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Author Manuscript

J Dev Behav Pediatr. Author manuscript; available in PMC 2012 August 11.

Published in final edited form as:

J Dev Behav Pediatr. 2011 May ; 32(4): 307–315. doi:10.1097/DBP.0b013e31820f7a47.

Patterns of Disclosure of HIV- Status to Infected Children in a Sub-Saharan African Setting

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Abstract

Objective—Adult caregivers provide children living with HIV with varying amounts and types of information about their health status that may affect their coping and health care behaviors. We aimed to describe patterns of information-sharing with children and thoughts around disclosure among caregivers in the Democratic Republic of the Congo.

Methods—259 primary caregivers of children 5–17 years old in an HIV pediatric care and treatment program were screened; 8 adult caregivers (3%) had informed their child of the child's HIV status. We conducted structured interviews with 201 caregivers whose children had not yet been told their HIV status.

Results—Nearly 50% of caregivers provided no information to their child about their health; 15% had given partial information without mentioning HIV, and 33% provided information that deflected attention from HIV, whether deliberately so or otherwise. Almost all caregivers said that the child should be told their status some day, and three-fourths reported having ever thought

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Data were partially presented at XVII International AIDS Conference, Mexico City, Mexico, 3–8 August 2008 as Poster Presentation MOPE0180: Vaz LME, Maman S, Barbarin O, Bowling JM, Tshikandu T, Badinga T, Mbuyi A, Kayumba Baye J, Kitelele F, Behets F. Resolving quandaries about what to say and how much to disclose: Caregiver patterns of communication with HIV-infected children in Kinshasa, Democratic Republic of the Congo (DRC).

about what might lead them to tell. However, nearly one-third of caregivers saw no benefits to informing the child of her/his HIV status. A majority of caregivers felt that they themselves were the best to eventually disclose to the child, but some wanted support from health care providers.

Conclusion—HIV-infected children are given limited information about their health. Health care providers may serve as important sources of support to caregivers as they decide when and how to talk candidly with their children about their health.

Keywords

children; HIV/AIDS; disclosure

INTRODUCTION

In 2007, an estimated 2 million children under 15 years of age (range 1.9–2.3 million) were living with HIV infection; while children represented only 6 percent of overall HIV infections, they accounted for over 13 percent of deaths due to AIDS¹. However, the once-bleak futures facing children infected with HIV is now improving as a result of access to antiretroviral therapy. Perinatally-infected children who, without access to antiretroviral treatment were likely to die before reaching their fifth birthday², may survive into adulthood.

The Democratic Republic of the Congo (DRC) reported some of the earliest cases of HIV/AIDS in Sub-Saharan Africa. In the latest national prevalence estimates, 37,000–52,000 children under age 15 are living with HIV/AIDS¹. The latest treatment figures include an estimated 44,000 children aged under 15 years needing ARV therapy (range 20,000–81,000) and only 1,632 receiving it as of September 2007^{3, 4}.

The aims of this paper are to describe patterns of communication to HIV-positive children who have not yet been fully informed of their HIV status, and to describe caregivers' opinions and intentions regarding full disclosure of HIV status. While work has been conducted on the psychosocial aspects associated with HIV/AIDS in infected children, limited amounts have been done in non-industrialized settings. Understanding how families and health care providers communicate with children about their health is important to maximize the positive psychosocial and clinical benefits associated with knowing one's status, including children being able to engage in their own health care.

Cultural context of pediatric disclosure in the Democratic Republic of the Congo

Understanding the role of children within families is important if we are to understand how communication with children and decisions about children are made—and how they may differ within the context of HIV disclosure. However, there is very little written on the experiences of children and childhood, for Sub-Saharan Africa as a whole, and the DRC in particular. Traditionally children are seen as a source of investment for the future, and their proliferation strengthens families, lineages, and kinship systems⁵. This view gives the child a sense of belonging, a role, a living environment and a series of expectations and shapes the child's behavior towards adults. Submission and docility are expected⁵, good children treat their elders with utmost respect and perform chores without complaint. Within the context of

health, therefore, children are expected to be compliant recipients of services, with an adult caregiver interacting with the health provider on their behalf.

Evidence of the role of children and their function in families can also be found in the constitution of the DRC, finalized in November 2005 and ratified by voters in January, 2006, defining family as “the natural group unit of society” and placing it under the “protection of public authorities.”⁵ The care of children is defined as a natural right and obligation of parents, with help to be provided by public authorities⁵. The duty of children is specified as assisting their parents; parents have a duty, in turn, to care for children and to assure their protection⁵.

While a 1994 study found that the presence of a concerned extended family appeared to minimize any adverse health and socioeconomic effects experienced by children orphaned by HIV⁶, there is growing evidence that precarious family relations due to prolonged adversity in the DRC may limit the resources available to families with HIV-infected children. The ability to mobilize the family network, enabling a child to move around the extended biological family, has suffered significant transformations in recent years; the child is now first and foremost a burden for the host family^{7, 8}. When adversity of change hits the family, collective support with regard to children may suffer; the dynamic of family relations rather than family structure is a risk factor for poor outcomes^{7, 8}.

