Parental disclosure of HIV status:
Experiences and perceptions of HIV positive parents in Nairobi, Kenya

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Abstract

Parental disclosure of HIV status: Experiences and perceptions of HIV positive parents in Nairobi, Kenya

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Background: Research on parental disclosure of HIV status to children is limited, especially in sub-Saharan Africa where most HIV-infected adults reside. Rates of parental HIV disclosure cited in the literature range from 11-50%. We conducted a mixed methods study to examine rates of parental HIV disclosure and explore factors that influence a parent's decision to disclose their HIV status to their children in Nairobi, Kenya.

Methods: Among HIV-infected parents enrolled in the ongoing *Counseling and Testing for Children at Home (CATCH)* study, we determined rates and cofactors of disclosure of parental HIV status to partners, family members and children. The study recruited HIV-infected adults from HIV treatment clinics and enrolled those who had at least one ≤12 year old child of unknown HIV status. In addition, in-depth interviews were conducted with 6 parents to ascertain perceived barriers and facilitators of the process of disclosing one's HIV status to one's child and factors that influence the decision to disclose.

Results: Among 74 adult participants, median age was 35 years (IQR 32-38) with a median of 5 years since HIV diagnosis; most (84%) were female. Although 77% had disclosed their HIV status to their partner, and 55% to another family member, only 4% had disclosed their HIV status to their child ($p < 0.001$ for both comparisons). Participants who had disclosed their HIV status to someone (partner, family member or other person) were more likely to be female, have knowledge of their partner's status, and have a longer time since HIV diagnosis. Five of the six parents interviewed in-depth planned to

disclose their status to their children; all mentioned that the child's age or perceived maturity inhibited disclosure and that they feared causing their child anxiety or stress by disclosing their status. Parents mentioned that child sexual activity was a motivator for disclosure, as well as the belief that disclosing was the "right thing to do" and noted that peer or counseling support would be useful to gain insight on appropriate ways to disclose their status.

Conclusions: The decision of parents to disclose their HIV status to their children is more complex than disclosure to other family members and is influenced by concerns regarding the child's ability to understand and process knowledge of their parents' illness and lack of insight on ways to appropriately disclose. Peer groups, counseling, and standardized guidance may be beneficial to facilitate parental disclosure.

Specific Aims

Aim 1: To determine the prevalence of disclosure of parental HIV status to partners, other family members, and children and to identify cofactors associated with disclosure.

Aim 2: To describe the factors that influence an HIV-infected parent's decision to disclose their own HIV status to their children and perceived barriers and facilitators of the disclosure process among parents in Nairobi, Kenya. To specifically evaluate how the child's age factors into the decision to disclose.

Background and Significance

The disclosure of one's HIV-positive status may cause anxiety and stress before and after the disclosure event with implications for the individual and family, and for public health outcomes in the community.[1] The stigma, and potential blame, shame and/or fear associated with HIV infection may contribute to the challenge of disclosure.[2] Numerous studies have examined the process of disclosure of an adult's positive HIV status to his or her partners, with rates for sub-Saharan African women disclosing to a partner ranging from 16.7% to 86%.[3] Many studies have also examined disclosure to family members with a review finding rates ranging from 8% to 98% depending on the family member and relationship.[4] However, fewer studies have evaluated the process of disclosure of a parent's positive HIV status to his/her children. A systematic review regarding parental HIV disclosure found 38 articles addressing disclosure of parental HIV infection to children.[2] The majority of these studies were conducted in the United States or other developed countries. Sub-Saharan Africa is home to >90% of the world's HIV-infected children and 67% of the 33 million HIV-infected adults and the decision to disclose and impact of disclosure may vary dramatically in low-resource settings for various social and cultural reasons, yet only 4 of the 38 studies in this review were conducted in Africa.[2,5] In this review, prevalence of parental HIV disclosure ranged from 11% to 50%.[2]

Factors that influence the parents' decision to disclose or not disclose their HIV status included the child's age and developmental level, presence of stigma in the family or community, and perceived benefits of disclosure to the child.[2,6] Disclosure is commonly accidental or unintentional, through relatives or family members, other members of the social network or community or as a result of the child observing first-hand their parent's symptoms of illness or medicine.[2] Accidental disclosures often force a parent to disclose to their child despite their desire to keep their status private. A study of mothers in the United

