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Parents' Disclosure of Their HIV Infection to Their Children in the Context of the Family

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Abstract We interviewed 33 HIV-infected parents from the HIV Cost and Services Utilization Study (HCSUS), 27 of their minor children, 19 adult children, and 15 caregivers about the process of children learning that their parents were HIV positive. We summarize the retrospective descriptions of parents' disclosure of their HIV status to their children, from the perspective of multiple family members. We analyzed transcripts of these interviews with systematic qualitative methods. Both parents and children reported unplanned disclosure experiences with positive and negative outcomes. Parents sometimes reported that disclosure was not as negative as they feared. However, within-household analysis showed disagreement between parents and children from the same household regarding disclosure outcomes. These findings suggest that disclosure should be addressed within a family context to facilitate communication and children's coping. Parents should consider negative and positive outcomes, unplanned disclosure and children's capacity to adapt after disclosure when deciding whether to disclose.

Keywords Disclosure · Qualitative methods · Parents and children · Families

Introduction

Parents who learn that they are HIV-infected need to decide if, when, and how they will disclose their illness to their children. Although physicians often encourage parents to disclose to their children [1, 2], many parents delay because they fear negative consequences [3]. They worry that the psychological burden of shock, fear, and stigma will be more than their children can handle [2, 4]. Indeed, parents believe that they are protecting their children by not disclosing [5].

The effects of disclosing to children appear to be mixed. Some studies support parents' reluctance to disclose by demonstrating an association between disclosure and negative outcomes, such as increased problem behaviors [1], diminished quality of family relationships [6], lowered

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self-esteem and mood [5], and enduring negative memories of disclosure [4, 7]. In contrast, other studies show positive effects, such as improved family relationships, decreased childhood depression [8, 9], and little regret. Some studies show that the initial negative effects of disclosure dissipate over time [6], the development of behavior problems is not connected to disclosure [10], or negative effects are mediated by a supportive child-parent relationship [11]. Non-disclosure, on the other hand, is linked to children's increased fears and concerns [10].

A possible key to understanding variation in outcomes for children after disclosure is a greater understanding of the family context of disclosure. Some have argued that HIV is a family disease and treatment of HIV in the context of the whole family improves long term adolescent outcomes and reduces potential effects of stigma [12]. However, most studies of parental HIV disclosure focus narrowly on the intentional disclosure process between an infected parent and one child. This analytic approach—focusing on one person intentionally disclosing to another person—is common across different types of disclosure settings [13]. However, assuming that the disclosure process is intentional and exists within a closed dyadic relationship ignores various ways that information about the HIV status of a parent can flow within the network of familial and social relationships in which the parent-child dyad is embedded.

Figure 1 depicts a range of pathways through which a child can learn that his or her parent is HIV positive. The figure shows that the parent-child dyad is embedded within a network of relationships within a family, which is itself embedded within a network of relationships outside of the

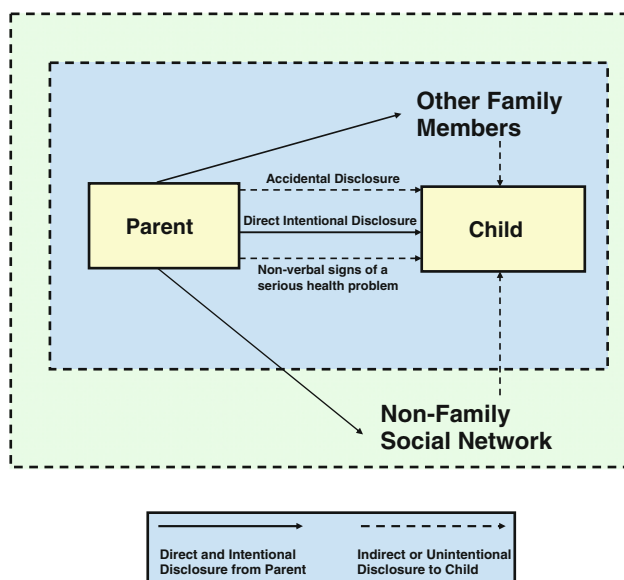


Fig. 1 Pathways of parental disclosure of their HIV positive status to their children

family. The diagram depicts direct disclosures (solid arrows) and indirect/unintentional disclosures (dashed arrows). Indirect disclosures include finding out from another member of the family or from the non-family social network. Unintentional disclosures include accidental disclosures or observing behaviors and symptoms that indicate a serious health problem.

