

# The Perceived Impact of Disclosure of Pediatric HIV Status on Pediatric Antiretroviral Therapy Adherence, Child Well-Being, and Social Relationships in a Resource-Limited Setting

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## Abstract

In resource-limited settings, beliefs about disclosing a child's HIV status and the subsequent impacts of disclosure have not been well studied. We sought to describe how parents and guardians of HIV-infected children view the impact of disclosing a child's HIV status, particularly for children's antiretroviral therapy (ART) adherence. A qualitative study was conducted using involving focus groups and interviews with parents and guardians of HIV-infected children receiving ART in western Kenya. Interviews covered multiple aspects of the experience of having children take medicines. Transcribed interview dialogues were coded for analysis. Data were collected from 120 parents and guardians caring for children 0–14 years (mean 6.8 years, standard deviation [SD] 6.4); 118 of 120 had not told the children they had HIV. Children's caregivers (parents and guardians) described their views on disclosure to children and to others, including how this information-sharing impacted pediatric ART adherence, children's well-being, and their social relationships. Caregivers believed that disclosure might have benefits such as improved ART adherence, especially for older children, and better engagement of a helping social network. They also feared, however, that disclosure might have both negative psychological effects for children and negative social effects for their families, including discrimination. In western Kenya, caregivers' views on the risks and benefits to disclosing children's HIV status emerged a key theme related to a family's experience with HIV medications, even for families who had not disclosed the child's status. Assessing caregivers' views of disclosure is important to understanding and monitoring pediatric ART.

## Introduction

**A**NTIRETROVIRAL THERAPY (ART) saves the lives of HIV-infected children.<sup>1-7</sup> For the 2.3 million children around the world currently living with HIV, initiating and maintaining ART is crucial to slowing their progression to AIDS and preventing deaths.<sup>8,9</sup> Ninety percent of the world's HIV-infected children live in Africa,<sup>8</sup> often in resource-poor settings with limited treatment options. In these settings, it is especially crucial to determine factors that enhance or hinder the provision of ART to children.

The caregivers of HIV-infected children, whether parents, relatives, or other guardians, play a crucial role in the provision of ART to children. Children are usually dependent on adults to receive effective HIV therapy; to varying degrees, children may require that adults give them their medications, access the clinical care system, and obtain medication refills. In this context, disclosure of HIV status plays a unique role in the interactions of children and adults around HIV medications. Whereas adults generally know why they are taking their medications, control their own medication usage, and have some sense of the importance of adherence, many

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HIV-infected children have not been explicitly told of their diagnosis or why adherence to their medications is important.<sup>10-13</sup>

Disclosing a diagnosis of HIV to the child presents a unique challenge for maintaining appropriate ART for children. In some settings, children's awareness of their HIV status has been associated with the quality of adherence to ART. In a study from Maryland, children who were aware of their HIV status were significantly less likely to be categorized as adherent.<sup>14</sup> In a study from New York, children's knowledge of their HIV status was also associated with lower CD4 counts and higher viral loads.<sup>15</sup> In another study of HIV-infected children in New York, adherence was not significantly associated with the child's awareness of their diagnosis, but less disclosure to other people or less social disclosure was significantly associated with increased nonadherence.<sup>16</sup> Despite these studies connecting disclosure to children with nonadherence, the perception of many pediatric health care providers is that disclosure helps children understand the need for ART and creates a trusting relationship that facilitates adherence.<sup>17-19</sup> A small qualitative study examining pediatric adherence in Belgium found that, in some cases, disclosure of HIV status was necessary to overcome the child's opposition to taking the HIV medications; however, disclosure to the child led to better adherence only when the caregiver was also adherent to their own ART.<sup>20</sup>

Most of the current understanding of how children's awareness of their HIV diagnosis impacts their adherence to long-term ART is drawn from work in resource-rich settings. In resource-limited settings, neither the perceived impact of disclosing a child's HIV status, nor the actual impact of disclosing a child's HIV status is well described. Emerging studies among developing pediatric care systems show that many HIV-infected children are not aware of their HIV status. One study from Thailand reported that only 1 in 5 HIV-infected children ages 5-16 years (mean age, 9.6 years) had been told of their HIV diagnosis.<sup>10</sup> A cross-sectional study from the same country showed that, among children ages 6-16 years (average age, 9.2 years), 30.1% of the children knew their HIV status.<sup>13</sup> In both studies, disclosure was perceived to carry certain risks. Parents raised concerns about disclosure to a child psychologically harming the child.<sup>10,13</sup> Other reasons for not disclosing to children included concerns that the child was too young and that the child could not keep a secret.<sup>10</sup>

