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Telling Children They Have HIV: Lessons Learned from Findings of a Qualitative Study in Sub-Saharan Africa

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Abstract

HIV-infected children in developing countries are living longer lives as they gain access to antiretroviral treatment programs. As they grow older, their parents/guardians are faced with the difficult decision of if, when, and how to inform their child of his/her HIV status. Both negative and positive social, psychological, and behavioral impacts of disclosure to children have been reported, including improved adherence to medication regimens. Understanding the disclosure process from the perspective of HIV positive children, therefore, is critical to developing these interventions. Through children's experiences we can learn about what works well, what needs to be strengthened, and what is missing in current disclosure practices. We conducted in-depth interviews with eight caregiver-child dyads in Kinshasa, Democratic Republic of the Congo. The children were in a comprehensive HIV pediatric care and treatment program and had already been told their HIV diagnosis. For the analysis we placed particular emphasis on children's reports of communication with their caregivers and health care providers about their illness. Patterns emerged of limited communication between children and their caregivers as well as their providers, before, during, and after disclosure. From the perspective of children in this study, disclosure was largely a discrete event rather than a process. Sociocultural contexts surrounding HIV/AIDS, as well as health status, variations in parent-child communication and the relationships between health providers and children under their care, should inform psychosocial interventions delivered alongside treatment programs.

Introduction

WITH THE INCREASING AVAILABILITY of antiretroviral treatment in sub-Saharan Africa, more HIV-infected children will survive into adolescence and adulthood. However, despite evidence from industrialized countries indicating that informing children can have positive psychosocial and clinical outcomes,^{1,2} limited research has been conducted on what, when, and how HIV-infected children are told about their illness.

The literature on disclosure of HIV status to infected children conceptualizes disclosure two ways. The first envisions disclosure as a one-time event, when information about the diagnosis of HIV or AIDS is provided to the child.³⁻⁶ The second conceptualization sees disclosure as a process. One perspective of the process is from caregivers/parents

providing information and the steps they undertake.⁷⁻¹⁰ A second perspective is from the child receiving the information.¹¹⁻¹⁷

Prevalence of disclosure to infected children varies. A recent review of pediatric disclosure literature from the United States, Canada, and Europe reported that 10-75% of HIV-infected children had been informed of their HIV status.¹⁸ The review noted most studies provided limited details on when full disclosure occurred, what was discussed and how often. Table 1 summarizes disclosure prevalence from four studies in developing countries, which reported 29-62% disclosure.

Table 2 summarizes factors influencing disclosure. Reasons for disclosure most frequently reported in the United States, Canada, and Europe were child's age and cognitive development.^{4,7,8,13} Similar factors were reported by studies in developing countries.

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TABLE 1. PREVALENCE OF DISCLOSURE AMONG HIV-INFECTED CHILDREN IN DEVELOPING COUNTRIES

<i>Authors</i>	<i>Country</i>	<i>Disclosure details</i>
Bikaako-Kajura et al., 2006	Uganda	29% of sample of 42 children 5–17 years had been fully disclosed their status, 38% had been given partial information
Menon et al., 2007	Zambia	37.8% of 127 HIV-infected adolescents, ages 11–15 years, had been told of their HIV infection.
Oberdorfer et al., 2006	Thailand	30.1% of 103 caregivers reported having disclosed to children 3–13 years old; however, only 53% had actually mentioned HIV and/or AIDS to their child (16% of the total sample)
Butterworth, 2007	Thailand	Disclosure is greater in older age groups: 0% of 6–9 year olds, 18.8% of 10–13 year olds, and 62.5% of 14–17 year olds had been disclosed ($n = 87$).

Both negative and positive social and psychological impacts of disclosure to children have been reported. Children with other illnesses, such as cancer, have been found to be at risk of emotional and behavioral difficulties resulting from disclosure.^{19–21} Others have found that children benefit from an open discussion of their illness and that nondisclosure does not necessarily protect them from psychological distress.^{22–24} HIV-infected children in industrialized countries fared well after disclosure, and better than children who were unaware of their HIV infection.^{1,19,25,26}

While studies have looked at correlates of disclosure, few have investigated the process of disclosure to HIV-infected children specifically, particularly in developing countries. This study was, therefore, exploratory and focused on the experiences of infected children in a comprehensive HIV pediatric care and treatment program in Kinshasa, the Democratic Republic of the Congo (DRC). The study's aim was to explore the events before, during, and after disclosure to generate a narrative of Congolese children's experiences with being told their HIV status. Findings could be used to inform future interventions to support families and pediatric care providers through the process of disclosing HIV status to infected children in the DRC and other similar settings.

