AIDS PATIENT CARE and STDs
Volume 28, Number 10, 2014
© Mary Ann Liebert, Inc.
DOI: 10.1089/apc.2014.0040

Using Health Provider Insights to Inform Pediatric HIV Disclosure: A Qualitative Study and Practice Framework from Kenya

Kristin Beima-Sofie, PhD,[1,6] Grace John-Stewart, MD, PhD,[1–4] Brandi Shah, MD, MPH,[4] Dalton Wamalwa, MBChB, MMed, MPH,[7] Elizabeth Maleche-Obimbo, MBChB, MMed, MPH,[7] and Maureen Kelley, PhD[4,5,8]

Abstract

Optimal pediatric HIV disclosure impacts illness and developmental experiences while improving access to timely treatment. However, disclosure rates in high HIV prevalence countries remain low and there are limited data on best practices. We conducted a qualitative study of disclosure practices and interviewed healthcare providers from five pediatric HIV clinics in Kenya. We identified themes central to disclosure practices, rationale for approaches, barriers to implementing disclosure, and creative strategies to overcome challenges. We used these insights to develop a practice-based framework for disclosure that is sensitive to practical challenges. Overall, providers had limited training but extensive experience in disclosure, endorsed individualized disclosure practices, invested substantial time on disclosure despite clinical burden, and noted adverse outcomes associated with unplanned or abrupt disclosure. Providers advocated for an approach to disclosure that is child-centered but respects caregiver fears and values. Caregiver support was provided to enable caregivers to be the person who ultimately disclosed HIV status to children. Unplanned or abrupt disclosure to children was reported to have severe and persistent adverse impact and was a stimulus to accelerate disclosure in scenarios when providers believed children may be suspecting their diagnosis. Based on these expert insights, the framework we developed incorporates concurrent evaluation of child and caregiver readiness, identifies cues to prompt disclosure discussions, includes caregiver education and support, and utilizes a gradual approach of unveiling HIV diagnosis to the child.

Introduction

Pediatric HIV disclosure is an evolving practice that remains a challenge for healthcare providers. Access to antiretroviral therapy (ART) has improved survival of HIV-infected children,[1–4] and many will now reach ages at which disclosure of HIV diagnosis is important. Disclosure may improve emotional health of the child as well as medication adherence.[5–9] Despite these benefits, disclosure rates for children in resource-limited countries remain low.[9–11]

Caregiver fears are a primary barrier to pediatric HIV disclosure.[9,10] Disclosure requires infected caregivers to come to terms with their own HIV status and to face feelings of guilt surrounding transmission to a child. Caregivers also fear children blaming parents, being ostracized, or inadvertently disclosing their family's illness.[9,12–22] While studies have identified these concerns, few have identified mechanisms to overcome these barriers.

The World Health Organization (WHO) guidelines recommend that school-aged children be informed of their HIV diagnosis.[23] Kenyan guidelines similarly recommend disclosure to school-aged children.[24,25] However, these guidelines do not provide approaches for implementing disclosure in practice.

Few pediatric HIV disclosure studies have evaluated models of disclosure in practice,[18,26,27] and to date, none have evaluated provider decision-making processes for disclosure. Yet pediatric healthcare providers have accrued considerable experience in practicing disclosure despite lack of guidance. As such, providers provide an untapped repository of knowledge about how to optimize disclosure to inform best practice guidelines.

Departments of [1]Global Health, [2]Epidemiology, [3]Medicine, [4]Pediatrics, and [5]Bioethics and Humanities, and [6]Institute for Public Health Genetics, University of Washington, Seattle, Washington.
[7]Department of Paediatrics and Child Health, University of Nairobi, Nairobi, Kenya.
[8]Treuman Katz Center for Pediatric Bioethics, Seattle, Washington.

We evaluated the processes, beliefs, attitudes and experiences of providers conducting pediatric HIV disclosure using in-depth interviews with providers in Kenya. To inform disclosure best practices, we developed an experience-driven model for disclosure, rationale behind current approaches, challenges in practice, and strategies for overcoming challenges.

Methods

Study design and population

In-depth, one-on-one interviews were used to collect qualitative data on disclosure experiences of providers working with HIV-infected children and adolescents aged 0–17 years. Providers were defined as those involved in the care of HIV-infected children and adolescents including clinicians, clinical officers, counselors, nurse counselors, psychologists, and nurses. Providers were recruited from five clinics throughout Kenya selected to represent a diverse array of settings, including a large public tertiary referral and teaching hospital, a district level hospital, a private hospital, a faith-affiliated clinic, and a small public clinic (Table 1). These clinics reported caring for between 287 to 1233 children and adolescents, the majority from low income families.

Ethical considerations

This study was reviewed and determined to be exempt from full review by the University of Washington IRB and went through full review and was approved by the Kenyatta National Hospital/University of Nairobi Ethical Review Committee. In addition, the protocol was reviewed and approved separately for three study sites. All participants provided oral and written informed consent.

Recruitment

Using purposive sampling, clinic supervisors identified 3–5 providers with direct experience with disclosure. The first author (KBS) or a trained interviewer met with these staff members, presented the research procedures, and re-affirmed willingness to participate.

Participant characteristics

Our study included 21 providers, 3–5 from each clinic; 2 clinicians, 5 clinical officers, 3 nurses, 3 nurse counselors, 4 counselors, 2 psychologists, 1 clinic assistant, and 1 peer educator. Participants ranged between 25–55 years of age and had between 1 and 17 years of experience working with HIV-infected children. Most reported receiving only brief disclosure training within trainings focused on other HIV issues. Involvement in disclosure ranged from assessment and referral to personally facilitating the disclosure event, defined as the moment when HIV is named to the child.

