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Facilitators and Barriers to Discussing HIV Prevention with Adolescents: Perspectives of HIV-Infected Parents

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Abstract

Objectives—We examined HIV-infected parents’ conversations about HIV prevention with their uninfected children, including what facilitated or hindered communication.

Methods—Parents with HIV/AIDS ($n=90$) who had children aged 10 to 18 years were recruited for a mixed method study from 2009 to 2010. Interviews assessed facilitators and barriers to discussing HIV prevention. A questionnaire identified the frequency and content of conversations, parental confidence level, and perceived importance of discussing preventive topics.

Results—Eighty-one percent of parents reported “sometimes” or “often” communicating about HIV prevention. A subset of parents found these conversations difficult; 44% indicated their desire for support. Facilitators to communication included utilizing support, focusing on the benefits of talking, and having a previous relationship with one's child. Barriers to discussions included fear of negative consequences, living in denial, and lacking a parental role model who discussed safer sex. Parents varied as to how they believed their HIV status affected communication. Those who did not disclose their HIV status to their children reported less frequent communication; self-efficacy partially mediated this relationship.

Conclusions—Findings highlighted the need for communication skills training that support HIV-infected parents in their efforts to discuss HIV-related information with adolescents.

Parent–child communication about sexual behavior has been associated with a range of protective behaviors in American youths, including later onset of sexual activity,^{1–3} greater likelihood of using contraceptives,^{4–7} less chance of pregnancy,^{7,8} and a decreased risk of

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Contributors

L. Edwards and J. Reis were involved in study design, data collection and analysis, and writing of the article. K. Weber contributed to the study design, data collection, and writing of the article.

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Human Participant Protection

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HIV transmission.^{9,10} The role of communication about sexual activity may be particularly important for children living with an HIV-infected parent. Some studies report that adolescents living with an HIV-infected mother initiate sex at a younger age,^{11–13} have more sexual partners,¹¹ report riskier sexual behavior,^{11–13} and have a higher rate of early childbearing.¹⁴ Other studies find that these adolescents have greater intentions to abstain from sex,¹³ less sexual risk behavior,¹⁵ and that HIV status may not contribute any unique risk or benefit to adolescent HIV risk.^{16–18} Given this paradoxical evidence and the lack of a systematic review on this topic, more information is needed on parent-child communication in families where 1 or more parents are HIV-infected.

In the broader realm of family interaction, factors that generally facilitate communication include parental knowledge, communication skills, confidence, and comfort discussing sexual topics,^{19–23} beliefs that one's child is ready to learn about sex,^{21,24} and perceptions that talking will have positive consequences for parents and for youths.^{23,25} Although previous studies have queried HIV-infected parents on whether they discussed safer sex and HIV prevention with adolescents,^{13,26–30} the content^{13,26–30} and context of such talks,²⁷ their perceived conversational outcomes^{27,30} and comfort level,^{27,28} and what role their HIV status played in these discussions,^{13,30} no study has focused on factors that encourage or prevent parents from broaching these important topics.

We summarized HIV-infected parents' perceived facilitators and barriers to communicating with adolescent children about ways to prevent HIV infection. Because disclosure of HIV status,²⁷ child age,^{21,23} and parent and child gender^{21,23} were associated with the frequency and content of preventive parent-child conversations, we also examined these factors. Parents' qualitative feedback on facilitators and barriers was put in the context of 4 quantitative dimensions known to be influential in parent-adolescent communication. Juxtaposition of these quantitative measures against parents' personal descriptions of what they find helpful in talking about HIV prevention with their children provided a more complete understanding of family communication,^{31–33} and therefore, ways that prevention programs might be tailored to better support HIV-infected parents.

