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HIV-Positive Parents' Accounts on Disclosure Preparation Activities in Kenya

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HIV disclosure from parent to child is a complex and challenging issue that plagues parents and healthcare professionals. Little is known about how HIV-positive parents prepare themselves and their children for full disclosure and what resources they need. This study was conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya, particularly the activities performed by parents in preparation for HIV disclosure. Qualitative phenomenological data was collected via in-depth semistructured interviews conducted with 16 HIV-positive parents with biological children aged 8–17 years who had no, partial, or full disclosure of their parent's (or parents') and/or a child's illness. The Van Kaam method was used to analyze data using NVivo Version 8. A number of themes emerged, indicating that most parents take years to prepare, proceeding when they judge themselves and their children adequately prepared. Preparation activities included thinking about and making disclosure plans, improving family relationships, reading information, teaching children about the disease, seeking counseling, attending support group meetings, praying, and attending religious activities. As more resource-poor nations prepare their own HIV disclosure guidelines, data presented here should be incorporated into guidelines, manuals, and programs in countries that mirror the Kenyan culture.

Keywords: *HIV/AIDS, HIV disclosure, child HIV status disclosure, parent HIV status disclosure, resource-poor nation, qualitative research, Kenya*

Introduction

As of 2012, there were 35.3 million persons infected with the HIV globally; 90% of them live in resource-poor nations, especially those within Sub-Saharan Africa (UNAIDS, 2013). By 2011, there were 1.6 million people in Kenya living with HIV (NACC & NASCOP, 2012); 1.4 million were adults, and 200,000 were children (UNAIDS, 2013). In 2012, the HIV prevalence rate within the country among adults aged 15–64 years was 5.6% and that of children aged 18 months to 14 years was 0.9% (National AIDS and STI Control Programme, 2013). HIV infected persons are living longer in Kenya due to increased access to antiretroviral treatment. However, HIV prevalence is expected to continue rising and will become even more of a national priority within the decades to come (NACC & NASCOP, 2012).

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HIV disclosure of a parent's and/or a child's illness to HIV-negative and HIV-positive children is widely known to be a challenge for parents (Blasini et al., 2004; Delaney, Serovich, & Lim, 2008; Gachanja, Burkholder, & Ferraro, 2014; Kallem, Renner, Ghebremichael, & Paintsil, 2011; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana, 2005; Menon, Glazebrook, Campain, & Ngoma, 2007; Vallerand, Hough, Pittiglio, & Marvicsin, 2005; Vaz et al., 2008). Some families have several of its members who are infected (Republic of Kenya, 2009), and this further complicates the disclosure planning and delivery process. Parents have been shown to delay disclosure until they accept their own illnesses (Nelms & Zeigler, 2008; Tasker, 1992). In the meantime, they think about and formulate vague disclosure plans to be performed in the future (Nam et al., 2009; Wiener, Battles, & Heilman, 1998). Additionally, infected persons might make and remake their minds several times on if and when to tell others about their illnesses (Black & Miles, 2002). We recently reported the factors that should be taken into consideration when parents are deciding if, when, and how to disclose to a child their own or their children's HIV infection status (Gachanja et al., 2014). These factors include a parent's right to decide when to disclose, a child's right to receive timely disclosure of all family members' illnesses and deaths, a parent's and child's health statuses, a child's maturity and understanding level, and the most suitable person to disclose to a child.

HIV disclosure is a dynamic process that evolves over time and should address local sociocultural practices (Blasini et al., 2004; Kallem et al., 2011; Vaz, Eng, Maman, Tshikandu, & Behets, 2010; Vaz et al., 2008). There are limited published details from Sub-Saharan Africa on how parents prepare themselves and their children for HIV disclosure. When preparing for disclosure of their HIV-positive children's illnesses, parents in the Democratic Republic of Congo prayed, planned answers in anticipation of children's questions, and spoke to a healthcare professional (Vaz et al., 2008). Vaz et al. (2010) also reported only 50% of parents prepared their HIV-positive children for full disclosure of the children's illnesses. Those who prepared their children did so immediately before disclosing by expressing love for the child, providing gifts, and cooking the child's favorite foods. In Botswana, only two of 32 parents taught their children about the disease in preparation for disclosure of the parents' illnesses (Nam et al., 2009).

The four-phase model of HIV disclosure (Tasker, 1992) formed the conceptual framework for the study. Tasker (1992) proposed that HIV-positive parents go through four phases when preparing to fully disclose their own illnesses to their children. In the first phase (secrecy), parents tell their children nothing while parents absorb the news of their diagnoses. In the second phase (exploratory), parents begin to provide limited details of the disease (without mentioning its name) to their children, such as indicating that the parents are attending clinic visits and/or taking medications for a chronic illness. Parents also begin to make future tentative disclosure plans. In the third phase (readiness), parents provide even greater details of their illnesses to their children and start initiating disclosure plans. They attend support group meetings to speak with peers and disclose to trusted loved ones and/or healthcare professionals whom they want to be present when fully disclosing to their children. Finally, in the fourth phase (full disclosure), parents tell their children all the details of their illnesses including its name. The four-phase model has not been extensively tested for use in disclosing HIV-positive children's illnesses or both a parent's and a child's illness in families where both parent(s) and child(ren) are infected.