In sub-Saharan Africa, research describing factors effecting disclosure of a child's HIV status is just emerging. Studies from South Africa using semistructured interviews suggest that caregivers and health care providers are concerned about how the disclosure of pediatric HIV infection might impact medication adherence.<sup>21,22</sup> In the Democratic Republic of the Congo, a qualitative study with 19 youth and 21 caregivers found that the median age at disclosure was 15 years, and one of the most common reasons for disclosure was to improve the child's adherence to their treatment regimen, as well as the child's need to stay healthy or to protect herself/himself.<sup>23</sup> In a qualitative study with 42 pediatric caregivers in Uganda, complete disclosure of pediatric HIV status to children ages 5-17 years (median, 12 years) was related to good ART adherence.<sup>24</sup> There are data to suggest that both disclosure to children and disclosure to others may affect important aspects of therapy such as adherence. In another Ugandan study, which used a standardized questionnaire to assess adherence and disclosure, not disclosing the child's status to anyone

other than the primary caregiver was associated with pediatric nonadherence, but disclosure to the child was not associated significantly with adherence.<sup>25</sup> In a larger cross-sectional study from Ethiopia, children who did not know their own HIV status and children who were not aware of their caregiver's health problems were actually more likely to adhere to ART than their counterparts, even when adjusting for other characteristics such as age.<sup>26</sup> A cross-sectional survey of 127 HIV-infected adolescents in Zambia found high rates of emotional and peer problems among the group, but disclosure of HIV status was not associated with worsened mental health.<sup>12</sup> Thus, existing studies examining the relationship of disclosure of children's HIV status to ART adherence suggest that the effects of disclosure may vary from one setting to another.

How pediatric caregivers communicate with their children or with others, particularly about issues related to HIV, may impact both disclosure and adherence. A qualitative study from the Democratic Republic of the Congo suggests that patterns of limited communication between caregivers and children greatly impacted the experience of disclosure, making it more of a discrete event than a process.<sup>27</sup> Therefore, understanding how pediatric caregivers in a given setting view the sharing or withholding of information about a child's HIV status, either to the child or to social others, may shape the delivery of pediatric HIV care in that setting, including how to facilitate disclosure and how to maintain ART adherence.

Qualitative research methods offer a way to explore caregivers' perceptions, choices, and patterns of behavior in a particular setting.<sup>28-30</sup> In grounded theory, a qualitative research method, a theoretical framework to describe a pattern of behavior is derived from the systematic analysis of individual interviews or focus group discussions.<sup>31,32</sup> We used a grounded theory approach to describe how a sample of pediatric caregivers in western Kenya view the disclosure of a child's HIV status and how these perceptions of disclosure might impact pediatric ART adherence.

## Methods

### Setting

This study was conducted in western Kenya within the USAID-Academic Model Providing Access to Healthcare partnership (AMPATH). AMPATH grew out of a partnership established in 1989 between Indiana University School of Medicine, Moi University School of Medicine, and Moi Teaching and Referral Hospital (MTRH).<sup>33</sup> Since 2001, AMPATH has been a model HIV care system for resource-limited settings.<sup>33,34</sup> The AMPATH clinical care system operates in Kenya, a country with a national HIV prevalence of 7.8%, where over 1.4 million persons live with HIV, including 150,000 children.<sup>35</sup> As of February 15, 2010, AMPATH has enrolled more than 111,404 patients in western Kenya, and currently follows more than 68,740 active patients (including more than 14,603 children) at 23 urban and rural clinic locations and 23 satellites. AMPATH provides free antiretroviral therapy (ART) to all patients qualifying for therapy, as well as comprehensive nutrition services, psychosocial support, and economic development training.

This study was conducted within four representative AMPATH clinics. One site was the urban referral center in

Eldoret, which has been in operation since November 2001 on the grounds of MTRH. As of April 15, 2010, the MTRH clinic currently cares for a total of 22,537 patients. Of those patients, 4618 are children 14 years of age or younger, and 1,052 children at MTRH are currently on ART. The three rural locations were the Chulaimbo Provincial Rural Health Training Centre, Burnt Forest Rural Health Centre, and Mosoriot Rural Health Centre. The Chulaimbo clinic currently cares for 1865 children, with 360 on ART. Burnt Forest clinic cares for 654 children, with 164 on ART. Also, the Mosoriot Rural Health Centre cares for 1054 children, with 192 on ART.

### Research design

Focus groups and individual interviews were used to elicit data from parents and caregivers of HIV-infected children taking ART through the AMPATH care system. Information on the process of medicine-taking, barriers and supports to maintaining ART, and beliefs about disclosure of HIV status were queried. An overview of the factors sustaining pediatric ART adherence in this setting has been published elsewhere.<sup>36</sup> This analysis focuses on the cross-cutting theme of disclosure or information-sharing and the participants' dialogue related to that theme. We used both focus groups and individual interviews in order to garner the benefits of both techniques, so that a more comprehensive understanding could be achieved. The group discussions allowed for amplification of the shared perspectives and themes,<sup>37,38</sup> while the individual interviews potentially lessened biasing effects from social norms.<sup>30</sup> Participants in both the focus groups and the key interviews met the same inclusion criteria; they were all parents of HIV-infected children on ART through AMPATH.

The focus groups and interviews were conducted in Kiswahili, one of the two national languages in Kenya. The groups and interviews were conducted between March 1 and November 30, 2007 by a trained facilitator who was not part of the clinical care system. A prepared interview guide, containing open-ended questions, was used to solicit responses during a 2-h session for focus groups and a 1-h session for individual interviews. Questions were based upon review of the literature, the input of local health care providers, and pretesting with a series of five, in-depth key informant interviews conducted within subjects' homes. The final questions covered multiple areas related to the experience of caring for HIV-infected children ART. The interview guide covered the cultural context of HIV treatment, including treatment decision-making, cultural reactions; disclosure, including disclosure to other people and to children, and beliefs about disclosure; medication handling, which included questions about travel and water practices; beliefs about medicines; interactions with children around medicines; and barriers to medication adherence. As examples of the questions about disclosure, participants were asked the following: "What do you think about telling other people that your child has HIV?" and "How do you feel about giving your child medicine for HIV in front of others?" Other questions focused more generally on the family's social context: "Caring for a child who is infected with HIV can be very difficult. Many parents tell us that it is more difficult when family members or others in their community or in their village do not support them. How is it for you in your community?" [Complete focus group and

individual interview guides available from the corresponding author on request.] The same interview guide was used for both the focus groups and individual interviews, with some additional questions added to the guide through the course of data collection in following a grounded theory approach. All data regarding the caregivers and their children were based on the participants' self-reports. All of the participants granted permission to digitally record the sessions to allow for later transcription. Field notes were also taken during and immediately after the encounters. All of the recordings were transcribed and translated into English by a trained translator. Translations were checked for face validity by a bilingual study investigator (W.M.N.).