States' experiences with disclosure of their HIV infection to their children found that mothers often cited disclosure of their status was "the right thing to do" or that the child "had a right to know".[6] Another reason parents may choose to disclose their HIV status is the desire to make arrangements for the care of their children in the case of parental illness or death.[6] Parental disclosure could have a positive effect on children, such as influencing them to practice safer sexual behaviors.[7] Additionally, parents disclose their status to elicit care from older children.[2] All parents who had their children tested for HIV as part of a Ugandan study had disclosed to at least one child; this suggests an association between parental disclosure and having one's children tested for HIV.[8] Non-disclosure of parental HIV can have important health implications for HIV-infected children as it is likely that the parent has not disclosed the child's HIV status, in addition to not disclosing parental status; this can lead to delayed treatment and care for HIV-infected children.[9]

Reasons given by parents for not wanting to disclose their status include a belief that their child was too young or immature to fully grasp the information, fear of causing their child stress or anxiety about HIV or about the possibility of parental death.[6] Parents also may be unwilling to discuss uncomfortable topics regarding behaviors associated with HIV infection.[6] As a result of these concerns, parents struggle to decide whether, when and how to disclose their HIV status to their children.[7,10] In addition, parents fear that disclosing their status to their child may result in the child sharing the information with others. This could result in the family losing confidentiality about their HIV infections and facing stigma and discrimination.[10] Parents also note that disclosure could result in the child fearing catching HIV from their parent.[10] Finally, parents delay disclosure to protect a child's innocence or carefree childhood.[2,11]

Non-disclosing parents may go to great lengths to keep their HIV status a secret that can potentially jeopardize their own health (i.e. delaying taking medications when children are present or only scheduling medical appointments when children are in school).[9,10] The anxiety caused by keeping their status a secret can take a toll on parents emotionally and mentally.[10] Non-disclosing parents report more symptoms of depression than those who have disclosed.[10] Together, these studies suggest that parents living with HIV need counseling and other supportive services to deal with the challenging and complex process of disclosing their HIV status to their children.[2]

Studies that examine parental disclosure have reported mixed long-term effects on the child, the parents and the family following the disclosure event.[2,12] Some studies have shown increased problem behaviors among children who know their parents' HIV status, negative memories of the disclosure event, and strained family relationships.[12] Other studies show the opposite, that disclosure improves family relationships, decreases childhood depression and that parents are satisfied with the disclosure decision.[12]

This study determines the prevalence of disclosure of parental HIV status to partners, other family members and their children as well as cofactors associated with disclosure. It also describes experiences and perceptions of HIV positive parents in Nairobi, Kenya with disclosing their HIV status to their children. The study was nested within an ongoing study that examines barriers and facilitators to pediatric HIV testing.

Methods

This is a mixed methods study that determines the prevalence of parental disclosure of their HIV status to their partners, other family members and their children and examines cofactors associated with disclosure including age, gender, marital status, socioeconomic status, time since diagnosis and other relevant variables. It also examines HIV positive parents' thoughts about disclosing their HIV status to their children in Nairobi, Kenya. The project is nested within the ongoing *HIV-1 Counseling and Testing for Children at Home (CATCH)* study currently being conducted in Nairobi, Kenya. The CATCH study has both qualitative and quantitative aims to establish the feasibility, acceptability and cost-effectiveness of targeted home- and clinic-based pediatric HIV testing.

Summary of eligibility and procedures for study

	Aim 1	**Aim 2**
Outcome of interest	Prevalence and cofactors of disclosure to partners, other family members and children	Identify barriers and facilitators to parental disclosure of HIV status to their children
Population	HIV-infected adults with children	
Age range	Adults over 18 years of age	
Health status	HIV-infected adults	
Source	Parents receiving HIV-related care and/or counseling	
Data collection	Enrollment Questionnaire	In-depth qualitative interview
Inclusion criteria	HIV-infected, with children of unknown HIV status <12 years of age	
Exclusion criteria	Participating in HIV treatment studies	

Data Collection

Participants were HIV-infected adults enrolled in care recruited from one of two clinics at Kenyatta National Hospital in Nairobi, Kenya: the Prevention of Mother-to-Child Transmission clinic (PMTCT) and the Comprehensive Care Clinic (CCC). For Aim 1 of this thesis, HIV-infected parents with children of unknown HIV status were enrolled in the study and filled out an enrollment questionnaire with basic demographic and HIV-related health information, from which prevalence of disclosure was calculated and cofactors for disclosure examined.

