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# HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya

HIV disclosure from parent to child is complex and challenging to HIV-positive parents and healthcare professionals. This study was conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya. Sixteen HIV-positive parents, seven HIV-positive children, and five HIV-negative children underwent semistructured in-depth interviews. Data was analyzed using the Van Kaam method in NVivo 8. Seven themes emerged that spanned the disclosure process. Presented here is data on the theme about how participants recommend full disclosure be approached to HIV-positive and negative children. Participants recommended disclosure as a process starting at five years with full disclosure delivered at 10 years when the child was capable of understanding the illness; or by 14 years when the child was mature enough to receive the news if full disclosure had not been conducted earlier. Important disclosure considerations include the parent's and/or child's health statuses, the number of infected persons' illnesses to be disclosed to the child, the child's maturity and understanding level, addressing important life events (e.g., taking a national school examination), and the person best suited to deliver full disclosure to the child. Recommendations are made for inclusion into HIV disclosure guidelines, manuals, and programs.

HIV-positive parents, HIV-positive children, and HIV-negative  
children's perspectives on disclosure of a parent's and child's illness in  
Kenya

Grace Gachanja, RN, MPH, PhD<sup>a\*</sup>

Gary J Burkholder, PhD<sup>a,b</sup>

Aimee Ferraro, MPH, PhD<sup>a</sup>

<sup>a</sup>Walden University  
College of Health Sciences  
100 Washington Avenue, Suite 900  
Minneapolis, MN, 55401  
USA

<sup>b</sup>National Hispanic University  
14271 Story Road  
San Jose, CA 95124

\*Corresponding author email: [g\\_gachanja@hotmail.com](mailto:g_gachanja@hotmail.com)

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## Abstract

HIV disclosure from parent to child is complex and challenging to HIV-positive parents and healthcare professionals. This study was conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya. Sixteen HIV-positive parents, seven HIV-positive children, and five HIV-negative children underwent semistructured in-depth interviews. Data was analyzed using the Van Kaam method in NVivo 8. Seven themes emerged that spanned the disclosure process. Presented here is data on the theme about how participants recommend full disclosure be approached to HIV-positive and negative children. Participants recommended disclosure as a process starting at five years with full disclosure delivered at 10 years when the child was capable of understanding the illness; or by 14 years when the child was mature enough to receive the news if full disclosure had not been conducted earlier. Important disclosure considerations include the parent's and/or child's health statuses, the number of infected persons' illnesses to be disclosed to the child, the child's maturity and understanding level, addressing important life events (e.g., taking a national school examination), and the person best suited to deliver full disclosure to the child. Recommendations are made for inclusion into HIV disclosure guidelines, manuals, and programs.

Keywords: HIV/AIDS; HIV disclosure; Child HIV status disclosure; Parent HIV status disclosure; Resource-poor nation; Qualitative research

## Introduction

By 2012, over 35 million persons were infected with human immunodeficiency virus (HIV) globally (UNAIDS, 2013). Resource-poor nations, especially those within Sub-Saharan African (SSA) bear the brunt of the pandemic; 90% of infected persons live in SSA. Kenya has 1.4 million adults and 200,000 children living with the disease (NACC and NASCOP, 2012). As of 2011, the prevalence rate of the disease for adults aged 15-64 years was 5.6%, and that of children 18 months to 14 years was 0.9% (National AIDS and STI Control Programme, 2013). Due to increased access to antiretroviral treatment (ART) these prevalence rates are expected to increase as infected persons live longer, thereby making control of the disease a national priority in the decades to come (NACC and NASCOP, 2012).

Disclosure of HIV status to children is important for HIV-positive parents, but many are extremely challenged by the disclosure process (Blasini et al., 2004; Delaney et al., 2008; Kallem et al., 2011; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana, 2005; Menon et al., 2007; Vallerand et al., 2005; Vaz et al., 2008). HIV disclosure is a process that moves a child from a state of no disclosure to partial and then to full disclosure of illness. Nondisclosure of illness has been defined as a state in which the child has no knowledge of the illness (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Oberdorfer et al., 2006; Vaz et al., 2011). In partial disclosure the child has limited details (for example, awareness of daily medication consumption and presence of chronic illness) of the illness (Bikaako-Kajura et al., 2006; Rochat, Mkwanzazi, & Bland, 2013; Vaz et al., 2011). A child with full disclosure is aware that the illness in question is HIV/AIDS (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Rochat, Mkwanzazi, & Bland, 2013; Oberdorfer et al., 2006).

HIV disclosure studies in SSA have mainly centered on telling children about their own HIV status, and a few have been on telling children about their parents' HIV statuses. Recent studies on disclosure to HIV-positive children have revealed HIV disclosure rates between 2-50% in Kenya (John-Stewart et al., 2013; Turissini et al., 2013; Vreeman et al., 2010; Vreeman et al., 2014); and 2-38% in other SSA countries (Biadgilign et al., 2011; Bikaako-Kajura et al., 2006; Brown et al., 2011; Feinstein et al., 2010; Fetzer et al., 2011; Hejoaka, 2009; Kallem et al., 2011, Menon et al., 2007; Moodley et al., 2006; Vaz et al., 2010). Research suggests that the typical age ranges of HIV-positive children receiving disclosure of their own HIV status was between 3 and 19 years in Kenya (Vreeman et al., 2014); 8 and 18 years in the Democratic Republic of Congo (Vaz et al., 2010; Vaz et al., 2008); and 5 and 15 years in South Africa (Heeren et al., 2012; Moodley et al., 2006).

