

The experiences of HIV-positive and HIV-negative children after receiving disclosure of their own and their parents' illnesses, respectively

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Research Brief

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The Experiences of HIV-positive and HIV-negative Children After Receiving Disclosure of Their Own and Their Parents' Illnesses, Respectively

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AIM

The aim of this research brief is to describe a study that sought to understand the post-disclosure experiences of HIV-positive and negative children after they received disclosure of their own and their parents' illnesses, respectively. This is the first study from Sub-Saharan Africa (SSA) that describes the post-disclosure experiences of HIV-positive and negative children in one study. Prior studies in SSA have mostly centered on the post-disclosure experiences of HIV-positive children after receiving disclosure of their own illnesses, or HIV-positive mothers' descriptions of the effect of maternal disclosure on their HIV-negative children.

BACKGROUND

As of 2012, Kenya's HIV prevalence among children aged 18 months to 14 years was 0.9% (National AIDS and STI Control Programme Kenya, 2014) and 2.7% among youth aged 15–24 years (UNICEF, 2013). The HIV prevalence among adults was 6% (UNAIDS, 2013). Five percent of homes in the country had a HIV-positive head of household (National AIDS and STI Control Programme Kenya, 2014).

There have been few studies conducted with HIV-negative children, so their post-disclosure experiences are not well understood. Following disclosure, HIV-positive and negative children

Key Aspects of Post-Disclosure Experiences of HIV-positive and HIV-negative Children:

1. HIV-positive and negative children were affected by disclosure; HIV-positive children took longer to recover than HIV-negative children.
2. HIV-negative children experienced less incidences of stigma, discrimination, misconceptions than their HIV-positive peers.
3. HIV-negative children wanted their parents to take their medications, stay healthy, and pay for their education so they can finish school and have a better life. HIV-positive children adhered to their medications in order to stay healthy but considered medication consumption as a burden that interfered with their daily lives.
4. HIV-negative children wanted their parents to speak to them about sex so they could protect themselves from infection. HIV-positive children had lingering questions about sex, condoms, relationships, marriage, and childbearing.
5. Post-disclosure, children coped by speaking to a close trusted person or withdrawing to perform activities that helped them feel better.

experience varying effects which may be positive (increased closeness with their parents) or negative (withdrawal), and displayed externally (sadness) or internally (depression: Kennedy et al., 2010; Vallerand et al., 2005). Understanding HIV-positive and negative children's post-disclosure experiences is important so that healthcare professionals (HCPs) can better facilitate disclosure

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from HIV-positive parents to their HIV-positive and negative children.

PROCESS

Participants for the study were recruited at the Kenyatta National Hospital Comprehensive Care Center located in Nairobi, Kenya. The children participated in a larger study conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process. Recruitment for the larger study was halted when interview data saturation was achieved, resulting in a child sample size of seven HIV-positive and five HIV-negative children. These children's post-disclosure experiences are highlighted in this present study. During their interviews, HIV-positive children were asked about their experiences after they received disclosure of their own illnesses. HIV-negative children were asked about their experiences after receiving disclosure of their parents' illnesses. Phenomenological qualitative data analysis was performed with NVivo8 using the Van Kaam method (Moustakas, 1994).

FINDINGS

Six of the HIV-positive children had full disclosure of their illnesses; one knew he had tuberculosis. Three HIV-negative children had full disclosure of their parents' illnesses; two knew their mother had back problems. The children's demographic profiles are displayed in the table below:

Table 1: Sample demographic characteristics.

Variable	Frequency	
	HIV-positive children	HIV-negative children
Age		
12-13	2	1
14-15	1	3
16-17	4	1
Gender		
Female	3	3
Male	4	1
Educational status		
Primary	2	3
Secondary	3	2
HIV disclosure status		
Partial disclosure	1	2
Full disclosure	6	3

The five themes that emerged from the data are displayed in the following figure and they are further described below:



1. **Acceptance of illness:** All children regardless of their HIV statuses or disclosure levels (full or partial) were shocked to learn of theirs or their parents' illnesses. HIV-negative children recovered within a few hours to a few weeks later; none received counseling. Most grew closer to their parents and were empathetic about their illnesses. HIV-positive children took weeks to months to recover and some needed counseling to overcome the effects of disclosure. Two remained angry with their parents for infecting them.

Recommendations: In many HIV-affected families, HIV-positive parents may need to disclose their own and their HIV-positive children's illnesses to their HIV-positive and negative children. Therefore, HCPs should counsel HIV-positive parents that HIV-positive children may take longer to recover from disclosure than HIV-negative children. All HIV-positive children should be offered post-disclosure counseling so that they can recover faster from the effects of disclosure. Although none of the HIV-

negative children in this study received post-disclosure counseling, stakeholders need to investigate if this service might be beneficial for them.

2. **Stigma and Discrimination:** HIV-negative children did not experience direct incidences of stigma or discrimination but knew that high levels were present in the community. As such, they hid their parents' illnesses from their siblings, and extended family and community members. HIV-positive children were affected by indirect incidences of stigma, discrimination, and misconceptions directed at them by their HIV-negative peers, and extended family and community members.