For the qualitative Aim 2, in-depth individual interviews were conducted with participants enrolled in the larger CATCH study "to determine structural, organizational, social and emotional barriers and facilitators to pediatric HIV-1 testing". The data collected for this nested study come from a subset of specific

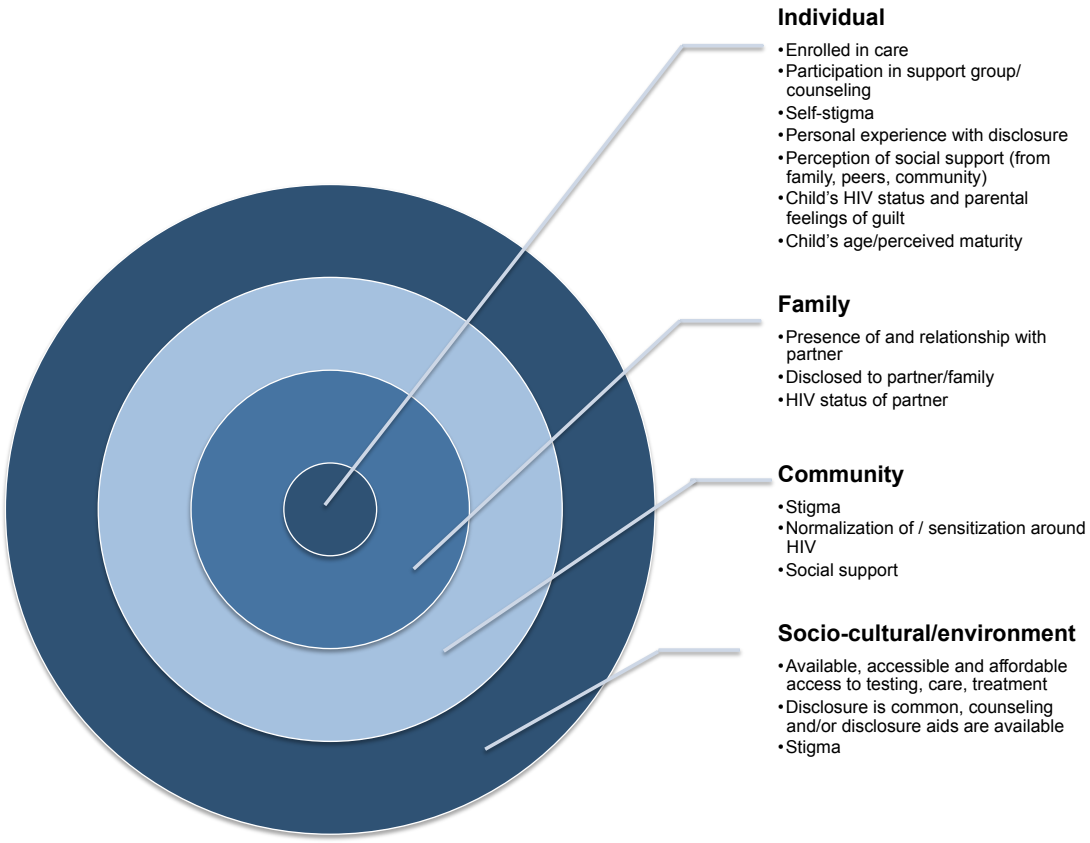
questions about participants' experiences with the process of disclosure of their own HIV status to their children, whether or not they have disclosed and reasons for their disclosure decisions. Parents were also asked to offer suggestions on what types of support they believe would ease the disclosure process within the context of understanding barriers and facilitators of pediatric HIV testing. Written consent was obtained from each participant. Interviews were conducted by study staff in either English or Kiswahili per the participant's request. Interviews were audio recorded and translated into English if needed, and then transcribed. This study was approved by the University of Washington Institutional Review Board and the Kenyatta National Hospital Ethics & Research Committee.