Rates of parental HIV infection status disclosure to children are higher than those of disclosure of the child's infection status. Recent studies conducted within SSA have revealed such rates ranging from 29-85% (Madiba & Matlala, 2012; Nam et al., 2009; Palin et al., 2009; Rochat, Mkwanazi, & Bland, 2013; Rwemisisi et al., 2007). The age ranges of children receiving disclosure of their parents' HIV statuses was between 9 and 17 years in Botswana (Nam et al., 2009); and 10 to 18 years in Uganda (Rwemisisi et al., 2008). We found only one study in SSA that examined the process of disclosure of a parent's HIV status to their HIV-negative children (Rochat, Mkwanazi, & Bland, 2013). Therefore, the knowledge on how parents approach and perform disclosure of their own HIV status as well as that of their children to their HIV infected and uninfected children within the same household is relatively undeveloped in the literature.

However, data indicate that it is not uncommon for families to have infected and uninfected family members that may include both parent(s) and child(ren) (Republic of Kenya, 2009).

We modeled the current study after one conducted by Vaz et al. (2008) in the Democratic Republic of Congo following establishment of a comprehensive care clinic geared towards HIV-positive youth and their families. Vaz et al. (2008) sought to explore issues surrounding HIV-positive youth receiving disclosure of their own illnesses. We enlarged our study to include HIV-positive parents; and HIV-positive children and HIV-negative children from a wider age group of 8-17 years in order to understand more clearly the dynamics associated with disclosure within families representing different HIV statuses. The purpose of our study was to understand the lived experiences of HIV-positive parents and their HIV-positive and negative children before, during, and after the disclosure process in Kenya. The present study focuses on disclosure of parent and child illnesses to HIV-positive and negative children.

## **Methods**

### **Sample Selection**

This study was conducted at the HIV Comprehensive Care Clinic (CCC) located at the Kenyatta National Hospital (KNH) which is near the center of Nairobi, Kenya. HIV-positive parents and children were purposively recruited by the lead author from the waiting areas of the CCC. Participants were also referred by clinical officers (equivalent of physician assistants in the U.S.), nurses, and peer educators from the examination and triage rooms during their regularly scheduled clinic visits. Additionally, a different group of HIV-positive parents were requested to nominate and bring their HIV-negative children at a time of their choosing to the clinic for participation in the study. Selected parents and children were not parent-child dyads because we

aimed to obtain rich data representing the perspectives of parents and children from different families. Potential participants were informed of the research procedures through the informed consent process; if they agreed to participate, they were escorted to a private room within the clinic where informed consent was obtained and study procedures performed.

HIV-positive parents recruited into the study reported having biological HIV-positive and negative children between the ages of 8 and 17 at various stages of disclosure (no, partial, full) of their parents' and/or child's own illness. To prevent inadvertent disclosure during conduct of the interviews we selected HIV-positive children with partial and full disclosure of their own illnesses; and HIV-negative children with partial and full disclosure of their parents' illnesses. Children with partial disclosure of illness were interviewed based on what illness (for example, tuberculosis or backache) those children knew they themselves or their parents were suffering from. Purposive selection of participants was conducted over a six-week period; interviews were conducted until saturation was reached. Ethics approval was received from the KNH Research Standards and Ethics Committee (Approval # P373/10/2010), and the home university institutional review board (Approval # 11-10-10-03904). HIV-positive and negative children provided written assent to participate in the study and their parents provided written informed consent. HIV-positive parents also provided written informed consent. All participants consented to the digital recording of their interviews.

### **Data Collection and Instruments**

Interpretative qualitative data were collected using in-depth semistructured interview guides adapted from those used by Vaz et al. (2008). We adapted (with permission) the guides by removing questions that did not specifically address disclosure. The adapted guides were

reviewed and approved by members of the research team familiar with qualitative instrument design. Interviews were performed in English (the official language of Kenya) in a private room at the hospital and lasted from 30 to 90 minutes. All selected participants were fluent in English. Parents of HIV-positive and negative child participants were given the option of being in the room while their children were being interviewed but all declined; all child participants consented to being interviewed alone.

HIV-positive parents' interview guide questions explored various aspects of the disclosure process including reasons for and against full disclosure, parents' activities conducted in preparation for full disclosure, the family's needs during the disclosure process, when and how partial and/or full disclosure was performed to their children, their recommendations on how full disclosure to children should be approached, and the anticipated/actual reactions and consequences to full disclosure. HIV-positive and negative children's questionnaires explored when and how they had received partial or full disclosure of their own and parents' illnesses respectively, how they felt during and after partial or full disclosure of their own and parents' illnesses respectively, and their recommendations on how full disclosure should be performed to children.

### **Data Analysis**

Recorded interviews were immediately transcribed by the first author and a local university student trained in transcription. Transcripts were rechecked against the interviews for accuracy; and five participants were also sent their transcripts to verify the accuracy of the transcription. Transcripts were uploaded into NVivo 8 for management and analysis. Data analysis was performed using the modified Van Kaam method (Moustakas, 1994); this included

thorough reading of transcripts, listing and grouping those with similar information while checking for codes, then clustering codes into emerging themes combined with predetermined themes (age of disclosure, child maturity and understanding level, person to perform disclosure) from prior research. Over 300 total codes emerged from the data, and these were crosschecked by members of the research committee against a select group of transcripts. Seven themes emerged that spanned the disclosure process. Data presented here is extracted from the theme on how the participants' advised that full disclosure be approached and performed.