This study was embedded within a comprehensive, family-centered HIV care and treatment program in Kinshasa, DRC. Funded by the U.S. Centers for Disease Control and Prevention (CDC), the program had enrolled over 800 children and 200 of their first-line relatives as of July 2008, providing them with clinical and psychosocial care, including antiretroviral treatment when appropriate.

Methods

In-depth interviews were conducted with children, ages 8–17 years, who had undergone full HIV disclosure, as well as with their primary caregivers. The research was approved by the Institutional Review Boards at the University of North Carolina at Chapel Hill in the United States and the Kinshasa School of Public Health in the DRC. Informed consent, parental consent, and informed assent were obtained as appropriate.

Recruitment

Program staff contacted potentially eligible participants based on their existing knowledge of the enrolled children; primary caregivers were informed of the study and invited to come with the child to the hospital at a time most convenient to them. In addition, staff screened all caregivers of children, ages 8–17 years, when they presented for a regularly scheduled visit to identify those who might have disclosed to their HIV-infected child without informing the clinical team. Those meeting eligibility criteria were told of the study; if they agreed to participate, an appointment was made for them to return for the interview.

Eligibility was reassessed by program staff on the day of the interview, before obtaining informed consent. A child was considered to have been fully informed of his or her status if the terms HIV, AIDS, or any local term specifically associated with HIV/AIDS had been used in a discussion with the child about the child's health. If the child was unable or unwilling to state that she/he had HIV, AIDS, or other local terms used for

TABLE 2. FACTORS INFLUENCING DISCLOSURE TO HIV-INFECTED CHILDREN, FROM EXISTING LITERATURE

<i>Industrialized Countries</i>
Child's age and cognitive development (DeMatteo et al., 2002; Funck-Brentano et al., 1997; Gerson et al., 2001; Ledlie, 1999)
Child's deteriorating health status (Funck-Brentano et al., 1997; Gerson et al., 2001; Grubman et al., 1995)
Questioning by the child (Lester et al., 2002; Wiener et al., 1996)
Need to maintain family trust (DeMatteo et al., 2002; Nehring et al., 2000)
Child's right to know (Lester et al., 2002b; Nehring et al., 2000)
<i>Developing Countries</i>
Starting treatment or problems adhering to treatment (Azondekon et al., 2005; Nannyonga-Musoke et al., 2007; Oberdorfer et al., 2006)
Level of cognitive development and the age preceding the onset of puberty (Myer et al., 2006).
Reasons for NOT disclosing: young age, the desire to protect the child from psychological harm and to protect the child and/or family from social stigma (Ayres et al., 2006; Kouyoumdjian et al., 2005; Oberdorfer et al., 2007; Oberdorfer et al., 2006)

HIV/AIDS during eligibility screening, she/he was not interviewed to avoid causing emotional distress to the child. In the one occasion this occurred, only the caregiver was interviewed.

If both the caregiver and the child consented, the two interviews were conducted separately and simultaneously, each by a different interviewer. If the caregiver preferred to be present during the child's interview, the adult interview was conducted first, in the absence of the child, followed by the child's interview, which was conducted by the same interviewer.

Data collection and analysis

The adult interviews began with structured questions on individual (demographics, time since diagnosis, educational levels of both caregiver and child) and family characteristics (relationship of caregiver to child, marital status, child's orphan status). The remaining questions were open-ended in order to best capture disclosure experiences. These questions explored preparation activities, anticipated reactions of child, the moment of disclosure, and what had taken place since the initial disclosure moment. The child's interview did not include structured questions; instead, it began with an exploration of the child's understanding of his/her health prior to disclosure, moved into a description of the disclosure event and his/her reaction, and then into events since the full disclosure moment. The child's opinion on disclosure and his/her understanding of HIV before and after disclosure were also explored. Questions were adapted from interview guides used in previous studies^{7,27,28}; additional questions were developed from themes emerging from the analysis of formative research completed the previous year.²⁹ Interviews were semistructured, with open ended questions and lists of probes provided to interviewers.