METHODS

Participants were a convenience sample of HIV-infected parents living in the Midwest who self-reported a diagnosis of HIV or AIDS, having a child aged 10 to 18 years infected with HIV, and living with or having frequent visits (an average of 14 days/month) with their adolescent for the past year. One parent from each family consented and participated in the study; children were not interviewed. Parents with children as young as 10 years were included because of less frequent reports of sexual communication at early ages.^{23,34} Because African Americans and Latinos are disproportionately affected by HIV/AIDS, race/ethnicity was assessed.³⁵

Recruitment took place from 2009 to 2010 via study fliers placed in participating public health departments, HIV/AIDS organizations, and university hospitals or clinics. Eligible mothers were also recruited from a research cohort of HIV-infected women by telephone contact. Of the 116 parents who expressed interest in participating, 90 met the eligibility criteria and completed the study. Interviews took place in private rooms in parents' homes, medical clinics, and HIV-related organizations, and lasted approximately 1.5 hours. During this time, parents completed a family tree (15 minutes), an in-depth interview (1 hour), and a structured questionnaire (15 minutes). Parents were told their responses would be confidential and received \$30 compensation for their time.

Interview and Questionnaire Data

Interview data examined parents' underlying rationale for talking about HIV prevention, what facilitated or hindered communication, and what impact (if any) they felt their HIV status had on HIV-related talks. A life span interview approach was used, with parents reporting on their cumulative experiences discussing HIV-related topics with each of their adolescents.^{36,37} Interviews were audio-recorded, transcribed, and analyzed using qualitative data analysis software (NVivo).³⁸

The questionnaire included demographic characteristic information, an item assessing whether parents had disclosed their HIV status to “none,” “some,” or “all” of their children,³⁹ and 3 scales measuring the overall frequency, content, self-efficacy, and perceived importance of parent–adolescent communication about HIV-related topics. Scales were adapted from measures of sexual communication in the broader parent–adolescent population because of a lack of validated scales for HIV-infected parents.¹³ Final measures were reviewed by HIV content professionals and experts in behavioral research and instrument design; they were then pilot tested on 5 HIV-positive parents. A description of each scale is provided in the following (see Edwards⁴⁰ for detailed study methodology and measures).

Frequency and content—These dimensions were assessed using a modified version of the Parent–Adolescent Communication Scale.⁴¹ The original scale (Cronbach α |=|0.88–0.90) included 5 items on how often parents and adolescents talked about sex, condoms, sexually transmitted diseases, HIV/AIDS, and pregnancy in the past 6 months. Response options ranged from 1 (“never”) to 4 (“often”). Four items were added to assess communication about drug use, sexually transmitted disease testing, HIV testing, and parental HIV/AIDS status. The modified (9 item) version of the scale had high internal reliability in this sample (α |=|0.94). These items also formed the basis for the self-efficacy and perceived importance scales.

Self-efficacy—This scale assessed how confident parents were discussing the 9 content items with their adolescent(s). Wording and response options were created to be congruent with previous measures of parental self-efficacy about sexual communication.⁴² Item responses ranged from 1 (“not sure at all”) to 4 (“completely sure”) that parents could talk about the various topics (α |=|0.91).

Perceived importance—The perceived importance scale assessed how much parents wanted their adolescents to know about the 9 content items (α |=|0.92). Item responses ranged from 1 (“not at all important”) to 4 (“very important”).

Qualitative and Quantitative Analyses

Initial coding proceeded using a grounded theory approach, a systematic method for identifying recurring themes.⁴³ Approximately 25% of the transcripts were coded by 4 coders to generate a comprehensive list of barriers and facilitators identified by parents; these codes were then grouped into larger themes. Codebooks were created for each theme, including the code definition, when to use versus not to use the code, and example quotes.⁴⁴ One coder returned to the transcripts and analyzed all 90 according to the codebook definitions. Interrater reliability checks were performed by a faculty expert on a random 10% of examples in each code. Frequencies for themes were tabulated, and Cohen's κ ⁴⁵ was calculated at 90% or greater for all themes.