The current study was modeled after the study conducted by Vaz et al. (2008) in the Democratic Republic of Congo as part of a newly established family care center offering comprehensive HIV care to infected youth. To understand the lived experiences of HIV-positive parents and their children during the HIV disclosure process in Kenya, we expanded on the Vaz et al. (2008) study (which

focused on HIV-positive youth) by including HIV-positive parents having both biological HIV-infected and -uninfected children from a wider age group (8–17 years) and HIV-positive and negative children aged 12-17 years (Gachanja et al., 2014). Data presented here are derived specifically from the parents' accounts and focus on expanding the knowledge about the activities undertaken by parents as they prepare themselves and their children for HIV disclosure.

Materials and Method

Setting and Design

Qualitative interpretive phenomenological data were collected at the Kenyatta National Hospital Comprehensive Care Center located a few kilometers from the center of Nairobi, the capital city of Kenya. Kenyatta National Hospital is a national government research and teaching hospital that caters to sick people from all over the country. The Comprehensive Care Center is located in a separate building from the hospital and mainly serves HIV-positive persons from Nairobi and accepts referrals from other Comprehensive Care Centers within the country. The Comprehensive Care Center is funded by the United States President's Emergency Plan for AIDS Relief. Patients are seen every 3 months via appointment or as a walk-in if they have a health problem that needs to be taken care of. Most patients walk to the clinic from the nearby slum areas close to the hospital or take public transportation from middle-income communities in the city. A few drive in from affluent areas.

Because the HIV disclosure process from parent to child is poorly understood in Kenya, we chose to use the interpretive phenomenological approach to understand the lived experiences of parents as they prepared themselves and their children for full disclosure. Ethics approval for this study was received from the university's Institutional Review Board (Approval # 11-10-10-03904), and the Kenyatta National Hospital Research Standards and Ethics Committee (Approval # P373/10/2010). Potential participants were notified of the study's details via the informed consent process and asked if they were willing to participate. Those who agreed to participate provided written informed consent to be in the study and verbal consent for digital recording of their interview sessions.

Participants

HIV-positive parents in the study were recruited at the Comprehensive Care Center's waiting areas by the first author during their regularly scheduled clinic visits. The parents were also referred to the first author from the reception area by peer educators as well as from the triage and patient examination rooms by nurses and clinical officers (equivalent to physician assistants in the United States). Eligible participants were informed of the study details by the first author, and those who agreed to participate were then taken to a private room within the clinic where the interviews were conducted. HIV-positive parents having at least one biological child aged 8–17 years were purposively selected to be in the study. To gain a good understanding of the HIV disclosure experience from a parent's perspective, these parents had children to whom they had performed no, partial (child had limited information about the illness), or full disclosure (child was told the name of the illness) of a parent's and/or a child's illness. Sixteen HIV-positive parents, including one married couple, were recruited into the study.

Data Collection and Measurement Protocols

All parents underwent in-depth, semistructured interviews conducted by the first author. Demographic questions were asked first, followed by disclosure-related questions. Interview guides were adapted from the study conducted by Vaz et al. (2008) by removing questions that did not address disclosure. The adapted guides were carefully reviewed with two members of the research committee (the last two authors) who are familiar with qualitative research and instrument design. The interview guides explored, among other things, the activities performed by parents to prepare themselves and their children for disclosure. Parents who had already disclosed to their children were asked how they had prepared for disclosure, and those who were in the process of disclosing to their children were asked what activities they were performing or planning to perform as they neared the time of full disclosure to their children. Interviews lasted 30–90 min and were performed in English, the official/national language of Kenya used in schools and in the conduct of business within the country. All recruited participants were well versed and fluent in the language.

Data Analysis

Recorded interviews were transcribed immediately following the interviews by the first author and a local university student well versed with transcription. Transcriptions were cross-checked twice against the recorded interviews for accuracy. Transcription accuracy was also ascertained with member checking; interview transcripts were sent to five (15%) of the participants for review. Transcripts were then imported into NVivo Version 8 software for data management and coding. We were guided by the modified Van Kaam method of analysis (Moustakas, 1994). The transcripts were listed, grouped, and examined for codes, and the resultant codes were clustered into seven themes spanning the HIV disclosure process. The final codes and themes were cross-checked against selected transcripts by the two committee members supervising the study. Presented here are results from within the preexistent disclosure framework about how parents prepare themselves and their children for full disclosure delivery.

Results

The 15 families (two parents were a couple) comprised a diverse mix of HIV-infected and uninfected children with different HIV disclosure statuses; one parent's spouse was HIV-negative. The parents' demographic profiles and HIV disease characteristics are presented in Table 1. Their children's demographic and disclosure statuses are presented in Table 2.

