

# Brief Report: A Qualitative Analysis of Discussions about HIV in Families of Parents with HIV

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**Objective** To explore communication about HIV prevention, risk behaviors, and transmission in families affected by HIV. **Methods** Semi-structured interviews were conducted with 33 parents with HIV, 27 children (9- to 17-years old), and 19 adult children ( $\geq 18$ -years old) across the U.S. Coders reviewed transcripts, identified themes, and coded transcripts. **Results** Youth felt uncomfortable discussing HIV with their parent who has HIV because they worried about upsetting and reminding the parent of his/her illness. Adult children reported learning about HIV prevention by watching how the illness affected their parents. Few siblings reported talking with one another about HIV because they worried about upsetting their brother/sister and about their sibling unintentionally disclosing the parent's illness to others. **Conclusions** Discussions between youth and their parent with HIV and their siblings vary, highlighting the need for further research in this area.

**Key words** communication; HIV; prevention.

## A Qualitative Analysis of Discussions about HIV in Families of Parents with HIV

Parents play a critical role in HIV prevention by talking to youth about sexuality. When parents and adolescents communicate openly about sex, adolescents are more likely to use condoms and less likely to become pregnant (DiIorio, Pluhar, & Belcher, 2003). However, the process of communication and topics discussed between youth and parents with HIV may differ from communication in non-affected families. Knowing a person with HIV may increase adolescents' fear of contracting HIV (Boone et al., 2003), and in turn, their desire to talk with parents about sex (Carroll et al., 1999). In one study, 60% of mothers with HIV did not discuss HIV prevention with their children but they were more likely than uninfected mothers to have these discussions (O'Sullivan, Dolezal, Brackis-Cott, Traeger, & Mellins, 2005).

These findings provide a snapshot of prevention discussions in families of parents with HIV. Family systems theorists emphasize the interdependence and reciprocal nature of relationships and that family members affect

one another directly and indirectly (Minuchin, 2002). Thus, parental difficulties resulting from chronic illness (like HIV) may extend to other parts of the family system so that family members take on new responsibilities. Siblings, for example, influence each other's sexual health behaviors (East & Khoo, 2005) but no studies have examined sibling communication in families of parents with HIV. The perspectives of fathers with HIV and adult children of parents with HIV are also understudied.

We conducted qualitative interviews to examine HIV-related discussions between youth (including reports from children who are now adults) and their mother/father with HIV, and communication between siblings. Participants were drawn from the HIV Cost and Services Utilization Study (HCSUS), a representative sample of people receiving care for HIV in the United States. We hypothesized that emergent themes would reflect participants' comfort talking about HIV-related topics, parental warnings about unsafe practices, and that topics would include risk behaviors, transmission, and protection. We also expected themes unique to families affected by HIV

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(e.g., lessons learned from observing a parent living with HIV) to emerge.

## Method

### *Study Design, Participants, and Research Team*

Between March 2004 and March 2005, we conducted semi-structured interviews with a sub-sample from HCSUS. Parents were eligible if they participated in HCSUS' third wave (1997–1998) and HCSUS' Risk and Prevention survey (1997–1998); if they had  $\geq 1$  child  $\leq 23$  years old on March 1, 2004; and if they lived with or had seen  $\geq 1$  of their children in the past month when they were contacted for the present study. The sample is a stratified random sub-sample of 509 (52%) of 975 eligible parents; 23 were duplicates leaving 486 parents. We over-sampled parents in the follow-up database and selected all families with a child  $< 18$ -years old. We located 146 of 486 parents (30%): 69 were deceased (47%), 19 were ineligible because they did not live with or had not seen their child in the past month (13%), 22 declined (15%), three were initially reached but unreachable during the interview period (2%), and 33 agreed to participate (22%). There were no differences between participants and non-participants on demographic and health variables. In the 33 families, 27 children (9- to 17-years old) and 19 adult children ( $\geq 18$ -years old) were interviewed (including 14 siblings). Youth were eligible if they knew their parent's HIV status. Children's HIV-status was not obtained. Adults provided written consent, parents provided written permission for minor children, and youth provided written assent. UCLA and RAND Corporation IRBs approved the study.

