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

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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.
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 group10 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

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<tr>
<th>Table 1. Clinic, Healthcare Provider, and Children Characteristics</th>
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<td><strong>Characteristic</strong></td>
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<tr>
<td>Health facility</td>
</tr>
<tr>
<td>Type of clinic</td>
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<tr>
<td>Health facility level (2–6)a</td>
</tr>
<tr>
<td>Children in HIV program</td>
</tr>
<tr>
<td>Total children</td>
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<tr>
<td>Children age 8–17</td>
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<tr>
<td>Aware of status</td>
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<tr>
<td>Clinic burden (no. children/no. providers)</td>
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<tr>
<td>Healthcare providers</td>
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<td>Providers</td>
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<td>No. interviewed</td>
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aKenya 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...”

Caregiver barriers and concerns

- It's the age, you feel that even after 15 (years) the child is still young aging them understand them and give them time and continue encouraging them...” – 017
- 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
- “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
- “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

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
- “You remember when you were 10 years old and you want the child to get hurt with the news.”’’ – 010
- “[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
- “[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

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.

“[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

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.

“[T]here 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...
PROVIDER INSIGHTS ON PEDIATRIC HIV DISCLOSURE

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

<table>
<thead>
<tr>
<th>Trigger category</th>
<th>Representative quote</th>
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<tr>
<td>Age</td>
<td>“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</td>
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<td>Understanding and awareness</td>
<td>“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</td>
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<td>Personality</td>
<td>“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</td>
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<td>Medication adherence</td>
<td>“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</td>
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<tr>
<td>School transitions</td>
<td>“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</td>
</tr>
<tr>
<td>Social situations</td>
<td>“He was an orphan. And the aunties didn’t actually want to disclose. So when I talked to the aunt 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</td>
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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 aunts 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. 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.
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. 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. 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.

Current guidelines emphasize age as the primary trigger for disclosure. 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,\textsuperscript{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.\textsuperscript{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.\textsuperscript{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,\textsuperscript{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.\textsuperscript{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.

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Author Disclosure Statement

No competing financial interests exist.

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