Table 1: *HIV-Positive Parents' Social-Demographic Profiles*

Variable	Frequency
Age	
31–40	8
41–50	7
51–60	1
Gender	
Female	11
Male	5
Employment status	
Employed	16
Unemployed	0
Educational status	
Primary	2
Secondary	7
College	7
Marital status	
Single	1
Divorced	1
Widowed	4
Married	10
Religion	
Catholic	6
Protestant	9
Muslim	1
Years since diagnosis	
<1	2
2–5	6
6–10	6
10+	2
CD4 count at diagnosis/at time of interview	
<350 cells/mm^3	9/5
>350 cells/mm^3	5/10
Not available (1 parent newly diagnosed)	2/1
Medications	
ART and Cotrimoxazole	14
Cotrimoxazole only	1
None (1 parent newly diagnosed)	1
No. of children	
1	2
2	8
3	2
4	1
5	2
6	1
No. who had performed full disclosure to at least 1 child in the household	
Parental HIV infection status	9
Child HIV infection status	8
Both parent and child HIV infection statuses	6

Table 2: *Children's Demographics, Testing, and Disclosure Status*

Family	No. of Children	Sex of Children	Age of Children	No. of Children Tested	No. of HIV+ Children	Child's HIV Status	No. of Children With PD/FD of Parent's Illness	No. of HIV-Positive Children With PD/FD of Own Illness
A	2	M, F	13, died at 6 months	1	1	+, Unk	0/1	0/1
B*	1	F	11	1	0	–	1/0	NA
C	1	M	17	1	1	+	0/0	0/1
D	3	M, M, F	26, 17, 10	3	2	+, +, –	0/2	0/2
E*	3	F, F, M	14, 7, 5	3	2	–, +, +	0/3	0/2
F	2	F, F	14, 9	1	1	Unk, +	2/0	1/0
G^	2	M, M	14, 12	1	1	+, Unk	0/2	0/1
H	4	F, F, M, M	21, 15, 13, 7	2	1	–, +, Unk, Unk	0/2	0/1
I*	2	M, F	16, 5	2	2	+, +	0/1	1/1
J*	2	M, M	12, 9	2	1	+, –	0/0	0/0
K*	2	F, M	8, 6	0	0	Unk, Unk	0/0	NA
L* (couple)	5	M, M, F, F, M	25, 24, 22, 20, 15	2	0	Unk, –, Unk, –, Unk	1/4	NA
M*	2	F, F	14/NC	1	0	–, Unk	0/1	NA
N*	6	M, M, M, M, Unk, F	19, 17, 14, 11, SB, 4	5	2	–, –, +, +, Unk, –	1/4	1/1
O	2	M, M	17, 11	1	1	Unk, +	1/0	1/0

Note. No. = number; PD = partial disclosure/limited details of illness; FD = full disclosure/fully aware of illness; M = male; F = female; + = HIV-positive; Unk = unknown; * = spouse HIV-positive; – = HIV-negative; NA = not available; ^ = spouse HIV-negative; NC = not collected; SB = stillborn.

Parents prepared and partially/fully disclosed to their children based on birth order regardless of the child's HIV status. Sometimes children close in age were prepared together and received full disclosure at the same time. Figure 1 displays the activities performed by parents in readiness for full disclosure, and these activities are further described in the subthemes that follow.

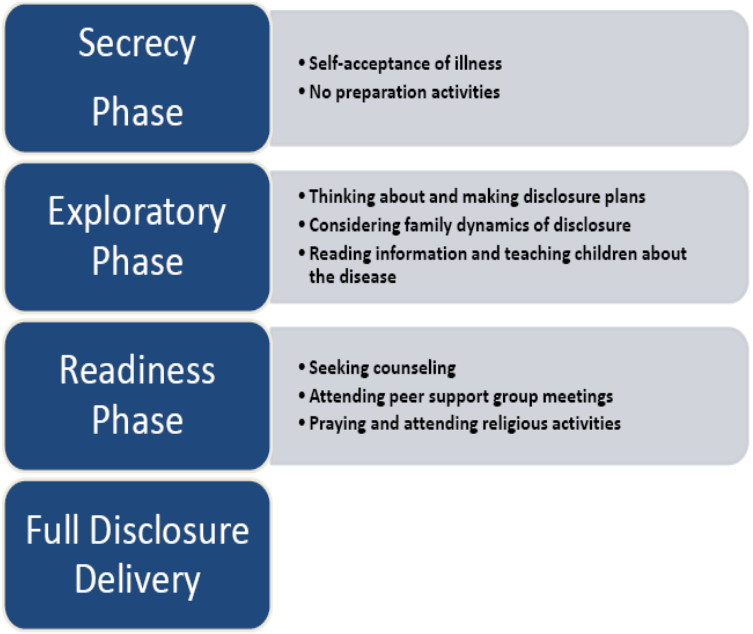

Figure 1: *HIV-Positive Parents' Disclosure-Related Preparation Activities*

Secrecy Phase

Acceptance of Illness

The impact of receiving their own diagnoses was stressful to parents, and they took time to accept their own illnesses. They went through a period in which they did not disclose anything to their children. A married father of one HIV-negative and two HIV-positive children stated the following:

> *It was very difficult for us to chew those words because we thought the world was over. It took time for me and my wife to give one another courage. We decided first to keep it a secret among us.*

Due to the challenges associated with full disclosure, some parents expressed the ideal time to start disclosure preparation was when a parent had contemplated, understood, and accepted the nature of his or her own illness. A married father of two HIV-negative and three untested children stated the following:

> *You can't tell them the same day you are tested, the same day involved you don't know anything … You need to prepare yourself to be normal then you talk to them.*

No Preparation Activities

Some parents did not prepare their children before full disclosure of illness; three mothers fully disclosed to their children without extensive preparation activities. Two of these mothers chose to fully disclose theirs and their teenage children's illnesses immediately following the children's diagnoses at the voluntary counseling and testing center as a form of encouragement. A widowed mother of one HIV-negative child, one HIV-positive child, and two untested children, whose daughter fell suddenly ill while away at boarding school and returned home for treatment, stated the following:

> *She came when she was very happy, she knew she was negative, and we told her exactly what happened. She burst into tears and said she doesn't have the what, we need to leave, she talked badly eh! We were all shocked, the counselor tried to counsel her, she was so confused, and she cried. She shouted she is going to kill herself, she is not seeing the reason for living … I told her don't worry this is life because even me personally I am sick and have you realized that I have been sick? I am also positive. She said Mum!*

The other parent was a single mother whose child was diagnosed before her. She remained secretive about his diagnosis until she fully disclosed his illness to him a year later in the presence of a doctor at the clinic. She herself was tested 6 years later and was again not planning to prepare her son for full disclosure of her illness. She explained,

> *I didn't prepare him, I just told him … I was to be tested* (clicks tongue) *but I waited, I didn't want to hear the news … I will keep them [antiretroviral therapy] in the place he keeps his so he can ask whose is this? It is mine, simple.*

(In Kenya, tongue clicks during difficult conversations usually convey discomfort or tension.)

Exploration Phase

After acceptance of their illnesses, parents began to explore how they would fully disclose to their children. Parents began to think about and lay the groundwork for full disclosure.

Thinking About Disclosure

One parent diagnosed within 6 months of her interview had not contemplated disclosure preparation. The realization that she would have to tell her children one day made her very emotional. One other parent had a 12-year-old disabled, infected child, and a 9-year-old uninfected child to whom she had not yet thought about fully disclosing. She explained,

> *The disabled one, I won't tell him … The younger one I have never thought about telling him for now.*

While contemplating disclosure, the need to test their children stayed in parents' minds because they wondered which of them was similarly infected and would need disclosure of illness. HIV testing for children was delayed until parental acceptance of illness or when children developed signs of illness. Testing was considered but postponed for siblings with different fathers from infected children and those children who looked healthy. A married mother of one HIV-positive son and one untested child stated the following:

> *One of them was becoming sick often so I decided to take him to the doctor and get him tested. The younger one I haven't decided … I am not ready for the news but I am preparing …* (Clicks tongue) *I might be shocked.*

After confirming which of their children were infected, parents weighed the need to disclose some or all the illnesses to their children sometimes for years, making and changing their minds on if and when to proceed with full disclosure preparation. In the meantime, married parents decided how they would answer children's questions about obvious signs of illness and/or antiretroviral therapy consumption. A married father of one HIV-negative child and two HIV-positive children stated the following:

> *It is very weighty because maybe some dishonesty between you and her mother, someone might have gone out … So you have to come to an agreement when one of them asks a question, which question how you are going to handle her.*

Some parents reported delaying disclosure to their children because of conflicting advice received from healthcare professionals and called for disclosure information to be presented in a comprehensive manner. A widowed mother of one HIV-positive child explained,

> *When he was about 6 years that is when I started thinking about it because actually I was concentrating on his [poor] health first, so I put off to tell him … I sought advice from the clinic here, and they told me to wait a bit. In fact it was a mixture of so many, I used to come I ask, others they say wait, others say wait until he is 8 years, others tell him when he is 10 … Every now and then it used to cross my mind, earlier it used to be after a week, but towards the ends when I told him it was almost on a daily basis that I used to think about it.*

A married father of one HIV-negative child added,

> *I would appreciate if there would be a way for others not to have done as I did. I did a lot of research myself and now if all was brought to one place in one book, it would be very simple for them, and very easy and cheap.*

Some parents who had fully disclosed to their older children expressed that children reacted differently to full disclosure. As a result, they carefully thought about and planned how to disclose to younger siblings. A mother who extensively prepared and fully disclosed to her four oldest children because her husband had a poor relationship with them explained,

> *They react so differently but this one [last born] has a temper, I don't know what he will do but he can surprise me I don't know* (laughs) *… Maybe I am just becoming over protective but given the [poor/emotional] reaction of the other ones I don't know how to [fully disclose] because the others were never too close especially to me, but this one I am not sure how he will react that is what is bothering me.*

As children grew older and began to show understanding and maturity and parents' confidence levels on their capability to fully disclose increased, the thoughts on disclosure increased in frequency from quarterly to daily, occasionally creeping into parents' minds during activities of daily living or when it was time to go to the clinic. A widowed mother of one HIV-positive child and one untested child explained,

> *I think of disclosure when we have just finished eating, when we are happy, that's when I think of it.*

Another widowed mother of one HIV-positive child and one untested child stated,

> *When times come when I am coming this side [to clinic] is when I think of it now* (clicks tongue)*, I wish I could have told my son the reason why am I going, but once I leave this place it disappears* (laughs).