Data collection

Twenty-one interviews were conducted by KBS and a research assistant during June and July 2012 and April 2013. Interviews ranged between 30 and 90 min, were recorded and transcribed verbatim. Interviews were completed in English. We used a semi-structured interview guide based on a published study by our group[10] and literature reviews. The interview guide was validated through informal focus group discussions with Kenyan providers. Using this guide, we first asked providers open-ended questions to explore their considerations in making decisions to disclose or withhold diagnosis, including how they decide when and what to disclose. Second, we queried providers' perspectives on the process of disclosure, barriers, and successful strategies. Finally, we probed their ideas for improving disclosure practice.

Data analysis

The goal of our analysis was to determine processes, concerns, successes, beliefs, and experiences of providers surrounding pediatric HIV disclosure. Transcripts were coded using thematic network analysis and modified grounded theory,[28,29] Using a modified version of the constant comparative approach,[29,30] an initial codebook was created by investigators KBS, MK, and BS based on a subset of transcripts. Resulting codes and preliminary themes were discussed among all authors and revised. This codebook was used to code all transcripts, which were read and coded independently by KBS and MK; a subset were reviewed by BS. The analytic framework focused on: (1) describing disclosure practices, including challenges, barriers, and successes (descriptive), and (2) eliciting provider's reasons, values and rationale for the timing and approach to HIV disclosure (normative). The descriptive perspective offers a window into current practice. The normative perspective offers a

Table 1. Clinic, Healthcare Provider, and Children Characteristics

Characteristic	*Clinic 1*	*Clinic 2*	*Clinic 3*	*Clinic 4*	*Clinic 5*
Health facility					
Type of clinic	Public	Public	Public	Faith-based	Private
Health facility level (2–6)[a]	3	4	6	N/A	N/A
Children in HIV program					
Total children	468	287	965	1233	1054
Children age 8–17	247	145	475	589	356
Aware of status	50%	40%	40%	55%	70%
Clinic burden (no. children/no. providers)	25	17	97	123	53
Healthcare providers					
Providers	19	17	10	10	20
No. interviewed	5	3	4	5	4

[a]Kenya Ministry of Health classification of health facility level: 2. dispensary; 3. health center; 4. subdistrict hospital; 5. district or provincial hospital; 6. tertiary referral hospital.

deeper insight into the values implicit in developing best practices from the perspective of the ''hands-on experts''—the providers navigating disclosure and pediatric HIV care.

Results

A practice-based framework for pediatric HIV disclosure

Provider experiences were used to develop an experience-based framework describing the current disclosure process. The framework consists of a disclosure assessment and decision-making process and disclosure timeline (Fig. 1); it is grounded in the experiences and decision-making rationale of providers currently involved in disclosure. Four themes identified during interviews were used to inform this practice-based framework. A fifth theme was identified to characterize barriers to implementation of the disclosure process and ideas for overcoming challenges. These themes are characterized in descriptive and normative terms, using reports of what is done in practice and views on what ought to be done, to reflect providers' experienced-based opinions regarding how to optimize pediatric HIV disclosure—that is, how to do the best for both child and caregiver within real world constraints.

Disclosure practices should optimize child well-being while including significant respect for caregiver values

All providers endorsed the importance of disclosure. The main rationale for disclosing status, and doing so in a thoughtful, timely way, was to support the well-being of the child, including improved participation in treatment. Recognition of the psychological harm that can occur from delayed or inadvertent disclosure motivated provider preferences for initiating a gradual disclosure process early (Table 2).

While providers viewed the child's well-being as central, they also viewed HIV as a disease impacting a family rather than an individual. Providers recognized the critical relationship between child and caregiver(s) and the importance of considering caregiver concerns surrounding disclosure and its timing. All providers believed that disclosure should occur in a supportive environment and noted that joint parental disclosure and accepting infection as a family often leads to improved outcomes, allowing HIV to be a shared burden and reducing the stress associated with keeping it secret.

''Disclosure is important because once disclosure is done, the family will be knitted together. They will now not look at this child differently, but now they will support the child.'' – 014

Caregiver concerns were the commonest reason for delaying disclosure (Table 2) and included reluctance to tell others, fear of blame and guilt regarding transmission, and inability to answer the child's questions. Providers believe they must balance child well-being against caregiver concerns. While they believe caregivers mean well in trying to protect their children from perceived harms, they observed that a failure to disclose often causes more harm because children often suspect or know their HIV status and feel frightened and isolated.

''You reach their [adolescence] and they just don't want to see you, they try to avoid mixing with others, they isolate themselves, they have these suicidal minds, they want to kill themselves, and all that.'' – 003

Despite a sense of urgency that children be informed, most providers showed strong sympathy for and deference to caregivers, recognizing that caregivers are wrestling with legitimate concerns, such as protecting family confidentiality.

