and psychological health status, and lowering stress levels (Collins & Miller, 1994). HIV-positive parents in SSA are challenged with disclosure to their children but consider it to be very important (Brown et al., 2011; Kallem et al., 2011; Madiba & Matlala, 2012; Vaz et al., 2008).

PROCESS

Participants for the study were recruited at the Comprehensive Care Center located within Kenyatta National Hospital in Nairobi, Kenya. We interviewed

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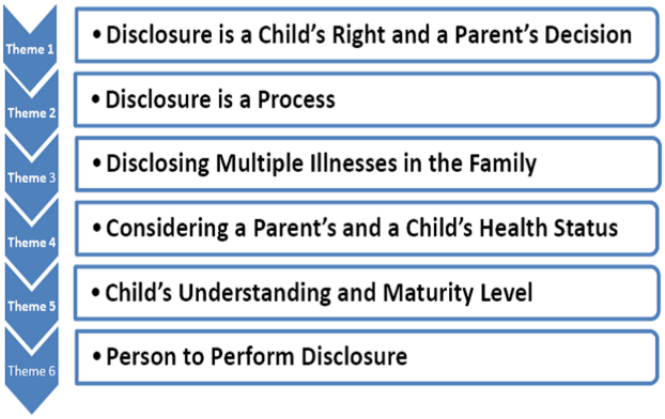
16 HIV-positive parents, 7 HIV-positive children, and 5 HIV-negative children between December 2011 and January 2012. The parents were aged between 30-54 years of age; and HIV-positive and negative children were between 12-17 years of age. During interviews, parents were asked how they had prepared for and disclosed to their children, and their recommendations on how parents approach disclosure to children. Children were asked when and how they had received disclosure, and their recommendations on how parents should disclose to children.

FINDINGS

Nine parents had disclosed a parent's illness to at least one child in their household. Eight parents had disclosed a child's illness to at least one HIV-positive child in the household. Only six parents had disclosed both a parent's and a child's illness to a child in the household. Six HIV-positive children were fully aware of their illnesses; one knew he had tuberculosis. Three HIV-negative children were fully aware of their parents' illnesses; two knew their mother had chronic backache. Participants' perspectives on how disclosure be performed to children are displayed in the following figure and further described below.



1. **Disclosure is a child's right and a parent's decision:** Parents thought it was a child's right to be fully disclosed to, but most expressed they needed help from healthcare professionals (HCPs) to prepare for disclosure. However, they wanted to be the ones making the decision on when to disclose to their children. HIV-positive children desired disclosure so they could take better care of themselves, while HIV-negative children wanted to be disclosed to so they could take measures to protect themselves from becoming infected.

   Recommendations: Provide disclosure-related training to HCPs who work with HIV-positive parents so they can better guide parents during the disclosure process. Encourage parents to fully disclose to children because children desire timely disclosure.

2. **Disclosure is a process:** All participants favored disclosure as a process delivered over time. Each child was to be prepared individually. When delivered as a process, children accepted the news better, did not forget what they had been told, and experienced less psychological impact.

   Recommendations: HCPs should encourage parents to prepare for and disclose to their children over time. HCPs should work with HIV-positive parents to create a targeted family oriented plan aimed at helping parents sequentially disclose to each child within the family.

3. **The decision to disclose multiple illnesses and deaths in the family is complex and involves**

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many considerations: Many families represented in our study sample had several infected family members and/or prior deaths from the illness. Parents preferred to fully disclose all family members' illnesses and prior deaths sequentially to their children based on birth order. Children agreed and expressed they desired timely disclosure of all illnesses and deaths in the family. However, those who received disclosure of many illnesses/deaths at the same time were impacted by the news.

Recommendations: HIV-positive parents with many infected family members and prior death need services and programs (e.g., disclosure training, counseling, support groups) to help them disclose to their children. Children need pre, during, and post disclosure services and programs (e.g., counseling, support groups) to increase their resiliency and capability to absorb the news. Children who receive disclosure of many family members' illnesses and deaths should be followed up until they are faring well.

4. To prevent psychological harm, disclosure to a child should not occur when the parent and/or child is unwell: Parents advised that disclosure of illness be done when a parent and child were in good health. Parents did not want to disclose their illness when they were in poor health unless a parent needed help around the house or a child to pick up ART at the clinic. Parents also advised against disclosing to a HIV-positive child in poor health unless it was related to poor ART adherence. Disclosing to this child would be prudent to boost adherence.

Recommendations: provide support programs (e.g., social worker and peer visits to help around the house) for parents in poor health so that disclosure is postponed until the parent is feeling better. Provide frequent adherence training and support programs for HIV-positive children so they remain compliant with ART consumption. Encourage postponement of disclosure until child is faring better.