Evidence on HIV disclosure to children

Despite concerns about the social and psychological impacts of disclosure to children⁹ some studies in industrialized nations show that HIV-infected children fare well after disclosure¹⁰, and even better when compared to children unaware of their HIV infection¹¹. Some publications have focused their attention on the resulting increased involvement of the child in medical treatment^{12, 13}, others note disclosed children have better access to social support¹² and tend to be less depressed over the long-term^{14, 15}. The literature on disclosure of pediatric cancer diagnosis corroborates the evidence surrounding HIV disclosure, noting that despite parents’ wishes to protect their children from the negative effects of knowing their disease condition, children who are not informed of their status experience just as much emotional and psychological distress as children who are told their diagnoses. Few studies from developing countries to date have documented outcomes of disclosure^{17, 18}. Some have found delayed or nondisclosure of HIV status to be associated with poor adherence, psychological and coping outcomes^{19, 20}. A Thai study found no changes in rates of depression or anxiety in children and a decrease in caregiver depression after disclosure, more positive attitudes among children about HIV-infection and hopes for the futures, a better understanding of the importance of adherence to drug regimens²¹.

Patterns of HIV Status Disclosure to Children

Studies conducted in the United States, Canada, and Europe indicated that the proportion of HIV-infected children who had not been told—or disclosed—their HIV status ranged from 25 to 70 percent in the U.S. and Canada and was as high as 75–82 percent in Europe^{22–24}¹⁶. Few studies published to date included information on disclosure prevalence among HIV-infected children in developing countries, which ranged from 24–30 percent, and was higher

in older versus younger age groups^{25–27}. Limited availability of antiretroviral regimes, high levels of stigma and low levels of HIV status disclosure among adults in developing countries may mean that disclosure to children in these settings is lower than what has been documented elsewhere.

Studies, mostly from industrialized countries, have explored reasons why parents/caregivers decide to inform—or not inform—their HIV-infected children about their HIV status. Studies from developing countries largely document reasons for not disclosing rather than for disclosing, a reflection perhaps of the low prevalence of HIV disclosure to date in these countries. Reasons and factors influencing disclosure in industrialized countries include increasing age and/or cognitive development; concerns that the child would learn his/her status from other sources or become sexually active; the deteriorating health status of the child or the desire to improve health care and medication adherence; questioning by the child or the child's right to know, and the need to maintain trust or not keep secrets from the child¹⁶. In developing countries, studies identified improving treatment adherence, the child's concerns about their health status, and the child's desire to know about their health as factors that have influenced disclosure²⁸.

Reasons for non-disclosure to children by families in industrialized countries included the child's young age; the desire to protect the child or have the child live a “normal” life and the fear of psychological harm or social stigma following disclosure; concerns that the child will not understand or be unable to keep a secret or that disclosure would change family relationships; and being unsure of what to say or fear of questions about transmission¹⁶. In developing countries, reasons to not disclose and concerns around disclosure included the child's young age; concerns about causing psychological harm, being judged by the child, the child telling others, and social stigma, and caregivers feeling emotionally challenged or unprepared to answer subsequent questions^{26, 29, 30}.

Conceptualization of Disclosure

Two conceptualizations of disclosure emerge from the pediatric HIV literature. The first approach treats *disclosure as a single event*, the provision of the diagnosis of HIV or AIDS to an individual^{24, 31, 32}. The second construes *disclosure as a process*. Disclosure as a process has been documented in two different ways. One way is from the perspective of the caregivers and is the *process undertaken to disclose*, which incorporates the time up until full disclosure^{13, 32, 33}. The other is from the perspective of the children and is the *process of information received*, which can, but does not necessarily include events both before and following disclosure^{19, 29}.

Although it was possible to conceptualize disclosure as the circumstances surrounding the first mention of HIV, for this study we felt it would be more informative to examine disclosure as a process of information provision to an HIV-positive child. Specific research questions included in this paper are: What are the existing patterns of information sharing with HIV-infected children? What are caregivers' thoughts on the most appropriate time to inform children? Who should be involved in the disclosure of HIV status to children? What are the perceived benefits and challenges to disclosure? The data presented here are part of a larger mixed-method study on disclosure practices to HIV-infected children, which was

embedded within a comprehensive, family-centered HIV care and treatment program in a public hospital in Kinshasa, Democratic Republic of the Congo (DRC).

METHODS

Structured interviews were conducted with primary caregivers of HIV-positive children ages 5–17 years who had not yet fully disclosed HIV status to their child. Recruitment took place at the time of a child's regularly scheduled clinical visit, either to the treatment program itself or to the Infectious Disease Unit of the pediatric hospital where it is situated. The research was approved by the Institutional Review Boards both at the University of North Carolina at Chapel Hill in the U.S. and the Kinshasa School of Public Health in DRC, and informed consent obtained prior to the interview. Interviews were conducted in Lingala or French, based on participants' preferences, by local interviewers trained in quantitative and qualitative research for this study. To overcome literacy barriers, questions were read out loud to the participants and answers recorded by the interviewers.