To address the limitations of previous studies of parental disclosure of an HIV infection, which have primarily focused on mother-child disclosure, we conducted a qualitative investigation of the disclosure process from the perspective of members of a diverse group of families across the United States. We conducted semi-structured interviews with HIV positive parents, their caregivers (often the other uninfected parent), and their children about their retrospective account of the disclosure process. Findings from qualitative research can help elucidate the disclosure process in several ways: by identifying the range of types of experiences; by triangulating the disclosure event from multiple perspectives within a household [14]; by facilitating data collection from children, who might have trouble understanding closed-ended survey questions about complex issues, allowing them to express themselves in their own words using their own categories; and by explaining relationships that may be complex and sometimes contradictory, such as HIV positive parents' desire both to shield their children from knowing about the infection and to ask them for support in dealing with it [15].

Prior qualitative studies of disclosure have found a mixture of positive and negative effects on children [3, 4, 16–21]. In the eight qualitative studies of disclosure that we identified, most focus on disclosure from the perspective of HIV positive mothers. Only one of these studies includes the perspective of HIV positive fathers and caregivers [20]. Only two studies include the perspective of children [4, 19]. None include the perspective of adult children. All but one of these studies are from limited geographical areas. This study aims to build on these prior studies by exploring the disclosure process from multiple perspectives—HIV positive parents, caregivers, and children of varying ages—within an ethnically diverse set of households across the United States.

Methods

Study Design

We conducted semi-structured interviews between March 2004 and March 2005 with a sample of HIV-infected parents from the HIV Cost and Services Utilization Study (HCSUS) about their memory of disclosure. HCSUS is a national probability sample of people ≥ 18 -years-old with

known HIV infection who made ≥ 1 visit to a medical provider in the contiguous United States during January–February 1996 [22]. HCSUS participants were eligible for this follow-up study if they participated in HCSUS' wave 3 and a 1997–1998 follow-up survey [23], had a child ≤ 23 years on 3/1/04, and had seen ≥ 1 of their children in the past month when they were contacted for participation.

To maximize sample diversity on key variables, we conducted a random stratified sampling of the 975 eligible participants using four strata: parent gender, parent race/ethnicity (African-American, Hispanic/Latino, White/Other), age of youngest child (<13 , 13–17), and level of contact with child (lives with children, does not live with any children). We over-sampled those who participated in the 1997–1998 follow-up survey and selected all families with a child <18 . The result of these procedures was a sample of 486 parents. We attempted contact with all sampled parents, located 146 using tracking information from previous surveys and a commercial address correction service, and discovered that 88 parents were deceased or ineligible. Among the 58 remaining parents, 33 agreed to participate along with 27 children (9–17-years-old), 19 adult children (≥ 18 years old), and 15 caregivers. Children were eligible to be interviewed if they knew about their parents' HIV status and lived with or had seen their parents in the past month. We followed procedures developed with the RAND and UCLA Institutional Review Boards to obtain informed consent from respondents. One of the authors, an expert in qualitative methodology, trained seven interviewers to conduct semi-structured interviews, with an emphasis on how to balance following an interview protocol with using various exploratory probing techniques, and how to interact with children of HIV positive parents. All of the interviewers had prior masters training in psychology, counseling, or social work and experience conducting interviews on sensitive topics. Parents consented for interviews with children <18 who knew about their infection, and these children gave their assent for study participation. Two nieces were interviewed as adult children because they lived with and considered target parents to be parental figures.

Sample Characteristics

The parents were 48% African American, 3% American Indian, 21% Latino, and 27% White. Most (73%) were mothers, and the mean age of parents was 44 years ($SD = 7$; Range = 30–62). Almost half (48%) reported annual household incomes of \$10,000 or less, a quarter reported annual household incomes of \$10,001 to \$25,000, and 12% reported annual household incomes greater than \$25,000. Over 40% had less than a high school education, 36% had a high school diploma or GED, 18% reported

some college, and only 3% had at least a 4-year college degree. Two-thirds (67%) of parents lived with their spouse or partner.

Of the 46 children in the sample, 59% were 9–17 years old (“children”) and 41% were 18 years of age or older (“adult children”). The majority of children were male (63%), and the majority of adult children were female (58%). Children's mean age was 14 years ($SD = 2$; range = 9–17), and adult children's mean age was 22 years ($SD = 4$; range = 18–30). Caregivers were the infected parent's spouse or partner (73%; 6 females and 5 males), mother (13%), and friend (13%). Caregivers' mean age was 46 years ($SD = 11$; range = 35–79).