''We should understand them because we should just imagine ourselves in their shoes. I think disclosure is not a very easy thing; it's very difficult, especially if a child reacts badly or if a child goes telling everyone. So we should just

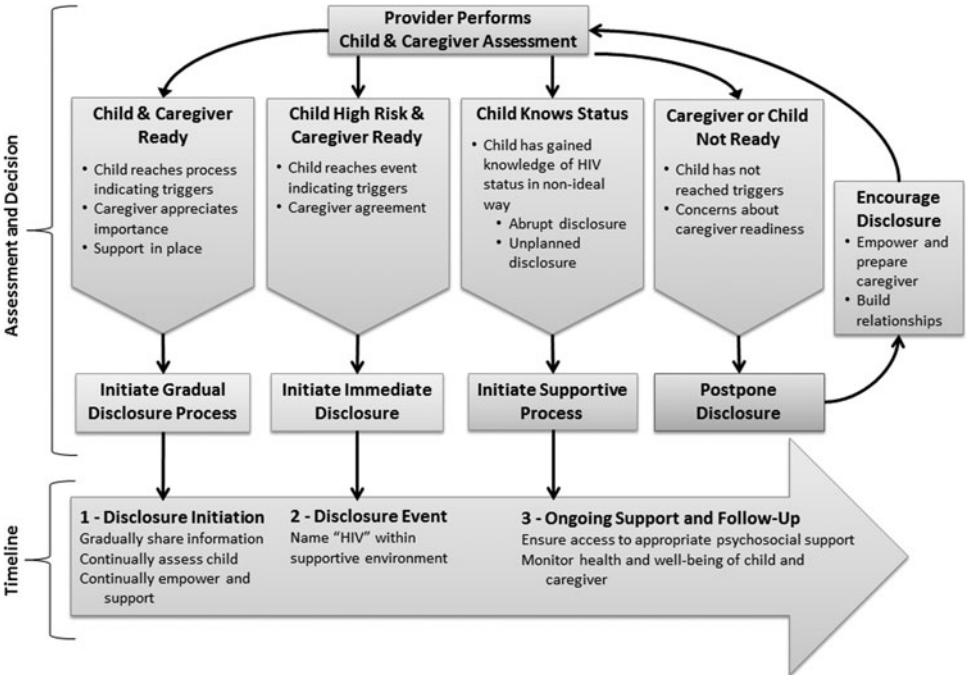

FIG. 1. Optimizing pediatric HIV disclosure in practice: A provider-informed process framework.

Table 2. Provider Identified Benefits and Barriers to Disclosure

Reason	*Number*[a]	*Representative quotes*
Benefits and positive impact		''I think first it is a human right. Anybody wants to know what is happening to them, anybody, even a child.'' – 015
Overcome stigma/discrimination	5	
Right to know/knowledge	5	''They get to be involved in support groups that help them to share their experiences with their peers and with that now they get to know that I am not alone, I have other peoples around me. I have support….''– 009
Independence/autonomy	17	
Preserves trust	12	
Creates self-esteem	11	''The disclosure is also good because it will help the child to care about themselves, they will take care of others and they will take care of themselves, prevention with positives, meaning when they are HIV positive, now they will not infect others.'' – 014
Ability to receive peer support	7	
Prevents spread of infection	12	
Medication adherence	21	
Physical health	12	''It is very important because it helps them in adhering well to their medication. Once they know the problem they have, they will actually try and adhere to medications, because they know, if I don't take my meds, I'll be sick.'' – 002
Psychological health	14	
Caregiver barriers and concerns		''It's the age, you feel that even after 15 (years) the child is still young and they don't know anything. And also they want to cushion, they don't want the child to get hurt with the news.'' – 010
Negatively impacts the child	9	
Child is too young	7	
Inability to answer questions from the child	12	''[T]he mother feels guilty so much that she infected the child so she doesn't want those questions. Maybe even the mother is still in denial, or there's still blame that the father brought this disease….so they fear such questions from the child.'' – 012
Failure to come to terms with own status	8	
Disclosure to child involves telling others	12	''[M]aybe the mother of the child, knows her status and the status of the baby but the husband is in the dark, doesn't know that these people are on ARVs, they are HIV positive, and now to bring the issue of disclosure in such a family, it will not happen.'' – 009
Alter family relationships and knowledge	6	
Blame and guilt regarding transmission	12	''When you see maybe it's a very old lady who has brought this child. And maybe they are not even understanding what we are talking about.'' – 010
Stigma/discrimination towards the child and family	9	
Lack of knowledge/information	8	

[a]Refers to the number of providers who explicitly stated this specific benefit or concern.

understand them and give them time and continue encouraging them…'' – 017

Providers did not view the caregiver as the barrier, but rather viewed the *concerns* of the caregiver as barriers to timely disclosure. They felt the solution was to empower the caregiver by offering support.

''[W]hen a parent tells me they have disclosed, I say…I salute you for that. I am grateful that you were able to disclose. It was not easy and we are here to support you.'' – 011

Disclosure should be gradual, not a one-time event

Providers identified an optimal disclosure timeline that involves three phases: (1) disclosure initiation, (2) the disclosure event, and (3) disclosure support and follow-up. This gradual approach allows for development of a plan for disclosure tailored to the individual child's developmental readiness.

Providers felt that well-delivered disclosure should involve significant preparation. Initially, providers prepare the child using partial disclosure to help the child understand the basics of their condition and the importance of taking medication.