## Results

### Sample Description

Sixteen HIV-positive parents, seven HIV-positive children, and five HIV-negative children were recruited into the study. The parents ranged in age from 30-54 years of age; 11 were women, and two were a married couple. Mothers typically have higher clinic attendance because they bring their children, so it was harder to identify and recruit men into the study. We sought to select children between 8-17 years but only found children aged 12 years and above who had already received partial or full disclosure of their own or their parents' illnesses. Selected HIV-positive children were between 12-17 years of age; for six children, parents had fully disclosed to them, and one was only aware he was suffering from TB. HIV-negative children were between 12-16 years of age; parents had disclosed their own statuses to three, and two were sisters who were only aware their mother was suffering from chronic backache.

Nine parents (56%) had fully disclosed their own illnesses to at least one child in the household, and eight parents (50%) had fully disclosed their child's illness to at least one of their HIV-positive children. Six HIV-positive children (86%) had received full disclosure of their

illnesses and three HIV-negative children (60%) had received full disclosure of their parents' illnesses. HIV-positive parents' sociodemographic profiles are presented in Table 1, and their children's demographics, testing, and disclosure status are presented in Table 2. HIV-positive children's sociodemographic profiles and disclosure statuses are presented in Table 3. HIV-negative children's sociodemographic profiles and disclosure statuses are presented in Table 4.

The perceptions of the adults and children regarding how full disclosure should be delivered to children are presented in the six subthemes below. These subthemes include considering the parent's right to perform and the child's right to receive disclosure as a process. Issues such as delivering disclosure to multiple HIV infected family members (parents and children), parent and child's health status, child's understanding and maturity level, and who should deliver disclosure to children are further discussed.

### **Disclosure is a Child's Right and a Parent's Decision**

All parents were willing at some point to fully disclose to their children; some felt it was the right of the child to know about the parent's and/or child's illnesses. Parents expressed they needed help from healthcare professionals (HCPs) to be able to perform full disclosure to their children. However, with the exception of one parent who advised parents perform disclosure without heeding from HCPs, a few were completely against being told by HCPs when to perform full disclosure to their children. Parents wanted HCPs' advice on how to proceed with disclosure and then be given adequate time to prepare and perform full disclosure at a time of their choosing:

Table 1. HIV-positive parents' sociodemographic profiles

Variable	Frequency	Percentage
<b>Age</b>		
31-40	8	50
41-50	7	44
51-60	1	6
<b>Gender</b>		
Female	11	69
Male	5	31
<b>Employment status</b>		
Employed	16	100
Unemployed	0	0
<b>Educational status</b>		
Primary	2	12
Secondary	7	44
College	7	44
<b>Marital status</b>		
Single	1	6
Divorced	1	6
Widowed	4	25
Married	10	63
<b>Religion</b>		
Christian	15	94
Muslim	1	6
<b>Years since diagnosis</b>		
< 1 year	2	12
2-5 years	6	38
6-10 years	6	38
10+ years	2	12
<b>Age at diagnosis</b>		
20-29 years	2	12
30-39 years	10	63
40-50 years	4	25
<b>CD4 count</b>		
<b><u>At diagnosis/At time of interview</u></b>		
<350 cells/mm <sup>3</sup>	9/5	56/31
>350 cells/mm <sup>3</sup>	5/10	31/63
Not available <sup>a</sup>	2/1	13/6
<b>Medications</b>		
ART and Cotrimoxazole	14	88
Cotrimoxazole only	1	6
No medications <sup>a</sup>	1	6
<b>No. of children</b>		
1-2	10	63
3-4	3	18
5-6	3	18

<sup>a</sup>Two parents were newly diagnosed within 1 and 6 months of their interviews respectively

Table 2. Demographics, testing, and disclosure status of children of HIV-positive parent participants

Parent's Family	A	B	C	D	E	F	G	H	I	J	K	L (couple)	M	N	O
Years since diagnosis	11	7	2 weeks	11	6	4	8	1	5	3	6 months	9	3	8	2
No. of children	2	1	1	3	3	2	2	4	2	2	2	5	2	6	2
Sex of children	M F	F	M	M M F	F F M	F F	M M	F F M M	M F	M M	F M	M M F F M	F F	M M M U F	M M
Age of children	13 Died at 6 mths	11	17	26 17 10	14 7 5	14 9	14 12	21 15 13 7	16 5	12 9	8 6	25 24 22 20 15	14 U	19 17 14 11 SB 4	17 11
No. of children tested	1	1	1	3	3	1	1	2	2	2	0	2	1	5	1
Child HIV status	+ NT	-	+	+ + -	- + +	NT +	+ NT	- + NT NT	+ +	+ -	NT NT	NT - NT - NT	- U	- - + + NT -	NT +
Child's disclosure status of parent's illness/Age at time of disclosure	FD/12 NA	PD/8	ND	FD/19 FD/15 ND	FD/10 FD/5 FD/3	PD/U PD/U	FD/11 FD/9	FD/20 FD/15 ND ND	FD/15 ND	ND ND	ND ND	FD/17 FD/16 FD/17 FD/16 PD/U	FD/13 ND	FD/U FD/U FD/14 PD/U NA ND	ND PD/U
Child's disclosure status of own illness/Age at time of disclosure	FD/13 NA	NA	FD/9	FD/19 FD/15 NA	NA FD/5 FD/3	PD/U NA	FD/11 NA	NA FD/15 NA NA	FD/15 ND	ND NA	NA NA	NA NA NA NA NA	NA NA	NA NA FD/14 PD/U NA NA	NA PD/U

Note. F = female; M = male; FD = full disclosure; NA = not applicable; ND = nondisclosure; NT = not tested; PD = partial disclosure; SB = stillborn; U = unknown