Data Analysis

In Aim 1, prevalence was calculated to examine the occurrence of disclosure to partners, disclosure to other family members; and disclosure to children among the selected study population. A series of t-tests and chi-squared tests were conducted to examine associated cofactors and predictors of disclosure. Cofactors include age, gender, marital status, socioeconomic status, time since diagnosis, education level, knowledge of partner status, presence of social support and whether the participant has also disclosed to another person. Analyses were conducted using STATA Data Analysis and Statistical Software, version 12 (StataCorp. 2011. College Station, TX: StataCorp LP).

The analysis of the qualitative data for Aim 2 began with a start list of codes created from the socio-ecological conceptual framework below. The framework was developed based on existing parental disclosure literature to examine likely factors that affect parental disclosure of HIV.[13] These factors represent four levels or spheres of influence: individual, family, community, and socio-cultural/environmental; the social-ecological model describes interplay between factors at each of these levels and how they affect the individual.

Figure 1: Conceptual Framework: Social-ecological model describing factors affecting parental disclosure of HIV



A content analysis approach was used to analyze interview transcripts and to understand the explicit and covert meanings in the text.[14] The first transcript was independently coded using ATLAS.ti software (Scientific Software Developments, Berlin, Germany, 2012) by this researcher, and by a secondary coder, a co-investigator for the CATCH study. After each independently coding the first transcript using start codes based on the conceptual model, both coders jointly modified codes and refined the codebook with definitions for the use of each code. This researcher conducted the primary coding and the secondary coder reviewed interview transcripts and noted any area of disagreement. The researcher and second coder resolved any disagreements over themes and codes through consensus. The codebook was continuously updated and modified after the coding of each subsequent transcript as new themes

emerged. The distribution of codes was then analyzed to identify themes as they emerged from the data.[15]

Results

Table 1 summarizes demographic characteristics for the 74 participants enrolled in this study to date. Among 74 participants enrolled, 84% were female and the median age was 35 years (IQR 32-38). More than half of participants (66%) were married or involved in a steady partnership. The median length of education was 12 years (IQR 9-14) and the median time since HIV diagnosis was 5 years (IQR 0.33-7). Socioeconomic status was evaluated by examining monthly income, monthly rent and whether the participant had a shared or communal toilet (Table 1). Most (63%) participants reported that they knew their partner's HIV status and 41% reported that they knew their partner was HIV-infected. Almost all participants (99%) noted they had experienced social support from a family member, partner, friend or counselor regarding their HIV diagnosis. The median age of oldest child was 13 years old (IQR 8-17).

Among 74 participants enrolled, most (77%) had disclosed to someone. Of the 48 enrolled who had a steady partner or were married, 37 (77%) had disclosed their status to their partner. Siblings and mothers were the most commonly disclosed to family members while none of the participants had disclosed to their father-in-law and very few had disclosed to their mother-in-law (Table 2). However, only 3 (4%) participants reported that they had disclosed their status to any of their children which was substantially lower than the percentage of those who had disclosed to any family member besides partner or child (55%) ($p = <0.001$) and substantially lower than the percentage of those who had disclosed to their partner (76%) ($p = <0.001$).

Table 3 shows cofactors associated with disclosure of HIV status to any person including partner, friend, parent, or child, among the study participants. Participants who have disclosed their status were more likely to be female than those who had not disclosed (89% versus 65%, respectively; $p = 0.015$). Individuals who had disclosed had a longer time since diagnosis than those who had not disclosed (mean 5 years versus <1 year; $p = 0.013$). Finally, among participants who had disclosed, a greater proportion knew their partner's HIV status than those who had not disclosed ($p = 0.007$). The knowledge of a partner's positive HIV status, also tended to be associated with disclosure ($p = 0.059$).