### Participants

Parents and caregivers of HIV-infected children on ART were recruited from within the AMPATH care system. Children whose parents or caregivers were eligible for participation were identified through a search of the AMPATH electronic medical record system. Fliers were placed on the charts of eligible patients, encouraging clinicians to refer them to the study team. Fliers were also placed around the clinic and in exam rooms to allow for self-referral into the study. Female parents and caregivers were selected based on a convenience sample; however, male caregivers were purposefully oversampled in order to include this minority population, which makes up only 8% of the primary caregivers for children. Inclusion criteria involved being a parent or primary caregiver of an HIV-infected child on ART through AMPATH. There was no minimum duration of time for the children to be on ART, nor was purposeful sampling done on the basis of disclosure practices. The AMPATH pediatric clinics only care for children up to the age of 14 years, so parents and caregivers were identified based on HIV-infected children less than 14 years of age. Parents may or may not have been HIV-infected or been on ART themselves. Parents or caregivers were excluded from participation only if they had a mental or physical impairment preventing them from being able to give informed consent. Parents and caregivers of children under the age of 5 or 6 years of age were included to provide a broad picture of how caregivers perceive disclosure to other people and to children throughout the child's developmental course and to provide a more representative cross-section of our enrolled population. Participants were randomly assigned to focus group versus the individual interviews and offered a focus group date or interview date accordingly. However, if a participant assigned to a focus group was not able to attend on the date of a scheduled focus group, they were then offered the option of scheduling an individual interview. We conducted four focus groups at the urban referral center in Eldoret, Kenya, and six focus groups at three more rural HIV clinics, with a total of 85 participants in the focus groups. Focus groups were divided by gender. One focus group with exclusively male caregivers was done at the urban referral center. At the rural health centers, all of the male caregivers were interviewed individually, and the focus groups contained only women. In addition, we conducted 35 individual interviews. We enrolled participants until thematic saturation was reached. All participants gave witnessed, verbal informed consent based on a written informed consent document prior to participating in the study.

Participants received a modest honorarium to defray the time and transportation costs of their participation.

### Analysis

A system of manual, progressive coding of the transcripts was used to identify emerging central concepts.<sup>31,32</sup> The initial stage of constant comparative analyses was done through open coding by two investigators (R.C.V. and E.G.W.), involving a line-by-line analysis of each transcribed page of informant data to elucidate meanings and processes. These analysts also independently extracted and compared themes. Both the open codes and the themes extracted by the two analysts revealed high degrees of agreement between the reviewers. Cohen's  $\kappa$  was 0.78, indicating substantial agreement.<sup>39</sup> Before condensing the codes, three analysts read the data several times, including comparison of a final review of all open codes from each of the analysts, followed by recoding based on consensus by the three analysts (R.C.V., E.G.W., W.M.N.). We then did axial coding, the process of relating categories to their subcategories and linking them together at the level of properties and dimensions,<sup>31,32</sup> to organize the themes into their causal relationships. Hypotheses and concepts were developed inductively from the data. Finally, relationships among the codes were integrated, refined, and diagrammed in the development of a contextualized, theoretical framework to describe HIV-related child care in this resource-limited setting (unpublished data). Selected quotations were used to illustrate key themes.

Triangulation or verification was incorporated on several levels, using accepted techniques to ensure the validity of qualitative data.<sup>40,41</sup> First, we analyzed and compared transcript data from two sources: the focus groups and the key informant interviews. Second, independent reading, coding, comparison, creation of figures for concepts, and data visualization were performed by three investigators (R.C.V., E.G.W., W.M.N.). Finally, we incorporated two sources of peer debriefing and peer checking of transcripts, coding strategies, themes, and diagramming of relationships (D.G.M., T.S.I.). For the peer debriefing, these two additional investigators reviewed the field notes, a subset of the transcripts, and discussed development of the coding strategies and emerging themes. The peer debriefing and peer checking primarily refined the organizational structure and conceptual map created from the data, refining the organization of the causal relationships and confirming the prominent themes.

### Regulatory Approvals

This study was approved by the Institutional Review Board of Indiana University in Indianapolis, Indiana and by the Institutional Research Ethics Committee of Moi University School of Medicine and Moi Teaching and Referral Hospital in Eldoret, Kenya.