Measures

We asked parents to recall everything that happened when they disclosed their HIV status to their children, in addition to other topics related to being an HIV positive parent [24, 25]. Interviewers asked parents follow-up questions and prompted them to remember and describe others' involvement, their decision to disclose, what they had said, and advice they would give other parents. Interviewers first asked children “ice-breaker” questions about their parents' health in general. Once children began to discuss their parents' infection voluntarily, interviewers asked children to recall the disclosure event, their thoughts during disclosure, and disclosure to siblings. These procedures had been used previously with children of HIV-infected parents and found to be comprehensible and to elicit useful information [19]. Interviewers asked caregivers to recount their involvement in the disclosure. Interviews were audio-recorded and lasted 60–90 min for adults and 30–60 min for children.

Data Analysis

We analyzed the interview data using two approaches. First, we conducted an across-interview team-based thematic analysis of interview transcripts, managing texts with *ATLAS/ti* [26]. A project team member identified themes relevant to the disclosure process from the scientific literature and from a close reading of a sample of interview transcripts, and developed a codebook based on standard inductive and deductive techniques [27]. The first two authors trained two coders with extensive experience coding this data set to follow the inclusion and exclusion criteria and to identify exemplary and atypical examples of each theme. These coders independently read all transcripts and marked appropriate text relating to these themes. The lead author identified subthemes within each topical area by sorting all instances of marked texts into piles based on similarities [28, 29]. Each pile (i.e., subtheme) was labeled

and added to the project codebook, which included sample quotations that exemplified each theme (see Tables 1, 2, 3, and 4 for exemplary quotations). To ensure that our codebook served as a reliable instrument for identifying and describing subthemes, two research team members sorted the original marked texts into subthemes [26, 30]. We assessed intra-coder reliability with Cohen's kappa and found high agreement among coders (kappa range = 0.75–1.0; mean = 0.89) (Tables 1, 2, 3, and 4) [31]. The only code with a kappa below 0.80 was the code with by far the largest number of quotes (fear, with 141 quotes compared to 12–40 quotes for other codes) and required the most amount of interpretation of indirect descriptions of fearfulness.

Our second analytic approach was to treat each household as a case and to conduct a within-household analysis of the

descriptions of the disclosure process. We read through each interview conducted for each household, wrote a summary of the household experiences on the themes identified in the across-interview analysis, and identified similarities and/or dissimilarities in the descriptions of the disclosure experience from the multiple perspectives in the household. Two coders rated each household as either “yes” or “no” for the following codes: parent mentioned a positive disclosure experience (kappa = 0.78); parent mentioned a negative disclosure experience (kappa = 0.80); child(ren) mentioned a positive disclosure experience (kappa = 0.74); child(ren) mentioned a negative disclosure experience (kappa = 0.85). We then compared these codes within households to assess the extent of intra-familial agreement regarding positive and negative aspects of the disclosure process.

Table 1 Preparation for disclosure

Exemplary quote	Quote context (child age)
(1a) Planned disclosure/non-disclosure (kappa = 0.97)	
“The best thing to do is tell them, definitely, but it has to be at a time that the child is old enough to understand...you don't want the child to find out from somebody else”	Mother's advice on disclosure when child is mature but before someone else tells the child
“My daughter, she, I never told her...she has such love for me I don't think she would be able to handle it”	Father explaining non-disclosure for his 13-year-old daughter
(1b) Unplanned disclosure (kappa = 1.00)	
“He turned around and said, ‘Is that what you have Mom?’ and I said, ‘Yep’.... They kinda figured it out.... Kids are pretty perceptive”	Mother describing disclosing to her child (6) after watching a television program
“I talked to a lot of people on the phone.... I tried to be discrete about it. I'd say I had a ‘compromised immune system.’ But the kids are smart...they understood”	Father discussing difficulty avoiding unintended disclosure to his children