Data were compared by race/ethnicity, parent and child gender, child age, time since parent's HIV diagnosis, and HIV disclosure. The impact of having both HIV-positive and HIV-

negative children on parent's communication about HIV was also analyzed. Pearson's χ^2 test or Fisher's exact test was used to compare categorical variables on disclosure to children. The independent *t*-test was used to compare dichotomous variables (including parental facilitators, barriers, and being HIV positive) on HIV-related communication scales. The Kruskal–Wallis test was used to examine associations between child gender, child age, self-efficacy, and importance; an analysis of variance was used to examine associations between disclosure and frequency. Mediation analysis was conducted to determine the relationship between disclosure, self-efficacy, and frequency of communication.⁴⁶

RESULTS

Parents' mean (SD) age was 45.5 (7.6) years. More than 90% had been living with HIV/AIDS for at least 5 years, with an average time since diagnosis of 12.6 (5.5) years. Most were mothers (69%), African American (77%), and had a high school education or less (90%). Collectively, these parents cared for 317 children, with a mean of 3.6 children per family (range=|1–9). Of the 317 children, 155 were HIV-negative adolescents aged 10 to 18 years.

Most parents (80%) lived with their adolescent(s). There were slightly more female adolescents (54%) than male adolescents, with a mean age of 14.6 (2.5) years. Almost 8% of parents also had an HIV-positive child (6% infected by childbirth and 2% by the child's own sexual risk behavior). Demographic characteristic information is shown in Table 1[[ID](#)][[TBL1](#)][[/ID](#)].

HIV Prevention Communication

Parents reported moderate to high levels of communication with adolescents about HIV-related topics (mean 27.2 [7.9], range=|9–36). Most reported that they sometimes or often talked about sex (86%), drugs (78%), condoms (67%), and protection from sexually transmitted diseases (82%), AIDS (81%), and pregnancy (77%). Similarly, many parents (|80%) felt confident they could discuss these various topics with their adolescent(s).

Parents also reported high levels of perceived importance of HIV prevention communication (mean 34.9 [3.1], range=|12–36). The majority (|90%) reported that it was very important to them that their adolescent(s) know about prevention-related content. Table 1 presents communication variables stratified by parent and child demographic characteristics. Of special note, no parent or child gender differences were found in terms of frequency, self-efficacy, or perceived importance of talking about HIV prevention. Significant differences were found for HIV disclosure status (parents with older adolescents [χ^2]=|6.40; *df*=|2; *P*=|.041] or those who also had an HIV-positive child [χ^2]=|4.39; *df*=|1; *P*=|.036] were more likely to disclose to all of their children), for frequency (parents with older adolescents were more likely to report frequent communication: [$F_{(2,87)}$]=|3.57; *P*=|.032]), and for self-efficacy (parents who had been HIV-positive |6 years reported greater confidence discussing HIV-related topics [t_{17}]=|3.40; *P*=|.003]).

Facilitators of Communication

The 3 most frequent facilitators of HIV-related conversations included (1) utilizing support, (2) focusing on the benefits of communication, and (3) having a previous relationship with one's child. Example quotes are shown in Table 2[[ID](#)][[TBL2](#)][[/ID](#)].

Utilizing support—Parents relied heavily on social and informational support to help make communicative interactions more manageable. Social support was provided by family members, friends, health care providers, therapists, and church personnel. Levels of support

ranged from completely relying on others (to communicate for them) to merely having another person present during conversation. HIV support groups led to several opportunities to discuss HIV and prevention in a supportive environment. Parents were also assisted by various types of informational resources, including books, pamphlets, brochures, television, radio, and the Internet.

Focusing on the benefits of talking—Many parents believed it was easier for them to talk about HIV if they focused on the potential benefits of open communication. Benefits especially salient in this sample were (1) the desire to protect one's child (from harm or from misinformation), and (2) fulfilling one's parental duty (by having conversations that fostered adolescent well-being). Parents expressed a deep desire to protect their children from HIV infection, along with the hope that circumstances would be “different” for their children than it had been for them.

Having a previous relationship with one's child—Parents felt it was easier to establish supportive relationships with adolescents in general before moving on to sensitive topics. Once broad communication patterns were established, specific conversations about sex, drug use, and HIV became less difficult. This focus on establishing close relationships was especially salient for parent-child relationships that were disrupted by absence or substance abuse.

Barriers to Communication

The 3 most frequently reported barriers to conversation were (1) fear and focusing on disadvantages, (2) living in denial, and (3) lacking a communicative role model. Example quotes for these themes are shown in Table 3[ID]TBL3[ID].

