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Fears about HIV Transmission in Families with an HIV-Infected Parent: A Qualitative Analysis

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Abstract

Objective—Children of HIV-infected parents may be affected by their parents' disease even if not infected themselves. Due to advances in HIV treatment that have reduced the risk of vertical HIV transmission from mother to child, more HIV-infected adults are having children. Few studies have examined whether families with an HIV-infected parent experience fears about transmission to children and how they address such fears. In this paper, we describe transmission-related fears in families with an HIV-infected parent.

Participants and Methods—This study uses semi-structured qualitative interviews, conducted in-person from March 2004–March 2005, with 33 HIV-infected parents, 27 minor children 9–17 years old, 19 adult children, and 15 caregivers (adult family members or friends who helped care for the children and/or parents) to investigate their fears about HIV transmission. The parents are a subset from the HIV Cost and Services Utilization Study (HCSUS), a study of people in care for HIV throughout the US. We analyzed the interview transcripts for themes related to transmission fears.

Results—In many of the families, participants identified 1 HIV transmission-related fear. Themes included specific fears related to blood contact, bathroom items, kissing/hugging, and food. Families addressed their fears by educating children about modes of HIV transmission and establishing rules or taking precautions to reduce the risk of HIV transmission in the household. HIV-infected parents were also concerned about catching opportunistic infections from a sick child.

Conclusions—Many of the fears experienced by HIV-infected parents and their children were based on misconceptions about modes of HIV transmission. Pediatricians and others treating these children may be able to offer counseling to allay fears that family members have about household transmission of HIV.

Keywords

HIV; family; children; adolescents; transmission

As recently as 2006, some adults in the United States believed that HIV can be transmitted through such casual contact as kissing (37%) and sharing a drink (22%).¹ Consequently, HIV-infected individuals (and by extension, their family members) may experience HIV-related stigma. For example, we showed in another paper that HIV-infected parents reported experiencing avoidance, ostracism, and verbal insults from family members and friends because of their transmission-related fears.² Thus, misconceptions about transmission may leave HIV-infected parents and their children vulnerable to experiencing isolation and stigma, which in turn are associated with poor mental health outcomes.³⁻⁶

Besides coping with fears of friends and family, HIV-infected parents also experience their own concerns about HIV transmission. Although the likelihood of vertical transmission of HIV from mother to infant has been greatly reduced through antiretroviral treatment in tandem with good prenatal care,⁷⁻¹⁰ some HIV-infected parents also worry about transmitting HIV through casual contact.^{11, 12} In one study, 36% of parents worried about transmitting HIV to their children through casual contact and avoided behaviors, such as kissing their children on the lips (19%) and sharing utensils with children (15%).¹¹ Parents also reported that 11% of children worried about contracting HIV from their parent.¹³ However, these fears are generally unfounded. A study on family contacts with HIV-infected children found that no family members contracted HIV through casual contact.¹⁴ Unfounded fears may affect ongoing development of the parent-child relationship by limiting the quantity and quality of their daily interactions.

Prior research on fears about HIV transmission from parent to child has mainly focused on parental fears, with limited input from children or other family members. In this study, we conducted semi-structured qualitative interviews with HIV-infected parents, their minor children, adult children, and caregivers about HIV transmission and the spreading of opportunistic infections in the household. We aimed to identify their transmission fears and how families address these fears. Prior work has shown that people who personally know an HIV-infected person tend to exhibit fewer stigmatizing attitudes about people with HIV.¹⁵ In our study, we would expect HIV-affected family members to also express some stigmatizing views, but not as many as the general public, regarding fears about HIV transmission. For those family members who do identify fears, their fears may be influenced by misconceptions about modes of HIV transmission.

Qualitative methods were used to obtain a richness of explanations that are not generally available through closed-ended survey questions, especially on such sensitive topics; qualitative methods also allowed us to include younger offspring. Knowledge about transmission-related fears and successful coping strategies could help pediatricians and other

clinicians who care for children to address children's specific fears; such knowledge could similarly assist clinicians who care for HIV-infected parents.

