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The Experience of Sexual Risk Communication in African American Families Living With HIV

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Abstract

Mother-daughter communication plays an influential role in adolescent development. The impact of maternal HIV infection on family communication is not clear. This study explores how living with HIV impacts sexual risk communication between mothers and daughters and whether maternal HIV status influences adolescent choices about engagement in HIV risk behaviors. Data were collected from 12 African American women and 10 of their adolescent daughters through focus groups. Both mothers and daughters shared information about issues that promoted and inhibited communication and engagement in risk behaviors. Findings show that HIV status served as a mechanism for behavioral change related to communication and risk engagement behaviors. Therefore, HIV-infected mothers should be supported in communicating values and expectations to their daughters.

Keywords

family relationships; parenting; risk behavior; African Americans

Parents, particularly mothers, play in influential role in the lives of adolescents, particularly as it pertains to sexual risk communication (Guzman et al., 2003; Hutchinson, 2002; Kapungu et al., 2010; Martino, Elliott, Corona, Kanouse, & Schuster, 2008; Pluhar, DiIorio, & McCarty, 2008). Maternal communication happens more frequently, with greater comfort, and covers a wider range of topics (DiIorio, Kelley, & Hockenberry-Eaton, 1999; Hutchinson, 2002; Hutchinson & Cooney, 1998; Pluhar et al., 2008) than communication with fathers. Mothers' communication deters high-risk behavior among their daughters when mothers have had ample and correct information about sexuality and responsible decision making (Dancy, Crittenden, & Talashek, 2006). In families where the mother is HIV infected, far less is known about mother-daughter sexual risk communication. To date, only three studies have examined how discussions about HIV may differ in families with an HIV-positive parent (Corona et al, 2009; Marhefka, Mellins, Brackis-Cott, Dolezal, & Ehrhardt, 2009; O'Sullivan, Dolezal, Brackis-Cott, Traeger, & Mellins, 2005). This study sought to add to our understanding of how living with HIV impacts mother-daughter dyads, particularly, sexual risk communication.

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Mother-Daughter Communication

Mothers are more likely to communicate with daughters (DiIorio et al., 2000; Martin & Luke, 2010; Pluhar et al., 2008; Wyckoff et al., 2008), particularly older daughters (Martino et al., 2008; Pluhar et al., 2008); daughters report greater comfort and frequency of sex discussions with their mothers (Guzman et al., 2003; Kapungu et al., 2010). Mothers more often take primary responsibility for caregiving activities, monitoring (DiClemente et al., 2001), and for discussing sexuality with their children (Hutchinson, 2002). Effective parent-child communication (defined by frequency of conversation, as well as knowledge-based and skill-based communication), specifically greater frequency of communication about sex by mothers, has been positively correlated with abstinence (Karofsky, Zeng, & Kosorok, 2000). Mother-adolescent communication about sex has specifically been shown to be a significant predictor of delaying onset or nonengagement in sexual activity (Guzman et al., 2003).

Higher level of condom self-efficacy (belief that one has the skills to effectively use a condom) is also associated with parent-child sexual risk communication (Hutchinson & Cooney, 1998). Communication not only increases self-efficacy but also condom use. Young women who had discussed sex with their parent before they became sexually active were seven times more likely to report consistent condom use once sex was initiated (Hutchinson, 2002). Another reports that youth whose parents discussed delaying sex, birth control, and STD prevention were close to two times more likely to report using birth control during their last engagement in sexual intercourse (Aspy et al., 2007). When parents talk with adolescents about condoms, youth are significantly more likely to have used a condom (Hadley et al, 2009; Weinman, Small, Buzi, & Smith, 2008). Communication about sexual risks can also increase likelihood of adolescents using condoms consistently (Romer et al., 1999). Furthermore, talking with parents about condom use can extend to the interaction the adolescent has with his or her partner; it can translate into an adolescent being more self-efficacious in negotiation of condom use. Adolescents who have discussed sex with their parents are more likely to be comfortable communicating with partners about sexuality issues (Aronowitz, Rennells, & Todd, 2005) and discuss condom use with partners (Dutra, Miller, & Forehand, 1999; Miller, Levin, Whitaker, & Xu, 1998). Greater frequency of sexual risk communication by parents has been found to be significantly associated with greater partner communication, including asking about previous history of STIs and numbers of past partners prior to having sex (Hutchinson & Cooney, 1998).

Sexual Risk Communication in African American Families

Although peer influence continues throughout adolescence, for African American adolescents, family is perceived as a stronger source of support (Peterson, Buser, & Westburg, 2010; Wills, Gibbons, Gerrard, Murry, & Brody, 2003). African American youth have been found to be more parent-oriented, perceive greater support from parents, and prefer parents to peers as sources of sexual and contraceptive information (Fasula & Miller, 2006; Henrich, Brookmeyer, & Schrier, 2006; Maguen & Armistead, 2006; Tinsley, Lees, & Sumartojo, 2004). Among African American young adults, parent-teen sexual risk communication (PTSRC) with mothers is associated with more conservative attitudes toward adolescent sex in general, greater perceived importance of parent's opinion, and toward a person engaging in sex in the next 3 months (Hutchinson & Montgomery, 2007). Furthermore, mothers as deliverers of the abstinence or risk-reduction messages have been found to be as effective as information given by health experts (Dancy et al., 2006).