''We tell them about the soldiers, do they know what the soldiers do?…We have soldiers who protect us from these enemies which are diseases.…'You remember when you were sick? It's because the enemy was overcoming the soldiers but now you are taking your medicines and the soldiers are becoming stronger than the enemies. The enemy is being defeated, so you don't fall sick.' '' – 010

Providers then described tailoring the process to the child's level of understanding, letting the child be the guide. In this way, during each visit, the caregiver and child make incremental gains in knowledge. As the child gets older, providers switch to more age-appropriate terms like virus, immune system, and CD4 count. At an appropriate age, understanding, or other key indicator, the disclosure event occurs (the first time the word ''HIV'' is used to describe the illness to the child). Here, providers use motivational counseling to allow the child to realize his diagnosis on his own as opposed to the direct divulgence: ''you have HIV.'' Following disclosure, the provider and caregiver monitor the child. Follow-up involves assessment of child health (medication adherence, emotional well-being), peer support (encouragement, helping the child understand ''there are others like me''), and support for the child's relationships with provider and caregiver.

Providers all believed that children will inevitably learn their diagnosis and that planned disclosure mitigates harm to the child. Providers reported that children commonly learn HIV status on their own by realizing they are different, reading signs or charts while in clinic, overhearing conversations about their health, or through television messages or internet searches.

''[There] was one child, she learned her status through the media. It was very emotional for her. She went into a very bad state because she felt the mom lied to her.'' – 011

Providers observed that many children who discovered their status before deliberative disclosure rebelled, exhibited

violent behavior, felt betrayed, and developed sometimes irreparable breaks with their caregivers and family, particularly with abrupt disclosure.

''…accidentally, the boy discovered that he is HIV positive and he became so violent like…'I don't want to take food in this house,….you are giving me this disease of the immoral people, this is a disease for prostitutes'. And he got so angry, even when he comes to the clinic he is so bitter…'' - 009

''…we were going through the disclosure process but somehow…disclosure was done in a wrong way. [T]he sister was calling out his name and they were playing outside with the boys and she shouted, 'Come and take your medicine, do you know these are for HIV. And if you don't take you will die.' And from that day, that boy changed completely. He doesn't want any relationship with the sister. In fact there was a time he was saying, 'My sister died.' When he comes to the clinic, he doesn't want to talk to us. He doesn't want to see us. He used to throw insults at us in the session and just leave; since then the behavior has never changed. He comes, looks at you, you call his name, he says 'I am not (Mentioning name).' He doesn't even want to be called that because the way disclosure was done was really, really bad.'' – 010

Overall, providers believed that children who discover their status independently were at greater risk of having adverse reactions and advocated that disclosure be done early as a planned process.

Key indicators let the provider and others know that the disclosure timeline should be initiated or advanced

Before initiating disclosure, providers assess child and caregiver readiness. During assessment (Fig. 1), the provider evaluates child readiness by identifying whether he/she displays pre-identified triggers, including age, understanding, personality, school transitions, adherence, and social situation (Table 3). While providers placed significant weight on age and maturity, no single trigger determined the child's readiness for disclosure. Providers considered a constellation of triggers, the combination of which is unique to each child.

Providers also identified transitioning to boarding school as a key factor motivating caregivers to disclose. Some caregivers viewed this transition as the time when children would need to learn to manage their illness and medications independently.

''The children will be expected to take the drugs by themselves when they go there. So I feel like the parents are driven to [disclosure] by such needs.'' – 020

Providers recognized that certain triggers may prompt immediate disclosure. These included the child directly asking the parent or recognition that the child may be figuring out his/her diagnosis.

Because providers believed in balancing the needs of child and caregiver, they simultaneously assessed caregiver readiness by evaluating caregivers' fears and concerns, psychological state, and knowledge of HIV. If determined unready, providers postponed disclosure, focused on empowering the caregiver to make disclosure possible, and returned to the assessment phase. Providers recommended accessible support resources for both child and caregiver.

Assessment leads providers to choose different pathways for children: (1) the ideal pathway of gradual disclosure; (2) a high risk pathway where the child is immediately told his diagnosis; or (3) the harm-reduction pathway where the child has accidentally or abruptly discovered his diagnosis and the provider steps in to provide support.

Table 3. Provider-Identified Triggers Indicating Pathway-Specific Entry Into and Movement through the Disclosure Process

Trigger category	*Representative quote*
Age	''If they are not yet 8, maybe they are 6, 5 (years), we postpone disclosure to a later date but we alert the mother or the caregiver that we might start the disclosure process at the age of 8 or even 7, so as you continue coming to the clinic, please think of how you will be able to start the process.'' – 011
Understanding and awareness	''A child and the caregiver will come in and they'll say, ''My child saw this advert on TV and looked at me and asked, 'those drugs are taken by people who are HIV+ and I take the same drugs.''' Those are the kinds of triggers that we see and we know that it has to be done immediately.'' – 010
Personality	''We ask them (the mother/caregiver), does the kid have mood swings or any behavioral (issues), you know. If you start seeing such then we tell them that it is time. Because some of the kids may never ask by the way, what disturbs them, so you observe, you should be able to observe and know if your child is in their right senses, in their right mood. If you start seeing anything different, then you should start to ask, what is the problem?'' – 006
Medication adherence	''They have complaints of challenges in trying to reinforce adherence to their kids. The child at times doesn't take medication and maybe coming to clinic. The parent will just force the child and they will come but there's that tension amongst themselves.'' – 004
School transitions	''For example tomorrow they might go into a boarding school or they are in high school and as such, they need to take care of themselves because at this time, there will be no caretaker. So at this time of the hour, they need to continue with their treatment even here as before when the guardian was there.'' – 013
Social situations	''He was an orphan. And the aunties didn't actually want to disclose. So when I talked to the aunty and I told her you need to disclose to the child, the aunty said no, no, no, no, no. I cannot disclose because even the time the mother died, the boy was not told that his mother died, so up to date the boy does not know that his mother died, he only knows that his mother travelled somewhere far, yeah. So the aunty actually did not want at all, she said it will traumatize the boy, we cannot disclose.'' – 012