Methods

Participants and Study Design

Between March 2004-March 2005, we conducted semi-structured interviews with a sample from HCSUS, a national probability sample of people 18-years-old with known HIV infection who made 1 visit to a medical provider in the contiguous U.S. during January-February 1996.¹⁶⁻¹⁸ HCSUS participants were eligible for the present study if they participated in the third wave (out of three waves) of HCSUS in 1997-1998 and the affiliated HCSUS Risk and Prevention survey in 1997-1998¹⁹; if they had 1 child 23-years-old on March 1, 2004; and if they lived with or had seen 1 of their children in the past month at the time they were contacted for participation in the present study. The sample consisted of a stratified random sub-sample of 509 (52%) of the 975 eligible participants, sampling all families with a child <18 and sampling participants in the follow-up database at a higher rate among the remainder. In the sample of 509 participants, 23 were removed because they were listed twice, resulting in 486 potential parents. These parents are referred to as “target parents” to differentiate them from caregivers who are also parents.

We interviewed selected HCSUS participants, their children (9-17-years-old), their adult children (18-years-old), and a caregiver who provided additional support or cared for the HIV-infected parent and/or a child in the family. Caregivers were usually the target parents' spouse/partner or parent, but in two cases were family friends who were considered “family members.” Caregivers provided additional information about how the child was affected by the parent's illness. Children were eligible to be interviewed if they knew about their parent's HIV status and had lived with or seen their parent in the past month. Two nieces were interviewed as adult children because they lived with and considered the target parents to be parental figures. Parents consented for minor children, and minor children gave assent for study participation. The project received institutional review board approval from RAND and UCLA.

We located 146 of 486 (30%) target parents using contact information from HCSUS records and Lexis-Nexis: 69 were deceased and 19 were ineligible because they did not live with their child and/or they had not seen their child in the previous month. Among the remaining 58, 33 agreed to participate, 22 declined to participate, and 3 were initially reached but could not be reached again during the interview period. For the 33 families in which the target parent participated, we interviewed 27 minor children, 19 adult children, and 15 caregivers.

Measures

Socio-demographic variables—Parents' race/ethnicity, annual household income, education, HIV exposure/risk group, and HIV diagnosis year were obtained from baseline (1995) HCSUS data. Household composition; geographic region; and interviewees' age and gender were obtained during the semi-structured interview.

Interview protocol—Interview questions were open-ended and broad to elicit a detailed description of family members' experiences, including: questions to parents about the nature of their physical contact with their children since their HIV diagnosis and concerns about infecting their children with HIV and/or catching an opportunistic infection from their children; questions to children and adult children about catching HIV from their parent and decisions not to touch, kiss, or share food with their parent; and questions to caregivers regarding fears about HIV transmission in the home and observations regarding the parent's and children's fears. In addition, follow-up questions asked respondents if these fears went away over time and what was done in the household to address them.

Prior to the in-person interview, target parents were asked by telephone whether their minor children knew about their parent's HIV-status and whether it was permissible to interview them. On the interview day, parents were again asked whether their child was aware of their HIV status, and if so, to consent for the child to be interviewed. Parents and children were interviewed privately. Children were screened to ensure that they were aware of their parent's HIV status, by asking them a series of open-ended questions about their family, their relationship with their parent, and their knowledge of different types of diseases, including HIV. If the child mentioned the parent's HIV at any point in response to the screening questions, the interviewer began the interview. All children indicated that they knew of their parent's HIV infection. On average, semi-structured interviews lasted 90 minutes with adults, and 60 minutes with children.

Data Analysis

Audiotapes were transcribed and managed with a qualitative data analysis program. Content analysis of the narratives was conducted using both inductive and deductive techniques.²⁰ Such analysis allows for a full range of themes and subthemes to emerge, including those that were not anticipated prior to analysis. Following Bernard's protocol for content analysis, we created a set of thematic-based codes, applied the codes systematically to the narratives, and tested the reliability between coders.²⁰ Specifically, the first author initially read through a sample of transcripts to identify the presence of text related to fears about HIV transmission. Coders were given basic operational definitions of these transmission-related fears, derived in part from prior literature,¹¹ and were instructed to identify all transmission-fears-related text in the narratives. The first author resolved discrepancies between coders. This procedure resulted in a body of 486 transmission-fears-related quotations.