A *primary caregiver* was defined as an adult aged ≥ 18 years responsible for the day-to-day care of the minor, including but not limited to biological parents, and identified through eligibility screening by program staff. Adults accompanying children who were not primary caregivers for the child or who did not know the child's HIV status were excluded, as were caregivers who were not at least 18 years of age. Prior research noted that disclosure to HIV-infected children was a rare event in this setting³⁴; for this reason, caregivers who had already informed their child of their HIV status were excluded from the structured interviews but invited for in-depth interviews, along with their child. Findings from the in-depth interviews are reported elsewhere³⁵.

The survey instrument was developed based on prior research^{14, 33, 34}, reviewed and modified for cultural appropriateness by the research study team, and pilot tested prior to the start of data collection. The questionnaire explored sociodemographic characteristics of the participant and the child; health status of the child; emotional closeness between caregiver and child; developmental stage of the child; patterns of disclosure; caregivers' thoughts on disclosure; individual and community-level stigma; and social support. Descriptive analyses were conducted using SAS version 9.1.

Questionnaires with mostly closed ended responses were used for structured interviews. Closed-ended questions were read out loud along with the response categories. In a few cases the categories were not read out loud but responses instead categorized by the interviewer; during training and pilot testing, interviewers were trained to code responses uniformly. For the few open ended questions mentioned below, the principal investigator coded responses along with one co-author. Discrepancies were resolved between the coders through mutual consensus.

Measures

Pattern of Disclosure—Pattern of disclosure was defined as our outcome of interest. Caregivers were asked an open-ended question about what had been told to the child about their health, with probes about how they respond to any questions their child asked. Based

on the responses provided, the original categories in the questionnaire were further defined. Answers were later categorized as no information, partial information, deflecting information, and both partial information and deflecting information. Box 1 presents the final definitions of the categories used.

BOX 1

Definitions of Disclosure Patterns Analyzed

No information provided

In this pattern, no information about the illness or the health status of the child is given, even if questions are asked. Questions are ignored and/or very general information is given to the child. Information was considered to be general if, from the perspective of the child being given the information, it provides no additional insight on their health. An example of general, nonspecific information that was categorized as “avoidance of discussion” is, “We go to the hospital so that the doctor can check your health.” If a child was given the name of an opportunistic infection they had but no other information about their health status, they were classified in this stage of disclosure. If a child is told to take preventive measures (do not play with sharp objects) without a reason given as to why, or for a generic reason such as to avoid getting hurt, it was classified as no information. Information on how to take medications without any reasons why was classified as no information given as it does not provide any information about the child’s health status. Most of these children have been brought to the clinic because they were symptomatic and know they have been sick; therefore, telling them that they have been sick was classified as no information given.

Deflecting information provided

Information given to the child was classified as deflecting if it was not true, if it would have to be retracted at a later date in order to provide other information, or if it focused on another health condition, regardless of caregivers’ intentions. Only cases where the caregiver denied HIV infection, said s/he lied to the child, or else gave information that, upon probing by the interviewer, was known by the caregiver to not be true were considered intentionally deflecting. Examples of ambiguous, but deflecting information include the child being told that they have sickle cell anemia or tuberculosis, or that their medications are to cure an opportunistic infection, rather than prevent it. If a child is told to adopt preventive measures to avoid being infected with HIV, this was categorized as ambiguously deflecting information because the child already has HIV.

Partial (truthful) information provided

Information that could be considered as providing some insight on their HIV status, even though HIV was not mentioned, was considered to be partially true. This included information that medications being taken help reduce the incidence of symptoms (but not that the medications are to cure the symptoms), or that the child is “sickly” or prone to falling ill. Statements encouraging children to take their medications or else they would die were classified as partially true as they provided some information—that they had a

potentially fatal condition—to the child. A child being told to adopt preventive measures to keep others from getting sick was categorized as partial information.

Some deflecting & some truthful information provided

This category was not conceptualized during the study's design. It became evident during data collection that adult caregivers sometimes provide many types of information, either simultaneously or separately, over a period of time. For example, a child could be told that her body has been ill since birth (true) and in response to a question told she does not have HIV (deflecting).

Opinions on Disclosure—We first asked if caregivers believed their child should someday be told her/his HIV status. We then asked whether they had ever thought of what specifically might lead them to inform the child. Those who responded in the affirmative were asked to provide details on what would lead them to inform the child and during what moments they think of these things. These questions were open-ended and responses were categorized for analysis. A closed-ended question determined the frequency of caregivers' thoughts about events of actions that would lead them to full disclosure. We also asked caregivers to list both perceived benefits and perceived harms of full disclosure to children. Caregivers were also asked to identify the best person to someday inform the child of his/her HIV status.

Additionally, a series of ten reasons other caregivers chose to disclose HIV status was read; the series was adapted from prior studies on the topic in industrialized settings^{33, 36} and augmented by findings from a formative evaluation conducted in 2005 on assent to research participation and disclosure of HIV status in Kinshasa³⁴. After each statement, caregivers were asked how likely they would disclose for that reason; answers were based on a 5-point Likert scale.

RESULTS

Over a five-month period, 259 caregivers of pediatric patients aged 5–17 years were screened for eligibility. Of those, only eight (3%) had already informed their child of his/her HIV status and were referred for in-depth interviews. Forty-one caregivers (16%) did not meet at least one of the criteria for inclusion into the study and were excluded. Nine caregivers (3%) refused to participate, requested to come back at another time to participate but did not keep the appointment, or were not interested in participating. In all, 201 caregivers were interviewed (78%). Most interviews were conducted in Lingala (87%); the remaining were conducted in French. Table 1 summarizes the sociodemographic characteristics of the 201 caregivers who participated in structured interviews and of their HIV-infected children.