African American female adolescents report more discussions about sex-related topics with their mothers than do their male counterparts (DiIorio et al., 2000; Hutchinson, 2002) and

more than White and Hispanic peers (Hutchinson & Cooney, 1998). Among African American young women, having discussed sex with parents prior to onset of sexual activity was found to exert a significant influence on likelihood of initiating intercourse (Hutchinson, 2002). Specifically for African American adolescents, parental communication considerably decreased their probability of engaging in unprotected sexual intercourse, an influence that did not decrease this factor among any other ethnic group in the study (Holtzman & Rubinson, 1995).

As with its positive impact of delaying sex, there is also positive association between parent-child sexual risk communication and the reduction in the sexual risk behaviors, which place adolescents at risk for HIV. In a study with African American older adolescents, the greater the amount of PTSRC, the less likely adolescents were to report sexual activity in past 3 months; for girls, greater amounts of PTSRC with mom were less likely to report unprotected sex and ever having been pregnant (Hutchinson & Montgomery, 2007). Similar findings were found with a racial/ethnic diverse sample of young men and women (Aspy et al., 2007). Adolescents who reported having had sex also reported that their parent had never or only some of the time (a) talked about problems, (b) understood their point of view, (c) had high expectations of them, (d) loved them, or (e) set clear rules. Those who had been taught to say “no” and those who had communicated with their parent about delaying sex were less likely to report ever having sex.

Knowing Someone With HIV

As the number of people infected with HIV increases, so does the number of individuals who know someone with HIV/AIDS. In a national survey of adults in the United States (n = 2,683), more than 4 in 10 Americans (43%) say that they knew someone who was either living with HIV/AIDS or has died of AIDS, and more than 1 in 3 (37%) were personally concerned with becoming infected (Kaiser Family Foundation [KFF], 2001). Subsequent research by the KFF (2004) found that African American parents are more than twice as likely than their White counterparts to say they are “very concerned” about their children becoming infected with HIV (66% vs. 26%, respectively).

Studies have linked perceived risk and sexual risk behaviors (Burkholder, Harlow, & Wachkwich, 1999; MacNeil & Anderson, 1998). They have found that behavior change is influenced by the extent to which an individual feels personally at risk of contracting a disease that they perceive to have serious consequences, is aware of ways to avoid infection, believes that the benefits of taking preventative action outweighs the costs, and believes that such measures would work (Ajzen & Fishbein, 1980; Bandura, 1986). Knowing someone with HIV/AIDS has been found to be positively related to reductions in risky sexual behavior (Burkholder et al., 1999); it may reduce an individual’s belief that he or she has no chance of contracting HIV. Familiarity with someone who is infected with the virus personalizes the risk and stimulates behavior change (MacNeil & Anderson, 1998).

Knowing someone who is infected with HIV can effect choices that an individual makes to engage in or avoid HIV risk behaviors (Camlin & Chimbwete, 2003; Cederbaum, Marcus, & Hutchinson, 2007; Macintyre, Brown, & Sosler, 2001; Palekar, Pettifor, Behets, & MacPhail, 2008). However, in most studies, the type of relationship the person has with the HIV-infected person (i.e., familial ties or acquaintance) and the quality and quantity of time spent with the HIV-infected person is undetermined. If merely a casual acquaintance can have an effect on behavior, what, if any, is the impact of having a HIV-positive parent on choices that adolescents make to engage in or avoid HIV risk behaviors?

Living With HIV: Impact on Individuals and Families

HIV-positive parents face several issues, some unique to having HIV/AIDS. These include fear, physical symptoms, disclosure to children and social networks, and depression (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Brackis-Cott, Mellins, & Block, 2003; Lee & Rotheram-Borus, 2002). Furthermore, HIV-positive women and their children living in inner cities in the United States are exposed to extremely difficult conditions affected by racism, classism, urban violence, environmental degradation, poor school districts, and exposure to illegal substance use (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007). Because of this, youth of HIV-positive mothers are often exposed at an early age to the same factors that placed their mothers at risk for HIV infection (Havens, Mellins, & Ryan, 1997). Among adolescent daughters of HIV-positive mothers, half had initiated sexual activity before the age of 14, 70% reported unprotected intercourse, 52% reported alcohol use and 41% reported illicit drug use (Lee et al., 2002). Chabon, Futterman, and Hoffman (2001) determined that among youth with known sexually or injection-acquired HIV, 19% reported at least one parent with HIV infection.