Fear and focusing on disadvantages—Parents expressed fears of the unknown situations or topics that might arise if they talked about HIV with their children. Three fears were especially prominent: (1) concern for the welfare of their child, (2) fear of damaged self-image, and (3) fear of awkward conversations. These parents feared that information shared during prevention conversations, including disclosing their HIV status, might worry their children or place an unnecessary burden on them. Parents also explained the tension between wanting to use their personal experiences (e.g., previous risky sex or drug use) as a learning tool for adolescents, yet worrying that revealing such information could portray them in an unfavorable light. Conversations about parents' past experiences brought up isolated instances of HIV risk behavior and also brought up deeper family issues like sexual abuse, extramarital affairs, and sexual orientation. Parents were not sure they knew how to best explain these complicated and often uncomfortable topics.

Living in denial—A number of parents viewed denial as a barrier to having productive HIV-related conversations with adolescents. Living in denial was defined as a parent's inability or difficulty accepting reality, usually in terms of their HIV status or related risk behaviors. Parents emphasized that it was important to have time to cope with their diagnosis before sharing information about prevention with their families.

Lacking parental role model—Most parents (78%) were unable to recall a parent or guardian who talked to them about sex or prevention of sexually transmitted infections. More than 20% of parents reported that lacking a role model who talked about sex contributed to their own difficulty conversing with adolescents about sexual activity. Although parents generally felt the current generation was more open about topics like safe sex and HIV/AIDS, it was difficult to let go of the contexts they were raised in and embrace a more open approach to conversation.

Role of Parental HIV Status and Disclosure

Being HIV-positive—Approximately one third of parents spontaneously brought up their HIV status as either a facilitator (27%) or barrier (7%) to HIV-related talk. When specifically asked how their HIV status affected parent–adolescent communication about HIV prevention later in the interview, 59% of parents reported their status made HIV-related conversations easier, 28% believed their HIV status did not affect these discussions, and 13% thought it made them harder.

Parents who viewed their HIV status as a facilitator believed being HIV-positive helped conversations because (1) they were more aware of the risks of contracting HIV, (2) they had better quality knowledge to share with their children (as a result of living with HIV infection themselves), and (3) HIV was more visible in their everyday lives and thus more likely to emerge as a topic of conversation.

Parents who viewed their HIV status as a barrier felt HIV-related conversations were more complicated because (1) they felt compelled to explain HIV in more detail, (2) conversations could end up focusing on their own status, and (3) they believed their children might not understand the information, already had negative attitudes about HIV, or would react negatively to HIV-related discussions. Example quotes from parents who reported their HIV status as a facilitator versus a barrier are shown in Tables 2 and 3, respectively. Parents who believed their HIV status made preventive talks easier reported more frequent HIV-related conversations and higher self-efficacy (Table 4[*ID*]TBL4[/*ID*]).

HIV disclosure—Over half (63%) of parents reported disclosing their HIV status to all of their children, 20% to some, and 17% reported that none of their children knew. Parents who did not disclose their HIV status to all of their children reported less frequent communication about HIV prevention with adolescents ($F_{(2,87)}=5.73$; $P=.005$); self-efficacy only partially mediated this relationship. Parental disclosure was not related to the content discussed or to parents' perceived importance of talking about HIV prevention.

Finally, few differences emerged between disclosure status and parents' reported facilitators and barriers to preventive conversations. Parents who did not disclose their HIV status to all of their children were more likely to report lacking a parental role model who communicated about sexual topics ($\chi^2=4.67$; $df=1$; $P=.031$) and to view their HIV status as either not affecting HIV prevention conversations or making conversations more difficult ($\chi^2=14.06$; $df=1$; $P=.001$; Table 4). Parents who reported focusing on the benefits of talking reported higher self-efficacy ($t_{88}=2.23$; $P=.028$) and perceived the importance of HIV-related talks ($t_{56}=2.85$; $P=.006$).