Disclosure ought to involve caregivers and providers

Providers viewed themselves as having dual roles in the disclosure process: to provide medical information and assessment, and to provide emotional support. Lack of caregiver readiness signaled that providers needed to shift to educating, empowering, and persuading caregivers on the importance of HIV disclosure. Providers identified strategies for empowering caregivers, including, coaching on how to broach disclosure, preparing them for what to expect and how to identify concerning behaviors in the child, helping them appreciate the importance of gradual disclosure, encouraging caregivers to build on what the child already knows, and ensuring that caregivers have correct information about HIV. Providers also stressed the importance of ensuring caregivers were psychologically equipped to support the child, using strategies such as peer support groups and sharing success stories to give caregivers hope.

Providers believed the caregiver's role includes assessment of the child, assisting in disclosure initiation, performing the disclosure event (naming HIV), and providing support to the child after disclosure. All providers strongly believed the naming of HIV should come from the caregiver, because they believe caregivers know the child best, have a trusting relationship with the child, and are the ones who will be in the best position to monitor the child's reactions after disclosure. Providers reported that caregivers often asked them to be the ones to name HIV to the child because they viewed providers as experts and found the naming of HIV emotionally challenging.

''We have always encouraged the parents to do disclosure because they are the key role people over this child. But they fear the blame so they tell you, 'just tell the child because you are the expert'.'' – 014

All providers believed that disclosure should not occur without caregiver consent and reported that requiring caregiver consent is standard practice in Kenya. Although giving ultimate control to the caregiver, almost all providers thought it important to persuade caregivers to disclose sooner rather than later.

''If the caregiver is nervous and resistant, we just try to give them continuous counseling…because if a parent really does not want you tell the child his status, you will not say….'' – 002

Strategies for overcoming barriers to disclosure

Providers identified challenges for implementing disclosure and shared creative techniques for improving training and practice (Table 4).

Providers identified challenges related to clinic logistics, the child's social context and fears and stigma associated with HIV. In the clinic, providers identified lack of time as a significant barrier to providing optimal disclosure given the time required to individualize disclosure, gain a child's trust, empower reluctant caregivers, and ensure continuity of care. Providers also described challenges related to the family social structure, such as fathers acting as the head of the household and blocking disclosure at home while refusing to come to clinic. In other cases, the challenges are related to lack of familial support, as in the care of orphaned children. Providers reported that uninfected caregivers who are not biological parents sometimes have trouble talking with a child about the death of a parent. Other caregivers of orphaned children simply do not know the child as well as a parent would, or do not have the same level of trust.

''He was an orphan… And the aunties didn't actually want to disclose. So when I talked to the aunty and I told her you need to disclose to the child, the aunty said no, no, no, no, no. I cannot disclose because even the time the mother died, the boy was not told that his mother died, so up to date the boy does not know that his mother died, he only knows that his mother traveled somewhere far, yeah. So the aunty actually did not want at all, she said it will traumatize the boy, we cannot disclose.'' – 002

Providers observed that messages used in prevention campaigns or taught in school often conflicted with the positive messages required for disclosure. For example, many children in Kenya are told that HIV is ''a killer disease'' or the consequence of promiscuous sex. For a child who has been exposed to these messages, it can be devastating to learn their diagnosis. Negative or inaccurate messaging can also affect how children view their parents' behavior when they learn their diagnosis.

''Most of the healthcare workers, the teachers, they emphasize so much on the sexual part of it so that by…the time you are disclosing, they are already thinking, 'you are so promiscuous mom'…. They already have an opinion. So that by the time you are telling them, they don't take it so lightly. Some of them, by the way, end up running away from home; others just withdraw.'' – 006

Providers believed that targeted trainings and networking could bridge gaps between current guidelines and provider-identified challenges. Overall, providers felt specific guidance on pediatric HIV disclosure was inadequate and practices would benefit from national standardized operating procedures and opportunities to network and share experiences with others. Almost all providers recognized the importance of receiving training in disclosure to increase confidence and competence and many believed training on incorporating alternative forms of communication, such as play therapy, would enhance disclosure practices.

Despite challenges, many providers were proactive and had developed their own best practices. They identified creative techniques used to optimize disclosure, such as peer support groups for caregivers and children. Support also offered benefits for providers who experience emotional exhaustion and stress in balancing urgency with caregiver reluctance.

''This is an emotional kind of a job, so we need to be helped emotionally, so that we can be able to help other people emotionally.'' – 011

Discussion

Our study found that despite few practice guidelines, providers in diverse clinic settings rely on similar strategies and rationales for what they view as the best approach to disclosing HIV status in children. We used providers' shared experiences to inform a practice-based framework for reflecting the provider-identified process for childhood HIV disclosure.

One of the most interesting insights involved seeing the child's needs as central and urgent, yet recognizing that those needs are best met within the supportive context of family.