Patterns of Disclosure

Of the 201 caregivers who participated in the surveys, nearly half reported not having provided their child with any information about their health (93, 46%); included in this category were children who were simply told that they were sick. A full third (67, 33%)

reported having given only deflecting information about this/her health, such as the child having a hernia or that the medication was to help him/her grow, and an additional 3 percent (n=7) had given the child deflecting information along with true information about their health—for example, that the child has been sick since birth but does not have HIV. Of the 67 caregivers who gave information, 11 (16%) gave intentionally inaccurate information—in these cases the caregivers explicitly stated that they lied to their children or did not tell them the truth; the remaining 53 (82%) gave responses that deflected attention from HIV, although caregivers' intentions could not be confirmed. Only approximately one in eight caregivers interviewed (31, 15%) had given their child only truthful, partial information about their health. Children ages 5–8 years were less likely than children ages 13 years and over to have been told both something true and deflecting information, versus nothing; children ages 9–12 years were more likely to have been told something misleading than something true. Box 1 provides additional detail on the definitions of the different categories of disclosure, including further examples for each category.

Opinions on Disclosure

Although the majority of caregivers surveyed had not provided any information to the child, almost all caregivers said that they felt the child should be told his/her HIV status (n=188, 94%). A majority of caregivers felt that they were the best person to eventually tell the child (98, 49%), while approximately one-third felt a health care provider was the best person to talk to the child (72, 36%); the remainder felt another family member might be the best person (10%), and only 4 (2%) said no one should tell the child. Some caregivers (n=25, 12%) noted that they wanted to be present although they preferred someone else to disclose; others (n=36, 18%) wished to disclose themselves but with either a family member or health care provider present. No significant differences were seen between biological parents and other family members on who they felt was the best person to inform the child of his/her HIV diagnosis.

Three-quarters of caregivers reported having ever thought about what might lead them to tell their child s/he has HIV (n=151, 75%). The open-ended responses of caregivers about what would lead them to fully inform the child about his/her health fell into two general categories: time-related factors (triggers), that fit a response of “When *x* takes place”; and outcome-related factors (reasons), that fit a pattern of “So that *y* happens”. A majority of caregivers who had thought about what might lead them to fully inform their child gave both triggers and reasons (65%, n=98). Responses to the open-ended question “When do you think about these things” were classified into moments centered around the child—such as when the child asks questions, or when the child goes to school—health-care related moments, such as on the day of clinic appointments; and other types of moments. Table 2 summarizes the data on patterns of disclosure and caregiver opinions about disclosure.

Nearly one-third of caregivers felt there were no benefits to telling the child her/his HIV status. The most commonly cited benefits were that the child would be able to protect him/herself and others from possible harm (93 (46%) and 72, (36%), respectively), and that the child would be able to take better care, in general, of her/himself (66, 33%). The most commonly cited harms resulting from telling the child were psychological in nature: that the

child would be worried (100, 50%), and that the child would be sad or lose the will to live (78, 39%). Table 3 lists the benefits and harms cited by caregivers. The percentages add up to more than 100% as caregivers could list more than one harm and/or benefit.

DISCUSSION

This is the first study from a Sub-Saharan African context to explore what caregivers have communicated to their HIV-positive children about their health *prior to* full disclosure of their HIV status. The proportion of children who have been told something deflecting about their HIV status (33%) is higher than what was reported in Funck-Brentano's European sample (21%)²².

Reasons to disclose among caregivers in our study are not so different from what have been reported by caregivers in other settings¹⁶. Older age and eminent onset of sexual activity were main reasons or triggers to inform the child, similar to prior studies in developed countries, and medical care reasons, including improving adherence to treatment regimens as well as attending health care visits by themselves¹⁶, were also mentioned by caregivers. Most commonly cited potential harms to the child upon full disclosure, including negative psychological reactions and subsequent disclosure to others, were also among the more frequently identified barriers to disclosure in other studies¹⁶.

Our study's finding on the provision of deflecting information to children, whether intentionally deflecting or otherwise, bears further examination. Funck-Brentano and colleagues documented "deceptive" information provided to HIV-positive children in France as information that intentionally confused the child's HIV status with another medical condition totally unrelated to HIV infection²². Oberdorfer and colleagues noted in their Thai study that over 80 percent of caregivers, who said that their child did not know of her/his diagnosis, had told the child they had another illness²⁶. We saw similar practices among caregivers in our study, although we are unable, in most circumstances, to determine the intent of caregivers in providing this information. Among caregivers who had not fully disclosed, one-third had provided some information to the child that could deflect attention from HIV. All of the caregivers in this study were aware of the child's HIV status, but their full comprehension of the diagnosis and the progression of illness were not assessed; for those who did not explicitly state that they were misleading the child, the deflecting information could have been therefore reflective of the caregiver's comprehension of the illness status rather than intent to deceive the child. The 2007 Demographic Health Survey reports high levels of accurate knowledge of HIV among adults in Kinshasa, noting that 99.2% of women and 100% of men surveyed in Kinshasa had heard of HIV, 93.1% of women and 94.1% of men knew that a healthy-looking person could have HIV, 88.3% of women and 90.3% of men knew that HIV could not be transmitted by sharing a meal with an infected person. However, complete knowledge of HIV—which also includes rejection of erroneous information—is low, with only 25.1% of women and 33.1% of men in Kinshasa falling in this category.