Two local interviewers trained in research methods and issues surrounding disclosure conducted the interviews, which were audiotaped with participant permission. One conducted the interviews with adults, and the other conducted interviews with children, in order to maintain consistency in technique across interviews. Participants had a choice of being interviewed in either French or Lingala, the local language; one child and one caregiver were interviewed in French. Adult interviews lasted approximately 90 min, while child interviews lasted between 60–90 min each. All interviews were transcribed directly into French by the interviewer who conducted the interview, and then verified by a second interviewer, both for completion of the transcript as well as accuracy of the translation from Lingala to French. Analysis was conducted in French.

Data were analyzed using qualitative content analysis to identify themes and patterns related to research questions.³⁰ Deductive and inductive codes were developed and applied to the data using Atlas.ti v. 5.2. To ensure intercoder reliability, selected transcripts were independently coded by two analysts, who then compared codes and resolved discrepancies where necessary. Data display and reduction tables were developed with feedback from the research team.

Results

Of the 259 children screened, only 8 (3%) were identified as having been told their HIV status. One child did not state she

had HIV during the screening process and was not interviewed; only her caregiver was interviewed. In the case of another child, both biological parents requested to be interviewed. In total, we completed in-depth interviews with 8 families, represented by 7 children and 9 of their caregivers. All children interviewed were on antiretroviral regimens at the time of the interview. Table 3 provides basic demographic information about the families interviewed.

The findings are presented linearly to create a narrative of the events before, during and after disclosure. Although findings emerged from responses from both caregivers and their children, particular emphasis was given to the views expressed by youth. To provide a detailed picture of the children's experiences within families and with the health care system, special attention was paid to the communication within caregiver-child dyads as well as between health providers and the children.

Before full disclosure

Before being told their HIV status, children knew they were sick and suffering from multiple symptoms but believed they would be cured one day. They described receiving either no information about their health or information that was incomplete or misleading. One mother reported telling her child that she had an inoperable spleen condition, which was misleading. Another child thought he had tuberculosis, based on symptoms and a prior diagnosis.

Before full disclosure, children rarely communicated directly with their health care providers about their illness. Only 1 of 7 children reported a direct conversation with a health care provider about her illness before being told her HIV status. The other children either made no mention of communicating with health care providers or noted providers only initiated conversations with their parents. Two children expressed concerns about their illness directly to their providers; they received general information on chronic illness, recommended actions to avoid contaminating others, or were told not to worry.

Interviewer: And the doctors from those hospitals, what did they tell you?

Participant: They also told me nothing. They would always say that it was malaria. (17-year-old female)

Before full disclosure, communication between children and caregivers revolved around children's questions about their health. Only one child reported having no conversation about his illness before he was disclosed his HIV status. All other children described posing questions to their parents, especially mothers, about what sickness they had, why they were constantly ill, or why they had to continually take medications.

Parents' responses were described by children as none, nonspecific, or advice to stop worrying and place their faith in God. The nondirectness of such responses from parents had an emotional effect on children:

There are times when I cried, why only me and not my sisters . . . when I said that, only me, sometimes they would say to me . . . it's nothing, it's just the way it is . . . it will change. (15-year-old female)

. . . I would worry inside me, mother suffers, I suffer also, but who will help whom? . . . Mother told me nothing. Perhaps

TABLE 3. BASIC DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF FAMILIES INTERVIEWED

Family	A	B	C	D	E	F	G	H
Adults								
Age	34	38, 45	30	46	41	53	44	48
Gender	F	F, M	F	F	F	M	F	F
Relationship to child	Biological mother	Biological mother, father	Biological mother	Biological mother	Biological mother	Biological father	Biological mother	Biological mother
Child's biological parents alive	Yes, both	Mother yes, Father yes	Mother yes, Father no	Mother yes, Father yes	Mother yes, Father no	Mother unclear, Father yes	Mother yes, Father yes	Mother yes, Father yes
Caregiver HIV status	Mother HIV+ Father's status unknown	Mother HIV+ Father HIV-	Mother HIV+ Father's status unknown (likely HIV+)	Mother HIV- Father HIV-	Mother HIV+ Father HIV+	Unknown, father presumed negative	Unknown (presumed negative)	Mother HIV- Father's status unknown
Minors								
Gender	F	M	F	F	F	M	F	F
Age at interview	11	8	9	15	15	14	17	17
Age at diagnosis	10	8	8	12-13	< 1 year	11-12	16.5	15
Parent present at interview	Yes	Yes (mother)	Minor not interviewed	Last section	No	Yes	No	No

it is an illness that disturbs her and bothers me as well.
(15-year-old female)