## Results

### Study participants

Data were collected from 120 parents and caregivers of HIV-infected children on ART, including 21 males and 99 females. Eighty-five parents and caregivers participated in the 10 focus groups and 35 in individual interviews. The participants, who ranged in age from 18 to 84 years, were repre-

sentative of all local major ethnic groups in the area, including Kalenjin, Luhya, Luo, Kikuyu, and Kisii. Of the caregivers, 17.5% were male. Of these caregivers, 42% were not parents of the children, but were other relatives or nonbiological guardians. The parents and caregivers provided care to 123 children on ART who ranged in age from 0 to 14 years (mean, 6.8 years of age; standard deviation 6.4). Thirty children were 0–3 years of age, 30 were 4–6 years, 42 were 7–10 years, and 20 were 11–14 years (with age missing for 1 child). All of the children were presumed to be infected perinatally with HIV although one child had also had a blood transfusion prior to diagnosis. The children had been diagnosed with HIV for between 1 month and 8 years (mean, 2.7 years), and had been on ART for time periods ranging from 1 month to 4 years (mean, 1.9 years).

### Antiretroviral therapy adherence

Parents and caregivers commonly reported difficulties with medication-taking. In the focus group discussions, 87 adherence problems were reported by group participants (range, 5–17 per group). Nineteen of the 35 interview participants volunteered problems they had experienced with ART adherence. The most commonly cited problems with medication adherence included delaying or skipping doses because they did not want to give the child medicines in front of others, the caregiver just forgetting to give the medicines when busy, having difficulty traveling to the clinic to get the medicines, not having food to give the child with the medicines and thus skipping doses, and not being able to give the medicines because the only caregiver who knew about the medicines was away.

### Caregiver disclosure of the child's HIV status to the child

Disclosure of the child's HIV status was an important and common theme throughout the qualitative inquiry, with caregivers expressing their beliefs about and perceptions of disclosure as a central theme to the experience of having a child on ART (Table 1). Although disclosure was frequently discussed, most of the pediatric caregivers had not told the child that they had HIV. Only 2 of the 120 caregivers reported having told the child why they were taking ART. In both cases, these caregivers were grandparents of children whose mother and father had both died from HIV. Both children who had been told of their diagnosis were 14 years of age at the time of the interview; one had been 13 at the time of disclosure, and the other was 14 at the time of disclosure. Older or "big" children were generally categorized as those 11- to 12-years-old and above. "Small" children were seen as those under the age of 6 or 7 years. Children in between 7–11 years were typically seen as being too young to know their diagnosis, but old enough to begin taking some responsibility for their medications and old enough to start asking questions about why they were taking the medicines. Caregivers viewed disclosure as having the child know "why they are taking the medicines." Some parents and caregivers reported that they had begun partial disclosure by telling the children the general purpose of their medicines, such as that the medicines "stop [him or her] from being sick again," without mentioning HIV specifically. Caregivers did not consider this the same as the child knowing why they were taking medicines. Many caregivers also reported that they had told the children that they needed the medicines for other reasons, such as a

TABLE 1. PERCEIVED IMPACT OF HIV DISCLOSURE TO CHILDREN AND TO OTHERS

	Perceived impact	Illustrative quotes
Disclosure to children	Benefits: Improved adherence for older children Increase in child's responsibility for medications	"I had to tell her about her condition and that is when she had the courage of taking [the medicine]." (Interview, grandmother of 14-year-old describing improved adherence after disclosure)
	Risks: Adverse psychological consequences Disclosing before developmentally ready Child's subsequent disclosure to other people leading to discrimination	"If the child knows and they are naughty and you call them to take the drugs, they may tell the other children, 'I am taking drugs because I have AIDS.' So, the other children run to tell their mothers and report what the child has said." (Focus group, mother of 7-year-old describing fear of child disclosing to others, leading to feared stigmatization)
Disclosure to others	Benefits: Engage supportive network Support in child care Receive help Eliminates need to hide the child's medications or delay doses	"When I came to [the clinic], my [family] brought me. My mother, [the child's grandmother], told my uncle, who helps me. She told him that I have HIV. If I tell people, they will be talking about me and gossiping. They will laugh at me. It is my secret... But my uncle, he assists me. When I am not there, my uncle's wife gives [the child] the medicines." (Interview, mother of 5-year-old, describing her supportive family network)
	Risks: Isolation Stigmatization Discrimination Exposure to negative attitudes toward HIV treatment that might	"When they discover that you have it, they will obviously separate you. You will have to fend for yourself. When I discovered my child's status, I was staying with my brother. When we knew our conditions and told him, he chased us away. Whoever knows will automatically separate you. If I die, there will be no one to care for my son and it will also force him to die." (Interview, mother of 4-year-old describing experience of discrimination)

"chest problem" or a "stomach problem," and felt that lying to the child about why they needed medicines was not bad.

*Benefits of disclosing child's HIV status to the child*

Disclosure to children was viewed as having potential benefits for maintaining pediatric ART adherence (Table 1). Parents and caregivers suggested that disclosure to children could improve pediatric adherence as children became older. These older children would then better be able to take responsibility for their medications. The parents and caregivers reported that the converse was true; parents and caregivers reported that children not knowing they have HIV becomes a barrier to ART adherence as time goes on. Specifically, nondisclosure becomes a problem for getting the children to take their medicines as they get older and begin to "ask questions." The child not knowing why they were taking the HIV medicines was cited as a prominent challenge for medication adherence:

Disclosure is a problem [for adherence]. My child has not reached the stage of asking the reason for them swallowing the drugs because he is still young. There are some whose children ask, "Why am I swallowing the drugs?" (Focus group, mother of 5-year-old)  
"One challenge is with the big children. I don't see a problem with the small ones because they are given and they take [the medicines], but when they reach a certain age, and they start asking themselves, "Why do I take medicine in the morning and in the evening?"... This is where we as caretakers have a problem. The problem is when this child starts getting wise and starts asking why they are taking these drugs. (Focus group, grandmother of 13-year-old)

*Fears of negative effects from disclosure to children*

Although the participants felt that informing the child why they were taking the medicines might reduce these questions and help with adherence, they also reported that they feared negative effects from disclosure. For some, these fears seemed to be what prevented them from telling the child about their HIV status. The major concerns about disclosure for caregivers in Kenya included the following: fear of adverse psychological consequences for the child, believing the child was not developmentally ready to understand the implications of the HIV diagnosis, and wanting to avoid the child's subsequent disclosure to other people.