Age of the child has been shown in other studies to be associated with disclosure to HIV-infected children¹⁶. The actual age of disclosure varied across the many studies, but

prevalence of disclosure generally increased with increasing age of the child. Children under age 6 years were least likely to have been told their HIV status. Cohen et al, for example, found an overall prevalence of disclosure of 30 percent among children ages 5–10 years, but 95 percent for those over age 10³⁷. In this study, correlational tests found that younger children were more likely to receive no information than either deflecting or partial information, and that children in the 8–13 year old range were more likely to receive deflecting information than partial information..

Funck-Brentano showed that children who had been given partial or full information about their health had better understanding of their condition and were coping better with their health than children who had been given deceptive information or else not told anything about their health²². This, coupled with evidence that children with serious health diagnoses, including HIV, do not fare worse in psychosocial or health outcomes if they are told of their diagnoses¹⁶, provides some impetus to promote accurate disclosure of information to children. It is possible that providing deflecting or deceptive information can erode the trust between children and their caregivers, which could lead to anxieties, emotional distress, and maladjustment²².

Limitations and Future Directions for Research

The study has several limitations. The cross-sectional nature of the study does not allow us to fully explore the process of disclosure, but only to capture it at a particular moment in time. Current conceptualizations of disclosure do not distinguish between different paths taken toward full disclosure, only noting that there is a process^{13, 15, 22, 32, 33}. Future longitudinal studies, therefore, could distinguish various paths taken by caregivers toward full disclosure and incorporate measures of psychological and emotional well-being and distress for children, to assess the impact on children.

Our study's population represents a unique group of children within Sub-Saharan Africa. The children were all accessing medical care for their HIV infection, and were almost all (95%) enrolled in a program at a public hospital providing antiretroviral treatment for those requiring it. At the time of the study, only 13 percent of children in Sub-Saharan Africa requiring antiretrovirals had access to them³; this proportion had increased to 35 percent by 2009³⁸. The impact of having access to antiretroviral regimens, which extend children's lives, on what caregivers tell children about their health can only be determined by comparing children with access to these life-prolonging regimens to those with no access.

Another limitation of the study is its focus on what has been told to the child, rather than what the child has discerned about his/her health, whether from information provided by others or gleaned on their own. Youth may learn of their HIV status on their own, by piecing together clues, or overhearing conversations, or even directly from providers, without caregiver knowledge. While we can draw upon the experiences from other chronic illnesses, as well as limited data available on nondisclosure and secrecy as it relates to HIV^{17–19}, we must remember that disclosure by others is only one way children learn of their HIV status, and that these different ways of learning may affect their psychosocial well-being.

This study did not systematically collect clinical data on the children of interest or the HIV status of the caregivers. As mentioned earlier, the health status of the child has been shown to influence caregivers' decisions to disclose. Other studies have shown that caregivers' own HIV status can play a role in decisions regarding communication with infected children^{13, 16, 33, 39} Findings of this study must be interpreted taking these other factors under consideration.

As this study focused on communication prior to full disclosure of HIV status, we are unable to ascertain what factors actually play into caregivers' decisions to finally disclose. However, qualitative work from this study as well as from a prior one indicate that when disclosure is planned, caregivers have considered the ability of the child to understand and accept the information and their concerns with medication adherence in their decisions to fully inform the child.^{35, 40}

The expansion of access to HIV care and treatment programs to children has continued to be a global priority since this study was completed. More children are being diagnosed at younger ages, translating into more potential time for communication with children. Programs are adopting disclosure guidelines, although the guidelines are not always evidence-based. Were this study to be replicated today, we would likely have larger numbers of children enrolled and more children who have been told something, whether deflecting or partially true. The numbers of children who have experienced full disclosure of HIV status may have also increased, and patterns are perhaps approaching what was seen in Funck-Brentano's work²². However, sociocultural factors play a role in communication with children; patterns may not have changed substantially.

Implications for Research and Practice

It is clear from this study is that caregivers provide a variety of information to HIV-infected children before the children are disclosed their HIV status, and have a range of opinions regarding when the child should be informed, under what circumstances, and who should be involved in the process. While there is evidence that earlier age of disclosure has not been associated with worse psychosocial and adherence outcomes⁴¹, it is not clear whether or not some patterns of information sharing lead to better psychosocial and adherence outcomes for the children than others. It is also not clear exactly what factors influence communication decisions, and how they do so. Further studies should follow children through their experiences of disclosure, assessing the impact of different factors as well as the different paths taken towards informing children. The information acquired from these studies would help refine programs designed to help caregivers and children through disclosure by knowing what paths ought to be avoided and what paths ought to be promoted, and under what situations. Future studies should also incorporate measures of psychological and emotional well-being and distress for children, to better assess the impact of experiencing different paths towards full disclosure on children.

