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"They said 'be careful'": Sexual health communication sources and messages for adolescent girls living with perintally-acquired HIV infection

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Abstract

Due to advances in highly active antiretroviral treatment (HAART), children "who perinatally acquired HIV infection" (PHIV+) in the United States have been reaching adolescence and adulthood in large numbers. As youth PHIV+ become sexually active it is important to understand their sources of sexual health information and the messages communicated by those sources to safeguard their sexual health and that of their partners. This paper explores sexual health communication for adolescent girls PHIV+ in comparison to adolescent girls who were exposed but did not acquire HIV perinatally (PHIV−) to understand how HIV infection influences the sexual health communication needs of the former. A convenience sample size of 30 (20 PHIV+ and 10 PHIV−, mean age 14.5) girls completed survey and participated in a 45–90 minute developmentally appropriate semi-structured interview. The interviews aimed to elicit the girls' sources of sexual health communication, the sexual health messages they receive, their comfort or discomfort with these communications, and to determine how their sexual health communication experiences differ from those of their PHIV− peers. Transcripts of the interviews were coded and analyzed for themes related to sexual health communication sources, sexual health communication messages and comfort/discomfort with sexual health communication sources. Our findings suggest that girls PHIV+ do not differ significantly from Girls PHIV− in their sources of sexual health information, yet girls PHIV+ are most comfortable receiving sexual health information from their health providers, whereas for girls PHIV, the comfort is higher with caregivers. However, the messages Girls PHIV+ reported receiving from their providers and caregivers were vague. Both providers and caregivers of Girls PHIV+ are uniquely positioned to provide information to adolescents about sexuality and responsible sex decision-making. Some caregivers and providers may need training to prepare them to provide appropriate and accurate sexual health information to girls PHIV+.

Keywords

perinatal HIV; sexual health communication; mother to child transmission; provider-patient communication; parent-child communication

Introduction

Children who perinatally acquired HIV (PHIV+) in the United States have reached adolescence due to highly active antiretroviral treatment (HAART) (Centers for Disease Control and Prevention [CDC], 2014a, 2014b). Youth PHIV+ deal with HIV-specific physiological issues that challenge their romantic and sexual lives (Bauermeister, Elkington, Robbins, Kang, & Mellins, 2011; Marhefka et al., 2011; Mellins et al., 2009). They experience conflicts around sexual desires (Marhefka et al., 2011)—desiring sexual intimacy and reproduction while protecting their partners and babies. The risk of transmission to partners is greater among youth PHIV+ compared to adults living with HIV (Koenig et al., 2010), therefore it is important to supply them with information to lead healthy sexual lives. Unlike their peers, youth PHIV+ cannot communicate with friends and family about their sexual lives because their network is often unaware of their HIV status (Lam, Naar-King, & Wright, 2007). Few evidence-based interventions for this population exist, partly because few studies have examined their sources of sexual health information and the messages communicated by them. This study describes sexual health communication received by girls PHIV+, compared to girls PHIV− (i.e., exposed perinatally but uninfected (Mellins et al., 2009).

Methods

Girls were recruited from the quantitative parent study (Mellins et al., 2009) and pediatric infectious disease clinics. None refused to participate, but some were scheduled for interviews but didn't show. Eligible girls were 12–16 years old and attended HIV clinics in New York, NY. Girls PHIV+ were aware they acquired HIV perinatally and had no documented significant cognitive impairment. Girls PHIV− were perinatally exposed to HIV and knew it. Informed assent/consent procedures were undertaken. Girls completed a structured interview (Dolezal et al., 2012) and 45–90 minute semi-structured interview.

Audio-recorded interviews were transcribed. Descriptive coding (Sandelowski, 2000) was conducted using NVivo8. Two coders (SM and research assistant) independently identified emergent themes, established reliability (κ ranged from 0.78–0.90), resolved discrepancies through discussion, and completed coding.

Results

Sample characteristics

Participants (Table 1) reflect sociodemographics of PHIV+ cases in New York City (Dolezal et al., 2012; Mellins et al., 2009) and populations served at recruitment clinics.

Sexual health communication sources

Girls PHIV+ and PHIV− reported communicating with caregivers, providers, and others about HIV Knowledge, Transmission Risk, and Sex (HKTS). Greater proportions of girls PHIV+ (80%) reported communicating with an "other;" the highest proportion of girls PHIV− reported communicating with a caregiver (80%). Girls PHIV+ received information from healthcare providers and caregivers in equal proportion (65%).

For girls PHIV+, a provider was the most frequently listed *comfortable* source, followed by caregiver. For girls PHIV−, a caregiver or "other" was the most frequent *comfortable* source. Girls were more *comfortable* receiving sexual health information from her primary caregiver if it was her biological mother (vs. not).

Reasons for comfort/discomfort with sexual health communication sources— The comfortable source did not **judge,** evoke fear of punishment, assume she was "bad" or "immoral" for initiating conversations about HKTS, or prompt concerns of **confidentiality** breaches; they **understood the girl's situation or experiences**. She **valued the sources' input** as "good" or "accurate." Girls preferred sources that discussed HKTS **positive**ly, rather than focusing on risks. Discomfort arose if the girl **did not value input from the source** or the source was **awkward or had difficulty** discussing HKTS.