The caregivers frequently described that disclosure might have negative psychological consequences for the child, such as children being "affected" or "having lots of thoughts." More emotional components of depression or anxiety, such as being sad, crying, or worrying, were not mentioned. The potential psychological consequences of disclosure were described primarily with their cognitive or behavioral components. The feared psychological consequences were described as concerns that the children would be "thinking and thinking" and "refuse to play with other children" and "lose their memory." The caregivers did not describe the children losing hope or becoming depressed or anxious in emotional terms, but instead described cognitive components of these conditions such as repetitious thoughts or becoming forgetful. Other symptoms of mental health challenges, such as withdrawing from others, were also described.

Although caregivers felt that “big” children were more prone to nonadherence in the face of nondisclosure, the caregivers questioned whether even the “big” children had the developmental readiness to understand and cope with their diagnosis. Parents and caregivers typically defined being “big” as “reaching the age of 11 or 12 years,” and this was typically regarded as the age at which full disclosure should occur. The caregivers frequently expressed that they were waiting to inform the child of their HIV status until the child was older or more mature:

*At the age of twelve, I will sit with him and look for someone who will explain it all to him. . . at that age, his mind will be mature and he will be able to understand what is going on, but at the age that he is now, if you start explaining it to him, he will start wondering and utter statements like “the way I have heard, that AIDS kills, it means I will also die.” I feel that he is still young.” (Focus group discussion, mother of 10-year-old)*

Even among these “big” children, concerns remained about their readiness for disclosure. One grandmother of a 12 year old expressed the concern that if she disclosed to the child who was “getting wise and start[ing] to ask why they are taking these drugs,” it would be like “the grandfather or grandmother has killed the child’s thoughts.” “Kill[ing] the child’s thoughts” was used as a cognitive description of losing hope or being depressed, in which the child stops thinking of the future or having hope for the future. The caregivers felt that disclosure must be done as a process, “slowly by slowly until you know that she or he has understood why they are using that medicine,” and they emphasized that even the “big” children might not be ready for this.

Caregivers were very concerned about avoiding the child’s subsequent disclosure to others. They strongly emphasized that they did not want to tell the child about their HIV status for fear that the child would tell others that they had HIV, and that negative social reactions, such as increased stigma and discrimination, would result:

*If they know, the questions might be more than that, because [the child] may ask you, “How did I get this disease? How was it?” And the child goes to announce to others that he has this disease, and he may spoil everything. This is what disturbs parents and it may be a barrier to taking [the medicines]. Telling your child that they have HIV. (Focus group, mother of 9 year old)*  
*I don’t know how [other people] will take it, so I don’t tell the child. I fear they may segregate him. (Interview, aunt of 14 year old)*

Caregivers wanted to avoid this additional disclosure because they were concerned about the potential negative effects for the child and for the family. They expressed concern that children would hear from others that people with HIV “won’t get well and will die,” or that the children would learn from others that the HIV “came from your parents.” This suggested concerns that disclosure could impact the child’s psychological state, resulting in a lack of hope, but also that family relationships might be damaged. Parents and caregivers repeatedly expressed fears that the child’s self-disclosure to others might reveal the mother’s HIV status, but they were most concerned that disclosure “may spoil everything” because the community’s knowledge that HIV was present in the family might result in isolation and discrimination. The caregivers deeply feared isolation and stigmatization of both the child and the family, fearing that the other children would

“refuse to sit with [the HIV-infected child]” and that the HIV-infected children would “be alone” and the family “would receive no help.”

#### *Caregiver disclosure of the child’s HIV status to others*

Caregivers suggested that disclosing a child’s HIV status to other people could result in benefits for shared childcare, sustained adherence, and community support. However, many participants also believed that disclosure to others could result in negative effects, depending on whether the attitudes and beliefs of those receiving this information were negative or positive (Table 1). Among the 99 participants who described which people knew that the child took medicines for HIV, 13.1% reported that they had told no one else, 25.3% reported telling only one other person, 16.2% had told 2 other people, 10.1% had told 3 other people, and 35.3% had told more than 3 people or told an unspecified number of people (e.g., “those who live in the household” or “my whole family”). Based on the 120 persons reported to know that the child was taking medicines for HIV, 28.3% of those who knew were the siblings of the parents or caregivers, 24.2% were the caregiver’s spouse or the parent of the child, 20.8% were the grandparent of the child, 15% were neighbors or friends, 10% were siblings of the HIV-infected child, and less than 1% were house help or teachers of the child.