Recommendations: High levels of stigma and discrimination are present in high prevalence nations. Communities in these nations would benefit from regular HIV awareness programs aimed at increasing accurate knowledge about the disease and reducing the high stigma and discrimination levels present within these communities. HIV-affected children need services that help them cope with stigma and discrimination.

3. **Medication consumption:** Most HIV-negative children helped their parents take their medications because they wanted them to stay healthy and keep paying their school fees so they could finish school and have a better life for themselves. Some wanted to financially support their parents in the future. Most HIV-positive children were diagnosed when severely sick, so they took their medications religiously to remain healthy. They viewed medication consumption as a burden that interfered with their daily lives

especially since all were in boarding school and had to hide their medications from their peers.

Recommendations: HIV-negative children should be offered services that help them assist their parents to maintain ART adherence. Their desires to finish their education should be encouraged and financial support offered as needed/appropriate to HIV-affected families so the children in these families can attend and finish school. HIV-positive children would benefit from programs that help ease the daily medication consumption necessary to keep them healthy.

4. **Sexual awareness:** All the children were not sexually active but expressed that some of their peers were having sex. Two HIV-negative children with full disclosure had spoken to their parents about sexual matters and expressed a desire for regular parent-child communication about sex to help them protect themselves from becoming infected. Some HIV-positive children had many questions about sex and condom use. They also worried about being accepted as relationship/marriage partners and how they would bear children of their own while having protected sex.

Recommendations: In many SSA countries, parents are unable to speak to their children about sex but it appears that children desire to be spoken to about sexual matters. Since children are initiating sex early, regular sex education should be offered in schools and communities with high HIV prevalence. HCPs should offer regular services and programs that counteract cultural practices that inhibit provision of sexual education and also train parents on how to approach the topic within the home. HIV-

positive children need programs that regularly update them on research findings (e.g., pre-exposure prophylaxis [PrEP] for conception) that improve their treatment and living options (Chadwick et al., 2011; Lampe et al., 2011; Savasi et al., 2013; Vernazza et al., 2011).

5. **Coping mechanisms:** All the children except one preadolescent HIV-positive child had self-identified an older sibling, cousin, aunt, uncle, grandparent, or friend to speak with about their circumstances. HIV-positive children gained extra support from their infected peers within support groups. HIV-positive children expressed a desire to be understood, respected, educated about the illness, and loved by their parents, relatives and peers. HIV-negative children wanted to be educated on how best to support their parents. They expressed a desire to meet with other similarly affected children so that they can share their experiences and learn from each other. When feeling overwhelmed, all the children withdrew to be by themselves and perform activities (e.g., singing, reading, praying, crying, napping) to help make themselves feel better.

Recommendations: Post-disclosure services (e.g., education on the disease, how to care for parents, and support groups) need to be extended to and include HIV-negative children. Both HIV-positive and negative children are in need of services that help them cope better with their circumstances other than self-withdrawal. For optimum outcomes, disclosure services should preferably be extended to include the whole family as a unit.

POLICY IMPLICATIONS

The following policy implications emerge from this study:

1. Typically, HIV disclosure services are offered to HIV-positive children but should also be extended to HIV-negative children as they may also benefit from them. Ideally, services should be offered to all family members going through HIV disclosure.
2. HCPs should counsel parents that their HIV-positive and negative children may have different post-disclosure experiences and desires.
3. Post-disclosure, HIV-positive children may need additional support and counseling services to recover faster. They also need programs and services to assist them with ART adherence; involvement of HIV-negative children in these programs would also aid them in assisting their parents maintain ART adherence.
4. HIV-positive children need services that regularly update them on new research findings that would improve their outlook and healthcare/living options.
5. Regular sex education programs and services should be offered to children to try and reduce early sex initiation and to increase the number of protected sexual acts. All parents should be encouraged to regularly have sex-related conversations with their children.
6. Countries with high HIV prevalence should hold regular HIV awareness programs aimed at counteracting the high stigma and discrimination levels directed at HIV-positive persons and their families.

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FUTURE RESEARCH

Future researchers should focus on:

- **Increasing the number of studies that involve HIV-negative children so that their disclosure experiences and desires can be understood.**
- **Conducting larger studies to determine if disclosure needs of HIV-positive and negative children/siblings differ.**
- **Conducting studies with HIV-positive and negative children from different age groups, locations, and cultural backgrounds in order to understand how disclosure affects children in different settings.**
- **Determining what are the most suitable programs and services to offer HIV-positive and negative children post-disclosure, so that they are better able to cope with their circumstances.**

CONCLUSION

This study's sample size was small and the results may not be generalizable to other HIV-positive and negative children who have received disclosure of their own and their parents' illnesses, respectively. However, until larger studies are conducted, the results of this study are important and should be used by HCPs to offer targeted advice to HIV-positive parents who wish to disclose to their children of mixed HIV statuses.

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