Considering Family Dynamics of Disclosure

Kenya is a patriarchal based society and of the five married men interviewed for the study, four had taken the lead in preparing their children for full disclosure. These men decided with their wives who would be the one to perform the actual disclosure. A married father of one HIV-negative child stated the following:

> *She asked her mother why do you and dad take medicine? Then her mother came and told me and I told her I will handle her from there.*

Three of five married women actively had to take the lead in preparing children because their husbands did not want to or felt unable to participate due to the guilt of bringing the illness into the home. A married mother of two HIV-positive children stated the following:

> *He [husband] has not accepted his illness* (laughs) *… With these HIV matters, he doesn't discuss the truth, in fact he doesn't want to discuss, so it is my own decision.*

Widowed, divorced women, and other parents who felt unable to fully disclose on their own involved or planned to involve persons (e.g., parental siblings, grandparents, pastors, healthcare professionals) the parent or child was close to. A widowed mother of one HIV-positive child and one untested child stated the following:

> *In a family there is an uncle that the child loves so much, in the church a pastor he loves so much … Now my work is to identify who he loves most so that I bring these people together we sit and talk.*

To help children receive the news well, parents started providing increased attention or gifts to children they were preparing for full disclosure, so the children would receive the news in a better fashion. A married father of three HIV-negative children, two HIV-positive children, and one untested child stated the following:

> *Normally [before full disclosure] whenever he [14-year-old infected son] asked for anything then we gave it to him, he asks for money, any food he wants, it was made available so he can come nearer to us … The 11-year-old [also infected] I am trying to study his behavior and character, what annoys him and what not annoys him you see? I am trying to take him for an outing probably next year then I will tell him.*

Reading Information and Teaching Children About the Disease Without Disclosing

Parents increased their knowledge on the disease and disclosure by reading printed information provided by the clinic, churches, and their children's schools. These materials comprised their children's textbooks and HIV/AIDS-related pamphlets, brochures, and magazines. Some parents passed these printed materials to their children to read as well. Parents expressed that their

children were known to be sexually active and, therefore, needed to be taught regularly about the disease. To maintain child awareness of the disease, older children with full disclosure continued to receive teachings alongside their younger siblings with no or partial disclosure who were being prepared for full disclosure. A married mother of two HIV-negative children and three untested children stated the following:

> *I usually used to come with pamphlets from hospitals I ask them to read. In school they were being taught about it so they were not so green.*

HIV/AIDS-related shows were televised and broadcast regularly on TV and radio, respectively, and parents watched and listened with their children. Additional exposure to the disease for children was obtained through the community and schools, but parents reported their children held misconceptions about the disease. Typically, parents asked their children innocuous questions about what they knew about the disease to find out their understanding and stand on the disease. They then actively and regularly taught their children about the disease to clear any identified misconceptions and lower the stigma and discrimination their children held against infected persons. Teachings were provided during family meetings or in the conduct of daily living activities when an opportunity presented itself. A married father of one HIV-negative child and one untested child stated the following:

> *I asked her can you really explain to me, what do you understand not what is written, or what your teacher tells you HIV is, but can you explain to me you yourself what is HIV to you? Then she said to me dad it is a disease you get and you die* (laughs). *She called it a killer disease* (laughs) … *I started laughing and then told her no, no, no this is not right, your understanding is not correct. I started teaching her real sense what is HIV virus, and how you go about it to reach the stage of being HIV then having AIDS. I think at that point I didn't tell her but I made her understand that being positive doesn't mean you're going to die, being positive doesn't mean all those things she thought it meant and I taught her the difference between having AIDS and being HIV-positive. So I think through that angle now I opened a door that now it is easier than yesterday to tell her of my situation because she understands the disease.*

Readiness Phase

When parents started perceiving themselves as being ready to fully disclose and they judged their children as being receptive to the news, they started actively seeking activities that would assist them to deliver the news. Parents then began to focus on an intended time for full disclosure by planning a disclosure session at the clinic or waiting for the right opportunity to present itself at home.

Counseling

Parents sought disclosure advice during clinic visits from healthcare professionals or made appointments for counseling with the psychologists at the clinic. A married mother of two HIV-positive children stated the following:

> *When I used to come here for clinic [before disclosure], we were free to ask any questions and it's good we were being answered positively, from there we could pick what to tell our children especially teenagers because they are very sensitive.*

To prevent inadvertent disclosure, discussions between healthcare professionals and parents in children's presence were kept in line with parental wishes on the child's current disclosure status. A widowed mother of one HIV-positive child and one untested child stated the following:

> *I usually come with him, the doctor talks to me but not using the same words with him because the doctor knows and respects the situation that he doesn't know.*

Parents credited the counseling received at the clinic in contributing to their readiness and preparedness to fully disclose, especially the words to use. A married father of one HIV-negative child and two HIV-positive children explained,

> *I had a lot of difficulty on how I was going to start telling her … The counseling gave me morale, a lot of energy to go and sit and talk to her.*

No parent mentioned bringing their HIV-negative children to the clinic for counseling in preparation for full disclosure. However, parents were assisted by healthcare professionals to identify HIV-positive children who were ready (e.g., those asking questions about antiretroviral therapy, clinic visits, nature of illness) for full disclosure so they could be taken for counseling before full disclosure delivery. A married father of three HIV-negative children, two HIV-positive children, and one untested child stated the following:

> *As they take the medicine you know sometimes they will ask why am I taking this medicine always? They will ask you some questions and he has not reached the age to tell him about his disease or even if you tell him he will just get in that 15 min time, after 15 min he has forgotten. It is better for the child to reach at a mature age then you counsel him slowly with the help of the counselors here … The doctors said it was the right time to tell him, I had to agree with them.*

Use of Support Groups

Due to high stigma levels directed against people with the disease, parents mostly sought disclosure advice from similarly infected persons within the confines of support group meetings or from trusted infected and affected family members and friends. Two parents recently diagnosed were not aware of the presence of support groups, and some parents had formed their own support groups outside the clinic with members of their communities they had met at the clinic. Two mothers revealed while waiting to be attended to in the waiting rooms; parents informally spoke and advised each other on HIV-related and disclosure matters. One, a widowed mother of one HIV-positive child and one untested child, explained,

> *In fact when they are there I feel they talk when they are so free, they are more free than maybe when somebody is standing there to teach, to talk about it because they keep quiet and listen, but when they are there everybody talks … Like today there are the ones who are talking but they wonder why you have not told your child.*

Support group sessions at the clinic were held weekly and run by peer educators; within this setting, parents felt freer to share and advice each other on their disclosure experiences. Parents shared that during meetings, other parents relayed they also had difficulty disclosing to their young and adult children. In fact, one parent who was a peer educator at the clinic also needed help with disclosure. She explained,

> *I needed advice from the other peer educators so that they can help me to talk to him, so the first step I had to ask my peer educators to help me … I tried to talk to my friends to get advice, some they are from support groups, some there are just friends, relatives, I have even relatives who are also HIV-positive, so I share a lot with them.*

HIV-negative children did not attend support group sessions at the clinic, but the clinic held quarterly support group meetings for HIV-positive children when school was out of session. During meetings, HIV-positive children were separated based on their disclosure status and age so they would be provided with the appropriate information leading up to full disclosure. A married father of one HIV-negative child and two HIV-positive (5- and 7-year-old) children explained,

> *They are only told about the medication and how to associate with others.*

Religion and Prayer

Parents found the contemplation of full disclosure so challenging, many prayed about it. Kenyan society is very religious and attends church and mosque services frequently. Prayer is a regular way of life performed in different faiths. In preparation for full disclosure, parents encouraged or planned to encourage their children to increase their faith in God so they could cope with the disease. A widowed mother of one HIV-positive child and one untested child stated the following:

> *I am going to tell him the experience of what I have gone through, now at least I have words to encourage him … You know son it was in me before I gave birth to you, but look at the far we have gone, so that means God can take you farther than that.*

Some parents disclosed to their religious leaders and/or church members and asked for prayer. Some met regularly with persons to whom they had disclosed to pray over issues associated with the disease and disclosure in fellowship meetings or masses held at their homes. A married father of one HIV-negative child and two HIV-positive children stated the following:

> *I had to tell him [church chairperson] we have this problem and make it private and confidential for us … They [church members] had to come visit us at home, we had masses.*

When parents were finally ready to fully disclose, they prayed for courage and the words to use. A divorced mother of two HIV-positive children and one HIV-negative child stated the following:

> *I had to pray to God first and ask God to give me* (sighs)*, I mean to try and give me how I can talk to him.*

Discussion

Our small qualitative study indicated that most parents preferred to carefully prepare themselves and their children sometimes for years before disclosing a parent's and a child's illness. Similar to Tasker's (1992) research, most parents in this study were initially secretive about their illnesses but later moved on to the other phases of disclosure. Unlike parents in Tasker's (1992) research, who mainly prepared themselves to deliver the news, in this study, when acceptance of parental illness occurred, parents proceeded to carefully prepare themselves and their children for lengthy periods before fully disclosing. They moved into an exploratory phase, during which they thought about and began making disclosure plans. They read about and taught their children about the disease while also trying to improve their relationships with their children. When parents reached the readiness

phase, they sought counseling for themselves and their HIV-positive children, attended support group meetings with their HIV-positive children, and performed/attended religious activities. Finally, most completed the four phases of disclosure and fully disclosed a parent's and/or a child's illness to at least one child within their households.

Parents in our study have previously described disclosure preparation and delivery with descriptors such as "hard," "burden," "weighty," and "hurting" (Gachanja et al., 2014). HIV disclosure is known to be psychologically and emotionally challenging for parents due to the stress and pain associated with disclosure (Kouyoumdjian et al., 2005; Palin et al., 2008; Vallerand et al., 2005); and guilt and a perception of incapability to fully disclose (Blasini et al., 2004; Kallem et al., 2011; Kennedy et al., 2010; Kouyoumdjian et al., 2005; Vaz et al., 2008). As a result, a few parents chose to maintain secrecy of the illnesses within the family and did not follow the four sequential phases of Tasker's (1992) four-phase model. Similar to the findings of Nam et al. (2009), some parents had not yet thought of disclosing, whereas a few others had thought about it but postponed it to a later undecided time. Three mothers fully disclosed their HIV-positive children's illnesses without preparation; one out of choice and two immediately following testing at the voluntary counseling and testing center. Healthcare professionals need to be aware that some parents may choose to skip some phases of the disclosure model and proceed straight to full disclosure, whereas others may remain entirely secretive for lengthy periods. These parents (and newly diagnosed ones) may benefit from additional counseling on the merits of preparing themselves and their children for full disclosure and acceptance of illness respectively.