Table 2 Perceived positive reactions

Exemplary quote	Quote context (child age)
(2a) Emotional support (kappa = 0.81)	
“It was good. She hugged me.... It's almost like she...looks out for me sometimes. It's kinda weird, but...cute too”	Father discussed his daughter's (13) reaction to disclosure
“She told me, ‘Mama I still love you, of course, and I'm your daughter. I'll be here with you and for you’”	Mother recounting her daughter's (14) initial reaction
(2b) Familial closeness (kappa = 0.95)	
“I think he was probably glad that he told me. Because...now we can be more a family and we can all talk about it without being all hush, hush”	Daughter (16) describing increased closeness with her father since disclosure (at 13)
“I'm more open with them than before. ‘Cause before.... I would not open my personal...relationships.... But now, it's like, I ask them...’. What do you think about this person?”	Mother giving an example of how she is closer to her children (15–23) after disclosure
(2c) New outlook (kappa = 0.83)	
“When I first found out I was in shock.... It was just a reality check that nothing is promised. If you don't take care of yourself...you could be taken away...”	Adult daughter (27) describes change in perspective after disclosure (at 13)
“From that time, it's just like, right now...I cherish both of them more than I ever had. Now, nine years older, I wouldn't want...to be any different than what the situation is”	Adult son (20) explaining why life is better after disclosure (at 11)

Table 3 Perceived negative reactions

Exemplary quote	Quote context (child age)
(3a) Fear ($\kappa = 0.75$)	
“(M)y grandma said everything is going to be alright and my mom said it, and the therapist said it...and I said I must believe it cause if I don’t my mom might die”	Daughter (9) describing fear of mother dying after disclosure (at 8)
“When I told him, he was upset for a week. He wasn’t eating...going to school.... He wanted to be with me everywhere I went”	Mother describing her son’s (18) fear reaction after disclosure (at 10)
(3b) Shock ($\kappa = 0.94$)	
“(He) was like in shock. His eyes were big; his mouth dropped opened. It looked like a cartoon character”	Mother describing disclosing to her nephew (10)
“It’s like when she told me I felt like my whole entire world was just gone. It felt like my life just went away. I was really, really shocked at that moment”	Daughter (13) describing shock after her mother’s disclosure (at 10)
(3c) Anger ($\kappa = 0.90$)	
“My oldest, he’s been...very hostile.... He doesn’t try to...show me any type of affection”	Mother describing her son’s (18) hostility since she disclosed
“And he yelled at him, ‘How could you do this to my family? That’s my sister! That’s my mom! You’re not there for us! What if something happens to my mom?’”	Mother describing her 16 year old son’s (16) angry reaction towards his father after she disclosed

Table 4 Perceived absence/mitigation of negative reactions ($\kappa = 0.82$)

Exemplary quote	Quote context (child age)
(4a) Absence of reaction quotes	
“Same ol’ ‘Hi, mom. Let’s go outside and play’ Nothing different”	Mother described the lack of reaction from her daughter (8)
“I just told her that I was sick and I needed to take the pills.... She said, ‘OK’, and ran off...Haha...and it was over. I think it was more painful for me than it was for her”	Mother describing her 8 year old child’s reaction to disclosure (at 4)
(4b) Knowledge about HIV	
“I wasn’t scared or anything. I mean, classes and in school, I was aware of what it is so I wasn’t scared”	16 year old son discussing how knowledge of HIV helped him cope with disclosure
“So I say, ‘OK c’mon family discussion.... Daddy’s got HIV.... Any questions?’.... They just spattered questions, 2 hours and 25 minutes sittin’ at that table...my brain was pounding”	Non-infected mother/caregiver describing disclosure to her children (11,14) about her husband’s HIV infection

Results

Themes

Two central themes emerged in the across-interview analysis: preparation for disclosure and perceived outcomes of disclosure. We divided the preparation theme into two sub-themes: planned and unplanned disclosure. We divided the perceived outcomes theme into perceived positive reactions, perceived negative reactions, and perceived absence/mitigation of negative reactions based on how the respondents characterized their experiences.

Preparation for Disclosure

Planned Disclosure

All parents in our sample had disclosed to ≥ 1 child. Parents reported a range of rationales for disclosing

(Table 1a). Some discussed disclosure as necessary to maintain an honest, trustful family relationship and because “you don’t want the child to find out from somebody else.” Some parents mentioned that disclosure was required to receive help and support from their children. When asked for advice that they would give other parents about disclosure, parents commonly suggested to “have a plan” and to disclose with help from a therapist or clinician.