The coders next identified instances of fears related to specific modes of HIV transmission, fears about the parent catching an opportunistic infection from a sick child, and mechanisms families used to address their fears. The two coders then pile-sorted the body of transmission fears-related quotations based on similarities, representing the themes and related subthemes, described above.^{20, 21} As recommended by qualitative methodologists,^{20, 22} the salient subthemes were mutually exclusive categories within the major themes. The first author then examined the codes and suggested revisions; disagreements between the first author and the coders were discussed and resolved. For Table 2, the rank order was derived by counting each respondent as having the fear if he/she or (in a few instances) another family member reported that the respondent had the fear. Due to the nature of qualitative

analysis, we were unable to quantify the magnitude of the fears. Instead, we grouped fears into 3 frequency categories (bottom, middle, top) based on the number of respondents who identified having each fear. Cohen's Kappa was used to check consistency between the coders²³ and was satisfactory or better for all identified themes (0.69-1.00).^{24, 25} (Tables 3-5).

Inductive methods were used to derive a better understanding of the shared experiences of fears about HIV transmission within the family. For the primary analysis of the narratives, all quotations were grouped by family unit. We also explored the ways in which families addressed transmission fears. After identifying themes, we examined potential differences by racial/ethnic group and exposure/risk group by dividing themes from each respondent into their appropriate sub-group.

Results

Respondent Characteristics

Table 1 shows respondent characteristics.

Transmission-related fears

In 21 of the 33 families, 1 family member reported an HIV transmission-related fear in the household. Table 2 shows a rank ordering of fears identified by respondent type. Specific themes are discussed below. In addition, some respondents did not explicitly mention one of these themes, but expressed general fears about HIV transmission in the home. In the qualitative analysis, no patterns emerged that suggest a difference in transmission-related fears or coping strategies by subgroup.

Contact with blood—Family members were concerned about HIV transmission through contact with the infected parents' blood (Table 3a). In some instances, the parents' fears about blood contact affected how the children felt and reacted when the parents were bleeding. Some parents yelled at their children to stay away. Children recalled vivid memories of these experiences, which made their HIV-infected parents' disease “real.” Family members also mentioned fears about transmission in the bathroom that involved possible contact with blood (Table 3b). Here, concerns arose about children using parents' razors or when mothers were menstruating.

Contact with saliva—Fears suggesting transmission through contact with saliva arose when sharing a bathroom (Table 3b), while hugging or kissing (Table 3c), or when sharing food or beverages (Table 3d). Respondents worried about children using the same toothbrush or washcloth as the HIV-infected parents. Families were sometimes unsure about continuing to kiss the HIV-infected parents on the lips and altered their displays of affection from kissing on the lips to kissing on the cheek or hugging the parents. Sharing plates of food, using the same utensils, and drinking out of the same cup as the HIV-infected parents also concerned some family members.

Fears about contracting an opportunistic infection—HIV-infected parents were concerned about catching an opportunistic infection from a sick child or other family

member (Table 3f). Parents were especially concerned about being able to care for a child with chicken pox, a cold, or the flu.

Variation among family members' fears

Family members' fears about HIV transmission differed by respondent group (Table 2). Parents were most concerned about exposing children to their blood and described tense experiences with their children when parents cut themselves. Parents were more likely to express fears about blood transmission than about using the same bathroom as their children or continuing to hug and kiss their children. Similar numbers of children and adult children identified fears about HIV transmission through blood contact and through contact with saliva. Many of the children reported that they were more concerned shortly after their parents' HIV disclosure, when they were unsure which activities were unsafe.

HIV-infected parents expressed concern about contracting an opportunistic infection when their children were sick. Very few children, adult children, or caregivers shared this concern with parents.

Influences on children's fears

Children's fears or lack thereof about HIV transmission were influenced by a variety of sources (Table 4). Parents, extended family members, and teachers may have influenced a child's perception about the risks of HIV transmission in the household. Although some parents and caregivers dispelled myths about HIV transmission, others perpetuated them. For example, the 13-year-old daughter of an HIV-infected mother would purge herself after eating her mother's food. The girl's extended family told her she would “die” if she ate her mother's cooking.

Children also took cues from their parents' behavior, which shaped their opinions about possible modes of HIV transmission. For example, if a parent routinely continued to kiss and hug her child; the child would assume this behavior was safe. In many families, the parents did not explicitly state a behavior was safe, but the children made this assumption based on observing the parent's behavior.

Addressing fears in the household

Families dealt with their transmission-related fears using two approaches. First, parents educated children about the modes of HIV transmission. In many instances, this knowledge allayed their fears or taught them prevention strategies. Families also set household rules and took precautions to reduce the risk of HIV transmission from the parent.