Mother-daughter sexual risk communication when mothers are HIV-positive

As compared to HIV-negative mothers, communication with children about HIV is more frequently noted by mothers who are HIV-positive (O'Sullivan et al., 2005). Children of mothers infected with HIV also rate conversations with parents about sex as being of higher quality. African American mothers reported greater comfort in discussing drugs and sex with their children as compared to Latina mothers (O'Sullivan et al., 2005). However, adolescents are not always comfortable discussing HIV with their infected parent because they are concerned about these discussions serving as a reminder to the parent of their diagnosis, upsetting the infected adult (Corona et al., 2009). The impact of this communication, given the ecological stresses these families are presented with is a further limitation. Although communication may increase with HIV-diagnosis, Faithful (1997) found that the imminence of death made it difficult for HIV-positive women to set limits for their children. Unresolved grief can also contribute to their failure to take responsibility for their children's behavior and compromised their ability to discipline the children. This is an important finding and links to the increased levels of risk engagement in adolescents of HIV-positive parents.

Limits of Existing Literature

Discussed above are the multitude of factors that influence parenting behaviors and also those variables that may influence engagement in HIV-risk behaviors by adolescents. To date, only one study has specifically evaluated the impact of maternal HIV serostatus on engagement by adolescents in HIV risk behaviors (Mellins, Brackis-Cott, Dolezal, & Meyer-Bahlburg, 2005). Only three (Corona et al., 2009; Marhefka et al., 2009; O'Sullivan et al., 2005) have examined parent-child communication within families where the parent is HIV infected. Because of the reported risk among this adolescent group for their own sexually acquired HIV infection, more information about this population is needed to better understand their HIV risk reduction needs. As a whole, we know little about the impact of HIV serostatus on communication, the beliefs about risk for HIV infection in adolescents, and the impact of having an HIV-positive parent on engagement in risk behaviors. To elucidate these issues, the study aims were to gain a better understanding of how living with HIV influences mother-daughter communication about abstinence and safer sex and choices to engage in HIV-risk behaviors by adolescent girls.

Method

Focus groups were undertaken to better understand how parenting with HIV, as well as living with an HIV-positive mother, influenced mother-daughter communication about sex and adolescents' engagement/abstention from HIV-related risk behaviors (specifically sexual intercourse). A descriptive qualitative design was used to provide descriptions of the everyday experiences of participants (Sandelowski, 2000). All protocol was approved by the Institutional Review Board of the University of Pennsylvania.

Recruitment

A small convenience sample of mothers with a daughter between 14 and 18 years of age were recruited from two different social service organizations serving HIV-positive women in New Jersey. Recruitment was accomplished through flyers. Inclusion criteria for adult women were (1) self-identified as African American, (2) have a diagnosis of HIV symptomatic or AIDS, (3) live with an uninfected daughter (at least 50% of the time) between the ages of 14 and 18 who is aware of their HIV diagnosis and is willing to participate, and (4) English speaking. When the adult had more than one daughter between the ages of 14 and 18, the child that was closest in age to 16 (measured in months) was selected to participate (this was to reduce parent selection bias—potentially picking the child they thought would give the "right" or "best" answers). Each mother and daughter received US$20 and US$15, respectively (US$35 for the dyad), for their participation.

Due to the sensitive nature of the topic, the goal size for each group was 4 to 8 participants. This number proved hard to achieve. Although groups were held during the early evening hours and dinner was provided, many confirmed participants did not attend. Weather conditions, transportation issues, and inability to provide care for other children are some factors that may have contributed to the lower turnout. The agencies from which participants were recruited also serve very high risk women who proved to be more limited in their ability to attend. In the end, groups included 2 to 6 members, not uncommon with high-risk groups (Powell, Single, & Lloyd, 1996). For one session, only 1 dyad attended. Because focus groups need a minimum of 2 participants, individual interviews were conducted with the dyad instead. Although there is the loss of the group dynamic (the potential to spark new ideas among group members; Krueger & Casey, 2009), the rich data gathered from these participants was deemed important to include in the analysis.

Although a sensitive subject, focus groups in sex research have been shown, through the promotion of collective discussion, to enhance disclosure, improve access to understanding concepts through participants' own language, and provide conditions where individuals feel comfortable describing experiences (Hoppe, Wells, Morrsion, Gillmore, & Wilsdon, 1995; Wellings, Branigan, & Mitchell, 2000; Wilkinson, 1998). As has been recommended by others, groups were same-sex, age specific, ground rules were set, and warm-up questions were used to allow participants to speak first to more neutral topics (Hoppe et al, 1995). Ultimately, we believe that focus groups provided dynamic data that would not have been yielded to the same extent with individual interviews. The quality of this method for increasing our understanding of sensitive topics has been shown to be effective by others (Jemmott, Jemmott, & Fong, 1998; MacPhail & Campbell, 2001; Whaley, 1999).