5. The maturity and understanding level of a child is an important consideration in the disclosure process: All participants favored disclosure as a process starting at 5 years with increasing information provided over time. Parents expressed children were initiating sexual activity as early as 9 years; children agreed their teenage peers were having sex due to peer pressure. Participants felt children were capable of being fully disclosed to between 10-14 years of age when they were capable of understanding the illness and/or mature enough to receive disclosure. Disclosure within these years helped children learn about the disease and the danger of having unprotected sex (e.g., spread to others by HIV-positive children or acquiring infection by HIV-negative children). Also, participants advised children be allowed to take their final national primary school examination (taken at 13-14 years) before receiving disclosure. Some parents expressed they delayed disclosure for years because of conflicting advice provided by HCPs on if and when to proceed.

Recommendations: HCPs should advocate disclosure as a process starting at 5 years and

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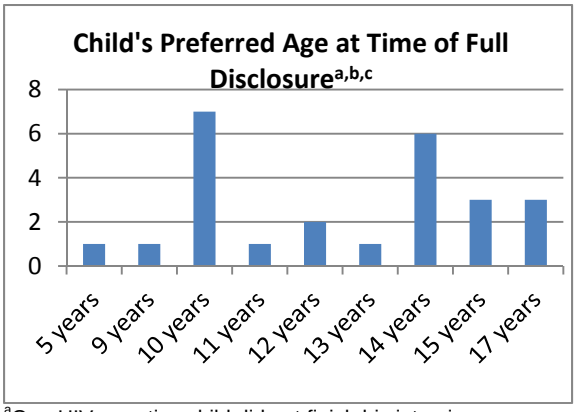
encourage parents to fully disclose between 10-14 years as soon as a child shows maturity and/or understanding of the illness. Provide programs aimed at counteracting early child sex initiation (e.g., avoiding peer pressure, increased sexual education counseling in schools/communities/religious facilities) and increased parent-child sexual education programs.



[a]One HIV-negative child did not finish his interview.
[b]one HIV-positive parent said when the child is mature.
[c]One HIV-positive parent said immediately ART is initiated.

6. **Person to Perform Disclosure: While parents (14 of 16) mostly preferred to be the ones to disclose illness to children, HIV-positive children (4of 7) preferred to be disclosed to by a HCP trained in disclosure. HIV-negative children preferred a parent (2 of 4) or close relative (2 of 4) such as older sibling or aunt to tell them.**

Recommendations: HCPS should help parents determine the most suitable person to disclose to a child. Relatives identified as part of the persons disclosing to a child should also be involved in disclosure-related services and programs (e.g., disclosure training, counseling, support groups).

	Person to perform disclosure		
	Parent	HCP	Relative
HIV-negative children ($N = 4$[a])	2		2
HIV-positive children ($N = 7$)	3	4	
HIV-positive parents ($N = 16$)	14	1	1
Total $N = 27$[a]	19	5	3

Notes.
[a] One HIV-negative child did not complete entire interview.

POLICY IMPLICATIONS

The following policy implications emerge from our study:

1. **HIV disclosure guidelines are urgently needed for heavily affected families where both parent(s) and child(ren) are infected. These guidelines need to address disclosure of a parent's and a child's illness as well as prior deaths to all children (HIV-positive and negative) within the family.**
2. **HCPs who work with HIV-positive parents and their children need disclosure training so they are better able to guide parents through the complex disclosure process. Training HCPs on disclosure will ensure good outcomes for both parents and children. Training should be based on validated disclosure models such as the four phase model (Tasker, 1992), disease progression theory and consequence theory of HIV disclosure (Serovich, 2001), disclosure process model (Chaudoir & Fisher, 2010), and the disclosure decision making model (Chaudoir, Fisher, & Simoni, 2011).**
3. **Increase services and programs (e.g., reading materials, support groups, counseling and disclosure practice sessions) to help HIV-positive parents fully disclose to children in a timely and appropriate manner.**

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FUTURE RESEARCH

Future researchers should focus on:

- **Determining the best way to disclose many family member's illnesses and deaths to children.**
- **Determining if disclosure needs of HIV-positive and negative children differ.**
- **Performing larger quantitative studies using local national or dialect languages which include parents and children from different cultural backgrounds.**
- **Determining which disclosure models are most effective in the facilitation of disclosure in SSA, other regions with high HIV prevalence, and resource-rich nations.**

CONCLUSION

HIV disclosure is challenging to parents and the HCPs who help them through the process. Implementing the recommendations and policy suggestions made in this research brief should lead to improved disclosure rates and better facilitation of HIV disclosure from parent to children within SSA and other heavily affected regions.

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