Becoming more educated about HIV transmission—In some families, parents were able to address children's fears by educating them about the modes of HIV transmission (Table 5a). Some parents corrected misinformation their children had received from school, the media, or extended family members.

Establishing rules to prevent HIV transmission—Many families addressed fears about HIV transmission by setting household rules (Table 5b). In some families, the HIV-

infected parents would not share their bathroom with the children. Additionally, children were instructed not to use their parents' toothbrushes or razors and not to share food or drink from the parent's cup.

Taking precautions to address fears about HIV transmission—Many families said they made a special effort to maintain a clean household to reduce their concerns about HIV transmission, particularly right after diagnosis (Table 4c). They also focused on personal hygiene. For example, a number of HIV-positive women acknowledged taking precautions during menstruation to keep blood away from family members. Precautions were also taken when someone was cut; children were taught to avoid parents when they were bleeding until the injury was properly cleaned and dressed.

Discussion

In this qualitative study, members in two-thirds of the families with an HIV-infected parent expressed fears about HIV transmission in their households. HIV-infected parents were concerned about transmitting HIV to their children and contracting an opportunistic infection while caring for sick children. Minor children, adult children, and caregivers were mostly worried about parental transmission. To address concerns, families educated children about HIV, took precautions in the home, and set rules to reduce the risk of transmission. Some fears were based on incorrect information about HIV transmission. Pediatricians and other primary care providers may be in a unique position to provide counseling about HIV transmission, given their medical knowledge and relationship with the family as a knowledgeable source. Prior to this research, fears about parental transmission of HIV to children in the home have only been studied from the perspective of the infected parent and not the affected family members, especially the children.^{11, 12}

HIV-infected parents were worried about catching an opportunistic infection from a sick child, a realistic concern for someone living with HIV. Pediatricians and parents' primary care providers or HIV care providers may be able to suggest how parents can care for a sick child. To limit HIV-infected parents' exposure to contagions, uninfected family members or friends could care for the sick child. When another caregiver is not available, clinicians may be able to outline precautions the family could take to minimize the spread of contagions. Experts also suggest parents receive the inactivated influenza vaccine and a pneumococcal vaccine to prevent bacterial respiratory infections; children of HIV-infected parents should be vaccinated against the varicella-zoster virus and influenza.²⁶

Parents' knowledge about the modes of HIV transmission can influence the development of children's fears. Having parents teach children about HIV has been effective in reducing children's misconceptions about the disease,²⁷ and exposure to HIV-infected individuals has helped reduce fears about contagion.²⁸ It is also important not only to provide children with information about how HIV is transmitted, but also to clear up any misconceptions.²⁹

In our study, many of the children's fears arose during or shortly after parents disclosed their diagnosis. Additionally, some parents and caregivers appeared to exacerbate children's fears by sharing incorrect information about HIV transmission. Some U.S. adults continue to hold

incorrect beliefs about HIV, including that AIDS can be transmitted through casual contact.³⁰ Families with an HIV-infected parent may share these misconceptions about HIV transmission, especially when the parent is first diagnosed.

Extended family members may also affect the development of children's fears. Results from this and another qualitative HCSUS study found that families experienced stigma and discrimination from extended family members who were concerned about HIV-infection.² In some cases, these same extended family members may become the custodians of the children, as up to half of HIV-infected parents experience difficulty maintaining custody of their children.³¹ Therefore, it is important to address misconceptions that arise from extended family members.

In our study, some children identified fears about contracting HIV during such common, daily activities as sharing food or hugging/kissing their parents, although these activities did not put the children at risk. A similar number of children mentioned concerns about transmission through blood and saliva. Due to the nature and goals of qualitative analysis, we could not make quantitative judgments and comparisons regarding the magnitude of these fears. An earlier study of HIV-infected parents who used illicit substances indicated that their children estimated their chances of getting AIDS to be relatively high and held misconceptions about realistic modes of HIV transmission.³² Children's concepts of health and illness should be considered when parents and other adults discuss how children view HIV/AIDS and its modes of transmission. In our interviews, some children held on to misconceptions about HIV transmission due to receiving incorrect information from a parent, extended family member, media source, or school-based program. Children may overestimate the perceived risk of contracting a rare disease like HIV³³ when they hear about its serious consequences. As children age, their understanding of contagious and non-contagious diseases becomes more sophisticated³⁴; thus, information provided to children about the modes of HIV transmission should be age appropriate.