#### *Benefits of disclosing a child’s status to others*

In the cultural context of western Kenya, caring for children, including sustaining ART adherence, usually involves the support of a network of family and community members.<sup>36</sup> Engaging this network of family and community members may require some degree of information-sharing, particularly regarding what needs the family has. For a family with HIV-infected members, engaging the social network may require disclosure about a child’s HIV status or about their need to take medications. Parents reported that disclosure to others could result in a positive response, engaging this supportive network and allowing the caregivers to receive support in child care, including help in maintaining ART adherence for the child. The mother of a 5-year-old girl describes how informing family members about the child’s diagnosis and ART allows them to assist in administering the medicines:

*I usually give [the medicines] and also the child’s aunt gives some other times, and we don’t fear because we all know what the disease [is]. The family members around know what the drugs are for, and I have explained to them such that when it reaches time, even if the child is asleep, we usually wake them up to take the medication. (Focus group, mother of 5 year old)*

#### *Negative impact of not disclosing to others*

In contrast, caregivers who do not disclose to others report that they “lack help.” Nondisclosure to others makes child care more difficult because caregivers do not have other people who can support them or assist with administering the medications:

*There is no one. I just depend upon myself. . . we are just on our own. (Focus group, mother of 6 month old)*  
*I have difficulty some times when I have left. Sometimes I am not near and I tell the children to give the child the medicine and when I come I find they have forgotten. They didn’t give*

the child medicine yesterday so there is that difficulty. (Focus group, aunt of 6-year-old)  
It was hard. It was just me and my boy alone. I had to ensure that he had taken his medicine, stay with him, and give him milk because he had TB." (Interview, mother of 14-year-old)

Not disclosing the child's diagnosis to other people reinforces caregivers' feelings that they need to hide the diagnosis or to hide the child's medicines from others. In this cultural setting, in which people often live in compounds with limited privacy, concealing an HIV diagnosis and HIV medications is not easily maintained and can interfere with taking the medications on time or taking them every day. The presence of household members or neighbors who did not know the child's diagnosis was frequently cited as a cause of missed or late doses of ART:

Some people fear because they have not disclosed to their husbands that the children are sick, so they can't give medicine when the husband is there. (Interview, mother of 7 year old)  
Someone can even come to my house and I will just sit. I can even delay giving the medicine for an hour [until] that the person leaves. (Focus group, mother of 5 year old)  
Others fear other people, colleagues, and friends. The fact that there is a person near who doesn't know that they are taking drugs makes them not want to be seen swallowing the medicine or to be associated with it." (Focus group, mother of 2 year old)

In contrast, disclosing the diagnosis to others might allow the caregiver more freedom in administering the medications, and might lead to better adherence.

#### *Fears related to disclosure to others*

Although disclosing the child's diagnosis to others could allow caregivers to receive help, to give the medications more freely, or to sustain adherence, the caregivers also feared the potential negative consequences of disclosure to others. The majority of parents and caregivers chose not to disclose the child's HIV status to other people because they thought that sharing this information would result in being isolated or stigmatized. The fear of isolation or stigmatization led them, instead, to try to hide the medicines and everything associated with the HIV diagnosis. The fears of isolation and stigmatization are clearly reflected in the following excerpts:

Many times I have seen one thing. For example, when people discover that a child has the virus they start isolating them. They leave that child alone. Then, they tell their children not to eat or share their food with the child who is infected. They should not play with such a child. Don't sleep with them, don't put on their clothes. So when such things happen, the child begins to feel lonely and they wonder why. So many times, grandparents like me can't tell anyone, anyhow about the status because they will not help. And if you tell them, others will spread the information, so even going on a journey with the child becomes a problem. (Focus group, grandfather of 13 year old)

If they discover that your child has the disease they will stop their children from playing with your own. If you are in the vehicle and they know that you have it, they move far away from you. They say that this is a bad disease, and everyone doesn't like it. (Focus group, grandmother of 6 year old)

In addition to anticipating negative impacts from being exposed to stigmatization and discrimination, caregivers ex-

pressed concern that disclosure to others might lead to non-adherence because of the negative opinions many community members hold towards the HIV medications. Caregivers expressed that exposure to the negative opinions of others, such as the view that ART use is futile, might make them "lose heart" and "leave the medicines:"

If someone hears that you are swallowing these drugs, they tell you that even if you take that medicine, you don't get well. "This disease—you hear them announcing everyday that it has no treatment. So, this is just wasting your time. There is no need for you to fill yourself with drugs—stop taking!" That is why many people stay in the state of hiding the medicine. They don't tell anyone because, you see, they will break your heart. (Focus group, mother of 3 year old)

In summary, parents and caregivers of HIV-infected children described how disclosure to others enabled them to enlist the help and support of their family and neighbors, but their fears of isolation, stigmatization, and being discouraged from taking the medicines often inhibited them from disclosing the child's HIV status to additional people. Choosing not to disclose to other people may also compromise the children's adherence to ART when caregivers struggle to hide the medicines from other people and do not receive support and assistance from those in the immediate community or household.

#### **Discussion**

Parents and caregivers of HIV-infected children on ART in western Kenya described disclosing or not disclosing information about a child's HIV status as central to the experience of having a child on ART. The caregivers' views about disclosure of children's HIV status included perceived risks and benefits for pediatric antiretroviral therapy adherence, child well-being, and social relationships. They perceived that informing children of their own HIV status or disclosing the child's diagnosis to other people could sustain pediatric ART adherence through addressing the children's developmental needs to understand why they are taking medicines or through engaging a supportive network of helpers. However, they were simultaneously concerned about the risks involved with disclosing HIV status, particularly the risks if others respond negatively by stigmatizing, isolating, or discouraging the family or if the child might be negatively affected by disclosure. Only two caregivers had actually informed children of their HIV status; however, more had disclosed the child's status to other people. While some of the caregivers were caring for children who were likely too young or developmentally unready for disclosure, the low rates of disclosure may stem from some of the caregivers' concerns about the potential negative impact on the child or on the family's social relationships. Assessing caregivers' disclosure practices and views of the effects of disclosure is important to the ongoing care of children on ART, particularly for understanding how the caregivers might interact with their children and with their peers and how this might impact the child's HIV care over time.