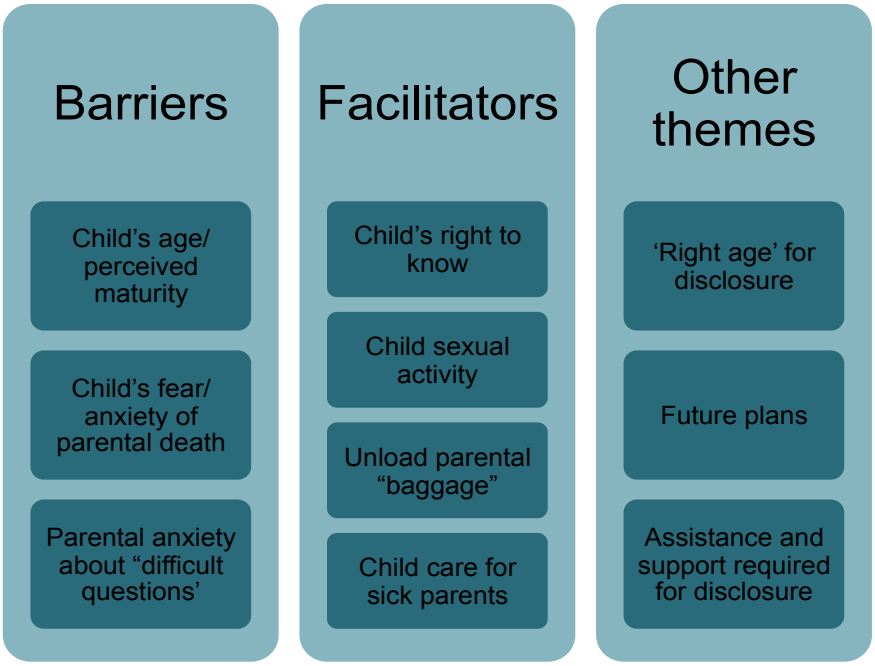
The three participants who had disclosed their HIV status to their child were all female and were older than the median range of ages of participants (43, 43 and 48). One of the participants was married, had disclosed to her partner and knew her partner's status, while the other two were widowed. The years of education varied among the three participants who had disclosed to their child (3, 8 and 24 years) and all participants indicated that they had experienced social support regarding their HIV diagnosis. Two of the participants had learned of their HIV diagnosis five years ago while the third had only been diagnosed

three months prior to enrollment in this study. The median age of oldest child among those who had disclosed to their child was 25 years (IQR 21-34), while the median age of oldest child among those who had not disclosed to their child was 12.5 (IQR 8-16) (p = 0.0001).

Table 4 describes demographic characteristics of the 6 in-depth interview participants. All were female, with a median age of 30.5 years. Four of the six had a steady partner and the median years of education completed was 11.5. All participants had at least one child of their own, with one also acting as a caregiver for two of her sister's children.

In the qualitative interviews, numerous issues were discussed regarding parents disclosing their HIV status to their children. The main themes that came out of the 6 interviews were: various barriers and facilitators of the disclosure process to one's children; the concept of the "right age" for disclosing to one's children; future plans for disclosure; and assistance and support required for disclosure. Barriers mentioned included: child's age/perceived maturity; child's fear/anxiety over parental death; and parental anxiety about answering 'difficult questions'. Facilitators of disclosure as discussed by participants included: the child's right to know the parent's status; child sexual activity; to unload parental baggage; or to elicit care and support from children.

Figure 2. Themes identified regarding parental disclosure



Barriers associated with parental disclosure to children

The theme of the child's age or maturity came up as both a barrier and a facilitator of parental disclosure of their own HIV status. In the context of a barrier to disclosure, parents mentioned that their children were too young or would not understand the implications of their parent's HIV status. They also worried that their children were too young to understand confidentiality and as a result would share their parent's status.

> *"Because, you know children, they don't understand what HIV is, some they don't know about the confidentiality, so they will think it is just normal, so they will go telling people and they will be discriminated."* -38 year old mother of four

Other barriers to disclosure voiced by participants included concerns that the children would fear parental death or that knowledge of their parent's status would cause them stress and anxiety.

> *"Because he has not matured mentally and [doesn't] understand much, so he will feel sorry for you all the time and whenever you get sick, he/she will feel that you are going to die, and that will create a lot of worries which is not good"* -32 year old mother of two

> *"It's 50/50, sometimes it's important [to disclose] and sometimes it's not important. The kids will start like, 'our mother is leaving us very soon' you know they don't understand, as you understand it. In my case as for me, I can't tell them. No I can't tell them, they will start thinking that I am dying tomorrow."* -30 year old mother of four

> *"Sometimes it not so fair because you might make them to lose hope of their life, if they are schooling, they might think that our parent is dying before we finish our education. You know sometimes some children think that if you have HIV you might die the next minute. It might kill their hopes."* -28 year old mother of one

Finally, a few participants mentioned that disclosing their HIV status to their children would lead to "difficult questions" that parents might not feel comfortable or willing to answer.