Data collection

Upon arrival, all participants sat together in one room. Consent/assent procedures were explained and forms reviewed. Once consent/assent was provided, all participants were given a short questionnaire to collect information on demographics, attitudes toward sex communication, actual sex communication, and risk engagement. Once collected, all

participants were asked to choose a celebrity name (which they wrote on a name tag) by which they were called during the focus groups. This was done to increase anonymity among group members. Each group met once; parent and adolescent groups were conducted separately, but simultaneously. The focus groups were scripted and each led by one female moderator (both trained social workers with experience running groups) and audio-recorded. Notes were also taken by the moderator to note the environment and any observations about the group at the end of each session. Moderators from both groups debriefed immediately after focus groups were completed. Time allotted for focus groups was 2 hours and all groups ran this length.

Instrumentation

The five (5) focus groups and two (2) interviews were conducted using a semistructured interview guide. The script was framed by the specific aim of the study—to understanding how HIV influences mother-daughter communication about abstinence and safer sex, and choices by adolescents to engage in HIV-risk behaviors. The structured script was developed as a guide for both the facilitator and the group participants (Krueger & Casey, 2009). The script provided an introduction/purpose for the group and then allotted 5 minutes to create group rules (i.e., talking one at a time, not putting others down, etc). It allowed 50 minutes to discuss the impact of living with HIV (how has it changed the adult, how its impacted how you have raised your daughter, etc.), 50 minutes to discuss sexual risk communication (beliefs about youth engagement in risk behaviors, if/how parents make a difference, facilitators/barriers to communication about sex), and then 15 minutes for wrap-up/final thoughts.

Data Analysis

All audio files were transcribed verbatim by an outside transcriptionist. All transcribed files were reviewed by the PI and insertions or corrections made for any incorrect transcription. These needed corrections occurred because of the colloquial language used by the adults and adolescents in this sample, which were unfamiliar or inaudible to the transcriber. Data was analyzed by the author with consultation from a senior mentor who reviewed the process of creating codes and themes. The final code list was also discussed with the cofacilitator and adjustments were made when the second facilitator believed the intent was not fully captured. Qualitative software program Atlas.ti (Muhr, 2005) was used to organize the data and during the coding process. Thematic analysis was employed to guide the process of data reduction, coding, and creation of themes (Sandelowski, 2000). Data was examined closely to identify topics and themes that were similar and different between the groups. Analysis began by reducing the data, a process of selecting, simplifying, and transforming data (Miles & Huberman, 1994). Purpose-driven profiles were created and data coding was systematic (deliberate and planned) and sequential (evolving process; Krueger & Casey, 2009). Using an inductive method, transcripts were reviewed and coded into specific and general themes (Padgett, 2008). Topics and themes were evaluated and further refined. Mother and daughter transcripts were analyzed separately. The findings presented are intended to elucidate the lived experience of HIV-infected women and their daughters, and to gain an understanding of their attitudes, beliefs, and behaviors related to communication about HIV-risk behaviors. Selected quotes from participants are used to highlight the themes and subthemes.

Description of Sample

The five focus groups (four with mothers and three with daughters) and 2 individual interviews were conducted with 12 adults and 10 adolescents. The first group consisted of 3 mother-daughter dyads. The second included 6 mother-daughter dyads. The third group was mothers only and consisted of 2 adult women (daughters were unable to attend this session

so mother group was run individually). The last scheduled “focus group” had 1 pair. Mean age of the mother participants was 41.5 years (range 30–48); mean age of daughters was 14.8 years (range 14–17). Sixty percent of mothers had graduated high school; 20% were employed. Half of the daughters were in 10th grade. All the mothers were HIV infected; 80% reported having been infected by a male partner and 30% had a current diagnosis of AIDS. Length of time since mother’s diagnosis was not ascertained. All adults reported sexual risk communication had occurred between mother and daughter. All participants self-identified as African American and had disclosed HIV status, study inclusion criterion.

Data Themes—Mother

Focus groups with mothers each began with the question, “What is it like being a mother who has HIV?” This provided an opening question to start dialogue, but more importantly, allowed the women, most of whom were not familiar with one another, to hear other’s stories and share their lived experiences. It further proved to be important in understanding the impact of HIV on women’s physical, emotional, and mental health. Impact of diagnosis emerged as important for mothers and later on for daughters as well.

Theme 1: Impact of Diagnosis—A Focus on Family

Mothers noted the impact their diagnosis had made on their lives; sometimes strengthening bonds with families. The women shared the impact of their diagnosis on individual lifestyle choices and parenting, and lastly shared how they felt that their diagnosis had impacted their daughters. An understanding of how their HIV diagnosis might have influenced their lifestyle choices was explored because of the importance of role modeling. The most common changes were use of condoms and a decrease/elimination of substance-use behaviors. Below is an expression of how two women changed their lifestyles:

> It saved my life. People have asked me, how could you say that. Because I did drugs. I go back again to the drugs. My story is basically drugs and if I hadn’t found out about HIV, that I was living with HIV or it was living with me, it move in, I think I would be dead right now. You know, I wouldn’t be sitting here talking to you because the drugs would’ve taken me out.