Children's reports on questions they posed to parents about their illness before full disclosure were largely corroborated by parents/caregivers. The parents of two adolescent girls mentioned questions about why they were not developing physically like their peers. The few parents who said their child had never asked them questions described initiating conversations on the importance of taking medication. Parents viewed these health-related conversations as an impetus for informing their children of their HIV status.

Parents thought about informing their children before telling them about their HIV diagnosis, but rarely prepared the child to receive the information. All parents interviewed anticipated that their children would react negatively to learning their HIV status. They thought their child would be worried, sad, or cry. A few thought their child could possibly try to harm herself after disclosure. Nearly half of parents reported not preparing the child at all for full disclosure; of those, two disclosed during moments of frustration with their children's adherence to treatment. Among parents who had prepared their child for full disclosure, they did so on the day of full disclosure, often in the moments immediately preceding the event. Preparation activities included preparing favorite foods, offering gifts, and making sure the child felt loved.

Medications featured strongly in parents' decisions to prepare their children for full disclosure, either because children were increasingly recalcitrant in taking them, or because they were starting antiretroviral regimens. Parents also cited

the need for children to take precautionary measures to prevent infection of siblings and others.

In any case, so that he take his medicines. He would resent and question taking his medicine every day, "Why this, mother?" He would also ask "Until when do I have to take it?" Another reason [to tell him] is that I was scared for his younger sibling. (38-year-old biological mother of an 8-year-old male)

Three parents specifically mentioned the increasing age of their daughters and concern about infecting others through sexual transmission.

... I told myself, no, I just have to tell her because she will ... as she is a young girl maybe men will chase after her, so it I really had to tell her the illness she has. (48-year-old biological mother of a 17-year-old female)

From children's perspectives, only one said she was well-prepared by her mother, who spoke to her of her health, showed her love and affection, and provided her with advice to seek strength in God. The mother explained that she strove to ensure that her child would not feel she was being treated differently from the rest of her siblings, and to explain that people often misunderstand what they do not experience themselves. This child also reported being prepared in the weeks before by health care providers, who had her research information about various chronic illnesses, including HIV.

The moment of full disclosure

Table 4 summarizes characteristics of the moment of full disclosure of the child's HIV status, as reported by adults and

TABLE 4. BASIC CHARACTERISTICS OF MOMENT OF FULL DISCLOSURE

Family	A	B	C	D	E	F	G	H
Child age at disclosure	11	8	9	13	14	13	16.5	16
Time between diagnosis & disclosure	5 months	3 months	9 months	6 months	14 years	1 year	Same day	~1 year
Time since disclosure	6 months	4 months	3–4 months	1.5 years	1 year	1.5–2 years	5–6 months	7 months
Location of disclosure	Home	P: home	Home	P: home	Home	Home	Hospital	Home
Who disclosed	Mother	Y: hospital P: mother	Mother	Y: hospital P: mother	Mother	Father	Nurse/ counselor	Mother
Who else Present	No one	Y: doctor P: no one Y: mother	Aunt	Y: doctor P: alone Y: mother & another doctor	No one	No one	P: no one Y: nurse trainee	P: no one Y: older sister
Disclosure planned	Yes	Yes	No	Yes	Yes	No	No ^a	Yes

^aDisclosure done at the moment of diagnosis.

Note 1: information from both interviews is included in the table where discrepancies exist between the parent and the child reports of the disclosure moment.

Note 2: All children were reportedly in good health at the time of disclosure.