DISCUSSION

This study provided new information about what helped and prevented HIV-infected parents' from engaging in preventive conversations with youths. Our findings added to previous estimates that 48% to 95% of HIV-infected parents discussed preventive topics with their uninfected children^{27,30} and provided the first descriptions of such discussions in the central United States. In addition, we offered insight on the role of fathers and examined how HIV disclosure might affect parent-child talks.

In response to the quantitative scales, parents reported communicating frequently about prevention, believed parent-child discussions were vital to adolescent health, and were generally confident they could talk to their children about prevention-related content. During the qualitative interviews, however, a more nuanced picture of family communication emerged. Even parents who reported frequent talks in the past 6 months by questionnaire

described factors that hindered their communicative efforts across various times. These data were consistent with previous studies indicating that at least a subset of HIV-infected parents found preventive conversations difficult; such parents expressed fears that their children would react negatively to conversations and might be less likely to initiate discussions if they had younger adolescents (10–13 years old) or had not disclosed their HIV status to their children.^{27,30} In addition, parents in our sample reported communication challenges that arose from personal difficulties accepting their HIV status and from lacking a parent who talked to them about sexual health. These barriers have not yet been reported in the literature on HIV-infected parents.

No data currently exist on the extent to which HIV-infected parents desire or rely upon support when discussing preventive topics with their families, although 44% of the parents in our sample emphasized the importance of social, informational, and professional support in making HIV-related conversations more manageable. In line with previous research, our findings indicated that parents would be appreciative of programs that are sensitive to how living with HIV/AIDS might affect family communication dynamics.³⁰ Most parents in our study believed their HIV status had a positive impact on HIV-related discussions with their children. Those who believed their HIV status facilitated conversations reported more frequent discussions and greater confidence discussing sexual health. A programmatic focus on fostering a positive parental self-image and highlighting how living with HIV might provide constructive opportunities to educate family members about sexual safety (e.g., more opportunities to discuss prevention, the ability to share firsthand knowledge) is recommended.

The role of parental HIV disclosure was examined in 1 previous study, which also found that mothers of children who knew their HIV status were more likely to report frequent talks about HIV.²⁷ Our study extended this finding by indicating that parents who did not disclose their status to all of their children might have lower confidence in their ability to talk or less opportunity to talk about prevention in a family context. Because most of the preventive conversations take place at home with siblings present,²⁷ guidance from practitioners might be needed to help parents employ alternative, effective strategies for communicating with children of different ages, different levels of knowledge about HIV infection, and different stages of awareness of their parent's HIV status.⁴⁷

Although mothers are often regarded as the primary source of sexual health information for adolescents,⁴⁸ we found no differences in communication by parent or child gender. This child gender finding was similar to 2 previous studies.^{27,29} The only other study to include HIV-infected fathers also indicated fathers were active in providing preventive information.²⁸ It might be that the salience of HIV in HIV-infected fathers' lives overcomes more traditional barriers that might prevent fathers from discussing sexual topics with their children. These preliminary findings indicated a need for further research on fathers and future programs that both encourage fathers to communicate and provide them with guidance on how to do so effectively.

Limitations

Although our findings offered a deeper understanding of HIV-related communication between HIV-positive parents and their children, they must be taken in context. The viewpoints of a convenience sample of predominantly African American parents who were living with HIV infection for a number of years might be unique within the overall population of HIV-infected parents. Future studies with larger samples are needed for more complex quantitative investigations; however, our data indicated that parental HIV disclosure, child age, having an HIV-positive child, length of time since HIV diagnosis, and parental beliefs about the role of their HIV status in preventive conversations merit further

study. Because this research relied on parental self-report, future work should also investigate adolescent or dyadic reports of HIV-related conversations, including how communication might vary by child in families with multiple adolescents. Finally, we did not assess other protective parenting practices like parental monitoring or supervision, parenting style, or overall quality of the parent-adolescent relationship, which are known predictors of adolescent risk-taking behavior.^{20,49,50}

Conclusions

Looking toward implications for the future, our data suggested that existing HIV prevention programs could be effectively tailored to meet the needs of parents living with HIV/AIDS, and that current HIV care programs could benefit by increasing their focus on prevention communication within families. Some of the facilitators cited by parents in this study were already components of existing HIV prevention interventions^{20,51} and had a strong theoretical basis in the health behavior, family studies, and communication literature.^{25,52,53} Despite the substantial day-to-day challenges HIV-positive parents face, most reported they would be open to receiving preventive communication training and would welcome attention from HIV care professionals with regards to their parenting concerns. Given the recent success of HIV disclosure programs in increasing parental disclosure to adolescents,⁵⁴ programs that also seek to either begin or maintain this communication in the form of preventive conversations with youths hold promise for future investigation.