To address their fears, families in our study educated themselves about modes of HIV transmission, set household rules, and took precautions to reduce the impact of these fears on family dynamics. This allowed families to continue showing affection toward each other through kissing and hugging one another and sharing meals with fewer concerns about transmission.

Interventions with pediatricians and other clinicians have had some success encouraging parents to discuss HIV with their children.^{35, 36} Parents are more likely to discuss HIV with their children when pediatricians educate them about HIV, outline developmentally-appropriate ways to do so, and provide them with brochures.³⁵ Clinicians have also increased mother-adolescent discussion about condoms by providing parents with information about sexual behavior and condom use.³⁶ The American Academy of Pediatrics Committees on Pediatric AIDS and on Adolescence recommend that pediatricians include information about HIV prevention and transmission as an important component of anticipatory guidance for adolescents.³⁷ Pediatricians, other clinicians caring for children of HIV-infected parents, and parents' primary care providers may all be able to educate families

about possible modes of HIV transmission in the home and suggest age-appropriate strategies to allay children's and other family members' fears.

This qualitative study has some limitations. The sample size and the fact that we drew a sample of parents who were in care for HIV during or prior to 1995 may limit our ability to reflect the full range of HIV transmission-related fears among U.S. families with an HIV-infected parent in the household. Parents not receiving health care at the time or parents who had not yet been diagnosed (or infected) may have had different experiences with HIV-related fears. Additionally, the families who were not reached may have had less stable living situations, in part due to experiences with stigma and discrimination related to their HIV-status. For example, families who experienced discrimination might have been more likely to have moved away from their communities.

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Abbreviations

HIV	human immunodeficiency virus
AIDS	acquired immunodeficiency syndrome
HCSUS	HIV Cost and Services Utilization Study
IDU	injection drug users
MSM	men who had sex with men

Table 1
Parent and Child Characteristics

	% or mean
Parent Characteristics (N=33)	
Sex	
Mother	73
Father	27
Age in years, mean $\pm$ SD (range)	44.2+7.2 (30-62)
Race/ethnicity	
African American	48
Latino	21
White/Other	30
Annual household income (1995 dollars)	
\$0-\$5,000	18
\$5,001-\$10,000	30
\$10,001-\$25,000	39
\$25,001	12
Exposure/risk group [†]	
IDU	27
MSM	12
Heterosexual	48
Other	12
Year of diagnosis	
Before 1990	36
1990-1993	42
1994-1996	21
Household composition	
With spouse/partner	67
With other adults	3
With no adults	30
Child Characteristics (N=27)	
Sex	
Female	37
Male	63
Age in years, mean $\pm$ SD (range)	13.9+2.3 (9-17)
Adult Child Characteristics (N=19)	
Sex	
Female	58
Male	42

	% or mean
Age in years, mean $\pm$ SD (range)	21.5+3.5 (18-30)
Caregiver Characteristics (N=15)	
Sex	
Female	60
Male	40
Age in years, mean $\pm$ SD (range)	45.8+10.5 (35-76)
Relation to Parent	
Spouse/partner	73
Parent	13
Friend	13

[†] These categories are hierarchical and mutually exclusive, so a parent who fits in more than one category was placed in the highest of these categories.

IDU: injection drug users

MSM: men who had sex with men

Table 2

Rank Order of Respondent's HIV Transmission-Related Fears. *

Parents (N=33)	Children (N=27)	Adult Children (N=19)	Caregivers (N=15)
Blood (top)	Food (middle)	Kissing/hugging (middle)	Blood (bottom)
Opportunistic Infection (top)	Blood (middle)	Bathroom (middle)	Bathroom (bottom)
Bathroom (middle)	Kissing/hugging (middle)	Blood (middle)	Food (bottom)
Kissing/hugging (middle)	Bathroom (bottom)	Food (middle)	Kissing/hugging (bottom)
Food (bottom)	Opportunistic infection (bottom)	Opportunistic infection (bottom)	Opportunistic infection (bottom)

Frequency of fear (if number of respondents with the specific fear fell in the following ranges):

Top = (30-40%)

Middle = (15-29%)

Bottom = (0-14%)

* The rank order table should be read down each column to identify the fears most often mentioned by the type of respondent. Fears within a given category should not be considered greater within the category compared to other fears listed within the same category, e.g., children's fears about blood and food are comparable. The rank orders represent a count of fears, not a representation of the magnitude of the fears.