P, parent report; Y, child report.

children. In all but one case, parents were aware of their child's HIV diagnosis for several months, if not several years, before the child was informed. At the moment of full disclosure, two children were on antiretroviral regimens and two were about to start. There were discrepancies between children's and adults' reports about who did the informing, where, and who else was present.

The moment of disclosing HIV status to children included minimal information about the illness itself. Two of the three youth informed by health providers mentioned some information provided to them in addition to being told of their status—one over several visits, the other through a video screening in a support group. The information provided clinical context to the illness by discussing chronic illnesses or how medications can keep a person healthy. One youth told her HIV status by a health provider said that she was given information about how HIV works and how the drugs work to keep the infection at bay. A few noted that medications featured in the disclosure conversation, whether as a starting point for discussion or as advice on staying healthy. Others specifically noted they were told not to worry as it will cause them to become sicker or die; this message featured in conversations with caregivers as well as with providers. Several youth who had been told by caregivers reported discussing the source of infection with a parent; none of the youth who had been informed by providers mentioned discussions about HIV acquisition during the conversations.

Interviewer: What else did mother do or say?

Participant: She said that I should not worry. If not I will die... (11-year-old female)

I was told to properly follow the treatment so that I may be cured. (14-year-old male)

They explained to me how that (the drug) works in the body and what it will do when I will stop. They explained how it's given... with the ARV [antiretroviral medications], one will lead it [to a cure]... it [the cure] is not yet there by regular means. (15-year-old female)

Medications feature prominently in disclosure discussions reported by parents. All conversations touched upon medications—as the entry point for full disclosure, as part of the description of the illness, or as part of the advice given to the child on how to act. A few parents stated they gave some description of how HIV/AIDS works in the body as part of the rationale for having to take medications. Several talked about avoiding contaminating others by not sharing sharp objects.

Some of the HIV-positive parents revealed their own status whilst informing their child of their own HIV status, to comfort and reduce the possible distress of the child. In the one case the mother did not inform the child of her status, but the father reports telling the child in a subsequent conversation. The one caregiver who did not share her own HIV status with the child had informed her child of her HIV status in a moment of anger. Only one child mentioned learning of her parent's HIV status at the same time as she learned about her own status.

Upon learning their HIV status, children felt sadness and worry, but also relief. Children described feeling heartbroken or sad immediately upon learning their HIV status. Those who offered reasons for these emotions specifically mentioned the stigmatizing nature of HIV.

That hurt me a lot. Because this illness, it is for the debauchers, but me, at this age, I cannot have this illness. (11-year-old female)

At the same time, children described feeling relief in learning what was causing their illness so that they could now take care of themselves.

I felt . . . well, I did not feel uneasy, I was well . . . really, as for worries, I did not have any, I did not have any worries . . . I was happy that they told me this news; I love my mother a lot up to today because she told me the truth beforehand. (15-year-old female)

Other initial reactions included feeling nothing because the child did not believe the diagnosis or feeling reassured after a family member explained that it was a disease like any other.

To probe further on children's reactions to learning their HIV status, interviewers presented a list of emotions expressed by other infected children. When asked whether they too had felt that way and why, most said they were worried upon first hearing their diagnosis, citing either fears that they would become sicker or disbelief that they could have this illness. Many felt sad upon learning their HIV status, because of their young age and the stigma associated with the illness. At the same time, most children reported being relieved to have a name to put to their suffering.

There was like a hard ball in me, I was uneasy . . . I only wanted to know my illness . . . as I heard the name of my illness, I was relieved: I found my inner peace. . . (15-year-old female)

Those who felt calm at the moment of the full disclosure explained that learning their HIV status brought them peace after not knowing from what they were suffering.

Well, when I left [the hospital], I implored God, told him to give me peace because I did not know . . . I risk dying like that [she says it with an affirmative head gesture]. I felt a calm fill my heart, I began to play. (15-year-old female)

In contrast, parents recounted quite different reactions of their child to being told their HIV status. Most parents described their child as having no reaction or not being surprised, attributing it either to the effective way the diagnosis had been communicated or that the child did not understand what had been told. Parents described their child's surprise or weeping upon being told their HIV status, explaining that the child did not expect it or did not understand how she/he could have gotten it. A few parents also reported their child asking questions.