Planned Non-Disclosure

Some parents discussed reasons for delaying or avoiding disclosure. The most common reasons for waiting were the child’s lack of maturity or a feeling that it was not “the right time,” typically defined as the beginning of the teenage years, although responses ranged from age 7 to 18. Parents also described avoiding disclosure because they were overcome by guilt, because they were afraid of hurting their children, or because they did not know how to

disclose properly. Some parents thought that there was no reason to tell children. One father planned to never tell his daughter because “I don’t think she would be able to handle it.”

Unplanned Disclosure

Despite parental desire to wait until an appropriate time to disclose, many families described at least one unplanned disclosure experience (Table 1b). Changes in their parents’ health and behavior prompted uninformed children to ask for an explanation. Children reported noticing parents taking an unusual amount of medication, going to the doctor’s office frequently, and developing noticeable symptoms. Sometimes they guessed their parents were HIV positive from these observations. Most parents decided to disclose or confirm their HIV status when children directly asked them about their health: “I just told them...because my daughter asked me why I was taking so many pills.” In several households, parents described disclosing to children who, when interviewed, said that they guessed that their parents were HIV positive based on observations.

Some parents and caregivers reported that arguments led to unintended disclosure. For example, a mother whose 16-year-old son confronted her about her negativity towards his father reacted angrily by disclosing that her ex-husband infected her with HIV. She recalled the incident: “He’s like, ‘what has my dad done to you...are you dying or what?’ And I said, ‘yeah, basically, that’s what’s happening...your dad did it.’” She later apologized for disclosing to him in this way. In another case, a father regretted impulsively telling his children in “a real hostile manner.” Another child told of a harrowing disclosure experience with her mother who, shortly after having a fight with her father late at night, took her 10-year-old daughter on a speeding, reckless drive that caused her daughter to fear for her life: “I was utterly terrified.” When she finally parked, she told her frightened daughter that she was HIV positive.

Children also indirectly learned that their parents were HIV positive. Sometimes they overheard their parents discussing HIV/AIDS or making a revealing statement, such as referring to their “compromised immune system.” Other times, they learned from family members or friends. Four of the caregivers we interviewed reported that they either directly disclosed to children or confirmed what the child suspected. Some children confronted their parents with what they learned, but others kept it to themselves. One parent described such a confrontation: “She heard it from somebody else...we had to talk about it.” One 19-year-old son remembered confronting his mom after an unintended disclosure: “I asked her, ‘I heard them say you have HIV, is it true?’ And she said yeah.” A 20-year-old described unintentionally learning that his aunt was HIV

positive: “I was listening to her conversation. I was eavesdropping to her conversation.”

Perceived Reactions to Disclosure

Family members (parents, children, caregivers) we interviewed often characterized the disclosure experience positively and/or negatively. Their reactions were often mixed, with both positive and negative aspects. Only a few households contained no mention of any positive result, and only one household had no negative characterizations of the disclosure experience. In addition to these positive and negative reactions, some families described disclosure events that were not positive, but were not as bad as parents anticipated.

Perceived Positive Reaction: Emotional Support

Families reported that children sometimes gave immediate emotional support to their parents after disclosure by displaying affection, such as giving hugs and stating their unconditional love (Table 2a). One 12-year-old boy (age 10 at the time of disclosure) reacted by feeling upset that his father was sick and suggested the whole family go on a vacation to distract them from thinking about the sad news. Some children emphasized to their parents that they did not have a problem knowing: “I’m not going to treat you no different.”

Perceived Positive Reaction: Familial Closeness

Respondents often described increased familial closeness over time as a positive result of disclosure (Table 2b). This increased unity primarily manifested itself after disclosure through children being more involved in their parents’ lives, taking on extra household responsibilities, and communicating with parents more frequently and about more important subjects. One mother who hid many aspects of her personal life before disclosure reported that her children (ages 15–23) were now helping her choose romantic partners: “Now I ask them...., ‘What do you think about this person?’” Some children expressed enthusiasm about being helpful to their families. One 13-year-old with an HIV positive mother took pride in making a contribution to the family by taking care of her younger sister when her mom had to stay at the hospital. Other children spoke of assisting with more household chores after disclosure, reminding their parents to take their medication on time, avoiding arguments with other family members, and being more independent. Some children were motivated to learn as much as possible about HIV/AIDS by doing research so they could aid their parents’ treatment, such as finding alternative remedies.