Table 3
Transmission-Related Fears Theme

3a. Fears about Transmission through Blood Contact (subtheme) (Kappa = 0.91)	
Sample Quote	Context of Quote
"When I get cut, I take care of it immediately. If my children are there, I wipe it up, and I keep bleach in this house. I bleach everything. It kills the germs."	Mother shares concern about transmission through blood.
"She [the HIV-positive mother] was bleeding and my first reaction was to run toward her. She literally pushed me really hard away from her. She said, 'Don't come near me!' ... And then she went to the bathroom and was you know washing it and she kept saying like, 'Don't come near me! Don't come near me!' And that was when it was so like real to me and I just, I don't even know what I felt, but I felt like a whirlwind of emotions."	Adult daughter recalls incident when she was younger and mother cut herself.
"I guess I'm comfortable with it, I know more about it now than I did before, but basically the same thing, like if he [HIV-positive father] cuts himself with something you can't use that cause you don't want to cut yourself and just like that. Like he's been, oh I accidentally cut myself bad so don't use it, like that."	16-year-old son expresses understanding about transmission through blood.
3b. Fears about Transmission in the Bathroom (subtheme) (Kappa = 0.81)	
Sample Quote	Context of Quote
"I used to, I used to [be concerned]. I used to ...buy new toothbrushes every month...I'd freak out if like someone used someone's toothbrush...I'd be like, oh by God. I don't do that anymore."	Mother explains initial fear about transmission by sharing toothbrushes.
"If I have an abscessed tooth, you know, or if I just brushed my teeth and flossed and I think that I've had blood – I get really scared to be real close to him [her son]. It's probably my own paranoia."	Mother expresses fear about transmission after cleaning her teeth.
"Back to me worried about catching it. I think there were a few times that she [HIV-positive mother] like used my razor if I left it in the bathroom or something and I never said anything to her, but that kind of bothered me. Like, oh, what if I can catch it, and I went and got tested several times."	Adult daughter recollects fear about catching HIV from her mother when they shared a razor.
3c. Fears about Transmission through Hugging/Kissing (subtheme) (Kappa = 0.86)	
Sample Quote	Context of Quote
"My daughter says, 'come give me a kiss, give me a kiss.' And I don't kiss her. I don't kiss her... Yeah; I wasn't used to it [having HIV]."	Mother shares concern about kissing daughter shortly after HIV diagnosis.
"At the beginning, I noticed a little resistance. They would hug me, but they hurry up and hug me."	Mother explains children were not sure if they could safely hug their mother.
"Let's say I come home, I always kiss my mom on the cheek or whatever. You know...certain kids; they kiss their mom on the lips and stuff. My mother doesn't like to do that. I don't know why... she's just careful about everything."	16-year-old daughter of HIV-positive mother describes her mother's fear about kissing on the lips.
"Kissing my mother...not on the lips...on the cheek and stuff. So I don't worry."	15-year-old son of HIV-positive mother explains how he kisses his mother.
3d. Fears about Transmission through Sharing Food/Utensils (subtheme) (Kappa = 0.77)	
Sample Quote	Context of Quote
"You knew you couldn't catch it from ...you know accidentally drinking out of the same glass...we know that. But for the next two [years] he was in such a panic that his glass – you know he would keep his glass away from everybody."	Wife of HIV-positive father explains his fear about someone drinking from his glass during the time after his diagnosis.
"Oh I'm going to be nice and call them mother and grandmother on their father's side. [My daughter] would come every time I had visitation. She was told not to eat the food that I cooked because she could get AIDS and die. So after she would eat, not to hurt my feelings, she would go to the bathroom and purge, stick her fingers down her throat."	Mother explains daughter's behavior after eating at her house.
"They [parents] are always being cautious with us. Like, you know, about cups and don't use the stuff [the parent] uses. It's always been a question mark there."	16-year-old daughter of HIV-infected mother describes her uncertainty about sharing a cup with her mom.
3e. Fears about HIV-Infected Parent Catching an Opportunistic Infection from a Sick Child (subtheme) (Kappa = 0.93)	
Sample Quote	Context of Quote