After full disclosure

After full disclosure, children received HIV-related advice and instruction from their caregivers, but were not engaged in discussions about their health. Children distinguished receiving HIV-related information from their parents from being engaged by their parents in discussions about their HIV status. Youth reported receiving advice from their caregivers ranging from medication adherence and appointment reminders, to avoid worrying, how to protect siblings from infection, and spiritual guidance.

He told me to take my medicines correctly. (15-year-old male, about conversation with his biological father)

She only said to have hope, even if it is what, even if it is AIDS, God, he, atoned for this illness on the cross, he will heal me. (15-year-old female, about conversation with her biological mother)

Nevertheless, all but one child interviewed said they had had no discussion with their parents about their HIV status. For this one child, the discussion was with her mother and not her father.

This pattern of one-way instruction from parents, rather than two-way parent-child discussion, was also described by parents, who reported giving the same kinds of advice as reported by their children following the moment of full disclosure. Those who noted that they had not discussed their children's health status since disclosure acknowledged feeling uncomfortable talking about HIV, preferring to only give advice.

I do not know if she is aware that I am not happy with this kind of chatter. (Biological mother of 17-year-old female)

One notable difference in parent-child communication after disclosure was reported by parents who are HIV-positive, who incorporated their own HIV status into their advice on the importance of taking medications.

Parents were unaware of children's questions and concerns following full disclosure. Most children reported having at least one question or concern following disclosure, wanting to know more about the source of their infection, confirming the diagnosis, getting better or cured, and AIDS being fatal. Most children did not voice their questions or concerns to anyone, but those who did said they had turned to their parents—in particular, their mothers. In two instances, mothers worked in tandem with health professionals to address their child's concerns. Only one child spoke to a health provider rather than to a parent. Children reported their questions were either ignored or deflected with advice to stop worrying or else they would become sicker.

It was not surprising, therefore, that most parents described their child as not having any questions or concerns following the moment of full disclosure. One mother acknowledged that her child may refrain from asking questions, knowing that the mother is uncomfortable discussing HIV. Parents who reported children expressing concerns cited questions about: whether a cure would be found; taking drugs for life; how a child could be infected; and being able to finish school. Following full disclosure, conversations between children and health providers remained clinically focused. All but one child interviewed described conversations with health providers following full disclosure of their HIV status. Conversations focused largely on instructions to take medications on time to avoid becoming ill again; ways of protecting others from infection; and the importance of not worrying.

They give me advice for me to not worry, like other children who are worried . . . you start to isolate yourself, to stay alone saying that AIDS is there to kill me, the way I am, I will die, I am going to die—me, I do not act that way. (15-year-old female)

Children also reported being asked questions about their physical well-being, any symptoms, and whether drugs were being taken as prescribed. Two children described conversations in their presence between health providers and their parents; one to persuade the child to adhere to the treatment plan and the other on AIDS being bad. This latter topic was reported by the youngest child interviewed, who repeatedly raised this message throughout his interview.

Interviewer: What did the doctor tell you?
 Participant: He said that it is bad.
 Interviewer: What is bad?
 Participant: AIDS.
 Interviewer: What else did he say?
 Participant: Just that.
 Interviewer: Who did the doctor say that to?
 Interviewer: To father. (8-year-old male, recounting words of health care provider)

In summary, after full disclosure, children's communications with health providers focused on clinical care.

Children felt that knowing their HIV status was important and necessary. Despite the negative emotions reported by children at the time of disclosure, they did not state any negative consequences of knowing their HIV status. Overall, the children interviewed named at least one positive aspect of knowing their diagnosis. The benefits cited included: knowing themselves or knowing their bodies; no longer worrying to avoid becoming sicker; and being able to protect others from infection.