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TABLE 1
 HIV-Related Communication Scales by Sample Characteristics: Midwest United States, 2009-2010

| Characteristic | Full Sample, No. (%) | Disclosure to Children | | HIV-Related Communication ^a | | |
|------------------------------|----------------------|------------------------|------------------------|--|--|---|
| | | None/Some, No. (%) | All, No. (%) | Frequency, No. (Mean) | Self-Efficacy, No. (Mean or Median) ^b | Importance, No. (Mean or Median) ^b |
| Race/ethnicity | | | | | | |
| [em]s[African American | 69 (76.7) | 25 (75.8) | 44 (77.2) | 69 (27.3) | 69 (31.4) | 68 (34.9) |
| [em]s[Other | 21 (23.3) | 8 (24.2) | 13 (22.8) | 21 (27.0) | 21 (31.6) | 21 (34.8) |
| Gender of parent | | | | | | |
| [em]s[Female | 62 (68.9) | 22 (66.7) | 40 (70.2) | 62 (27.2) | 62 (31.2) | 61 (35.0) |
| [em]s[Male | 28 (31.1) | 11 (33.3) | 17 (29.8) | 28 (27.3) | 28 (31.8) | 28 (34.6) |
| Gender of children | | | | | | |
| [em]s[Female only | 38 (42.2) | 15 (45.5) | 23 (40.4) | 38 (27.3) | 38 (33.5) | 38 (36.0) |
| [em]s[Male only | 26 (28.9) | 9 (27.3) | 17 (29.8) | 26 (26.5) | 26 (33.5) | 25 (36.0) |
| [em]s[Mixed | 26 (28.9) | 9 (27.3) | 17 (29.8) | 26 (27.9) | 26 (34.0) | 26 (36.0) |
| Age of children ^c | | | | | | |
| [em]s[Younger (10-13 y) | 22 (24.4) | 11 (33.3) [*] | 11 (19.3) [*] | 22 (23.5) ^{***} | 22 (31.5) | 21 (36.0) |
| [em]s[Mixed (10-18 y) | 25 (27.8) | 12 (36.4) [*] | 13 (22.8) [*] | 25 (27.9) [*] | 25 (33.0) | 25 (36.0) |
| [em]s[Older (14-18 y) | 43 (47.8) | 10 (30.3) [*] | 33 (57.9) [*] | 43 (28.7) ^{**} | 43 (34.0) | 43 (36.0) |
| Also has HIV-positive child | | | | | | |
| [em]s[Yes | 7(7.8) | 0 (0) [*] | 7 (12.3) [*] | 7 (28.0) | 7 (34.4) | 7 (34.6) |
| [em]s[No | 83 (92.2) | 33(100) [*] | 50 (87.7) [*] | 82 (27.2) | 83 (31.1) | 82 (34.9) |
| Years living with HIV | | | | | | |
| [em]s[0-5 | 8 (8.9) | 5 (15.2) | 3 (5.3) | 8 (31.6) | 8 (34.8) ^{**} | 8 (35.8) |
| [em]s[>6 | 82 (91.1) | 28 (84.8) | 54 (94.7) | 82 (26.8) | 82 (31.1) ^{**} | 81 (34.8) |

^a Possible scores on each scale ranged from 9 to 36.

^b Mean values for all characteristics except child gender and child age (median values are reported for these).

^c Analysis of variance post hoc least-significance difference tests showed significant differences in frequency between parents with younger vs mixed age children ($P=|.05$) and between parents with younger vs older children ($P=|.01$). Parents with mixed aged vs older children did not differ significantly on frequency scores.