Table 4. Informing the Development of Disclosure Best Practices: Logistical Challenges, Identified Needs, and Techniques Facilitating Success

Example	*Representative quotes*
Techniques facilitating success Give providers access to support Work as a team to encourage disclosure Involve the entire family in the process Provide support and follow-up post-disclosure for children Have adult mentors for children Have separate clinic days for adolescents Include access to peer support for children Include access to peer support for caregivers Have caregivers sympathize with the child during disclosure	''Even as a supervisor, when I am weighed down, my colleagues have to support me. We meet and we share the client work, the challenges we faced.'' – 014 ''I remember there was a time a child told the mother, 'if you know you were HIV positive, why did you have to give birth to me?' Unfortunately the child was mad with the parents, she refused drugs, but she died. So that is why we decided that these children have to be seen more often, every time they come to the clinic we have to assess them; it doesn't matter whether the adherence is good, we have to assess them, because every time things change.'' – 014 ''I also learned to tell these mothers later on that you should move with the child because [you should] let the child see that you are also maybe learning this for the first time because if you look strong and he is crying, he is emotionally crying, he feels that you are not with him on that.'' – 013
Identified gaps and needs Training to improve comfort and confidence for providers Training and materials to support alternative forms of communication Guidance on how to best support caregivers Continued medical education training to keep current with disclosure Development of standardized disclosure guidelines or SOPs Standardized National Approach National networking for the children	''Before I was trained on disclosure, it was a terrible experience…… But after learning how to disclose, it has been not smooth, I cannot say it has been smooth still, but because I have the skills, I am aware of what to do at what point.'' – 014 ''How we take care of the caregivers. The challenges they have, I think they need to be addressed because they are true, they are right. We keep saying awareness is out for HIV but no, when you talk to some people, the awareness is not yet out properly.'' – 015 ''We are all scattered, small pockets here and there, but if it was all consolidated into one, so that we have the same information, it would be easier.'' – 015
Logistical challenges and barriers Rotating or non-consistent counselors Having to watch what is said to the child when disclosure hasn't happened High patient volume Child knows, provider knows child knows, caregiver refuses to disclose Inability to disclose without caregiver's consent Inability to reach certain caregivers Father as head of household blocking disclosure Orphaned children Negative or inaccurate public health messages HIV fears and stigma	''They just tell you, I don't want you to tell the child this and this and that is the end of the story. And since you have empowered them, you don't know where to hit after that. You just live with it, you don't disclose.'' – 006 ''As long as this man is not coming to the clinic and he is the one who makes decisions in that family, disclosure will not happen.'' – 009 ''You want to correct the information they have. Some of the information that is given to these children is that HIV is a very dangerous disease, it's a killer disease, once you get that, it's over with your life. So you want to correct that information to let them know that even if they maybe having HIV, there is life after HIV, there is treatment, there is something that can be done to support the HIV positive people and they can lead a normal life just like other children, other young adults and even achieve their dreams….'' – 009

This holistic conception of the child within a family contrasts with the dominant ethical conception in American pediatric ethics surrounding disclosure of cancer and HIV. On the American/European approach, for older children and adolescents, the justification for disclosure emphasizes the developing autonomy of the child and the need to know, even and often against parents' wishes.[12,17,31–36] On the Kenyan conception, as articulated by our participants, there was greater sensitivity and empathy given to resistant caregivers and greater effort made to balance parent/caregiver and child interests. When caregivers were not ready for disclosure, providers took an insistent yet respectful approach to bringing caregivers along in the plan for disclosure and demonstrated remarkable sympathy for caregivers. The sympathetic but persistent approach offers a way of navigating a challenging tension between the child's needs and caregiver fears. They emphasized the need to consider the child within the family context and to tailor disclosure to each child while supporting caregivers. This approach affirms previously published studies demonstrating the importance of providing caregiver and family support for disclosure.[37,38] To provide support to caregivers, providers in our study attempted to empower caregivers to lead disclosure and emphasized the need to help caregivers come to terms with their own HIV status, an issue that is underappreciated in current guidelines.[23]

Current guidelines emphasize age as the primary trigger for disclosure.[23–25] We found that triggers in addition to age, and in combination, are important. School transitions and poor medication adherence emerged as critical triggers for disclosure. School attendance or education level has been

previously found to be associated with disclosure,[39,40] and caregivers of HIV positive children in the Democratic Republic of Congo reported that having a child attend school made them think more seriously about disclosing.[41] In our study, providers identified attending boarding school as an important symbol of the child's transition to being able to take medications independently and accept management of their diagnosis. This specific trigger may be especially important for children in sub-Saharan Africa where the attending boarding school is more common. Providers in our study identified the child's questioning or refusal of medication to be an important trigger for disclosure. This confirms previous studies that have shown that disclosure status is positively associated with medication adherence.[6,42–44] Providers in our study also identified an important link between medication and perception of illness that influences both the disclosure process and the child's acceptance of diagnosis. Medication adherence also emerged as an important symbol of the child's acceptance of diagnosis, as well as a potential symbol of illness ownership for those children who feel substantially empowered and confident. Overall, we found that providers and caregivers see medication adherence as central to the child maintaining health, which is what they communicate to the child during disclosure. Both school transitions and poor medication adherence were viewed as signaling a child's growing independence and autonomy that should include increased responsibility in managing their illness.

Providers also identified a tension between negative HIV messaging and the positive messaging needed to support disclosure. At a programmatic level, fear has been used as an HIV prevention tool. However, providers must counter these messages to ensure psychological well-being of the child. With a growing HIV-infected adolescent population, it will be important to evaluate whether the public health benefit of preventive messaging using fear tactics is worth the psychological impact on infected children when they learn their status.