Some researchers have reported incidences of unintended or unplanned disclosures showing that parents do not have complete control of the disclosure process (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Kennedy et al., 2010; Madiba & Matlala, 2012; Pilowsky, Sohler, & Susser, 2000; Vallerland et al., 2005). Additionally, parents in a United States study advised other parents to plan ahead in order to avoid inadvertent disclosure (Kennedy et al., 2010). Parents in this sample (Gachanja et al., 2014) and a South African (Madiba & Matlala, 2012) study have advocated for other parents to await improvement of parental health status before fully disclosing a parent's and a child's HIV status (Gachanja et al., 2014). One parent whose teenage daughter received disclosure of hers and her mother's illnesses' at a voluntary counseling center without preparation reacted poorly to the news and was suicidal. This indicates that children may need to be prepared first before full disclosure, more so if they are teenagers and/or in poor health. Hazra, Siberry, and Mofenson (2010) have previously called on healthcare professionals to start preparing parents for disclosure of their HIV-positive children's illnesses as soon as those children are enrolled for care. Healthcare professionals need to advise parents to anticipate that opportunities for full disclosure might present themselves before parents are completely ready to impart the news and how to handle those full disclosure sessions.

Currently in Kenya, guidelines for disclosure of a parent's and/or a child's illness are lacking and this may contribute to low HIV disclosure rates and the delay of full disclosure delivery. Conflicting advice provided by healthcare professionals caused some parents to delay full disclosure delivery to their children for years. A few parents called for disclosure information to be presented in a comprehensive book for their use. Ambiguous advice from healthcare professionals and a lack of disclosure guidelines have been found to impede full disclosure delivery in prior research conducted in Sub-Saharan African countries (Kallem et al., 2011; Myer, Moodley, Hendricks, & Cotton, 2006; Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008). Healthcare professionals may benefit

from training on the four-phase model so they are able to identify the disclosure phase a parent is in and help rather than deter/delay him or her from progressing into the subsequent phases. In 2011, the World Health Organization (WHO) issued guidelines for disclosure to HIV-positive children (of their own illnesses) up to 12 years of age. In the absence of culturally appropriate and country specific guidelines, these WHO guidelines maybe used by healthcare professionals to aid parents in the facilitation of full disclosure delivery.

Some parents were unaware of support groups, and HIV-negative children were not provided with support group services or counseling at the clinic. Only five parents (31%) attended support group meetings and all had fully disclosed to their children. It was interesting to note that parents advised each other in the waiting rooms on disclosure matters. These informal exchanges represent an untapped resource that may help parents to prepare and fully disclose to their children, especially those unaware of or unable to attend support group sessions due to work or time constraints. The use of support groups has been found to increase infected persons' confidence, disease awareness, and disclosure rates (Hardon et al., 2013; Gillett & Parr, 2010; Norman, Chopra, & Kadiyala, 2007). Attendance of support group sessions should be augmented with counseling because it has been shown to improve disclosure rates (Ssali, Wasagami, Kateeba, Nantume, & Kiboneka, 2012). Indeed, parents in this study credited the counseling received in getting them ready to fully disclose. As part of clinic procedures at the time of enrollment, parents should be informed of and encouraged to use all services available at a clinic. Additionally, efforts should be made to include HIV-negative children in clinic disclosure-related services (e.g., counseling, support group meetings).

The Kenyan culture is based in patriarchy, and four of the five married men in this study led the preparation activities within their households. A few fathers (one father and two spouses of mothers in the study sample) were too ashamed to participate in disclosure-related preparation activities and remained secretive toward their children about their illnesses. In these households in which husbands did not take the lead in disclosure preparations, women took up that role because either the man had not accepted his illness or felt guilty in his role in bringing the infection into the family. Cultural factors in Sub-Saharan Africa have been shown to reduce disclosure of illness from men to women (Miller & Rubin, 2007; Njozing, Edin, Sebastián, & Hurtig, 2011), and it appears this may have also affected preparation and disclosure of illness from some fathers to their children as seen in this and a Thai study (Oberdorfer et al., 2006). Some parents carefully prepared younger children because their older siblings had reacted poorly to prior full disclosure. One of these parents had prepared the older children extensively before full disclosure delivery, but the father had a poor baseline parent–child relationship. Improvement of parent–child relationships prior to full disclosure has been shown to lead to better outcomes (Bikaako-Kajura et al., 2006; Murphy, Armistead, Marelich, Payne, & Herbeck, 2011; Nam et al., 2009; Petersen et al., 2010; Vaz et al., 2010). Therefore, targeted predisclosure interventions geared toward men, both parents, or the whole family may assist parents to fully disclose as a unit, improve family dynamics and disclosure outcomes, and increase disclosure rates especially from father to child.