* P | $.05$

** P | $.01$.

TABLE 2
 Themes and Example Quotes for Facilitators of Communication: Midwest United States, 2009-2010

| Facilitator | Informant or Parent | Example Quotation |
|---|---------------------|---|
| Utilizing support | | |
| [ems]Supportive others (family, friends, health care providers) | Mother | It comes much easier when I'm with my sister, because when I was coming up, she was always there for me, and she told me a lot. When I'm with her and we talk to my kids, it just comes out—I'm comfortable. I don't sugar-coat nothing. I just tell them. . . . I've always had my family's (support). |
| [ems]Supportive resources (media, educational materials) | Mother | One day we were in the car. We were coming from church, and we were listening to the radio, and there was something on about it (HIV), so I just went on and told 'em. . . . My son asked "How do you get HIV?" I said, "Through sharing needles with drug users and through sex." And I just told him that I was HIV positive. It was already on the subject, so I just told him. |
| Focusing on benefits of communication | | |
| [ems]Protecting child | Mother | I don't find it hard (to talk) because when I look at it like "well I might have to be the person to save this person's life," in one way or another it makes it a whole lot easier. |
| [ems]Fulfilling parental duty | Father | To impart a lot of the knowledge that I have on my child, I feel that is my duty |
| Having previous relationship with child | Father | At that age (early adolescence), they got to be well-disciplined. Parents in their life. . . whatever they are doing, the parents do it with them. That makes a difference. . . those kids' have a better chance of not getting this virus. Because they're gonna tell them about it. They're gonna take them places. They're gonna do things with them. |
| Being HIV+ | | |
| [ems]Heightened risk awareness | Mother | I don't know if I would have talked to them about the disease if I had not been positive. But becoming positive made me be conscious of the danger of it, because even though we all know about the disease, knowing about it is different than living with it. So that made me be more cautious. . . . I would talk to them because I became very aware. |
| [ems]Better knowledge | Mother | If the person is living with the HIV disease, I think that they have more knowledge. . . . They're coping with it so they know how it feels to live everyday with the disease. And I feel that they can share their experience, what they know about it. You know, symptoms, the different things that you go through. So I think it does create room (to talk). |
| [ems]Visibility of illness | Mother | (It's easier to talk) because they've seen it first-hand. . . . They've seen Timmy (their stepdad who passed away from AIDS complications recently) being (sick). . . . It was all there for them to see. They could see the different mood swings. . . all these doctor visits. (They'd ask) "Why do you have to get all that blood drawn?" You know, they saw me go through that. So yeah, it made it easier to talk about. |

TABLE 3
 Themes and Example Quotes for Barriers to Communication: Midwest United States, 2009-2010