Participant: So... I no longer worry that I am sick. I take the drugs. Sometimes I even forget.
 Interviewer: What do you forget?
 Participant: I forget that I am sick, that I take drugs. It comes back to me only at the time to take the drugs... (15-year-old female)
 It was necessary that they tell me... so that I don't touch other people's things... So that they don't get AIDS. (8-year-old male)
 I was very happy that they told me this news. To this day I love my mother because she told me the truth before. If she had told me when I was an adult... ay! When I had grown up... that would not have been good. (15-year-old female)

Discussion

The experiences of disclosure captured here from parents of children infected with HIV are comparable to those reported by caregivers in other settings. Caregivers' decisions to disclose are influenced by their concerns around treatment adherence, the eminent onset of sexual activity of adolescents, and their desire to protect their children and to protect others from becoming infected.^{18,31} Caregivers often approach disclosure as a process, contemplating disclosure and preparing for the moment, and providing their infected children with partial and/or inaccurate information.^{4,13}

In addition, children's initial reactions to their diagnosis in this study are similar to those reported in other settings. Other youth also reported negative reactions upon learning of their HIV status, ranging from sadness to hurt and worry.^{7,17,25} From the perspective of the children in this study, disclosure is a discrete event rather than a process; only one child interviewed described receiving information preparing her to receive her diagnosis. A few mentioned follow-up discussions with caregivers or providers, but most did not have subsequent conversations, although many had questions and concerns.

Youth experiences after being informed of their HIV status, are not well documented in the literature.⁸ Here, similar to other studies,^{12,32} children had a sense of social isolation and emotional distress, noted in messages to not touch other people's belongings and not share common household items, and unexpressed questions and concerns resulting perhaps from messages that worrying will make them sicker, but also

possibly reflecting cultural norms around parent-child communication.

The reports in this study supporting youth being told their HIV status are also similar to what has been reported elsewhere. Blasini and colleagues²⁵ tested an intervention to support families and youth through the disclosure process; 85% of the youth (ages 9–13 years) afterwards reported disclosure as a positive event for them and their families, and 90% supported disclosure in general. However, we cannot determine whether the intervention itself is the reason for the positive perspectives. Researchers in Thailand found that youth who had participated in an intervention to be informed of their HIV status had more positive attitudes about HIV-infection and hope for future following the intervention.³³ Relief in finally knowing the source of their suffering has also been reported.⁷

Access to medication regimens clearly plays a role in disclosure to youth in this context. Difficulties adhering to long-term regimens, whether experienced or anticipated, influence parents' decisions to disclose. Youth, in turn, cite being more conscious of the importance of properly taking medications following disclosure. The findings here reflect findings seen in Benin and Thailand,^{31,34} and point to the need to consider the complexities of informing children of their HIV status as programs scaling-up access to AIDS care and treatment expand.

The experiences of the youth in this study must be understood within the cultural context of Kinshasa. Interventions should consider how communication takes place within families in order to inform the design of interventions to assist families in communicating illness information to children. Vygotsky^{35,36} theorized that interpersonal processes gradually become intrapersonal ones, and that interaction between individuals structures cognition; interactions between people therefore shape individuals' understanding of themselves and their environment. Within this context, how caregivers and providers interact with youth and communicate information about health status—either verbally or nonverbally—could theoretically have a strong influence on youth's understanding of their health and well-being. Cultural contexts no doubt influence parental roles and communication styles with children. However, little has been published about what these roles and styles are, and how culture influences them, particularly in sub-Saharan Africa. While populations in these and other similar settings often communicate with children in a directive, rather than participatory fashion, with few opportunities for questioning, discussion, and joint decision-making made available to children, communication styles will likely vary based on the age of caregivers, their education levels, and their exposure to a variety of both traditional and modern communication styles. A greater emphasis needs to be placed on understanding the role and function of communication between caregivers and youth in different contexts and settings as programs targeting parent-child communications are developed.

We must be conscious that disclosure may not always be beneficial. Some studies, including this one, have documented immediate negative reactions from children upon learning their HIV status.^{7,25,34} However, most studies have shown that in the longer term disclosed children are neither more distressed nor do they display more behavioral problems than children who have not been told their HIV status. Only one

participant in this study expressed any negative things about knowing her HIV status. Children with inadequate coping skills or insufficient support systems in place might fare poorly if inadequately prepared and if follow-up is not provided. The potential benefits of disclosure must therefore be weighed against possible negative consequences, before a decision is made to inform the child of his/her diagnosis, and adequate support must be put in place for the period following disclosure.