Perceived Positive Reaction: New Outlook

Some children reported a changed, improved outlook towards their parents and life in general after disclosure (Table 2c). They said they felt compelled to stop worrying about trivial things because they did not know how much time they had left together. Children reported loving and appreciating their parents more and intentionally spending more time with them. One 20-year-old, while acknowledging that the disease is terrible, spoke about his changed relationship with his parents since disclosure: “I wouldn’t want them to be any different.” Other reactions included having a new perspective on life, having a “reality check,” knowing that “nothing is promised,” realizing time was limited, feeling “more real,” and accepting the news as a challenge to be overcome and a new beginning.

Perceived Negative Reactions: Fear

Some children also experienced intensely negative reactions immediately after disclosure. The most common reaction for children was continued fear for the parents’ health and life (Table 3a). After disclosure, children often initially asked, “Are you going to die?” Parents and caregivers described being able to calm these fears by reassuring them that medicine was keeping them healthy. Other children were so frightened about their parents’ health that they did not want to leave the house or leave their parents alone, they checked up on them frequently, and they inquired about their health often. Parents’ overt poor health and discussions of future custody arrangements sometimes contributed to such distress. The fear of uncertainty was another powerful emotion discussed by some children. Even with an understanding of the disease and its progression, some children reported that they could not relax because of this fear. The immediate distress of children with healthy parents diminished over time when they realized that their parents’ health was not declining rapidly. Children’s other fears included concerns about who would take care of them if their parent died, having to take care of younger children, becoming infected, and being stigmatized if their friends found out.

Perceived Negative Reactions: Shock

Respondents in eight households described children’s immediate reaction after disclosure as shock (Table 3b). Some children were so shocked at the news and overcome with concern about their parents that they were unable to function normally for an extended period of time. Families reported children not going to school/being able to study, playing with friends, or sleeping. For other children, the

news was so dramatic that it took time for them to believe what they were told: “I was in a state of denial.”

Perceived Negative Reactions: Anger

In two households, parents described children’s immediate reactions as anger (Table 3c). One 16-year-old child yelled at his HIV positive father for infecting his mother, “How could you do this?” Some children described anger at their parents for not telling them earlier. Some children reported being angry at the situation rather than at their parents: “[my father] doesn’t deserve to have a disease like that.”

Perceived Absence/Mitigation of Negative Reaction

Some disclosure reactions were not positive, but were far less negative than parents feared (Table 4a). One mother described this fear: “I was like...what if they go crazy? What if they have a nervous breakdown?” Some expressed relief that these fears were not realized. One mother reluctantly disclosed but reported that her fear was unfounded: “They took it pretty well.” Once they had disclosed, many parents felt a strong sense of relief because it was finally “out there.” One parent stated: “It was more painful for me than it was for her.”

Several children who were very young when told confirmed that they either had no memory of disclosure, or that they did not understand enough to realize the full implications. Children reported knowing that their parents were sick, but they did not have a strong or painful memory of being told that their parents were HIV positive. Some respondents reported that their family lives did not change drastically after disclosure and HIV was rarely discussed.

Knowledge of HIV as an Attenuator of Negative Reactions

For some families, children had already learned a lot about HIV/AIDS from school or television, or they already knew an infected person (Table 4b). This preparation reduced disclosure’s negative impact for some children. One 16-year-old child reported that her knowledge of her father’s previous drug use kept her from being shocked at the revelation of his HIV infection when she was 12: “I was like, okay, so that kind of makes sense.”

Parents used the disclosure conversation to educate their children about the difference between HIV and AIDS, how HIV is transmitted, and the chances of living a long time with medication. This process of learning about HIV sometimes helped mitigate the negative impact of disclosure. Some older children initially assumed that their parents were going to die very soon and that the virus could be transmitted easily, and were calmed after they learned

more. On the other hand, young children had few preconceived ideas about the meaning of being HIV positive.