Socio-demographic data were drawn from baseline HCSUS and the interview. Seventy-three percent of parents were mothers. Parents' mean age was 44 years (range 30–62 years). Youth's mean age was 13.9 years (range 9–17 years); 63% were male. The mean age of adult children was 21.5 years (range 18–30 years) and 58% were female. Other characteristics appear in Bogart et al. (2008) and Cowgill et al. (2008).

The interview protocol was informally reviewed by parents with HIV and researchers and then pilot tested. Parents were asked what they think their children know about how people get HIV (including if they talked about this topic), whether they made an extra effort to talk about HIV risk with their children, and whether they find it difficult to talk about HIV risk and prevention with their children. Children, including adult children, were asked if they talk to their parent with HIV, their siblings, or others about the parent's health or HIV.

Children were also asked how people get HIV. Youth were screened to ensure that they were aware of their parent's HIV status (see Bogart et al., 2008; Cowgill et al., 2008). All youth indicated that they knew of their parent's HIV infection. Interviews were audiotaped and conducted separately from one another in a private location. Interviews lasted about 1.5 hr with parents, and 1 hr with children. Interviewers had advanced clinical degrees; were trained and supervised to maintain interview integrity across participants and; had no prior relationship with participants.

### *Data Analysis*

A qualitative data analysis program (*ATLAS/ti*) was used to link themes to the text. Following a content analysis protocol (Bernard, 2002), a set of codes was created and systematically applied to the narratives. A team member initially read through a sample of transcripts to identify text related to discussions about HIV prevention, risk behaviors, and transmission. Two coders were given a basic operational definition of these types of discussions (based on prior literature and transcripts), and asked to identify all such text. The coders then categorized quotations based on the themes and related sub-themes identified through the prior analysis; sub-themes were mutually exclusive (Bernard, 2002). Two new team members examined the codes, suggested revisions, and resolved disagreements between coders. Cohen's Kappa (Cohen, 1960), used to check consistency between coders, was  $> .95$  for all themes. Quotations were categorized by participant group, parent gender, and race/ethnicity to compare these groups.

## Results

Three themes emerged: comfort, risk behaviors/prevention, and transmission. Comfort included two process sub-themes: openness and discomfort. Risk behaviors/prevention included two process themes (sharing personal information and warnings; lessons drawn from the parent's experience) and one content theme (protection). Table 1 shows frequencies and percentages of themes/sub-themes by participant group and racial/ethnic group.

*Process themes:* (a) *openness*—family members who reported feeling comfortable talking with each other about HIV described a close relationship and an open conversation style. Comfort increased over time as parents talked more with youth, and as youth grew older. Openness was most frequent among White than other families. (b) Parent's reasons for *discomfort* included a concern

**Table I.** Frequencies and Percentages of Themes/Subthemes that Emerged from a Qualitative Analysis of Discussions about HIV among Parents with HIV and their Families ( $n = 79$  participants across 33 families)

	Comfort $n$ (%)		Prevention and risk behaviors $n$ (%)			HIV transmission $n$ (%)
	Openness	Discomfort	Sharing personal information and warnings	Lessons drawn from the parent's experience	Protection	
Parents ( $n = 33$ )	20 (61)	17 (51)	17 (51)	17 (51)	16 (49)	24 (73)
Mothers with HIV ( $n = 24$ )	15 (63)	13 (54)	11 (46)	11 (46)	11 (46)	16 (67)
Fathers with HIV ( $n = 9$ )	5 (56)	4 (44)	6 (67)	6 (67)	5 (56)	8 (89)
Children under 18 ( $n = 27$ )	16 (59)	17 (63)	13 (48)	7 (26)	13 (48)	18 (67)
Adult children ( $n = 19$ )	10 (53)	16 (84)	9 (47)	15 (78)	8 (42)	16 (84)
Race/ethnicity (does not include one family that was of American Indian descent)						
African American ( $n = 16$ )	12 (75)	13 (81)	12 (75)	7 (44)	9 (56)	15 (94)
White ( $n = 9$ )	9 (100)	8 (89)	8 (89)	5 (56)	6 (67)	8 (89)
Latino ( $n = 7$ )	5 (71)	5 (71)	6 (86)	4 (57)	5 (71)	6 (86)