The limited existing research from sub-Saharan Africa reveals that pediatric disclosure is a prominent concern among families,<sup>22,42</sup> but the perception of how disclosure might impact emotional health or health behaviors such as adherence are not clearly understood.<sup>12</sup> Our findings provide a more

detailed picture of how caregivers for children of varying ages view disclosure and its impact in a particular cultural context in Kenya. Qualitative work from other settings in sub-Saharan Africa suggests that understanding the existing framework in which children and caregivers communicate about health issues is important to shaping the process of disclosure that will follow.<sup>27</sup> These findings from western Kenya suggest that exploring caregivers' perceptions of how disclosure will impact the child's care and adherence, the child's psychological well-being, and the child and family's social relationships are key to health care systems caring effectively for children. These findings are similar to those found in qualitative work from Kenya's urban capital, in which potential societal discrimination, lowered self-esteem, and concerns about confidentiality featured prominently among adolescents' concerns with telling others about their HIV status.<sup>43</sup> Similar views and beliefs among pediatric caregivers can subsequently be explored in other resource-limited settings, including sub-Saharan Africa.

In addition to offering a description of the perceptions of disclosure within the culture, our findings also suggested ways that adherence to ART might be enhanced by a disclosure process that informs children about their HIV status in a developmentally appropriate manner. The idea that pediatric adherence might be enhanced by disclosure is in keeping with many studies from both resource-rich and resource-limited settings.<sup>24,44</sup> From the findings of this qualitative study, we cannot conclude whether disclosing a child's HIV diagnosis, either to the child or to other people, will improve pediatric ART adherence. However, our data do suggest ways in which disclosure could improve adherence, and what benefits to disclosure resonate with caregivers in western Kenya. Disclosure can allow older children to understand why they are taking daily medications and to begin to assume responsibility for their medical care. Disclosing the child's HIV diagnosis to even one or two supportive adults may create a context in which the priority can shift from hiding the medications to taking the medications routinely. Moreover, having at least one other adult who knows about the medications may enable the caregiver to receive the help and support that they need to provide consistent care to the child.

Parents' and caregivers' fears related to the negative impact of disclosure on the child's psychological state were common in this study, and have also been commonly reported in other studies of parents' beliefs and fears about disclosure.<sup>10,13,45</sup> However, evidence from both resource-rich and resource-limited settings suggest that rates of depression, anxiety, and emotional and peer problems are no higher among children who have been informed of their HIV status.<sup>46-48</sup> This existing evidence may be useful in allaying caregivers' fears about the impact of disclosure on the child's mental health. While the fears of subsequent disclosures of HIV status and resulting negative social responses have been reported in other studies,<sup>10,43</sup> we could not locate any literature evaluating whether disclosure to children does indeed increase the amount of stigma and discrimination that families experience. This suggests that stigma, isolation, and discrimination should be monitored closely when evaluating programs to increase pediatric disclosures. Understanding how caregivers in this setting perceive the benefits and risks of disclosure of a child's HIV status enables clinicians and care systems to address these fears and to open dialogue about how, when and

whether to undertake disclosure. Understanding the perspective of these parents and caregivers helps clinicians and health care systems to formulate appropriate strategies to support them in the process of disclosure and prepares evaluators and researchers to measure appropriately any positive or negative effects of disclosure.

The analyses included very few parents or caregivers who had actually disclosed to this child, with only 2 of the 62 children older than 7 years having been informed of their HIV status (3.2%). Among the younger children, it is not unexpected that the children would be considered developmentally immature or too young to be informed about their HIV status. Even among the older children, these low rates do not seem atypical for this region. Unfortunately, we do not yet have true population-based data from our setting to characterize rates of disclosure to children. Interviews with health-care providers in western Kenya for the purpose of disclosure training suggest that only a small number of children have been told about their status, and that this does not typically occur until age 12 or 13 years at the earliest. Possible factors related to these low disclosure rates could include the fears about negative impacts from disclosure, other cultural beliefs related to the view of children,<sup>49</sup> or the fact that no systematic program to facilitate or promote disclosure was currently in place within the HIV care program.

Strategies to support pediatric disclosure in health care systems in resource-limited settings should incorporate local perspectives into the entire disclosure process. The process of disclosure involves multiple steps over the child's developmental course, including gathering information about the family, preparing and educating the parents or caregivers about relevant health literacy and the benefits and drawbacks to disclosure, assessing the child's developmental stage, and the proceeding through partial and full disclosure. In addressing many of the fears raised by parents and caregivers in this setting, it is important to remember that partial disclosure, in which a child is given some, but not all of the information about their diagnosis, could be an important first step for younger children or in settings where families face the risk of significant discrimination. Moreover, postdisclosure counseling to address feelings, reactions, and family and community dynamics is a vital part of the disclosure process.