Deflecting information figured strongly in communication between caregivers and children in this study, more so in older age groups than among children 5–8 years of age. For this study, deflecting information was defined as information given to the child that was (1) intentionally misleading or (2) ambiguous in its intention, but served to draw a child away

from considering HIV as a possible diagnosis. Better understanding of communication from caregivers to children, and the reasons for these communication patterns, may help treatment programs assess families' support needs around communicating with HIV-positive children about their health. Service providers could assist caregivers in developing appropriate responses to questions from children, as well as providing children with age appropriate information about their health as they get older, instead of providing them with deflecting information.

It is apparent from this study's results that many caregivers see themselves playing a main role at the moment of full disclosure of HIV status to the child, although to date the majority have not provided the child with any information. One-third of the caregivers named health care providers as the best persons to eventually inform their child of her/his HIV diagnosis. Caregivers might want to disclose but might not feel capable to do so. In addition, caregivers' perceived benefits and harms to disclosure might reflect their own emotions rather than their child's. Providers can therefore work with caregivers to help assess children's readiness for information, to identify the best moment and approach to tell the child, and in cases where caregivers wish to inform the child on their own, help the caregiver to prepare for that conversation and the ones that may follow by building upon their knowledge, skills, and comfort level.

Acknowledgments

We wish to thank Karen Hawkins Reed, Kashamuka Mwandagaliwa, Vera Melotte and Steven Callens for their overall support in carrying out project activities; Jose Kayumba Baye, Angèle Mbuyi, Tshimanga Badinga, and Alphonse Itshieki for their hard work in data collection and entry; and Dr. Faustin Kitetele and the entire staff of the Pediatric HIV Care and Treatment Program at Kalembe Lembe Hospital for their assistance and support in participant recruitment and space for interviews. Professors Annelies Van Rie and J. Michael Bowling were invaluable in their guidance of the design of the study. Last but not least, we thank the study participants for sharing their thoughts and experiences with us. This study was conducted in a program funded by the US Centers for Disease Control and Prevention, Global AIDS Program (GAP), U62/CCU422422. Dr. Vaz was funded through a Ruth L. Kirchstein Pre-doctoral Dissertation Fellowship from the US National Institute of Child Health and Development.

References

1. UNAIDS. 2008 Report on the Global AIDS Epidemic. Geneva, Switzerland: UNAIDS; 2008.
2. Jones G, Steketee RW, Black RE, Bhutta ZA, Morris SS. How many child deaths can we prevent this year? *Lancet*. Jul 5; 2003 362(9377):65–71. [PubMed: 12853204]
3. WHO, UNAIDS, UNICEF. Towards universal access : scaling up priority HIV/AIDS interventions in the health sector : progress report, April 2007. Geneva, Switzerland: World Health Organization; Apr. 2007
4. WHO, UNAIDS, UNICEF. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections: Democratic Republic of the Congo, 2006 Update. Geneva, Switzerland: WHO/UNAIDS/UNICEF; 2008.
5. Aguilar Molina, J. The Invention of Child Witches in the Democratic Republic of Congo. London, UK: Save the Children UK; Feb 27. 2006
6. Ryder RW, Kamenga M, Nkusu M, Batter V, Heyward WL. AIDS orphans in Kinshasa, Zaire: incidence and socioeconomic consequences. *Aids*. May; 1994 8(5):673–679. [PubMed: 8060547]
7. Ziemke JJ. Democratic Republic of Congo. 2001 Accessed 27 February, 2006 <http://www.everyculture.com/Bo-Co/Democratic-Republic-of-the-Congo.html>