Table 3. HIV-positive children's sociodemographic profiles

Variable	Frequency	Percentage
<b>Age</b>		
12-13	2	29
14-15	1	14
16-17	4	57
<b>Gender</b>		
Female	3	43
Male	4	57
<b>Educational status</b>		
Primary	2	29
Secondary	5	71
<b>Religion</b>		
Christian	7	100
<b>Years since diagnosis</b>		
< 1 year	1	14
2-5 years	6	86
<b>Age at diagnosis</b>		
9-11 years	3	43
12-14 years	3	43
15-17 years	1	14
<b>CD4 count</b>		
<u>At diagnosis/At time of interview</u>		
<350 cells/mm <sup>3</sup>	5/1	71/14
>350 cells/mm <sup>3</sup>	2/6	29/86
<b>Medications</b>		
ART and Cotrimoxazole	7	100
<b>HIV-Positive Child Disclosure Status of Own Illness</b>		
<u>Full disclosure: Age at disclosure/Current age/Sex</u>	6	86
9/13/M		
“Very young age” (diagnosed at 11 years )/15/M		
13/16/F		
14/16/F		
14/17/M		
17/17/F		
<u>Partial disclosure: Age at disclosure/Current age/Sex</u>	1	14
9/12/M/Tuberculosis		

*The question of passing information is dependent on each and every family, the time they find is best suited for them. Even if they are talking to a counselor or anybody else, they should be encouraged to get the most suitable time they think is important for them to pass on the information to the child because they are the ones who know their child because they need from them personal information that causes a lot of repercussions good or bad. 54-year-old father of two HIV-negative children and three untested children*

Table 4. HIV-negative children's sociodemographic profiles

Variable	Frequency	Percentage
<b>Age</b>		
12-13	1	20
14-15	3	60
16-17	1	20
<b>Gender</b>		
Female	3	60
Male	2	40
<b>Educational status</b>		
Primary	3	60
Secondary	2	40
<b>Religion</b>		
Christian	5	100
<b>HIV-Negative Child Disclosure Status of Their Parent's Illness</b>		
<b><u>Full disclosure: Age at disclosure/Current age/Sex</u></b> 14/14/M 14/14/F 14/15/M	3	60
<b><u>Partial disclosure: Age at disclosure/Current age/Sex</u></b> 8/12/F 14/16/F	2	40

Both HIV-positive and negative children agreed with parents that they needed to know about the illness. HIV-positive children wanted to be told about their illnesses because once they became fully aware of their health statuses, they could more easily deal with the illness:

*Children should know because somehow we take care of ourselves, you know now we eat some fruits to boost our immune system, they should know.* 13-year-old HIV-positive boy

*At least I know so that if I get into a relationship without knowing I can infect the person, and so it is not good. So at least they told me earlier that I will take the measures not to make other people get infected so that we can eradicate AIDS for good.* 17-year-old HIV-positive girl

The three HIV-negative children with full disclosure of their parents' illnesses were curious about how their parents became infected but were happy to know because secrets were eliminated and they realized the disease was real. HIV-negative children were highly in favor of children being informed of their parents' illnesses followed by subsequent testing of all children:

*It is better for them [children] to know because this is what we live for, to know about our parents, about ourselves, about our family and to know our status is knowing your whole life, how it is going to be, how you are going to live it... If a parent hides his or her status from a child, let's say he is doing bad behaviors or something, he might be having it and contracts it to other people... I was relieved to know that me too, I can get tested for a reason... I got tested at school, there were these people coming to test us at school. Then they tested us, then we got our results, I was negative. 15-year-old HIV-negative boy*

Although parents thought children should know about the illness, they considered full disclosure to be very challenging, describing it as “weighty,” “hurting,” and a “burden.” Disclosure was even challenging to parents who had already performed full disclosure to their older children and were in the process of preparing younger siblings. Parents were only willing to proceed with full disclosure when they and their children were ready. In the meantime they postponed full disclosure by telling their children the parent or child was suffering from another illness such as tuberculosis, backache, and high blood pressure as explanation why there was daily consumption of medication.

Both HIV-positive and negative children were against being lied to about the illness by their parents because it betrayed their trust. They were all in favor of disclosure in a timely manner because at some point it would be inevitable for them to know the truth:

*Even if they didn't tell me sooner or later I would come to know. 16-year-old HIV-negative girl with partial disclosure of her mother's illness*

*Children should be given a chance to know because if you lie to your child, when he or she grows up it becomes very difficult for you to relay the message to your child. So you must tell your child when he or she is little coz a little child is easier for you to handle but for a grownup it becomes very complicated. 17-year-old HIV-positive boy*

## Disclosure is a Process

Parents expressed that full disclosure to a child should be performed as a process. By disclosing in stages, children absorbed the news better, suffered less negative impact, and did not forget what they had been told. Some parents who had performed full disclosure of their children's illnesses explained HIV-positive children needed to be reminded of their illnesses and to take ART. HIV-positive children agreed taking medications was tedious:

*You know you don't tell them today and then you forget about it, keep on telling them the awareness so as not to forget their status and their medication... They [5 and 7 year-old HIV-positive children] know they are taking medicine for HIV but they don't understand. Now we are waiting when they mature at 10, then we will tell them the problem you are taking medicine is this and you should not stop.* 45-year-old HIV positive father of two HIV-positive children and a HIV-negative child

*HIV is a non-curable disease and you have to take drugs each and every day and sometimes you forget and you become sick and many complicated issues.* 17-year-old HIV-positive boy

HIV-positive and negative children also stated that they preferred to receive disclosure over time. Some children who had received full disclosure without lengthy preparation expressed they had been impacted by the news:

*There is a newspaper that we had read together, it was about this woman who had lived with HIV for 20 years, so we talked about it briefly. Then she [mother] came after finishing cooking, I think she asked me how if I knew she was positive what would I do? And I just told her that I wouldn't do anything since she is the one who has taken care of us since the time we were young. So when she told me at first I was shocked... I really didn't know, it was just a shock, and it came as a shock to me.* 14-year-old HIV-negative girl

## Disclosing Multiple Illnesses in the Family

Many parents in the study had HIV-positive living (or dead) spouses and children. None of the HIV-positive children in the sample reported living HIV-positive siblings but some had

siblings or a parent who had passed away. None of these HIV-positive children expressed they had been told the deaths were due to an AIDS-related illness; however, they had voiced suspicions about it. HIV-negative children in the sample also had no HIV-positive siblings, but three had lost a parent due to a cause of death unknown to them. Children therefore had a need to know about the illnesses and causes of deaths within their families. A 17-year-old HIV-positive boy expressed he was surprised to learn of his illness because no one else in his family was infected except “maybe my mother, she passed away when I was three months.” A 12-year-old HIV-negative girl expressed she wanted her mother “to comfort me and tell me why father had died because he had no illness.”

HIV-positive parents in the sample had a mixture of children with no, partial, or full disclosure of illnesses within the household, and they performed preferential disclosures opting to fully disclose all illnesses in the family to older but not younger children. Incidences of full disclosure of a parent’s illness at the time of diagnosis and disclosure of an infected child’s illness were reported by two parents either because the child guessed the parent was similarly infected, or needed encouragement that they were not alone. Performing full disclosure of all illnesses in the family was cathartic for some parents. Some who had not yet performed full disclosure planned to disclose of all illnesses to their children:

*Because it was very difficult for me to disclose I wanted him to know everything at once... One day he asked about his [late] father in the morning and I got that opportunity... I told him it was the chest due to HIV, he was HIV-positive... He said oh, no, no, no then that explains why I take this medication am I also HIV-positive? So I just said yes... He asked are you also sick? That is when I told him I am also sick... It was a relief for me I just told him everything and then we discussed and it was a bit lighter. In fact at the end of it all he said I will pray for you, we will take care of one another. 37-year-old HIV-positive mother of one HIV-positive boy*

*I will try to do it in one session [disclose both parents' illnesses] if she understands me and I see she understands the situation and accepts it, then I'll do all of it in one session.*  
39-year-old father of a HIV-negative daughter

Although cathartic for parents, full disclosure of many family members' illnesses at the same time was traumatic for some children. Other children in the sample or children of HIV-positive parents' overcame their shock and moved on with their lives. One HIV-negative child was so upset recounting how he received full disclosure that his interview was stopped early and he was referred to the psychologist's office for counseling. Parents whose older children had received full disclosure poorly were hesitant to disclose to younger siblings:

*He [father] told me that when I was five years my mother died and told me not to tell anyone about it, I felt sad (starts to cry). He told he was using some drugs and I never asked him more... He told me the current mother who took care of me until today I am still staying with her is my stepmother (sniffles).* 14-year-old HIV-negative boy

*I told them [oldest two sons] the situation [parents' diagnoses], the reaction was unbelievable. The second born he cried, I have never seen a boy cry the way that one cried, he cried and cried for two days. The elder one just looked at me clicked and walked off, that one is affected up to now... I told them [middle daughters] much later also when they were in secondary school... When I told them they kept quiet, then they didn't react violently so for some time I thought they were stronger, but they were also like the elder ones... Now this last one (clicks tongue) it's a problem I don't know. He is so attached to us, you know he has been the baby and all that. I have been wondering how and when... Some things you don't become an expert.* 49-year-old mother of two HIV-negative children and three untested children

### **Considering a Parent's and Child's Health Status**

When considering full disclosure, parents took into account health status of themselves and their children. Both parents and children cautioned even without full disclosure children were highly aware of the disease and were able to guess the nature of illness:

*If you have been in and out of hospital, you get very ill you are taken to Kenyatta Hospital then you are tested you come out you are very weak, they will even know before*

*you tell them coz they might have already guessed, you are coughing, you are what. 54-year-old HIV-positive father of two HIV-negative children and three untested children*

*Some parents when they don't tell you, the signs just show and the child doesn't let's say study well, he just gets to feeling so low. 15-year-old HIV-negative boy*

Parents were unwilling to perform full disclosure of their illnesses to their children when they were in poor health however they advised it was permissible in certain instances. These included when the parent was too sick to take him/herself to the hospital or pick up medications from the CCC. The child with disclosure could take the parent to the hospital, pick up ART at the CCC, take care of siblings, and perform household tasks until the parent was feeling better. HIV-negative children provided responses similar to parents about being against disclosure when a parent was unwell, and described vivid memories of the time their parents had been severely sick:

*Father had died, she [mother] had an illness because she had carried a baby in her stomach, my last sister... She was weak, very weak that even she could just fall down... I thought that maybe she could pass away even her coz of the stress that she had. And with the stress how could she manage to get all the school fees for us all and feed the family. 12-year-old HIV-negative child*

Generally parents were of the opinion that HIV-positive children should not be told of their illnesses when they were in poor health because it might make them lose hope and cause their condition to worsen. They therefore advised other parents to wait until both the parent and child were in good health prior to performing full disclosure to a HIV-positive child:

*Tell them when you [parent] have the strength because she might have that feeling why did my parents wait until they are bedridden, they can't walk? You have to tell them early to prepare them psychologically. You also have to tell [HIV-positive] children when they have the strength, they are energetic, they know what they can do because sometimes if you tell them when they are bedridden it won't help. Tell them when they have the energy then they will know what food they can eat, this medicine is for this. 45-year-old father of two HIV-positive children and one HIV-negative child*