This study does have limitations that merit consideration. The results rely on the contextual data and lived experiences of participants in a very particular part of the world—four clinics in western Kenya. The results may not generalize to other geographic locations. Furthermore, the focus group methodology has the inherent limitations of using small, convenience samples that can limit the generalizability. The lived experiences of participants in this particular resource-limited setting, on the other hand, may have more generalizability for caregivers in other resource-limited settings than do similar studies conducted in resource-rich settings. Other aspects of the study population were fairly heterogeneous; it included both biological and nonbiological caregivers, caregivers from urban and rural settings, and care being provided to children ranging in age from infants to adolescents. While this may make it difficult to determine the relative views on disclosure for different ages of children or different types of caregivers, it offers a broad perspective on how caregivers of children perceive disclosure throughout childhood. The parents or caregivers of very young children would be very un-



likely to have disclosed the HIV status to their children; however, we were able to gather their descriptions of how they viewed this future event and how they viewed disclosure to other people. The study population included more female caregivers than males; however, this does reflect the population providing the majority of childcare within western Kenya. Health behaviors such as actual adherence were not measured, nor were parents and caregivers specifically asked about their own adherence, so other measures of health behavior or belief cannot be compared with the behaviors and attitudes reported in the focus groups and interviews. Because the research focus was to understand any difficulties in the care of HIV-infected children in this setting, confidentiality was prioritized within the group and participants were reassured that their own behaviors would not be investigated or reported. Because of this emphasis on confidentiality within the group discussions, it is possible that more accurate reports of difficulties with things like medication adherence were illuminated. While other analyses of adherence within the study population, based on the self-report or caregiver-reports given during clinic visits, reveal very high rates of perfect adherence,<sup>50,51</sup> the parents' and caregivers' relatively frequent admissions of nonadherence within the focus groups and interviews may actually reflect a more accurate picture of pediatric adherence than what is available from the clinical data. Finally, because so few of these parents and caregivers had informed their children of the child's diagnosis, the data had only a limited ability to describe the impact that disclosure actually had on the family and their health behaviors; however, there is ample data related to their concerns regarding disclosure. Understanding the caregivers' perspectives on sharing pediatric HIV status with the children or with others provides the first step in assessing the actual impact on these families.

### Recommendations for Clinicians

Although developmentally appropriate disclosure of HIV infection to children is widely encouraged by organizations such as the American Academy of Pediatrics,<sup>52</sup> there are few specific recommendations to guide clinicians who want to carry out disclosure to children, particularly in resource-limited settings.<sup>19,21</sup> Moreover, it is possible that disclosure to children or to others could carry real risks for families in some settings; certainly this is the perception of many caregivers and parents in western Kenya. These data, which emerge from the lived experiences of caregivers in a resource-limited setting, can inform clinicians caring for HIV-infected children as to how to open dialogue with families about disclosure. Based on the important challenges associated with disclosure to children and disclosure to others, clinicians could begin by asking caregivers who else knows about the child's diagnosis or knows that the child is taking medicines. Routine assessment of who else knows about the medicines may provide a valuable tool for assessing the context in which pediatric ART adherence does or does not take place. Enhancing the support system for caregivers may take the form of asking the caregivers if they can identify even one or two other people to whom they could disclose the child's HIV status. Concerns and fears related to disclosing could then be discussed and possibly addressed. If caregivers are willing to disclose to others, clinicians or dedicated disclosure counselors within

clinics could offer to participate as facilitators of disclosure to extended family members or others. Families who have chosen nondisclosure to others may benefit from alternatives to strengthen their social networks, such as referrals to psychosocial support or peer support groups in which they can receive peer support from other persons living with HIV or from other caregivers of children with HIV.

Clinicians also need to guide the process of informing children about their own HIV status. While disclosure to other people can be limited across a child's lifetime, children of increasing maturity and understanding will need to be informed of their diagnosis at some point. Well before the child begins to raise questions about why they are taking medications, clinicians should open a dialogue with families about the process of disclosure to the child. Ideally, disclosure would take the form of an ongoing dialogue across many years of the child's life, informing them about more details related to their condition and treatment as they get older. Prior studies have proposed that receiving developmentally appropriate information about HIV is key to pediatric disclosure and can even reduce children's emotional distress.<sup>44</sup> In settings such as Kenya, attention must be paid to the parent or caregiver's concerns about the child's developmental readiness, any fears they have about the subsequent effects of disclosure on the child's psychological and emotional state, and the perceived risks that ensue when the child has the capability to disclose the HIV diagnosis to other people. These challenges support the need for specifically training clinicians or counselors in pediatric disclosure. Moreover, they should assist in the development, implementation, and evaluation of culturally relevant, developmentally appropriate, and standardized materials to guide pediatric disclosure. The age at which the process of disclosure begins should be individualized based on the child's maturity and the family's situation. However, setting a standard age at which to begin disclosure may encourage clinicians to initiate routine disclosure practices within the clinic.

### Conclusions

In conclusion, clinical care systems must assess caregivers' disclosure and their views of the effects of disclosure in order to understand and maintain long-term pediatric ART. Increasing disclosure of the HIV condition to older children and to other supportive adults may be important targets for improving pediatric ART adherence. However, any efforts to assess or increase disclosure, no matter how well intentioned, must be sensitive to the concerns caregivers have about the negative impacts of disclosure. Efforts to increase disclosure must recognize, evaluate, and seek to minimize the very real risks that families may take when they disclose an HIV diagnosis more widely.

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