> It’s a process. I’m okay, you know, like I’ve come to accept it. There’s nothing I can do about it, you know, I’m not going to let it beat me, you know, my thing is to beat it to the best of my ability by doing what I got to do, because I have kids that I want to see graduate, grow up, make babies, get their own place, you know I want to see all these things.

Women also shared how they felt more supported and cared for after their diagnosis. Some of this support came from family, while others received support from service and care providers. One woman shared how even though she was still not taking good care of herself, her family increased their support of her while another found support through being part of clinical trials and from increased use of medical providers:

> they was more supportive towards me than, you know I was towards myself, cause I was still abusing myself and I still use, you know, but I’m just really trying to, you know, get into this, because I couldn’t believe it, like you say I couldn’t believe it. Oh no, you know, that didn’t happen to me and so it’s really like, dealing with my surroundings, dealing with what’s inside of myself, you know, like say you don’t know where.

> I started taking meds on the clinical trial and I didn’t think in terms of getting paid, I thought in terms of people are caring, people are there, they’re asking me questions … well, how do I feel, they call me up at home.

This is a unique outcome of a potentially devastating diagnosis but one that may be particular to women who, because of tensions with families and prior heavy involvement in stigmatizing behaviors (i.e., substance use) became isolated. Their HIV-diagnosis gave them a chance to reconnect, with family, friends, or to newly connect into a stable and caring service community.

Theme 2: Mothers' Parenting Behaviors

Participants identified the direct impact of their diagnosis on parenting. Many of the mothers expressed a deep sense of responsibility to decrease the risk of future HIV infection among their daughters and other young women in their lives. Messages about communication were pervasive both within and across focus groups. One area of importance was openness. Participants expressed the value of being open (both with communication and to answering questions). Whether it came from the mother herself, or someone in her daughter's life who could provide the adolescent with the "right" information, the comment below highlights how crucial they believed being open was to decreasing HIV risk.

> A lot of things would not be going on today if we, you know, if would just be open, you know, with our children no matter what, you know, sometimes you just got to be blunt to the point, just like you tell them, now if you touch that stove when it's hot you going to get burned, so you got to be the same way when it comes to sex.

Messages—Many of the women openly expressed their belief that sharing their lived experience was important in emphasizing the potential gravity of engagement in risky sexual behaviors. This sharing of lived experience was seen as relevant examples in stressing the outcomes of risky behavior. Examples of using lived experience to teach her daughter are highlighted by the following women's comments:

> So, and I think by me livin' with it and been through it and, you know, walkin' through it, that helps, too, it's easier. 'Cause they be curious a lot of times. They get somethin' good goin' they wanna know more and more.

> And I believe that me telling them what I went through and some of the things that I did that they know they can't go that way; they just know that's not the right way and I just know I'm teaching them … I had to go that way so they would, so I could train them up right.

Although not all mothers were comfortable sharing "their stories" with their daughters and saw this as glorifying "bad" behaviors, many in these groups, particularly those with substance-use histories, felt that sharing this information was critical. They were clear that there were appropriate ages at which to do this (although there was no consensus as to what age that was) and did not see all information as appropriate for all adolescents. General consensus was to use lived experience for teaching, particularly if it helped to bolster a particular message.

Types of messages were also discussed within and among groups. Although being HIV-positive was not something any of these women had expected, many took a negative experience and created an opportunity through which they could positively influence others. There were clear messages that stood out when individuals were discussing this topic. They included empowering their own daughters and other adolescents to make choices for themselves (not bow to peer pressure). For example,

> as far as my daughter goes or any youngster that I'm around, I feel it's very important that you instill in them, be they male or female, that they're very important, o.k., and they don't need someone else to make them feel important or special or loved. O.k.? They have to know that they are loved. This way, there

> won't be that desire to go out and reach outside themselves to find someone else to fill that void within them.

Mothers expressed their desire to feel approachable to their daughters and the meaning of being available to them. In this case, mothers were expressing their desire to have their daughters come to them for information about abstinence and safer sex; creating an atmosphere in which the child felt comfortable and safe asking questions or sharing information.

> And, you know, we talk about everything. I don't want her to hear it from somebody else; I'd rather her hear it from me. If it's gonna be said and if I did it, she can hear it from me. I think that will keep things on a personal one-to-one basis, you know, and keep her from being silent and not wanting to say anything to me.

Some shared how their positive HIV-status promoted more honest dialogue about sexual risk behaviors with their daughters. This was of particular interest to this study.

> I feel like she would have been so different because I wouldn't have talked to her, I wouldn't have nurtured her, I wouldn't have shared things with her. You know, I wouldn't have introduced her to condoms.

> I just think that at the appropriate time disclosure to your child … if you are positive, you need to sit down and talk with them, you know, because when they get to a certain age they're gonna be … she's goin' off to college.