The results have implications for future interventions to support families who decide to inform HIV-infected children of their status. Strong messages to children about not worrying need to be moderated by opportunities for children to express their concerns and gain additional information to answer their questions about their illness and health. While ruminating might be detrimental to mental and physical well-being, suppressing questions or not voicing concerns might isolate the child and promote poor coping skills. A Brazilian study found that prolonged silence, poor adult-child communications, and self-discovery resulted in psychosocial distress, self-stigma and adherence problems among HIV-positive youth.¹² In other studies in clinical settings, health care providers play a large role in initiating disclosure with children, sometimes telling parents that it is time that the child should be told.^{34,37}

In this study's setting, providers were concerned with finding the best way to disclose to children, and were therefore not intervening with what they saw as the "natural" disclosure process currently taking place until more information was made available. It is likely that for this reason, as well as the comparatively short period of time since ART was made available in this setting, the prevalence of disclosure among infected youth is lower than what has been documented in other similar settings,^{38,39} The Zimbabwe study looked at adolescents between the ages of 11–15 years only,³⁹ whereas this study included children ages 5–17 years; age is associated with disclosure studies.¹⁸

Data from the quantitative component of this study, presented in a separate article, note that caregivers want to be involved in the decisions and the processes revolving around disclosure, but that they also want support from health care providers. A Zimbabwean study examining health provider and community member perceptions of disclosure of HIV status to children found that over half of the community members would want health care workers involved in initiating disclosure and discussions about grief with their children.⁴⁰ In the data presented here, health care providers played a limited role in the preparation and follow-up to disclosure. Health service providers can provide more support to caregivers and children in several ways. First, they can modify the messages given to youth so that youth feel comfortable to ask questions and obtain more information as their understanding of HIV and their own health evolves. Second, they can help caregivers address youth concerns by discussing the questions and concerns brought up by youth and helping caregivers respond to them. Third, they can engage in conversations with youth about their health, both before and after they are told of their HIV status, providing them with accurate information that will ultimately prepare them to learn of their diagnosis. Finally, they can provide more psychosocial support, creating opportunities for youth to express themselves during regular clinic visits and developing sup-

port group sessions especially for youth, in order to help them adjust to their HIV status. Increased awareness and training of health care providers to provide appropriate support is needed.

The study has several limitations. We only interviewed children whose caregivers knew that they had been told their HIV status. The experiences of youth who learn of their HIV status without family knowledge, and the implications this has for their well-being as well as for health service delivery for youth, should be explored. We recruited from a facility that provides medical treatment including access to antiretrovirals in a resource-constrained environment. The experiences of families with youth who have been diagnosed but do not have access to medical care might be quite different and should be further explored. All of the adults interviewed were the children's biological parents, stemming from the fact that they were the only ones whose children had been told their HIV status. The caregiver's relationship to the child might influence when, where, why, and how a child is informed of their HIV status. Also, caregivers' own HIV status might be a strong influence on the disclosure process.

We did not collect clinical information about the children's health status. We felt that caregiver's perceptions of the child's health might be more important in understanding disclosure experiences within families. Also, while we have information about the age of the child at diagnosis, we do not have information about the probable mode of transmission to the child. Mode of HIV acquisition can only rarely be confirmed in this setting; however, half of the families interviewed had an HIV-infected parent. Only one of the youth in this study appears to have been sexually active prior to diagnosis. While the majority of children in this setting are perinatally infected, nonparental transmission is a factor, particularly in sub-Saharan Africa where blood supplies may not be fully secure and blood transfusions for malaria-induced anemia not uncommon. Furthermore, up until recently, when treatment became more accessible, children could be sick for many years before finally being diagnosed with HIV in this setting. Other literature suggests that HIV-infected caregivers are reluctant to disclose HIV status to infected children as it means disclosing their own status, subjecting them to both guilt as well as blame for the child's status.^{7,41,42} In this study, some of HIV-positive caregivers chose to tell their children in the hopes that they could serve as role models to the children in positive well-being; however, it could be that similar feelings of guilt or concerns around blame, albeit not mentioned in interviews, could influence disclosure patterns in this setting.

Despite these limitations, this study is an important step towards better understanding how youth experience disclosure of their own HIV status. The findings from this study point to the need for creating comprehensive care and treatment programs for HIV-infected children that address not only their clinical needs but also their overall well-being. Further examination of the needs and experiences of children living with HIV infection and their caregivers will help to define the roles of health system staff as well as psychosocial programs throughout the disclosure process.

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