> *"Maybe they will ask me where did you get it, now you see it's a very difficult question"* -38 year old mother of four

Facilitators of parental disclosure to children

As expected, parents mentioned fewer facilitators of disclosure to their children than barriers. Nonetheless, common themes appeared including that when their child was old enough for a girlfriend/boyfriend or to engage in sexual activity, parents would be motivated to disclose their status to their child.

> *"When I start seeing him/her with some girlfriend or boyfriend, so maybe he will come with a girl and tell me, 'Mum, this is my girlfriend' you see, and the way boys are, maybe she is not the only one. Then he goes and meets another girl and I might secretly hear about it before he tells me about it, so I will tell him, 'Yesterday you came with a different girl and I have heard there is another girl you are seeing, my son this is how the world goes, you should take care of yourself' so that is where I will start."* -28 year old pregnant mother of one

> *"I think my child has the right to know what is going on, what the mother is going through and I think I would be saving his life, maybe at that time he would be thinking of having a girlfriend, maybe he would be having the thought of having sex, but because I have said, I have talked to him and I have told him what I am going through, he will have a second thought…He would think, 'ok fine, I am going but I will use protection'."* -31 year old mother of one

Parents mentioned that their children had a "right to know" their parent's status and this was a large motivator for disclosure. One viewed disclosure as a way to "unload baggage" and earn their children's respect for sharing such a personal thing. Parents also mentioned that if a child is old or mature enough they can provide care and support for sick parents as a motivation for disclosure.

> *"You can disclose to one child who is mature enough to understand, because you might get sick and she is there and she is mature enough to take care of you, and she can give you medicine, she can take care of you because she knows what is going on."* -28 year old mother of one

> *"The baggage will be off now, there will be a load off now…Because I think he will even respect me more knowing that I have shared with him something so personal."* -31 year old mother of one

The 'right age' for disclosure

The majority of parents discussed that their children were too young or immature to know about their parent's HIV status; the median age of the children of parents who participated in the interviews was 7. They mentioned that they believed they should not disclose until their children were "older" but there were varying opinions about what the right age for disclosure was among the parents who were interviewed.

> *"At the age of maybe 12, 13, 14 [years] I would speak to them like in a third person, you know people get sick and this and this…but when I think they get to stage like 17, 18 (years), now I think they can start to understand, say I think at that age."* -31 year old mother of one

> *"You can disclose to a child…so that he/she can understand you but only when they are mature enough not when the child is still young…Like 15 years and above, or 18 years."* -32 year old mother of two

Future plans regarding disclosure

As none of the parents interviewed for this portion of the study had yet disclosed their HIV status to their children, many of them discussed their future plans for disclosure, whether they planned to disclose or not to disclose their status.

> *"In the future we can talk about it [my status] and I will explain to him because I will start from the earlier days, I will tell him, 'The world is not safe, even if you find girls, just have one girlfriend, and the reason I am telling you this is because I was also this way and that and this is what happened and I am not lying to you, I am telling you the truth and I have lived with this thing [HIV]…I will tell him and because he will be an adult he will*

understand and he knows, even at school they are being taught that AIDS kills." -28 year old pregnant mother of one

"In my case as for me, I can't tell them…And I don't even intend to." -30 year old mother of 4

One participant described her plan to gradually disclose her status to her child over the course of a few years.

"That is when will share my status [child aged 17 or 18], but all through, I will even be bringing them to the clinic, getting them to know, what is this that is going on, you know, but sharing my status, that is when I am saying I will share. But all through from that age, you just share small, small." -31 year old mother of one

Assistance/support required for disclosure

The five participants who revealed that they planned to eventually disclose their status to their children relayed their desire for support in disclosing in the form of counseling. One participant mentioned that support from a doctor would be needed in order to disclose, but not from family members or anyone else. Another participant mentioned that she would be interested in getting support from friends or other parents who have gone through the process of disclosing their HIV status to their children previously.