8. De Herdt, T. Hidden Families, Single Mothers and Cibalabala: Economic Regress and Changing Household Composition in Kinshasa. In: Trefon, T., editor. *Reinventing Order in the Congo: How People Respond to State Failure in Kinshasa*. London, UK: Zed Books; 2004. p. 116-136.
9. AAP. Disclosure of illness status to children and adolescents with HIV infection. American Academy of Pediatrics Committee on Pediatrics AIDS. *Pediatrics*. Jan; 1999 103(1):164–166. [PubMed: 9917458]
10. Wiener L, Theut S, Steinberg SM, Riekert KA, Pizzo PA. The HIV-infected child: parental responses and psychosocial implications. *Am J Orthopsychiatry*. Jul; 1994 64(3):485–492. [PubMed: 7977671]
11. Bachanas PJ, Kullgren KA, Schwartz KS, et al. Predictors of psychological adjustment in school-age children infected with HIV. *J Pediatr Psychol*. Sep; 2001 26(6):343–352. [PubMed: 11490035]
12. Lester P, Chesney M, Cooke M, et al. When the time comes to talk about HIV: factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *J Acquir Immune Defic Syndr*. Nov 1; 2002 31(3):309–317. [PubMed: 12439206]
13. Gerson AC, Joyner M, Fosarelli P, et al. Disclosure of HIV diagnosis to children: when, where, why, and how. *J Pediatr Health Care*. Jul-Aug; 2001 15(4):161–167. [PubMed: 11462122]
14. Mellins CA, Brackis-Cott E, Dolezal C, Richards A, Nicholas S, Abrams EJ. Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes. *Clinical Child Psychology and Psychiatry*. 2002; 7(1):101–114.
15. Hirschfeld S. Comment: Disclosing a diagnosis of HIV in pediatrics: Providing the best possible care. *AIDS & Public Policy Journal*. Spr; 2002 17(1):13–16.
16. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV Diagnosis to Children: History, Current Research, and Future Directions. *J Dev Behav Pediatr*. Apr; 2007 28(2):155–166. [PubMed: 17435473]
17. Slavin LA, O'Malley JE, Koocher GP, Foster DJ. Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment. *Am J Psychiatry*. Feb; 1982 139(2):179–183. [PubMed: 7055287]
18. Claflin CJ, Barbarin OA. Does “telling” less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *J Pediatr Psychol*. Apr; 1991 16(2):169–191. [PubMed: 2061787]
19. Abadia-Barrero CE, Larusso MD. The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in Sao Paulo, Brazil. *AIDS Patient Care STDS*. Jan; 2006 20(1):36–43. [PubMed: 16426154]
20. Enzama, R.; Mugenyi, P. Determining Barriers And Predictors To Adherence In Children Accessing HIV/AIDS Treatment In Uganda, Abstract no. WePe12.7C03. Paper presented at: 3rd IAS Conference on HIV Pathogenesis and Treatment; 24–27 July, 2005, 2005; Rio de Janeiro, Brazil.
21. Oberdorfer, P.; Phuthanakit, T.; Louthrenoo, O.; Charnsil, C.; Sirisanthana, V.; Sirisanthana, T. Effectiveness of a ‘5-step intervention technique’ for disclosure of HIV status to HIV-infected children, Abstract No. WEPDB05. 4th IAS Conference on HIV Pathogenesis and Treatment; Sydney Australia: International AIDS Society; 2007.
22. Funck-Brentano I, Costagliola D, Seibel N, Straub E, Tardieu M, Blanche S. Patterns of disclosure and perceptions of the human immunodeficiency virus in infected elementary school-age children. *Arch Pediatr Adolesc Med*. Oct; 1997 151(10):978–985. [PubMed: 9343006]
23. Lwin R, Melvin D. Paediatric HIV infection. *J Child Psychol Psychiatry*. May; 2001 42(4):427–438. [PubMed: 11383959]
24. Thorne C, Newell ML, Peckham CS. Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. *Child Care Health Dev*. Jan; 2000 26(1):29–40. [PubMed: 10696516]
25. Bikaako-Kajura W, Luyirika E, Purcell DW, et al. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behav*. Jul; 2006 10(4 Suppl):S85–93. [PubMed: 16791525]
26. Oberdorfer P, Puthanakit T, Louthrenoo O, Charnsil C, Sirisanthana V, Sirisanthana T. Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *J Paediatr Child Health*. May; 2006 42(5):283–288. [PubMed: 16712559]

27. Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV infection status in children. *Indian journal of pediatrics*. Aug; 2009 76(8):805–808. [PubMed: 19802549]
28. Azondekon, A.; Hinson, F.; Mignanhouande, D., et al. Disclosure of HIV status to Children in African context: outcomes and challenges, Abstract no. TuPe11.9C13. Paper presented at: 3rd IAS Conference on HIV Pathogenesis and Treatment; 24–27 July 2005; Rio de Janeiro, Brazil. 2005.
29. Kouyoumdjian FG, Meyers T, Mtshizana S. Barriers to Disclosure to Children with HIV. *J Trop Pediatr*. Oct; 2005 51(5):285–287. [PubMed: 16014763]
30. Nannyonga-Musoke, M.; Penazzato, M.; Morell, iE, et al. The challenge of disclosure in resource-limited setting: experience in Ugandan HIV-infected children, Abstract No. TUPEB143. 4th IAS Conference on HIV Pathogenesis and Treatment; Sydney Australia: International AIDS Society; 2007.
31. Flanagan-Klygis E, Ross LF, Lantos J, Frader J, Yogev R. Disclosing the diagnosis of HIV in pediatrics. *J Clin Ethics*. Summer;2001 12(2):150–157. [PubMed: 11642067]
32. Lee CL, Johann-Liang R. Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. *AIDS Patient Care and Stds*. Jan; 1999 13(1):41–45. [PubMed: 11362086]
33. DeMatteo D, Harrison C, Arneson C, et al. Disclosing HIV/AIDS to children: the path families take to truth-telling. *Psychology, Health and Medicine*. 2002; 7(3):339–356.
34. Corneli A, Vaz L, Dulyx J, Omba S, Rennie S, Behets F. The role of disclosure in relation to assent to participate in HIV-related research among HIV-infected youth: a formative study. *Journal of the International AIDS Society*. 2009; 12(1):17. [PubMed: 19712468]
35. Vaz LM, Eng E, Maman S, Tshikandu T, Behets F. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care STDS*. Apr; 2010 24(4):247–256. [PubMed: 20397899]
36. Wiener LS, Battles HB, Heilman N, Sigelman CK, Pizzo PA. Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatr AIDS HIV Infect*. Oct; 1996 7(5):310–324. [PubMed: 11361489]
37. Cohen J, Reddington C, Jacobs D, et al. School-related issues among HIV-infected children. *Pediatrics*. Jul.1997 100(1):E8. [PubMed: 9200382]
38. WHO, UNAIDS, UNICEF. Towards universal access: scaling up priority HIV/AIDS interventions in the health sector : progress report 2009. Geneva, Switzerland: World Health Organization; 2009.
39. Lesch A, Swartz L, Kagee A, et al. Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care*. Jul; 2007 19(6):811–816. [PubMed: 17573602]
40. Vaz L, Corneli A, Dulyx J, et al. The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care*. Jun 5.2008 :1–11. [PubMed: 18278609]
41. Wiener LS, Battles HB. Untangling the web: a close look at diagnosis disclosure among HIV-infected adolescents. *J Adolesc Health*. Mar; 2006 38(3):307–309. [PubMed: 16488835]