Within Household Analysis

Table 5 summarizes the distribution of perceived positive and negative experiences within the 33 households for parents and children and indicates the level of agreement between children and parents within households. In only 11 households, parents and children completely matched in their description of the disclosure experience as positive and/or negative. Parents and children more frequently disagreed about whether the disclosure process was negative or positive. In 11 households, children described the disclosure experience negatively but parents did not. For example, in one household, the children talked about the lasting emotional toll that disclosure had on them. One 18-year-old son, who was around 6 years old when he found out his mom was HIV positive, discussed the ongoing worries he has had about his mom's death. He said, "Well, I always thought that...one day I would wake up and see her dead...you know you have to cherish every moment." The 24-year-old daughter, who was 12 when she found out, described the enduring disruption in her life after disclosure: "I always felt extremely unstable...and always...never secure." On the other hand, their mother did not describe any enduring effects that disclosure had on her children. She described the immediate crying that her son did when she told him about being HIV positive but, on the whole, her description of the disclosure experience was primarily positive. When asked if she was happy that she disclosed to her children, she said, "I'm glad because I'm relieved 'cause it was like keeping a big secret...from them...it's better for them to know because then they know exactly what's happening."

On the other hand, there were 8 households in which children described the experience as positive but parents did not describe it positively. For example, in a one

household with an unintentional disclosure, the HIV positive father described disclosure in exclusively negative terms. He discussed not wanting to disclose to his children in order to protect them: "I didn't want to tell them about it when they're too young because of ignorance about their friends' parents." He said that he worried that, once his children's friends' parents found out, they would not let their children play with the children of someone who had HIV. On the other hand, his sons did not describe the effects of disclosure as being particularly negative. In fact, they described how disclosure helped them improve their relationship with their father. One of his sons described being happy to know about his father's illness ("It's always good to know how someone you love is doing") and also described his motivation to help his father ("I guess just to try to make him feel better").

Discussion

This study describes the process of parents disclosing their HIV status to their children. A key finding of this study is that HIV positive parents were not always able to disclose to their children according to a plan. Children often learned about their parents' HIV infection accidentally or through their own observations. Another finding is that, although the disclosure experience was difficult for parents and children, many families described positive results of disclosure. A third finding is that there was considerable disagreement between parents and children about the overall effect of disclosure on the household. In only a third of the households, parents and children matched in their descriptions of the disclosure experience as positive or negative. These findings underscore the need to understand the familial and social context of disclosure in order to explain positive and negative outcomes for individual children. These findings build on our previous analyses of the familial context of stigma from HIV [25].

Table 5 Comparison of overall household perceived experiences of disclosure ($N = 33$, average kappa = 0.79)

Disclosure experience ^a	Parental experience	child agreement with parent	
		Yes (%)	No (%)
Positive	Yes	6 (18)	5 (15)
	No	14 (42)	8 (24)
Negative	Yes	14 (42)	2 (6)
	No	6 (18)	11 (23)

^a Disclosure descriptions could have been coded as positive, negative, both positive and negative or neither positive nor negative. In 3 households, parents described disclosure as both positive and negative and in 14 households, children described disclosure positively and negatively. In 9 households, parents did not describe the disclosure process either positive or negatively. In 4 households, none of the children described the disclosure process positively or negatively. In 13 households, parents described the disclosure experience only negatively; in 8 households they only described the disclosure experience positively. Children described the disclosure experience as negative only in 11 households and there were no households in which children described the disclosure experience as positive only

To make informed decisions about how to disclose to their own children, parents may benefit from understanding how the disclosure process has proceeded in other families. Clinicians may be able to use such information to counsel parents and to support children as they fulfill their important role in helping families cope with parental HIV infection. Both parents and clinicians would benefit from being familiar with the range of children's reactions—both positive and negative—to disclosure. The findings from this study can help guide clinicians' advice and suggest future areas for more research. HIV-infected parents reported feeling a strong sense of guilt and considered not disclosing in order to spare their children the burden of worries and to postpone a potentially painful conversation. However, as this study shows, parents do not have complete control over the disclosure process. This finding is consistent with other studies that found that some children already knew about their parents' HIV infection or suspected that something was wrong before disclosure [16]; indeed, a motivating factor for parents to disclose is sometimes the fear of their children finding out from someone else first [3, 4, 16]. These findings suggest that parents should be aware that they might not be able to control how their children find out about their HIV infection. When deciding how and when to disclose, parents should evaluate not only the developmental readiness of the child and the family circumstances but also the possibility of unintentional disclosure.