Sexual health communication messages

Condom messages were most frequently communicated by providers (n=13); slightly less frequently by caregivers (n=9). A sexually active PHIV- girl explained: "She [my doctor] goes, 'No rubber, no loving. …'" (N3051) For Girls PHIV+, condom messages were often the primary focus of sex-related communication. Condom messages were often incomplete, with limited information about how to get, use, or negotiate condoms use. A girl PHIV+ shared: They gave me condoms. …They didn't talk to me about it, they said, 'Be careful… use the condoms, dental dams.' (P5435)

HIV transmission messages were more commonly communicated to girls PHIV+, although girls PHIV− were exposed perinatally and 70% lived with their HIV+ mothers. "[My providers] told me that you can't get it through kissing… they said…you have to be careful, you have to make sure everything is alright with the condom. (P6435)

Unclear safe sex messages, about "being careful" or "protecting yourself," were commonly received, especially for girls PHIV+ (vs. PHIV−; 50% vs. 20%). A girl PHIV− described her mother's messaging: "She said, 'I don't care about you having sex. Make sure you're protected and you know who you're doing it with...'" (N3092) For many girls PHIV+ "being careful" meant to prevent HIV-related harm to others. A girl PHIV+ said, "She [mother] told me about my disease and told me I got to watch when I have sex. … Because I can give it to others." (P6090)

Some girls PHIV- spoke of judgment-laden questions: "My auntie want to know everything. 'So do y'all kiss?' (laughter)… 'You have sex?' I was like, 14, I think. I was like, 'No. I'm a virgin.' She was like, 'I strongly do not believe that.'" (N3051)

Pregnancy prevention was only a common message type for girls PHIV−. Describing a conversation with her mom, a PHIV− girl said: "She gave me all these pamphlets…. 'That girl upstairs is pregnant. I don't want you getting pregnant. … mess up your life.'" (N1329) Neither girls PHIV+ nor PHIV− talked about positive messages related to pregnancy.

Abstinence messages—sometimes the only sex-related messages received—came from caregivers, primarily, and were mostly aimed at girls PHIV− versus girls PHIV+. A sexually

active PHIV− girl described, “She’s like, ‘Don’t have sex.’ …that’s the only thing she’s told me.” (N3051) Most abstinence messages focused on waiting until the girls were “older,” “mature,” or “ready.”

Discussion

Our findings suggest girls PHIV+ and PHIV− may share similar sources of sexual health information, yet they may prefer different sources of sexual health information and may receive different messages. Girls PHIV+ preferred communicating with providers, and girls PHIV− preferred caregivers. Both groups received messages about condoms—and sometimes vague messages about being “careful” and “protecting yourself”. Girls PHIV+ tended to receive messages about protecting *others* from HIV—not preventing pregnancy. Girls PHIV− tended to receive messages about protecting *themselves* and preventing pregnancy.

Our important findings have limitations, including the small sample size, yet qualitative data provide rich information to inform quantitative studies and intervention development. Information was not collected from the communication sources, who may have different recollections. Only girls were studied; similar studies are needed among boys PHIV+.

Caregivers and providers may both have important roles in sexual health communication. Providers can be integral (World Health Organization, 2013), yet provider training may be important—especially for pediatric providers who have less experience educating youth and parents about sex. Caregivers—especially biological mothers—were a preferred source of information for girls PHIV+ and could be great partners in sexual health communication. A biological mother of a girl PHIV+ has an opportunity to provide sexual health information and emotional support based on her experience living with HIV. Adolescents tend to be receptive to sexual health information from their parents (Donaldson, Lindberg, Ellen, & Marcell, 2013), provided they openly communicate (Jaccard, Dodge, & Dittus, 2002). To address potential communication barriers (Edwards, Reis, & Weber, 2013; Lebese, Davhana-Maselesele, & Obi, 2010; Wamoyi, Fenwick, Urassa, Zaba, & Stones, 2010), parents could be provided knowledge, skills, confidence, support and/or parent role models (Edwards et al., 2013; Miller et al., 2011). Educators should acknowledge that maternal-child transmission of HIV may exacerbate discomfort with talking about sex (Mandalazi, Bandawe, & Umar, 2014).

Most girls PHIV+ did not mention hearing empathic messages (Albright & Fair, 2014) regarding their [potential] sexual and pregnancy desires (Ezeanolue, Wodi, Patel, Dieudonne, & Olseke, 2006; Fair & Albright, 2015) or the psychological and interpersonal challenges that may result (Marhefka et al., 2011). Communication sources should take advantage of pre-risk periods by discussing abstinence and condom use to prevent HIV/STI transmission and early/unwanted pregnancy (Echenique et al., 2017; Marhefka et al., 2011). Opportunities for girls PHIV+ to speak freely about their sexual and pregnancy desires and fears (Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009) with a trusted, empathic and knowledgeable adult may facilitate informed sexual behavior and pregnancy planning (Birungi, Mugisha, Obare, & Nyombi, 2009). Discussions that include options for reducing

risk—such as Truvada® to prevent transmission during unprotected sexual encounters with HIV-negative partners (Hosek et al., 2016)— could help increase hope among girls PHIV+ for fulfilling sexual and reproductive lives. Evidence-based interventions that facilitate caregiver communication with children/adolescents PHIV+ about sex (McKay et al., 2004) could be updated to reflect such scientific advances.

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Table 1

Socio-demographics, Sexual Behavior, & HIV Knowledge

	Girls PHIV+ (n=20)	**Girls PHIV− (n=10)**
	Mean (std)	**Mean (std)**
Age	**14.2 (1.196)**	**14.8 (1.135)**
	n	**n**
Race/Ethnicity		
White, Non-Hispanic	0	0
White, Hispanic	6	0
Black, Non-Hispanic	8	6
Black, Hispanic	5	4
Other (Black/White, Non-Hispanic)	1	0
Primary Caregiver		
Biological mother	14	7
Other caregiver	6	3
Sexual Experience		
Vaginal sex	2/19	4
Anal sex	1/19	0
Oral sex *	3/19	5
HIV Knowledge		
Vaginal sex	18	9/9
Anal sex	9/18	4/9
Oral sex	12	2/9

*X^2=p>.05