"Because there are people who have gone through what I have, getting experiences from them, what they underwent, I will be more informed, what not to say and what to do, I think I will be more informed." -31 year old mother of one

Discussion

This study examined prevalence of disclosure to partners, other family members and children among HIV-infected parents with children of unknown status enrolled in care at either PMTCT or CCC clinics at Kenyatta National Hospital participating in an ongoing study. We found that 76% of the participants in this study who were married or had a steady partner had disclosed their HIV status to their partner. This is consistent with rates found in the disclosure literature, though at the higher end of the range of rates.[3] Similarly, the rate of disclosure to family members was consistent with what has been found in previous studies, although disclosure rates vary dramatically depending on the family member and relationship, with mothers, siblings and friends being disclosed to more often than fathers and in-laws.[4] In contrast, the prevalence of disclosure to children was substantially lower than to other family members in this study, and the rate of disclosure to children (4%) was lower than other published studies (11-50%).[2] Previous studies have noted that disclosure to children is associated with child testing;[8] as the inclusion criteria for the parent study required that the participants have at least one untested child, the population selected for this study may have artificially lower levels of disclosure of parental status to children. The exploratory

qualitative aim of this study served to further examine parental disclosure to children in order to understand why this rate is so low.

The study enabled us to examine cofactors of HIV disclosure and to determine whether disclosure rates were lower to children than to other family members. Among HIV-infected parents enrolled in this study, female sex was significantly associated with disclosure of HIV status to partners, family members, children or any other person. Data are conflicting on this association in previous studies with some studies noting more females disclosing while others note associations of disclosure with males.[16–18] We observed that longer duration of HIV diagnosis was associated with disclosure to a family member, consistent with previous studies.[16,17,19] Knowledge of partner status was significantly associated with disclosure of HIV status while knowledge of an HIV-positive partner status showed a trend towards significance with those participants who knew their partners status or knew their partner's status was positive being more likely to disclose. Both factors have been reported to be associated with disclosure and given the cross-sectional nature of this analysis, it is not clear whether disclosure or knowledge of partner status came first.[20–23] Presence of social support or participation in support groups has also been found to be associated with disclosure in previous studies;[23] however no statistically significant association was found among these participants, perhaps because there was little heterogeneity as nearly all participants reported social support about their HIV status.

The qualitative portion of this study sheds light on factors that influence an HIV-infected parent's decision to disclose their status to their children. On an individual level, all participants listed the children's age or perceived maturity as a barrier to disclosing their status to their child. This came across in several ways—parents feared that they would cause their children stress or thought that their children would fear the parent was going to die soon or they did not want to answer the difficult questions their children could ask. Parents also feared that children would not keep their parent's status confidential resulting in inadvertent disclosure. These fears resonate with what has been reported in the literature on parental disclosure and are commonly cited barriers that influence whether a parent will disclose their status to their children.[6,8,10,12]

The idea that a parent would be ready to disclose their status to their own child when they saw him/her possibly becoming sexually active was mentioned by some participants. This is a strong motivator for disclosure; parents have a desire to share their own experiences in the hope that their children will learn from them and protect themselves from HIV infection through safer sexual behaviors.[7] The firm belief that the child "had a right to know" the parent's status came up among the majority of participants in this study as a motivation for eventual disclosure. In a study examining maternal disclosure, this was also the most common reason given for disclosure both among parents who had disclosed and as a motivation for those planning to disclose.[6] This belief could come from the parent's ethical concerns for what is the right

thing to do or a more practical desire to ensure that their children knew of the parent's status in the event that they needed care or support from the children for their sickness, or if the parent were to pass away. It is also integrally linked to the presence of an enabling environment that is conducive and supportive of disclosure as detailed in the social-ecological model.

While all participants said that their children were too young to learn about their HIV status, there was not agreement among them as to what was the "right age" for disclosure. One participant mentioned that she would begin to tell her child about HIV gradually from the age of 12 and up and would fully disclose her own status when her child was 17 or 18. Another participant mentioned that 15 could be the right age for parental disclosure. Other participants did not explicitly list at what age they thought their children were old or mature enough to be disclosed to, simply stating that they were too young, and if they had plans to disclose, that they would when their children were older. In other studies, parents also commonly stated that they would disclose once their children were older, but there is rarely an agreed upon age as the decision to disclose varies based on each individual circumstance.[2,6,11]