about a child's ability to understand and cope with the parent's illness; youth worried about upsetting their parents or reminding their parent about their HIV infection. Siblings generally did not talk to each other about HIV because they worried about upsetting the sibling or a younger sibling unintentionally disclosing the parent's illness to others. Discomfort emerged more frequently among adult children. (c) *Sharing personal experience and warnings*—parents shared personal information and warned youth about unsafe sexual practices and drug use so their children would not “make the same mistake” they made. When parents shared personal information, some youth felt comfortable talking to their parents and asking questions. Others reacted negatively to the perceived inconsistency between parents' past behavior and current prevention messages. This sub-theme was more frequent with fathers than mothers. (d) *Lessons drawn from the parent's experience*—watching parents take medication, hospitalizations, and accompanying parents to medical visits reinforced HIV prevention messages for youth. This sub-theme was less frequent in child than adult child interviews and among mothers than fathers.

*Content themes:* (a) *protection*—Parents emphasized the importance of practicing safe sex, provided youth with information regarding contraception, and noted the importance of knowing sexual partners. In some families, parents provided youth with contraception or reviewed how to use a condom. Parents and youth noted that discussions about HIV prevention happened when youth started dating or were involved in relationships. When discussions with siblings did occur, they focused on prevention or the parent's health. Sibling communication depended on factors such as similarity in age or gender, living together, and knowledge of parental HIV status. (b) *HIV transmission*—youth reported learning from

parents, other adults, and peers that HIV was transmitted by sharing needles when using drugs, exchanging blood, or sexual intercourse. Some parents had to clarify or correct information children learned from school or their friends regarding the transmission of HIV. Transmission discussions were more frequent among fathers than mothers.

## Discussion

The field of parent-child communication about HIV has grown substantially over the past decade (DiIorio et al., 2003) yet gaps remain. For example, only one study has examined parent-child discussions about HIV in families of parents with HIV (O'Sullivan et al., 2005). The findings from this qualitative study provide new information about the process and content of HIV-related communication in families of parents with HIV and also suggest future areas for research.

Although prior work has demonstrated that parents and youth may feel uncomfortable talking with one another about HIV-related topics (DiIorio et al., 2003), the reasons youth in this study gave for this discomfort (i.e., worry about upsetting parents or reminding parents of their HIV-status) are unique to living with a parent with HIV. What remains unanswered is whether parents with HIV and their children feel more/less comfortable discussing some topics (e.g., the parent's health, how to use a condom) than others (e.g., going on dates, protection). Researchers should further examine whether parent and/or child gender moderate the associations between content and comfort. Finally, researchers should better understand how youth's experiences living with a parent with HIV may shape their sexual attitudes and behaviors. We found that youths' observations of their parent's fluctuating health,

hospitalizations, and medication regimens served as reminders to avoid risky behaviors. Quantitative research should explore whether there is an association between parent-child discussions and youth sexual behavior and whether this relationship is mediated by youths' experiences living with a parent with HIV.

No studies have examined sibling communication about HIV in families of parents with HIV yet siblings are often present during parent-child discussions about HIV (O'Sullivan et al., 2005). In this study, few siblings talked to one another about HIV because they worried about upsetting their sibling and their sibling unintentionally disclosing the parent's illness to others. Youth's concerns about accidental disclosure may be related to worries about stigma, highlighting an area of future research. Few studies have examined children's experience of stigma related to their parents' HIV (Bogart et al., 2008) and no studies have examined how stigma experiences affect parent-child or sibling discussions about HIV. For example, do children's experiences of stigma mediate parent-child (or sibling) discussions about HIV in families of parents with HIV?

This qualitative study has some limitations. Participants were drawn from a larger sample of parents receiving care for HIV as of 1995 and may not be representative of all parents living with HIV. Additionally, the families that were not reached may have had less stable living situations than participating families, and these experiences may affect communication patterns and processes. Finally, data on the sero-status of children was not collected yet it is possible that some children were also infected and that their sero-status affected parent-child discussions about HIV. Nevertheless, this study provides new information about the content and process of HIV-related discussions and the importance of obtaining reports from multiple family members.

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