3a. Fears about Transmission through Blood Contact (subtheme) (Kappa = 0.91)	
Sample Quote	Context of Quote
"You get the chicken pox, and you are doomed. That's all I can think of. This little boy is crying out for me and clawing everywhere. Now he's hallucinating because his fever is so high. I didn't know what to do. How am I going to pick him up and put him in the hospital? I wasn't really even able to think because I was so afraid of touching him and contracting his disease or giving my disease to him."	Mother shares fear about catching chicken pox from son.
"You get a cough, someone gets your cough. You get a cold, so you think they [family members] are going to get infected. You get one of their colds you think you are going to die."	Father shares concern about spreading an opportunistic infection within the family.
"There were lots of times where I would be drinking something out of a glass and she [HIV-positive mother] would come and take it and just drink from it and I wouldn't worry about catching something from her. I would worry that she would get sick from me - from me having a cold, or something."	Adult daughter recollects concern about mother catching an opportunistic infection from her.

Table 4

Influences on Children's Fears Theme (Kappa = 1.00)

Sample Quote	Context of Quote
"She [the granddaughter] said that they [the school program] told her you can get it from kissing...I said that wasn't my understanding, but if they say you can get it then you don't kiss."	Grandmother describes why granddaughter fears kissing her mother.
"I knew she [HIV-positive mother] wouldn't do it, like if she was kissing me and knew it wasn't good, [then] she wouldn't have done it."	12-year-old daughter explains why she is not concerned about kissing her mother.

Table 5
Addressing Fears in the Household Theme

5a. Becoming More Educated about HIV Transmission (subtheme) (Kappa = 0.72)	
Sample Quote	Context of Quote
"You can only get it through blood and you can't get it by drinking behind me and you know, sleeping with me and stuff like that."	Mother explains modes of HIV transmission to daughter.
"She actually came out and said that I'm afraid...They [schools and public in general] are not explaining to them the precautions you can take...You kiss a person, you got HIV. I'm like that's not true. A lot of these things I actually had to sit her down and explain to her and get literature that I had with proven facts."	Father corrects daughter's misconceptions about modes of HIV transmission.
"...at first I did. But then my mom told me that you can't catch it by just touching or kissing them. So I'm used to it, there is no fear about touching them or kissing them."	13-year-old daughter of HIV-positive mother describes initial fears about kissing her mother or HIV-positive sister.
5b. Setting Rules to Prevent HIV Transmission (subtheme) (Kappa = 0.77)	
Sample Quote	Context of Quote
"And you know, you see over here I take care of myself because if I use my toothbrush, I put everything separate. My things, I put separate. The shaver, I put that separate, and I told my daughter this is mine."	HIV-positive mother describes how she separates her toiletry items so her daughter knows not to use them.
"Everything is always separate, her soap, her razor, and she's like don't use it."	Adult daughter explains mother's ground rules in the bathroom.
"They are taught, always wash your hands, never do mom's laundry, never use mom's toothbrush, never use anything of mom's toiletries in the bathroom."	Husband of HIV-positive mother explains ground rules in their household.
5c. Taking Precautions to Reduce the Risk of HIV Transmission (subtheme) (Kappa = 0.69)	
Sample Quote	Context of Quote
"I feel like a constantly walking virus. I will – my hands are probably cleaner than anybody because I will wash my hand constantly, because I think that if I scratch you know a little something on my head and I'll go in and wash my hands because I'm afraid what if it bled."	Mother explains why she constantly washes her hands.
"I used to clean my house constantly with bleach and everything, buy new toothbrushes every month... I don't do that anymore...I guess I've become more aware of how the disease is passed along. As long as everyone is okay, there is no need to be overprotective in that way."	Mother explains why she constantly cleaned the house after first learning about being HIV-positive.
"If I cut my hands or anything with bodily fluids, or blood, I wait a minute. I have to wash my hands, and they realize."	Father explains the precautions he takes after cutting himself.
"Like if she has a cut, she's like, 'Okay, like, I'll be back, don't come around me right now.' Or like let's say a glass falls on the floor and somehow she got cut or something. You know she's like, 'You stay over there for a minute.'...she's very precautionary about everything."	16-year-old daughter explains the precautions her mother takes when she is bleeding.