Creating a safe environment for questions allowed mothers to share relevant information about readiness, negotiation, and reducing HIV-risk behaviors, as well as created a forum in which to mentor their daughters, allowing them to share their beliefs, values, and expectations.

Summary

HIV played an important role in bringing about a major life change. Overall, there was a sense gained from the groups that these mothers felt an obligation to communicate about HIV-risk behaviors, even when they believed that their daughters might be engaging in these behaviors anyway. They expressed their perspective, one of lived experience, and how they believed having "been through it" was a motivator to promote healthy behaviors among their daughters. Women shared that their journeys had not always been "perfect," some had become sober and had relapsed during this difficult time; others were reunified with their children after their diagnosis and sobriety. Still others had to manage changes in their physical and mental health; balancing their needs with those of their children. Some were more successful than others. Of great concern was their ability to be effective in influencing their daughters to make safer choices than those they had made. It was collective opportunities, including support groups, educational opportunities, and relationships built with providers, that assisted them in continuing to strengthen their families.

Data Themes—Daughters

As noted earlier, the focus groups with daughters took place simultaneously, but separately, with those of the mothers. Many of the questions asked of the daughters during the semistructured sessions were similar to those asked of the mothers. As such, themes that arose were similar in nature. Below are the major themes and supporting data that evolved from the focus groups with daughters of HIV-positive women.

Theme 1: Living With an HIV-Affected Family

Like mothers, daughters were asked to describe the impact of living with HIV. A number of the participants spoke of how knowing their mother's serostatus had changed them; they also spoke of how they perceived the positive HIV diagnosis had changed their mothers. Although not all adolescents in the groups felt that having an HIV-positive mother had changed them, many shared how learning of their mother's serostatus had evoked negative (fear and sadness), as well as positive feelings and behavior changes (closeness with mothers, changes in attitudes and risky behaviors). Fear and sadness were emotions expressed as responses to finding out mom's status. An example is given below:

> I thought about, well, I don't have that much time with her because I don't know when, what's gonna happen, but that's even worse for some-body who is just finding out because they're like, well, what's next, what happens next.

Most of the sadness and fear expressed by the participants was related to fear of losing their mother, either again or in the future. Fear manifested in two ways: fear of mother dying, and fear and frustration of stigma (perceived and actual). These adolescents understood that there was no cure for HIV/AIDS and therefore their mothers were living with a life-threatening illness. However, there is no clear path that HIV takes. How much time did they have with their mother? What was happening to her when she got sick? What will happen to me when she is no longer here? These are profound and deeply difficult questions to answer, providing these adolescents no respite for their concerns.

One positive outcome of the maternal HIV diagnosis was the feeling that mother and daughter had grown closer. In the quote below, this change was in the adolescent's attitude toward her mother; this closeness is framed in the context of not knowing how much time the adolescent has with her mother.

> I think it is because being that she does have it, it probably does bring us closer because, you know, and her being that she doesn't want that to happen to me and so she talks to me about, you know, making the right decisions and stuff like that. And I think that some people with moms who don't have it, it's probably, they're probably not as close … yeah, they're probably not as close.

This closeness provided an opportunity for the adolescent to build a strong relationship with her mother. Another positive change noted by some participants was how their attitudes, either in general or toward specific behavior choices, had altered. Two participants shared specifics about the types of behavior changes they had made:

> It makes me think twice or maybe three times before you lay down and do it what you doing.; It make me not want to have sex, especially not with anybody. [name] you better not be having sex, you still young you know. You got to know your partners sex history.

These changes in behavior may be linked to the changes in communication shared by the mothers.

Living with HIV had a weighty impact on adolescents. This included fear of death, fear of disclosure, and stigma, and the sense that their lives were not "normal." Because of the environments in which they reside, the "normal" many of these participants know, even before their mother's diagnosis, was not without stresses; this perception that it was the HIV that made their lives "un-normal" was profound.

Theme 2: Communication

Focus group participants were asked about sexual risk communication with their mothers. They spoke to things which bolster communication and those which were barriers. Candidness by mothers contributed to communication about sexual risk. As two participants shared, “She told me when like I did it … or when I do it or whatever to come to her and she is going to give them to me.”; and “But it’s [communication] easy because I know that she will talk to me and open up to me about stuff I need to know about how to keep myself safe and stuff like that.”

The participants also spoke of their mother’s lived experience as contributing to (and potentially being the impetus for) communication. This lived experience shared by mothers appeared to resonate with many of the adolescents; risky behaviors leading to HIV was a reality for their family. Adolescents stated that most of the lived experience shared by mothers was done as a sort of warning. One participant described how her mother sharing her lived experience was beneficial to her future successes, “Because I know she would be willing to tell me since she’s been through it, so, and really she knows that it will help me in my future, so …”

Poignantly, one participant was able to share how her mother having HIV and sharing her experiences made her parent-child relationship more unique than those of her friends. She expressed by saying,

> Most parents are like well they’re gonna experience this. You’ve already been there. You don’t want that for them ’cause you know what it is gonna be like. They won’t listen to you ’cause that’s not gonna be me. We have this feeling of security that is so false, but you know, parents who have been there, that’s their rule don’t do drugs, don’t be like me. Don’t do drugs. There’s no compromise. I don’t want to talk about it, no.

