"I definitely want grandbabies":

Guardians of adolescents with perinatally-acquired HIV reflect on dating and childbearing Cynthia D. Fair, LCSW, DrPH1; Jamie Albright, BA2; Devon Clark3, BA; Bethany Houpt, BA4

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BACKGROUND

- Approximately 9,100 individuals with PHIV live in the U.S. today, the majority of whom are sexually active (Mellins et al. 2011).
- Parents' perspectives can influence the sexual and reproductive decisions of their offspring (Martinez, Abma, & Copen, 2010).
- Little is known about the conversations between guardians and their adolescents with PHIV about sexual behavior, romantic relationships, and childbearing.

Study Purpose

- Discover the kinds of conversations guardians were having with their adolescents with PHIV regarding sex, dating, disclosure, and childbearing.
- Explore the perspectives of guardians concerning their adolescent with PHIV becoming a parent.

METHODS

Participants:

Semi-structured interviews lasting approximately 45 minutes with 18 guardians of adolescents with PHIV were recorded and later transcribed.

Questions included:

- What topics related to dating have you discussed with your child? (e.g. conversations about sex, pregnancy, etc.)
- What advice would you give another parent whose child has HIV about their son/daughter dating?
- What do you think about your son/daughter having children in the future?
- What, if any, concerns do you have about your son/daughter becoming a parent in the future?
- Guardian's understanding of the risk of mother-tochild-transmission (MTCT) was also assessed.

Analyses:

• Transcripts were entered into Atlas.ti. Data were analyzed using traditional qualitative methods

RESULTS

Demographic features (n=18) Guardians Biological mother 9 Relative 5 Foster/adoptive parents 4 African American 9 Mean age 45.4 years Adolescents Female 11 Pregnant/parenting 3 Mean age 20.1 years

Conversations about Sex and Dating

• All guardians felt that their adolescents with PHIV needed to be engaged in conversations about sex and dating, even if the child preferred not to speak specifically with them.

"I talk to him about it but it's like, "Ew Mom, you're so gross." And I said, "Okay, well talk to Dr. J. then." -biological mother

• Specific conversations about sex and dating focused on the adolescent's need to use protection for themselves as well as their partner (condoms, birth control, or both).

"Always use protection because you are also susceptible to anything that they have. You don't get anything on top of what you have" -biological mother

• Most of the guardians waited to talk about sex until they learned their child was dating or sexually active.

Disclosure

• Relatives frequently cautioned against disclosure.

"All of her friends know that she has HIV—all of her friends. And consequently for her, it's very hard to find somebody steady that will stay with her or will—don't talk about marrying because nobody would marry her."—maternal aunt

• Biological mothers' responses were mixed regarding their child's disclosure to parnters; their own experiences with disclosure influenced how open or closed they taught their child to be with their HIV status.

"I said you don't have to tell the person cause if they're not going to be your husband you're not going to be telling everyone that I'm HIV positive and then they're spreading your business all over town" -biological mother

"When I first told her [my daughter] she didn't understand and she wanted to know why this happened to her, why did her daddy do this....But I want you to be honest with somebody else, because I don't want you to do to somebody else what was done with me That's a bad pill to swallow." --biological mother

• Adoptive/foster parents emphasized the importance of disclosure.

Becoming a Parent

• The majority of guardians wanted their child to have children in the future

"I know she says three or four, but I want her to at least have one child, somebody that she can love like I have loved her" -biological mother

• However, several reservations were expressed.

"We just ask her to consider even the slightest possibility of putting a child in the same position she's in and is that something she really wants to do?" -adoptive mother

Qualitative Themes: Childbearing

In support of childbearing

- * Adolescent will be a good parent
- * Adolescent wants to have children someday
- * Part of normative development
- * Future partner will want children
- * Decreased HIV-related stigma

Opposed to childbearing

- * Concerns over their adolescent's health
- * Risk of transmission
- * Fear that their adolescent would not be able to raise a child due to illness or death

Knowledge of MTCT

- None of the biological mothers knew the risk of MTCT (1-2%). However, many were able to identify preventative measures.
- Most relative guardians stated they did not know the risk of MTCT and based their understanding of MTCT on the pregnancy outcome of their relative whose child they now cared for.
- All of the foster/adoptive mothers knew the risk of MTCT and, that with treatment, the likelihood of transmission was extremely low.

CONCLUSIONS

- Results indicated that the type of caregiver and the caregiver's views and experiences surrounding HIV, influenced the content of the conversations and messages conveyed.
- Research conducted in the 1990's found that many guardians kept their child's HIV status private as a means to protect against HIV-related stigma (Santacroce et al., 2002). Similarly, several guardians advised their child not to disclose to their friends or romantic partners.
- Relatives who are guardians need extra support when raising a child/adolescent with PHIV. Their negative views and past experiences with influence the information shared with their adolescent. Non-disclosure could adversely impact the health of their adolescent and keep them from engaging with others (Calabrese et al., 2012).
- It is imperative to provide sexual education and accurate information regarding MTCT to guardians because they are an important source of information for their adolescent.

References Calabrese, S., Martin, S., Wolters, P., Toledo-Tamula, M., Brennan, T., & Wood, L. (2012). Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS Care*,

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