The wide range of ages of children in this study allowed us to explore potential connections between age of child during disclosure and disclosure outcome. Our findings suggest that parents may be more aware of the negative aspects of disclosure than the negative aspects of non-disclosure, and they may over-estimate the effects of disclosure on younger children. For example, the descriptions of reactions of young children who did not understand HIV/AIDS at the time of disclosure were relatively innocuous. Also, older children who knew that HIV was a cause of death but not much else were strongly affected because they thought they were being told that their parents were about to die. The impact of disclosure often lasted a long time, despite explanations about the disease and treatment. Children who were told before they had much of an understanding of HIV remember knowing that their parents were sick, but not much else. These findings support the American Academy of Pediatrics' recommendation for disclosure to younger children as long as the information is individualized based on their cognitive ability and developmental stage [32]. The findings of this study also suggest that parents make clear to older children that HIV does not equate with immediate death. School programs that inform children about HIV may also help to minimize older children's negative reactions.

Another finding of this study was the degree of attention that children paid to the health of their parents both before and after disclosure. Several children reported sensitivity to slight changes in their parents' health and worried even before they became aware that their parents were HIV positive. Children sometimes guessed their parents' HIV infection from observations of health-related behaviors. Children also reported that, after disclosure, they enthusiastically pursued information about the illness and felt empowerment and pride while helping their families. The stories of children noticing their parents' health problems suggest that children experienced stress about not being able to help resolve an obvious, but secret, problem; contributing to their parents' well-being helped them to cope with this stress.

Our analysis also suggested that disclosure and non-disclosure had an impact on the quality of the parent-child relationship. Stories of increased closeness after disclosure suggested that these secrets may have been interfering with family functioning, cut off parents from a source of emotional and practical support, and delayed child coping behaviors. Other studies have identified similar results of disclosure [16, 33]. The analysis of descriptions of the effect of disclosure on the household demonstrated that within households there are multiple perspectives about the effect of disclosure on the family and that parents and children frequently describe the impact of disclosure very differently. The findings in this study support recommendations that clinicians treat families dealing with a parental HIV infection as a unit rather than treat parents and children separately; the study findings also suggest that disclosure decisions should be discussed and supported [34].

Limitations

Our sample was chosen to maximize the potential variation in types of families (with younger, older, and adult children) in order to explore and describe the range of possible experiences and uncover factors that have not been adequately addressed in previous research. The wide range of ages of children we interviewed aided our goal of uncovering the range of experiences by mixing in older children, who can articulate their experiences better than younger children but might experience memory bias, with younger children, who can recount recent disclosure experiences but can not describe long-term effects. Nevertheless, the study's high attrition/refusal-rate, non-random sampling strategy and exploratory, qualitative data collection limit the generalizability of these findings. We cannot generalize to families of parents who have never disclosed to their children or determine whether respondents' descriptions of disclosure are biased by denial, rationalization, or a desire to provide socially desirable answers. Also, we cannot

determine if disclosure experiences characterized by respondents as positive or negative were actually positive or negative for them in the long or short term. For example, children who described their increased household responsibilities positively may experience problems in the long term. Some recent studies of children with parents suffering from chronic illness have shown a negative effect of age-inappropriate caretaking responsibilities on children, while other studies show long term positive effects [35, 36].

Although a qualitative study is by design generally not used for hypothesis testing, these findings can be valuable in generating hypotheses for studies using methods better suited for hypothesis testing. For example, future studies can explore the relationship between unintended disclosure and child coping outcomes and test if unintended disclosure is more likely to result in negative outcomes than planned disclosure. Additional studies are also necessary to test how much the age of the child and the characteristics of the relationship between the child and parent before disclosure (e.g., how frequently they had contact) affect the outcome of disclosure. Additional research can help understand the intra-familial dynamics in communicating about parental HIV infection to determine which type of dynamic best promotes coping or to test if greater agreement between parents and children about the effects of disclosure is related to lower stress. These associations are only suggested by the findings of this study and they will have to be tested in additional studies with appropriate research designs. For example, a prospective research design that followed households over time starting before disclosure and continuing for many years after disclosure could measure the effect of child age and parent–child relationship characteristics at time of disclosure. Such a design would also allow for a better understanding of the effect of age and parent–child relationship on retrospective accounts of disclosure.

Conclusion

Disclosure may be difficult for parents, but in certain circumstances it can help the whole family adjust to the reality of living with HIV. Findings from this study can be used to augment the existing educational intervention materials that focus on fostering communication within HIV affected families [32, 37]. These materials focus on family communication and disclosure or disclosure to infected children, but they do not address the unique challenges faced by HIV positive parents disclosing to their children. These materials could also contain information for clinicians to guide HIV positive parents on how and when to disclose to their children by conveying the disclosure experiences described by families who have gone before them.

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