Although maternal directness was not seen by all participants as positive all the time, adolescents perceived it helped facilitate communication from their mother. Candor and shared experience enhanced sexual risk communication, allowing mothers to express their values, hopes, and concerns for their daughters’ sexual health choices.

The main barrier to sexual risk communication with parents was fear of their reaction and loss of trust. The adolescents expressed their apprehension to asking questions as it could lead their parent to suspect their engagement in said activity (whether or not this was true). Furthermore, disbelief that mom would really be open to hearing the information or questions (rather than respond negatively) was also a concern. This is exemplified below.

> Like you don’t want to lie to her, but she is basically forcing you to because you know how she will react. And you don’t want to have to have that barrier between you, but you know that if you say something, the most probable reaction from her is gonna be something that you don’t want to deal with.
>
> So like if like you tell your parent like, oh mom I’m having sex you be like, I already know she sexually be active or whatever. But you ain’t never, like some parents want you to tell them what you’re doing, then when you tell them, they get mad.

Reaction by parents to questions from their adolescents made many of these participants believe that there were significant impediments to communicating about sensitive subjects. The concerns identified were that disclosure would lead to distrust, increased monitoring, and general relationship strain between mothers and daughters.

Summary

Overall, living within an HIV-affected family was well managed emotionally by this group of adolescents. However, the HIV diagnosis highlighted the intrafamilial role changes for these adolescents. The diagnosis also appeared to influence sexual communication. As seen in the words of the participants, there were several factors that contributed to facilitating mother-daughter sexual risk communication. Daughters who perceived their mothers as open and willing to share their stories spoke of how this strengthened their relationship. In addition, they shared how their choices were impacted by having this information. Their mothers also served as educators, providing them with knowledge and skills to make safer choices. This was particularly true around topics such as abstaining from sexual intercourse and condom use. However, talking about sex with mothers concerned some adolescents; these concerns were legitimate. Although mothers wanted their children to be honest with them, knowing about their daughter's engagement in sexual activity was hard to process. This may have led to reactions that differed from what the adult previously suggested. Because of this, adolescents were reluctant to ask questions about sensitive subjects or share information.

Discussion

The focus groups with both HIV-positive mothers and their daughters high-lighted how the HIV diagnosis impacts mother-daughter relationships, particularly sexual risk communication. Both mothers and daughters shared information about family communication dynamics, modifications to engagement in HIV risk behaviors, and the issues which both promoted and inhibited sexual risk communication. What the positive HIV status appeared to do for the women who participated in these groups was to provide a trigger for change. Sometimes these changes were in their own behaviors; other times, the diagnosis changed how they perceived the support and caring from those around them. However, the changes were not always about the women specifically. The participants also identified that their diagnosis, at times, led to changes in behavior among their daughters. Mothers' perceived impacts on daughters included increase in fear, awareness, closeness, and changes in daughter's lifestyle.

Based on their shared experiences, adolescent girls of HIV-positive mothers may have a more realistic view of the potential for negative outcomes from sex; they are living with mothers who themselves experienced this negative outcome. Avoiding HIV-infection may contribute to their positive views of safer sex behaviors as well. Therefore, independent of parental influence behaviors (i.e., communication), being exposed to HIV (which may include seeing symptoms, attending appointments with mothers, seeking treatment) can be said to have an important, individual protective influence on adolescent beliefs. The findings highlights how adolescents felt as though they were more cautious than their peers in regard to engagement in risk behaviors and had stronger beliefs about abstinence and condom use self-efficacy. Adolescents further expressed their feelings of obligation to "do good" or make the "right" choices in terms of their engagement in HIV risk behaviors.

As highlighted in the work and by another (Martino et al., 2008), repetition of messages is important. Adolescents who receive messages more frequently feel closer to their both parents, more able to communicate with their parents in general and about sex specifically, and perceive greater openness in discussions. Given that behaviors are most influenced by immediate normative conditions, utilization of other sources of communication—school, media, adult mentors or role models—provides mothers a way to share values and expectations, both important to reducing daughter's engagement in risk behaviors. Changing this normed environment may be particularly important for adolescents of HIV-infected parents who are at increased risk for their own sexually acquired HIV infection (Chabon et

al., 2001; Mellins et al., 2005). When parents change the normative environment, they create the opportunity to target behavior change.