Table 1

Characteristics of Caregivers of Children Living with HIV (n=201)

Characteristics of Caregivers (n=201)			
Age	Median (Range)	40	18–70
		N	%
Gender	Male	39	19%
	Female	162	81%
Education	None	3	1%
	Some primary school	26	13%
	Completed primary school	7	3%
	Completed trade/professional school	12	6%
	Some secondary school	77	38%
	Completed secondary school	37	18%
	Any post- secondary school	39	19%
Marital Status	Single	37	18%
	Formally married	80	40%
	Living with partner	12	6%
	Has partner but not living together	3	1%
	Separated	3	1%
	Divorced	22	11%
	Widowed	44	22%
Relationship to child	Biological Mother	72	36%
	Biological Father	12	6%
	Grandparent	32	16%
	Brother or sister	13	6%
	Paternal aunt or uncle	16	8%
	Maternal aunt or uncle	42	21%
	Other	14	7%
Employment	None*	66	33%
	Big company	8	4%
	Public servant	15	7%
	Small company/home	9	4%
	Informal work	102	51%
	Other	1	0%
	*Never worked	13	6%
Length of Unemployment (Years)	Median (Range) (N=53)	3	(<1–20)
Characteristics of Children (n=201)			
Age	Median (Range)	8	5–17
		N	%
Gender	Male	94	47%

Characteristics of Caregivers (n=201)			
Age	Median (Range)	40	18-70
		N	%
	Female	107	53%
Orphan	Mother deceased	102	51%
	Father deceased	87	43%
	Double orphan	53	26%
Education	Ever been to school	170	85%
	Currently in school	135	67%
Current Medications	ARVs	149	74%
	Cotrimoxazole (prophylaxis) only	39	19%
	None	2	1%
	Don't know	10	5%
	Missing	1	0%
Reported Health Status	No symptoms	89	44%
	Minor symptoms	95	47%
	Frequent illness but no hospitalization	10	5%
	Frequent hospitalization, no overnight stays	2	1%
	Hospitalization, overnight stays	5	2%

*"Never worked" is a subset of those who responded that they had no current employment.

Table 2

Patterns of Disclosure and Caregiver Opinions on Full Disclosure

Characteristic		N	%
Pattern of Disclosure at time of the study	No information provided	93	46%
	Deflecting information provided	67	33%
	Some partial information provided	31	15%
	Some partial & some deflecting information given	7	3%
	Other/refuse answer/missing	3	1%
Should Child Be Told Status Someday?	Yes	188	94%
	No	9	4%
	Don't know	3	1%
	Missing	1	0%
Have you thought about what types of events would lead you to tell your child s/he has HIV?	No	48	24%
	Yes	151	75%
	Refuse to answer	2	1%
What types of things? (n=151)	Triggers only ("when...")	41	27%
	Reasons only ("so that...")	12	8%
	Both reasons and triggers given	98	65%
Triggers leading to full disclosure	Child gets older	106	70%
	Child asks questions	22	15%
	Eminent sexual debut	53	35%
	Other	24	16%
Reasons leading to full disclosure	So child can remain abstinent	34	23%
	So child can know self	17	11%
	Medical care reasons	27	18%
	So child can protect self	67	44%
	So child can protect others	71	47%
	Other	6	4%
What moments/under what circumstances think about these things (n=145)	Child-centered moments	88	61%
	Health-care related activities	34	23%
	Other moments	62	43%
How often do you think about these things? (n=151)	Not very often	64	42%
	About once a month	7	5%
	At least once a week	36	24%
	Every day	34	23%
	Another time	8	5%
	Refuse to answer	2	1%

Table 3

Caregivers' Responses to Specific Open-Ended Questions on Perceived Harms and Benefits of Full Disclosure of HIV Status to Children (n=201)

In your opinion, what are some GOOD things that can happen if your child is told that s/he has HIV?		
	#	%
Child will better protect self from possible dangers	93	46%
Child will better protect others from possible dangers	72	36%
Child will take better care, in general, of self	66	33%
Nothing	64	32%
Child will take his/her medicines as he/she should	50	25%
Child will be relieved	22	11%
In your opinion, what are some BAD things that can happen if your child is told that s/he has HIV?		
	#	%
Child will be worried	100	50%
Child will become sad/depressed/lose will to live	78	39%
Child will tell others	40	20%
Child will die of worry/shock	34	17%
Child will isolate him/herself	34	17%
Nothing	29	14%
Child will commit suicide	25	12%
Child will become rebellious	14	7%
Child will blame caregiver for being sick/hate me because of her/his illness	12	6%