An overriding theme across all providers was the importance of social support for children throughout the disclosure process. Similar to previous studies showing that family structure is associated with disclosure,[10,40,45–47] providers in our study identified that a positive home situation can influence whether disclosure happens at all, and whether it is done well or poorly. Two key social factors were identified. Fathers were often perceived as a barrier, suggesting a need to target education toward men. And orphaned children were at greater risk for not receiving timely, supported disclosure, suggesting a need for targeted programming and a more proactive role for providers. Providers explained that orphaned children are at greater risk of ''falling through the cracks'' related to timely, supported disclosure. If guardians of orphans and vulnerable children (OVCs) are unable or unwilling to take responsibility for disclosure, the burden may need to be shifted to providers to step in or to be more insistent and supportive of guardians throughout the disclosure process. This suggests a need for targeted programming and training to guide providers in supporting guardians of orphans, and in addressing the special concerns and stresses of children not living within a stable family situation.

Current guidelines do not adequately address challenges providers are encountering in practice. We recognize that the experiences presented by providers in our study, although diverse, cannot encompass all disclosure experiences. Given this limitation, our study findings will not necessarily be generalizable to all clinics in Kenya or to clinics in other countries. However, we believe that our findings can begin to fill a critical gap in expert, practical knowledge around how providers make disclosure decisions, as well as inform evidence-based practice guidelines that are more responsive to challenges faced by providers. In addition, limited studies incorporate the experiences of HIV-infected children and their caregivers who have been through the disclosure process.[41,48] Future studies should continue to explore caregiver and child disclosure experiences. Understanding disclosure comprehensively through multiple stakeholder perspectives can inform the development of optimal practices that balance conflicting considerations for child, caregiver, and provider well-being.

Acknowledgments

We would like to thank the clinics and providers who participated in the study. We also thank Helen Moraa, Sylvia Nyamache, Anne Gikuni, Mark Anam, and Kelly Edwards for their involvement and dedication to completing this project. This research was supported by the National Institutes of Health (NIH) research grants R24 HD056799 and K24 HD054314. KBS was supported by the University of Washington Institute of Translational Health Sciences Multidisciplinary Clinical Research Training Program (TL1 TR 000422) from the National Center for Advancing Translational Sciences, NIH and the Fogarty International Clinical Research Scholars Program (Grant Number 5 R24 TW007988) from NIH.

Author Disclosure Statement

No competing financial interests exist.

References

1. Kabue MM, Buck WC, Wanless SR, et al., Mortality and clinical outcomes in HIV-infected children on antiretroviral therapy in Malawi, Lesotho, and Swaziland. Pediatrics 2012; 130:e591–e599.
2. Wamalwa D, Benki-Nugent S, Langat A, et al., Survival benefit of early infant antiretroviral therapy is compromised when diagnosis is delayed. Pediatr Infect Dis J 2012;31: 729–731.
3. Violari A, Cotton MF, Gibb DM, et al. Early antiretroviral therapy and mortality among HIV-infected infants. N Engl J Med 2008;359:2233–2244.
4. Brady MT, Oleske JM, Williams PL, et al. Declines in mortality rates and changes in causes of death in HIV-1-infected children during the HAART era. J Acquir Immune Defic Syndr 2010;53:86–94.
5. Battles HB, Wiener LS. From adolescence through young adulthood: Psychosocial adjustment associated with long-term survival of HIV. J Adolesc Health 2002;30:161–168.
6. Bikaako-Kajura W, Luyirika E, Purcell DW, et al. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. AIDS Behav 2006;10:S85–S93.
7. Oberdorfer P, Louthrenoo O, Puthanakit T, et al. Quality of life among HIV-infected children in Thailand. J Int Assoc Physicians AIDS Care 2008;7:141–147.
8. Ferris M, Burau K, Schweitzer AM, et al. The influence of disclosure of HIV diagnosis on time to disease progression