However, if the HIV-positive child's health had deteriorated due to poor ART adherence then it was imperative he or she receive full disclosure:

*He has to know why he is taking medicine and why he is getting ill because maybe when he is not taking the medicine proper, you have to tell him or her you have to take your medicine so that you can be well. 46-year-old mother of two HIV-positive children and one HIV-negative child*

### **Child's Understanding and Maturity Level**

Parents expressed that children developed and matured differently; thus, the decision to fully disclose should be assessed individually. Parents were especially afraid to perform full disclosure to young children because they feared these children would not understand the meaning of the illness or keep the information a secret thereby exposing the family to stigma. Both HIV-positive and negative children agreed it was not wise to perform full disclosure to young children:

*You know when they are young they will just take it like this... She [nine-year-old daughter] does not know how to keep a secret because she will shout to the other children, that's why I fear to tell her. 32-year-old mother of one HIV-positive daughter and one untested daughter*

*Even if you tell them when they are small they cannot even know what they are supposed to do. 16-year-old HIV-positive girl*

*You cannot tell a child at seven that they have HIV, maybe he will not understand it or he will not handle it. 15-year-old HIV-negative boy*

One HIV-positive child thought children should receive full disclosure by five years because when they sensed the information was important, they would always remember it. One parent had fully disclosed his, his wife's, and two children's illnesses to all his children when aged 3, 5, and 10 years but the younger children did not comprehend what it meant and he

wanted to re-inform them again at 10 years of age. Other parents and children disagreed with full disclosure at an early age preferring to provide limited information over time corresponding to what children were being taught in school about the disease:

*When the child is about six years you cannot tell her or him that you are HIV-positive, but you can tell the child that I am on medication and then after two years you just disclose after 10 years. 10 years he has knowledge to know what is HIV. 46-year-old mother of two HIV-positive sons and one HIV-negative daughter  
I am saying [start telling them at] seven because by the time they are eight years most of them are in class three and nowadays they teach at school, it is already in their books.  
37-year-old mother of two HIV-positive children*

Some parents reported that children were initiating sex by 9 years and were therefore in need of full disclosure around this age. HIV-positive and negative children agreed that teenagers were having sex mostly due to peer pressure and they needed to know of the illness so they would not infect others or become infected respectively. The most (28%) cited age by both parents and children when full disclosure should be performed was 10 years because the child was capable of understanding the illness. Parents in the sample had delivered full disclosure of their own and their children's illnesses to children between the ages of 3-19 years. Five HIV-positive children had received full disclosure of their illnesses between the ages of 13-17 years and three HIV-negative children had received full disclosure of their parents' illnesses when they were 14 years. The participant's preferred ages of disclosure are displayed in Table 5:

*When the parents feel comfortable from 10 and above, tell them [HIV-positive children] slowly about their illnesses. 13-year-old HIV-positive boy*

*Tell them [about a parent's illness] when the child is young, maybe about 10 years because the child will have grown a bit. 12-year-old HIV-negative child*

*You can tell a child whom you can tell and understand, like now you can't tell a five-year-old. I think that age of between 10 and 13 because the child is a bit mature but since*

*the way he said I should have told him earlier I feel that 10 is the best age. 37-year-old mother of one HIV-positive son who received full disclosure at 12 years.*

*Table 5: Age at which disclosure should be performed to children*

Age of child at disclosure	5	9	10	11	12	13	14	15	17
HIV-negative children (n=4 <sup>a</sup> )			1		2			1	
HIV-positive children (n=7)	1		1			1	2	2	
HIV-positive parents (n=14 <sup>b,c</sup> )		1	5	1			4		3
Participants <i>N</i> = 25 <sup>a,b,c</sup> (%)	1(4)	1(4)	7(28)	1(4)	2(8)	1(4)	6(24)	3(12)	3(12)

<sup>a</sup>One HIV-negative child did not complete the entire interview

<sup>b</sup>One HIV-positive parent said when the child is mature

<sup>c</sup>One HIV-positive parent said immediately after ART is commenced

If full disclosure was not performed by 10 years, 24% of parents and children expressed children were mature enough to receive full disclosure by 14 years of age. At 14-15 years, most children were in Standard 8 when they took their national primary school exit examination. Subsequently the majority of children were admitted to a boarding secondary school. Some parents and children advised children be given the opportunity to take the examination first before being told of theirs and/or their parents' illnesses:

*I liked it because if she [mother] had told me a while back, I don't know how I would have done my KCPE [Kenya Certificate of Primary Examination], so I'm just glad she told me after. 15-year-old HIV-negative girl who had just finished standard eight*

*When I knew about my HIV status I was about to do my KCPE, I was in class eight, I fell so sick... The message really (pauses) intruded into my life and I was very depressed so it made me to fail my exams. 17-year-old HIV-positive boy*

*I was feeling the best time will be after he completes his class eight because that is the time we take them to a boarding school. So we feel it is good when the child knows because he will be carrying his own medicine. 39-year-old mother of one HIV-positive son and one untested son*

## Person to Perform Disclosure

Participants were asked to state who they thought was the best person to deliver disclosure of illness to the child. Their responses are presented in Table 6:

Table 6: Person to perform disclosure to children

Person to perform disclosure	Parent	HCP	Relative
HIV-negative children (n=4 <sup>a</sup> )	2		2
HIV-positive children (n=7)	3	4	
HIV-positive parents (n=16)	14	1	1
Total N = 27 <sup>a</sup> (%)	19(70)	5(19)	3(11)