All but one of the participants discussed their plans to disclose to their children in the future, in light of the above-mentioned barriers and facilitators. The most common plan described fell along the lines of telling the child once they were older, for the reasons elaborated above. In discussing their plans for disclosing to their children in the future, several participants felt they would benefit from support to help them through the disclosure process. For example, one participant suggested a peer counseling or a peer support group where other HIV-infected parents shared their disclosure experiences and described what they said and did when they disclosed their own status to their children. This would provide an opportunity for a safe space for parents to impart advice and offer support to other parents going through the same things as them. This could be an area of further research as a mechanism to support parents to disclose their status to their children as we could not find any examples peer or group disclosure interventions or programs; to our knowledge, programs currently in existence to support parental disclosure worked only at the individual and family level through counseling and education.[24,25]

Results from this study are not intended to be generalizable to HIV positive parents. Rather, the qualitative analysis sheds light on the experiences of the participants in approaching the process of parental disclosure of HIV. In addition, the experiences and views of the participants enrolled in the parent study who elected to have their children of unknown status tested may not be representative of the entire population of HIV-infected parents. The participants were selected from a mainly urban population, therefore their experiences may not necessarily be applicable to those in more rural areas. Finally, participants were selected from among those enrolled in some form of HIV-related care and/or counseling and these individuals may differ from those who are not enrolled in care.

The knowledge gained regarding factors that influence HIV-infected parents decisions to disclose their status will serve as a start to inform gaps in the literature regarding the process of parental disclosure to their children. It will also be useful to highlight the necessity for further study into the sensitive and often stressful process and, based on feedback from participants, could inform programs aimed at supporting parents through the disclosure process to their children in the future, such as the creation of a peer support group for parents.

Table 1: Demographic Characteristics of participants for Aim 1 (N=74)*

Characteristic	Median (IQR) or N (%)
Sex (female)	62 (84%)
Age	35 (32 - 38)
Married / has steady partner	48 (65%)
Years of education	12 (9 - 14)
Time since diagnosis (years)	5 (0.33 - 7)
SES: shared toilet	36 (50%)
SES: monthly income ($USD)	73 (0 - 169)
SES: monthly rent ($USD)	28 (0 - 62)
Knowledge of partner status	31 (63%)
Knowledge of partner positive status	20 (41%)
Experience of social support	73 (99%)
Age of oldest child	13 (8 - 17)

*Age N=73; years of education N=73; shared toilet N=72; knowledge of partner status N=47; knowledge of partner positive status N=47;

Table 2: Prevalence of disclosure (N=74)*

Person disclosed to	**N (%)**
Anyone	57 (77%)
Partner	37 (76%)
Any family (besides partner or child)	40 (55%)
Mother	25 (34%)
Father	9 (12%)
Mother-in-law	4 (5%)
Father-in-law	0 (0%)
Sibling	26 (35%)
Friend	11 (15%)
Child	**3 (4%)**
Other *(aunt, uncle, former boss, pastor, niece, sister-in-law)*	7 (9%)

*Partner N=49; any family N= 73

Table 3: Cofactors of disclosure of HIV status

Characteristic	**Disclosed status** N=57*	**Not disclosed status** N=17**	p-value
	Median (IQR) or N (%)		
Sex (female)	51 (89%)	11 (65%)	0.015
Age	35 (32 - 38)	35 (29 - 39)	0.65
Years of education	12 (9 - 14)	12 (10 - 14)	0.73
Time since diagnosis (years)	5 (1 - 8)	0.92 (0.038 - 4)	0.013
SES: Shared toilet	27 (49%)	9 (53%)	0.78
SES: monthly income ($USD)	68 (0 - 152)	85 (11 - 226)	0.75
SES: monthly rent ($USD)	28 (0 - 62)	29 (11 - 56)	0.69
Knowledge of partner status	29 (74%)	2 (25%)	0.007
Knowledge of partner positive status	19 (49%)	1 (13%)	0.059
Experience of social support	56 (98%)	17 (100%)	0.58

*Years of education N=56; shared toilet N=55; knowledge of partner status N=39; knowledge of partner positive status N=39;
**Age N=16; knowledge of partner status N=8; knowledge of partner positive status N=8;

Table 4: Demographic characteristics of participants for Aim 2 (N=6*)

Characteristic	Median (IQR) or N (%)
Sex (female)	6 (100%)
Age	30.5 (28-38)
Has steady partner	4 (67%)
Years of education	11.5 (9-15)
SES: monthly income (Kenyan shillings)	102 (68 - 282)
SES: monthly rent (Kenyan shillings)	51 (23 - 56)

*SES: monthly rent N=5

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