in a cohort of Romanian children and teens. AIDS Care 2007;19:1088–1094.
9. Vreeman RC, Gramelspacher AM, Gisore PO, et al. Disclosure of HIV status to children in resource-limited settings: A systematic review. J Int AIDS Soc 2013;16: 18466.
10. John-Stewart GC, Wariua G, Beima-Sofie KM, et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. AIDS Care 2013;25:1067–1076.
11. Vreeman RC, Scanlon ML, Mwangi A, et al. A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. PLoS One 2014;9:e86616.
12. Wiener L, Mellins CA, Marhefka S, et al. Disclosure of an HIV diagnosis to children: history, current research, and future directions. J Dev Behav Pediatr 2007;28:155–166.
13. Domek GJ. Debunking common barriers to pediatric HIV disclosure. J Trop Pediatr 2010;56:440–442.
14. DeMatteo D, Wells LM, Salter Goldie R, et al. The 'family' context of HIV: A need for comprehensive health and social policies. AIDS Care 2002;14:261–278.
15. Lipson M., Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. J Dev Behav Pediatr 1994;15:S61–S65.
16. Klitzman R, Marhefka S, Mellins C, et al. Ethical issues concerning disclosures of HIV diagnoses to perinatally infected children and adolescents. J Clin Ethics 2008;19: 31–42.
17. Slavin LA, O'Malley JE, Koocher GP, et al. Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment. Am J Psychiatry 1982;139: 179–183.
18. Blasini I, Chantry C, Cruz C, et al. Disclosure model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and evaluation. J Dev Behav Pediatr 2004; 25:181–199.
19. Gerson AC, Joyner M, Fosarelli P, et al. Disclosure of HIV diagnosis to children: When, where, why, and how. J Pediatr Health Care 2001;15:161.
20. Cohen FL. Research on families and pediatric human immunodeficiency virus disease: A review and needed directions. J Dev Behav Pediatr 1994;15:S34–S42.
21. Lee CL, Johann-Liang R. Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. AIDS Patient Care STDS 1999;13:41–45.
22. Kouyoumdjian FG, Meyers T, Mtshizana S. Barriers to disclosure to children with HIV. J Trop Pediatr 2005;51: 285–287.
23. Krauss B, Letteney S, De Baets A, et al. *Guideline on HIV Disclosure Counselling for Children Up to 12 Years of Age*. 2011, World Health Organization: Geneva Switzerland.
24. National AIDS and STI Control Program; Ministry of Public Health and Sanitation, K., *National Guidelines for HIV Testing and Counseling in Kenya*. 2008, NASCOP: Nairobi, Kenya.
25. National AIDS and STI Control Program; Ministry of Public Helath and Sanitation, K., *Guidelines for Antriretroviral Therapy in Kenya: 4th Edition 2011*. 2011, NASCOP: Nairobi, Kenya.
26. Boon-Yasidhi V, Chokephaibulkit K, McConnell MS, et al. Development of a diagnosis disclosure model for perinatally HIV-infected children in Thailand. AIDS Care 2012;25:756–762.
27. Cantrell K, Patel N, Mandrell B, et al. Pediatric HIV disclosure: A process-oriented framework. AIDS Educ Prev 2013;25:302–314.
28. Attride-Sterling J. Thematic Networks: An analytic tool for qualitative research. Qual Res 2001;1:385–405.
29. Starks H, Trinidad SB. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. Qual Health Res 2007;17:1372–1380.
30. Birks M, Mills J. *Grounded Theory: A Practical Guide*. 2011, Thousand Oaks, CA: Sage Publications.
31. Gupta VB, Willert J, Pian M, et al. When disclosing a serious diagnosis to a minor conflicts with family values. J Dev Behav Pediatr 2008;29:231.
32. Mitchell CD, Armstrong FD, Goodman KW, et al. Disclosure of HIV status to an infected child: Medical, psychological, ethical, and legal perspectives in an era of ''super-vertical'' transmission. J Clin Ethics 2008;19:43–52.
33. Mack JW, Joffe S. Communicating about prognosis: Ethical responsibilities of pediatricians and parents. Pediatrics 2014;133:S24–S30.
34. Thorne C, Newell ML, Peckham CS. Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. Child Care Health Dev 2000;26:29–40.
35. Informed consent, parental permission, and assent in pediatric practice. Committee on Bioethics, American Academy of Pediatrics. Pediatrics 1995;95:314–317.
36. Flanagan-Klygis E, Ross LF, Lantos J, et al. Disclosing the diagnosis of HIV in pediatrics. J Clin Ethics 2001;12: 150–157.
37. Jemmott Iii JB, Heeren GA, Sidloyi L, et al. Caregivers' intentions to disclose HIV diagnosis to children living with HIV in South Africa: A theory-based approach. AIDS Behav 2014;18:1027–1036.
38. Nicastro E, Continisio GI, Storace C, et al. Family group psychotherapy to support the disclosure of HIV status to children and adolescents. AIDS Patient Care STDS 2013; 27:363–369.
39. Bhattacharya M, Dubey AP, Sharma M. Patterns of diagnosis disclosure and its correlates in HIV-Infected North Indian children. J Trop Pediatr 2011;57:405–411.
40. Kallem S, Renner L, Ghebremichael M, et al. Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. AIDS Behav 2011;15:1121–1127.
41. Vaz LM, Maman S, Eng E, et al. Patterns of disclosure of HIV status to infected children in a sub-Saharan African setting. J Dev Behav Pediatr 2011;32:307–315.
42. Brown BJ, Oladokun RE, Osinusi K, et al. Disclosure of HIV status to infected children in a Nigerian HIV Care Programme. AIDS Care 2011:1–6.
43. Fetzer BC, Mupenda B, Lusiama J, et al. Barriers to and facilitators of adherence to pediatric antiretroviral therapy in a sub-Saharan setting: Insights from a qualitative study. AIDS Patient Care STDS 2011;25:611–621.
44. Haberer JE, Cook A, Walker AS, et al. Excellent adherence to antiretrovirals in HIV+Zambian children is compromised by disrupted routine, HIV nondisclosure, and paradoxical income effects. PLoS One 2011;6:e18505.
45. Oberdorfer P, Puthanakit T, Louthrenoo O, et al. Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. J Paediatr Child Health 2006;42:283–288.
46. Moodley K, Myer L, Michaels D, et al., Paediatric HIV disclosure in South Africa— Caregivers' perspectives on discussing HIV with infected children. S Afr Med J 2006; 96:201–204.

47. Biadgilign S, Deribew A, Amberbir A, et al. Factors associated with HIV/AIDS diagnostic disclosure to HIV infected children receiving HAART: A multi-center study in Addis Ababa, Ethiopia. PLoS ONE 2011;6:e17572.
48. Vaz L, Corneli A, Dulyx J, et al. The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. AIDS Care 2008;20: 842–852.

Address correspondence to:
Dr. Kristin Beima-Sofie
Harborview Medical Center
Box 359909
325 Ninth Avenue
Seattle, WA 98104

E-mail: beimak@uw.edu