<sup>a</sup>One HIV-negative child did not complete the entire interview

Overwhelmingly, parents (70%) felt they were the ones who should perform disclosure to their children. Married parents felt it was better for them to liaise and present the news to their children together within one taking the lead. Parents who had already performed full disclosure advised other parents to disclose in a calm manner at a time when they could address all of the child's questions:

*You have to be straight to the point, you have to control yourself when you are saying this in order for them also to be calm. You have to be their pillar now you are saying you are sick they are seeing your emotions are controlled so they will sort of get the strength from you. But if you break down and also bring words that will make them think the situation is hopeless, now you also you have given up. Actually you have to choose your words but generally the choice of words don't come in, it's just how well you are managing your emotions in front of them. 49-year-old mother of two HIV-negative children and three untested children*

Where parents felt incapable of performing disclosure on their own, they advised these parents have a HCP familiar to the child or a relative (e.g., aunty, grandmother) close to the child be present as a support person:

*It is the duty of the parent to tell their children they are HIV-positive maybe through the help of social workers, counselors, doctors or nurses to make their children understand*

*what is HIV coz HIV is a scare if you do not understand what it is. It can destroy a child's life if the child does not understand what HIV is. 39-year-old father of one HIV-negative child*

Half of HIV-negative children were in favor of their parents' disclosing to them while the other half wanted a relative (e.g., their older sister or aunty) close to them to perform full disclosure. The majority of HIV-positive children thought full disclosure should be delivered to them from a HCP trained in disclosure:

*Somebody who is not trained can come and tell you straight to the point. You know what you are HIV-positive and he or she cannot explain more about it. And then after all you hear about HIV it's a killer disease, some people end up committing suicide and so many things, so I think a trained person is the one who should. 17-year-old HIV-positive boy*

One parent who had performed disclosure at home to her child agreed it was wise to have a trained HCP present:

*I think what I should have done is at least disclose in the presence of somebody else who is aware like a counselor or something because immediately when he cried, I panicked, I really panicked because he really cried, he cried a lot and I was like now what do I do next, but I thank God I was able to control it. 37-year-old mother of one HIV-positive boy*

## **Discussion**

This study revealed that many families are heavily affected by HIV; having multiple infected family members increases the challenges of disclosure. Overall, parents appear to favor disclosure at their own time without prompting from HCPs; they did acknowledge needing guidance in the process. Parents have reported requiring guidance during disclosure preparation (Heeren et al., 2012; Nam et al., 2009; Nostlinger et al., 2004; Oberdorfer et al., 2006; Rwemisisi et al., 2008; Vallerand et al., 2005; Vaz et al., 2010; Vaz et al., 2008). Prior researchers have called for discussions to occur between HCPs and parents to resolve differences that occur when HCPs perceive children to be ready for full disclosure but parents are not willing to proceed

(Lesch et al., 2007). Despite parents' resistance and urge to delay full disclosure to their children, both HIV-positive and negative children reported wanting to receive full disclosure in a timely manner. Prior researchers have reported that disclosure to children is the right thing to do and the right of the child (Heeren et al., 2012; Pilowsky et al., 2000; Weiner et al., 1998); the children in this study seem to ask for it.

Parents are known to delay testing their children due to fear of obtaining another positive test result; when they do have their children tested, it is typically those with signs of illness (Eisenhut et al., 2009; Ferrand et al., 2007; Ishikawa et al., 2010; Rwemisisi et al., 2008). After receiving the child's results, parents delay full disclosure of illness to those children (Vaz et al., 2011; Vaz et al., 2010; Vaz et al., 2008). In this study, HIV-negative children encouraged testing of all children post full disclosure of a parent's illness so they would know their statuses in order to prevent HIV-negative children from becoming infected and to prevent spread to others by HIV-positive children. HIV-positive children wanted to be informed of their illnesses so they could adhere to their ART, take better care of themselves, and gain self-independence. These needs expressed by HIV-positive and negative children should be a part of regular counseling provided to HIV-positive parents who seek guidance on disclosure to their infected and uninfected children.

HIV-positive and negative children have a desire to receive full disclosure of all illnesses within the family and do not like to be lied to. Those with dead siblings and/or parents wondered about the causes of deaths. As seen in prior research (Petersen et al., 2010; Vaz et al., 2010) and in this study, there were incidences of full disclosure of a parents' illnesses at the same time of disclosure of a child's illness for the purpose of achieving full disclosure of all illnesses, to

encourage a child, or because children guessed their illnesses came from the parent. Disclosure of many family members' illnesses at the same time had been cathartic for parents; however, some HIV-positive and negative children who received many disclosures at the same time were affected by the news for years. One mother who had performed full disclosure of both parents' illnesses at two different times to her older children stated one could not become "an expert" because each disclosure session had been different. If multiple illnesses are to be disclosed to a child, intense predisclosure counseling should be provided to improve the child's resiliency and capability to absorb the news; and also to assist the parent deliver the news in an appropriate manner (Murphy & Marelich, 2008). Post disclosure, HCPs should assess the family to check how they are doing (Bikaako-Kajura et al., 2006; Murphy, Roberts, & Hoffman, 2006).