There were high levels of stigma and discrimination in the country. Parents, therefore, felt the need to educate their children thoroughly about the disease and clear misconceptions in the hope that full disclosure would be easier. Parents aimed to increase acceptance of infected persons by their children prior to fully disclosing. Corona et al. (2006) have previously called for healthcare professionals to assist parents with information on how to initiate conversations/teachings with children as they prepare for full disclosure. Unlike studies in Botswana (Nam et al., 2009) and Uganda (Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013) that found that parents had inhibitions

about discussing sexual matters with their children, some parents in this study initiated disclosure preparation activities and spoke to their children about sexual matters because children were known to be sexually active.

The results of this study appear to support the four-phase model of HIV disclosure with some exceptions. Most parents sequentially negotiated the four phases of disclosure moving from secrecy to exploratory to readiness and finally to full disclosure. However, a few moved straight to full disclosure of theirs and/or their children's illnesses to their infected children. It is important to note that many parents in this study were simultaneously in multiple phases of the four-phase model, as they sequentially moved their children with no disclosure to full disclosure based mostly on birth order. This further demonstrates the complexity and challenging nature of HIV disclosure from parents to their children, especially when there are many children in the family and/or many HIV-positive family members whose illnesses need to be disclosed to children. Additionally, the model worked for disclosure of both parental and child HIV infection status. As part of disclosure planning, healthcare professionals should create a targeted family-oriented disclosure plan aimed at assessing child disclosure levels and that assists parents in navigating the complex disclosure process until all their children have been fully disclosed to. Further studies (especially quantitative ones) are necessary to test the four-phase model's utility in disclosure of HIV-positive children's illnesses and disclosure of both a parent's and a child's illness within families in which both parent(s) and child(ren) are infected. With training, healthcare professionals can adapt and tailor the four-phase model for use in resource-poor and -rich countries based on local available resources and cultural/religious preferences. Additional studies (especially quantitative ones) may be necessary to ascertain which disclosure services are most effective in HIV disclosure facilitation and delivery using the model.

This study's strengths include providing detailed information about the phases parents go through and the activities they perform in each phase to get themselves and their children ready for full disclosure delivery. Additionally, the parents we interviewed had both infected and uninfected children who had different types of disclosure statuses (no, partial, and full), thereby providing rich data on the HIV disclosure process. Furthermore, the results of the study address the knowledge gap on how HIV-positive parents prepare themselves and their infected and uninfected children for full disclosure in a resource-poor setting and the services available to them. The limitations of this study include a purposively selected small sample size of participants fluent in English who may not be representative of the target population. These findings may not be generalizable to settings that do not closely mirror the studied population. To address these limitations, future HIV disclosure studies should be larger and preferably quantitative in nature, with interviews conducted using a common national (e.g., Swahili) or local-dialect language. Future research should also focus on identifying the process and rates of full disclosure from HIV-positive parents to all infected and uninfected children within the same household.

Implications for healthcare policy arise from this study. Households represented in this study had a mixture of infected and uninfected family members including HIV-positive discordant and serodiscordant parents and HIV-positive and negative children. Guidelines are available for disclosure to a HIV-positive child (of his or her own illness) up to 12 years old from WHO (2011). However, as indicated in this study, parents with HIV-positive children diagnosed after 12 years, HIV-positive children who have not been fully disclosed to by 12 years, those with only HIV-negative children, and those in serodiscordant relationships are still in need of disclosure guidelines. Further

studies are needed to inform creation of guidelines for parental HIV infection status disclosure. More training programs on HIV disclosure are needed for healthcare professionals who work with HIV-positive families. The resources needed or used by parents in resource-poor nations during the HIV disclosure process need to be investigated, reported, and also incorporated into these guidelines. There has been little involvement of HIV-negative children in HIV disclosure studies, and their perspectives (especially on the use of counseling and support groups) need to be ascertained because they may be different from those of HIV-positive children. Programs are needed to assist parents and children who have undergone an unplanned or unintended full disclosure to ensure a good outcome. Finally, given the rising global rates of HIV infection among children aged 10–19 years (UNICEF, 2014), the reasons why children have early sexual debut in an era of high HIV/AIDS awareness needs to be studied with the aim of creating programs and services to counteract this.

Conclusion

In conclusion, this study indicated that parents are challenged by full disclosure delivery. They go through four main phases that include secrecy, exploration, readiness, and finally full disclosure. For most parents, navigating the phases takes years until all their children have been fully disclosed to, and conflicting advice received from healthcare professionals may further delay the disclosure process. Healthcare professionals are in need of HIV disclosure training so they can better facilitate the disclosure process from parent to child. As part of this training, the disclosure phases identified in this and Tasker's (1992) research should be included to help healthcare professionals provide targeted family-specific advice that helps parents navigate the disclosure process in a timely manner. Other important considerations for HIV disclosure to include in the training are parent and child health statuses, parent–parent and parent(s)–child relationships within the family, child's age of sexual debut, and when to refer parents and/or their children for disclosure-related services (e.g., counseling, support groups). As more and more resource-poor nations formulate their own disclosure guidelines, programs, and manuals, these findings should be extrapolated into these guidelines for countries with cultures and communities that mirror the Kenyan population.

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