Findings here highlight the importance of open and honest communication as well as clear boundaries of roles and expectations. The biggest misstep for parents may be in not sharing their values and expectations with their children, particularly around engagement in safe sex (Aronowitz & Morrison-Beedy, 2004; DiIorio, Pluhar, & Blecher, 2003). When parents share their values, beliefs, and expectations around engagement in HIV-risk behaviors, as well as provide young people with the skills to negotiate abstinence or safer sex, adolescents are able to make healthier decisions about engagement or abstention from risk behaviors. This is true for children of HIV-positive and HIV-negative women. However, this may be a hard dialogue to start. Parents may feel like they do not have enough information to provide accurate information (Guilamo-Ramos, Jaccard, Dittus, & Collins, 2008), may feel uneasy about when and how to start this type of communication, and often wait until after they have learned of the child's engagement in the behavior to express their thoughts.

By middle adolescence (15–17), independence increases (often seen through a decrease in time spent with parents and an increase in time spent with peers) as does capacity for caring. Thus, as adolescents are becoming more independent, they are also contending with increased feelings (both emotional and sexual) toward others. At this stage, although sense of right and wrong and complex thought is greater, adolescents are often still not thinking rationally during decision making. Because of this, it is less common for adolescents (as compared to individuals who are older) to think about the pros and cons of the alternative, weigh the likelihood of various outcomes, evaluate their choices in terms of their goals being met, or learn from their mistakes. It is because of these factors that parents need to be aware of the child's environment, particularly social networks. Thus, parents need to be involved in knowing not only where there child is, but who their child is with and the environmental influences on those children as well.

We know that sexual risk communication prior to the child engaging in the behavior has more positive outcomes for delay in sexual initiation (Dittus & Jaccard, 2000; Vesely et al., 2004; Whitaker & Miller, 2000). Therefore, helping parents gain the skill, confidence, and comfort with sexual risk communication is essential. Messages differ based on the age and developmental readiness of the child. Helping the parent assess where their child may be on this continuum and providing them access to the material will increase the likelihood of successful communication opportunities. This successful communication can in turn help to strengthen parent-child relationships.

Limitations

This study is one of few to explore the influence of maternal HIV status on parenting behaviors, particularly parent-child sexual risk communication, and family functioning. Through the words of the participants, we are able to gain a better understanding of the unique pressures HIV infection places on infected mothers, and their HIV-affected daughters. This study should be viewed as a mere starting point to understanding the issues. The participants for these groups were all drawn from AIDS service organizations in northern and central New Jersey. This limits the diversity of the group and should be interpreted within those parameters. Furthermore, this was a self-selected group; those participants who had less positive relationships with their daughters likely did not participate. Lastly, this is a small sample of women and their daughters and this too has potential limits for having met saturation.

Conclusion

Because the daughters of HIV-positive women often remain living in the same environments in which their mothers' were exposed to HIV, their social conditions (including education, employment opportunities, norms about sex and pregnancy, and rate of HIV infection within the community) place them at high risk for their own sexually acquired HIV infection. Furthermore, adolescents who live in high-risk environments may be exposed to norms, attitudes, and behaviors that are different from what larger society may view as "mainstream" (Wilson, 1987). This setting of "exceptional" norms leaves adolescents with few other obvious options, and as such makes "alternative" norms of behavior a powerful influence (Wilson, 1987). As such, support to HIV-positive mothers is imperative for reducing future HIV infection among their HIV-negative daughters. Mothers need to be supported in communicating values, expectations, and skills.

Given that HIV status appeared to influence adolescent daughters' beliefs about sex, knowing a mother's HIV status is incredibly important. One area where clinicians can work with families to facilitate honest dialogue about HIV status is around disclosure. For many women, the fear of how the child will react to their diagnosis, whether or not the child will disclose this "family secret," and what questions might be raised by the child because of the disclosure of HIV status, may inhibit them from sharing their serostatus. However, because of the potential protective factor in knowing mother's HIV status, the positive consequence of disclosure may outweigh the perceived (or actual) "negative" outcomes. As such, disclosure may be the key to changing how adolescents perceive the potential negative outcomes of engaging in unsafe sex.

Lastly, children of HIV-positive mothers may be able to serve as important and relevant peer educators. Because of their unique understanding of the reality of HIV infection, these youth have the potential to help create positive peer norms, which in turn can influence behaviors. When structural barriers limit communication opportunities, and inadvertently promote behaviors that larger society may see as nonnormative (i.e., teen pregnancy), then within that neighborhood the "negative" behavior becomes the norm. As most communities (particularly ones that are of lower socioeconomic status) are fairly insular, overcoming these norms can be a significant barrier. Clinicians have the opportunity to explore with families opportunities outside the norms of their current environment. With adolescents of HIV-positive mothers, clinicians, capitalizing on the influence of the HIV status can help adolescents become community leaders and role models. This requires helping youth gain the knowledge and skills to (1) access information and resources, (2) dispense information to their peers in a manner that is acceptable to them and in a manner in which they are able to receive it, and (3) be role models for their peers, doing their best to engage in the healthy behaviors they are promoting.

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Biography

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