Parents did not advocate for full disclosure of a child's illness when the child was ill, but they advocated for full disclosure if the ill health was due to poor ART adherence. ART adherence has been shown to increase following full disclosure (Bikaako-Kajura et al., 2006; Brown et al., 2011; Fetzer et al., 2011; Hejoaka, 2009; Vaz et al., 2008) with improvements in CD4 counts leading to fewer incidences of disease progression and death (Enzama & Mugenyi, 2005; Ferris et al., 2007). HCPs should encourage parents of infected children with deteriorating health status and reducing CD4 counts to perform full disclosure to these children. Parents were also hesitant to disclose their own illnesses when they were in poor health. Current improved availability of ART in SSA allows parents to improve their health and live for a long time (NACC and NASCOP, 2012), so it is possible for those parents diagnosed in poor health to postpone full disclosure until their health improves. However, full disclosure might be necessary when there is high child anxiety since children are able to guess the nature of illness.

Subsequently, parents and children can support each other (Ishikawa et al., 2011; Kennedy et al., 2010; Madiba & Matlala, 2012; Rwemisisi et al., 2008).

As recommended by participants in this and another study (Heeren et al., 2012), full disclosure should be a process starting with limited information at 5 years of age. One parent expressed that his 5 and 7-year-old children with full disclosure of their illnesses did not understand what it meant. It therefore appears children should receive disclosure when they are mature and capable of understanding. The most cited aged when full disclosure should be delivered from among all participants was 10 years. The age of 9-10 years has been cited as an ideal age for children to receive full disclosure because they can understand the nature and consequences of the illness (Schonfeld, 2002). Other researchers have reported similar suitable age ranges for full disclosure of 11-12 years in South Africa (Moodley et al., 2006); and 14 years in Ethiopia (Biadgilign et al., 2011) and Thailand (Oberdorfer et al., 2006).

However, few children in this study at 10 years had full disclosure even where parents or children had been diagnosed years before. The age when most children received full disclosure of a parent's or child's illness was 14 years although there were outliers (3, 19). Other researchers have also reported children receiving full disclosure of a parent's illness (Biadgilign et al., 2011; Nostlinger et al., 2004; Pilowsky et al., 2000) and a child's illness (Oberdorfer et al., 2006) as early as 4-5 years. The age range of 10-14 years is in alignment with recommendations by prior researchers that children receive full disclosure of illness before they reach adolescence where more negative impacts have been noted (American Academy of Pediatrics, 1999; Blasini et al., 2004; Lester et al., 2002; Siripong et al., 2007). Additionally, this study revealed that important

life events such as completion of a national examination should be incorporated into full disclosure planning and delivery.

Parents knew children were starting sexual activity at 9 years and children confirmed they knew their teenage peers were having sex. Early sexual debut, many partners, and low condom use has been cited as some of the reasons why HIV spreads in Kenya (Republic of Kenya, 2009). This early onset of sexual activity among children is worrisome and has implications for the control of the disease within the country. Imminent onset of sexual activity in children has been shown to prompt full disclosure to children (Oberdorfer et al., 2006; Vaz et al., 2011; Vaz et al., 2008; Wiener et al., 2007) especially to prevent asymptomatic infected children from infecting others (Kallem et al., 2011; Siripong et al., 2007; Vaz et al., 2011). The recommended ages of 10-14 years for full disclosure from participants in this study are achievable if HCPs recommend parents test all their children soon after the parent is diagnosed as being HIV-positive (Rwemisisi et al., 2008; Were et al., 2006). This testing would help in identifying children who maybe long-term non-progressors with no signs of illness (Vaz et al., 2008; Warszawski et al., 2007) who should then be enrolled into a treatment and disclosure program. As found in this and a Batswana study (Nam et al., 2009), HIV-positive parents and their children in Kenya are highly in need of sexual programs aimed at counteracting the early initiation of sex, sexual-related peer pressure, and improved use of protection during sex.

Overwhelmingly parents in this study wanted to be the ones performing full disclosure to their children, some alone and a few others with assistance from HCPs or close family members. The successful delivery of full disclosure is crucial to sustaining a good family environment post disclosure, and prior researchers have advocated for parents incapable of performing disclosure

on their own to seek help from HCPs, friends, or extended family members (Bikaako-Kajura et al., 2006; De Baets et al., 2008; Heeren et al., 2012; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana, 2005; Nam et al., 2009). It is interesting to note that most HIV-positive children preferred to receive disclosure from a HCP trained in disclosure delivery rather than a parent. As part of disclosure planning, an assessment maybe necessary to decide who is the best suited person to perform disclosure to a HIV-positive child even where parents may want to be the ones delivering the news.

The limitations of this study include a small sample size that was purposively selected to lend insight into the HIV disclosure process in Kenya. This sample may not be entirely representative of the target population. Interviews were conducted only with participants fluent in English thereby limiting representation and generalization of the findings to the target population. Future studies should be conducted using local national or dialect languages and have larger sample sizes. Further studies are needed to determine the best way to perform full disclosure of many illnesses and deaths within heavily affected families. The disclosure needs and preferences of HIV-positive children and HIV-negative children respectively need to be investigated. Children and parents are highly sexual-related programs to counteract early sex initiation with the aim of limiting the spread of the disease and control of the disease into the next generation.

This article presents rich data on how HIV-positive parents approach full disclosure to their HIV-positive and negative children; and how full disclosure is received and perceived by HIV-positive and negative children. Prior studies have mostly focused on disclosure of a parent's illness to their children or disclosure to HIV-positive children. This study's results are therefore

important because they provide a thorough view of full disclosure delivery from HIV-positive parents to children; and disclosure reception from the viewpoint of HIV-positive and negative children. The recommendations provided by participants in this study help address the gaps in knowledge on disclosing many family members' illnesses to children. Other important factors that should be considered include parent's and/or a child's health statuses, children's understanding and maturity level, important life events (e.g., national examinations), and the person best suited to perform disclosure to a child. These recommendations should be incorporated into preexisting or new guidelines, manuals, and programs on HIV disclosure from parent to child.

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