| Barriers | Informant or Parent | Example Quotation |
|------------------------------------|---------------------|--|
| Fear and focusing on disadvantages | | |
| [em]s[Concern for welfare of child | | Well my fear is that I don't want to worry them. . . . kids are good like that. . . I don't care how horrible of a parent you are, they still have this inability to just forgive and love. . . . So it's hard for me to deal with just scaring the mess out them. And I know this is an issue that people who are educated in HIV and AIDs still fear. . . . To put that (HIV) on your kids with all the extra things that they go through: peer pressure, things like that. It's just unbearable to think of. It's just one added thing for them to go through. And I wouldn't wish that on any kid. |
| [em]s[Fear of damaged self-image | Father | I think (it's hard) because they (parents) are not open with their children. The reason I say that is because some parents may think their kid may shun them. So they don't want to be ostracized by their kid. |
| [em]s[Awkward conversations | Father | I guess it's (hard because) it's just uncomfortable dealing with the issue of sex with your own children. At least that's the biggest part for me. . . . I think it's just uncomfortable for a lot of parents to talk to their kids about sex—they don't want to talk to them. |
| Living in denial | Mother | Well first of all the parents have to be comfortable with themselves. They need to not be in denial. . . . Because, see, in the beginning I wasn't like that. I couldn't stand the fact that the illness was running through my veins and I hated it. I was ashamed of it—I thought it was dirty. I thought people were gonna reject me. But once I learned about the illness and once I was going to support groups and taking care of myself I didn't care what people thought. I just knew I needed to take care of myself. I think you have to get there before you can go any further. |
| Lacking parental role model | Mother | Well to tell you the truth, the way I was raised and the way I raised my kids, you were told "this is bad, this is good, this you don't do." So there's never any reason to have to talk about it because I've explained to you "this is a no-no." If (only) my parents had been able to talk with me and express with me about it before. . . . because the questions that baby asks me, we would get popped in the mouth for. And it's really hard to communicate when you got everything set up as "this is bad. |
| | Father | We don't talk about. . . .sexuality or drugs until the blister bursts and we're ready to discuss everything about it—or go into denial. I think maybe parents just want to give you a book to read, or let society teach you. It's not a societal issue though. . . . In my own home we didn't discuss a lot of things, especially sexuality and my being bisexual. . . . It was like "We're just going to ignore that." |
| Being HIV-positive | Mother | It's harder (because) you've got to explain it in more detail. . . . I had a lot of rebellious kids when I did say something about it. We just went through so much with it, because there was a lot of rebellion and (a lot of) "You're dying anyway and nobody is going to be with us" when conversations about HIV came up. Then eventually, after we went through all of the storms, we were closer. We're real close now. |
| | Mother | It's harder because I just don't want them to know, period. . . . I just don't want them know that I'm HIV positive. |
| | Father | I just tell them "be careful." It's hard because I don't use myself as an example (I don't tell them that I have HIV). |
| | Mother | (It's harder) because they have a negative attitude toward HIV+ people. . . . the kids do. . . . they have made little (HIV-related) cracks. |

TABLE 4
Parental Facilitators and Barriers by HIV-Related Communication Measures: Midwest United States, 2009-2010

| | Full Sample (n =90), No. (%) | Disclosure to Children | | Frequency (n =90), No. (Mean) | Self-Efficacy (n =90), No. (Mean) | HIV-Related Communication ^d Importance (n =90), No. (Mean) |
|--|------------------------------|----------------------------|-------------------------|-------------------------------|-----------------------------------|--|
| | | None/Some (n =33), No. (%) | All (n =57), No. (%) | | | |
| Facilitators | | | | | | |
| [ems]Utilizing support | 40 (44.4) | 16 (48.5) | 24 (42.1) | 39 (28.4) | 39 (31.9) | 39 (35.5) |
| [ems]Focusing on benefits of talk | 37 (41.1) | 12 (36.4) | 25 (43.9) | 36 (28.5) | 36 (33.0) ^{**b} | 36 (35.8) ^{**c} |
| [ems]Previous relationship with child | 20 (22.2) | 10 (30.3) | 10 (17.5) | 19 (28.0) | 19 (32.8) | 19 (34.8) |
| Barriers | | | | | | |
| [ems]Fear/focus on disadvantages | 27 (30.0) | 12 (36.4) | 15 (26.3) | 26 (26.8) | 26 (31.8) | 26 (35.1) |
| [ems]Living in denial | 20 (22.2) | 6 (18.2) | 14 (24.6) | 19 (27.8) | 19 (33.1) | 18 (35.7) |
| [ems]Lack parental role model | 19 (21.1) | 11 (33.3) [*] | 8 (14.0) [*] | 18 (26.2) | 18 (31.7) | 18 (35.4) |
| Being HIV-positive | | | | | | |
| [ems]Makes talk easier | 53 (58.8) | 11 (33.3) ^{**} | 42 (73.7) ^{**} | 53 (28.9) [*] | 53 (32.4) [*] | 53 (34.9) |
| [ems]Makes talk harder/does not affect | 37 (41.1) | 22 (66.7) ^{**} | 15 (26.3) ^{**} | 37 (24.9) [*] | 37 (30.0) [*] | 36 (34.9) |

Note. Facilitators and barriers are not exhaustive categories; being HIV-positive categories are exhaustive.

^a Possible scores on each scale ranged from 9 to 36.

^b Mean score|=30.3 for parents who did not report this facilitator.

^c Mean score|=34.3 for parents who did not report this facilitator.

* P| .05

** P| .01.