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Reproductive health perspectives of young women with perinatally and behaviourally acquired HIV: A qualitative study

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Abstract

Introduction: The aim of this study was to describe the sexual and reproductive goals of female adolescents with human immunodeficiency virus (HIV) in an urban cohort and decipher if they vary depending on the mode of HIV acquisition.

Methods: We conducted in-depth qualitative interviews with 25 Black and/or Hispanic/Latinx female adolescents living with HIV (14 perinatally, 11 behaviourally acquired) aged 17–25 years who have access to care and antiretroviral therapy at an urban public hospitals (NYC, NY). Interviews were transcribed, coded and analysed using thematic analysis.

Results: Interviews demonstrated that access to antiretroviral therapy and HIV disclosure to a sexual partner were critical aspects of sexual health for the majority of participants. Persons with perinatal HIV defined motherhood as a source of self-validation and were confident that antiretroviral therapy prevents HIV transmission. Persons with behaviourally acquired HIV viewed their status as an insurmountable barrier that will prevent them from attaining sexual intimacy

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AUTHOR CONTRIBUTIONS

Research concept: Jessica Atrio, Jacob Abadi, and Dana Watnick. *Design/research tools:* Jessica Atrio, Dana Watnick, and Melissa Peskin. *Data collection (interviews):* Julie Gutierrez, Lizelle Comfort, and Jessica Atrio. *Analysis:* Lizelle Comfort, Jessica Atrio, and Dana Watnick. *Manuscript:* Jessica Atrio, Lizelle Comfort, Dana Watnick, Julie Gutierrez, Jacob Abadi, and Melissa Peskin.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ETHICS STATEMENT

This study received Institutional Review Board approval from Albert Einstein College of Medicine before participant recruitment. Written informed consent or assent, if under 18 years of age, was obtained from all participants. Research data may be made available upon request.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

with a partner and expressed persistent concerns about HIV transmission during pregnancy despite reassurance from medical providers.

Conclusion: Sexual and reproductive perspectives of adolescents/young women living with HIV are multifactorial, highly stigmatized, and likely influenced by the mode of HIV acquisition. This population may benefit from patient-centred care models, including sexual health counselling that addresses sexual agency, intimacy, parenting and transmission risk reduction.

Keywords

adolescents; family planning; HIV; pregnancy; qualitative research; reproductive health; sexual health

INTRODUCTION

Approximately 37 million people are living with human immunodeficiency virus (HIV).¹ Adolescents aged 12–24 years account for over 40% of new infections worldwide. In the United States, 1.2 million people are living with HIV,² and over 9500 were perinatally acquired.³ With improved antiretroviral therapy, individuals with perinatally acquired HIV are now of reproductive age and face unique challenges as they navigate sexual relationships, fertility and pregnancies.^{4,5} They have often contended with repeated hospitalizations, the stigma of HIV and the anxiety associated with the possibility of transmission to others.^{6,7} Despite concerns about transmission, the majority of persons with perinatally acquired HIV want to have children.^{7,8} Adolescents with behaviourally acquired HIV also experience unique health challenges, including lapses in medication adherence, and poor linkage to and retention in care compared to older adults living with HIV.⁹ Stigma, judgement and provider discomfort can contribute to limited or inadequate sexual and reproductive health care among adolescents with HIV.¹⁰

Multiple studies and national data suggest that youth living with HIV are at substantial risk for teen pregnancy and unintended pregnancy.¹¹ Some cohorts have reported high rates of pregnancy among adolescents with perinatally acquired HIV as well as a high risk of unplanned pregnancy.^{5,12} Other research has reported a median age of 19.5 years at first pregnancy among persons with behaviourally acquired HIV, with many having a second pregnancy by age 24 years.¹³

We conducted qualitative interviews to describe the sexual and reproductive perceptions, goals and needs of adolescents living with HIV. Attention was paid to how the mode of HIV acquisition may influence reported findings. An understanding of these issues may guide provider communication, goal setting, shared decision making and risk mitigation. Furthermore, acknowledgement and integration of these needs into our care setting can offer opportunities for meaningful patient-centred care.

MATERIALS AND METHODS

Recruitment

Recruitment occurred through provider referrals and hospital network announcements posted in paediatric, infectious disease and women's health clinics affiliated with three hospital systems in the Bronx, NY. Inclusion criteria were age 14–25 years, English proficiency, absent medical conditions that would preclude future childbearing and no self-reported pregnancy at the time of interview. We used a stratified purposive sampling approach to ensure a minimum of 10 participants with perinatally acquired HIV and 10 with behaviourally acquired HIV for comparative purposes; recruitment ended once we achieved thematic saturation on key themes per strata. Interested participants contacted recruiters directly; among those who expressed interest and met inclusion criteria, all were arranged for an interview. Written informed consent or assent, if under 18 years of age, was obtained from all participants. The study was approved by the home Institutional Review Board.

Data collection

Three trained interviewers conducted in-depth, in-person one-on-one qualitative interviews with participants between December 2014 and August 2015. A semistructured interview guide addressed sexual health attitudes, pregnancy/family planning intentions and the impact of HIV status on sexual and reproductive goals and relationships. The interview guide was reviewed by behavioural scientists and was piloted with six participants who met the inclusion criteria. Highlighted questions from the interview guide included plans for pregnancy, partner/outside influence on pregnancy intentions and participant reported opinions about pregnancy and HIV. Persons were also asked questions related to their family environment, birth control use, past relationships, and their medical provider team. Interviews took place in private rooms in recruitment medical facilities and were recorded and transcribed. Data from one interview with a participant with perinatally acquired HIV was unable to be analysed due to equipment malfunction.

Data analysis

Using thematic analysis methodology, interview transcripts were independently reviewed by two analysts to identify common themes, which were compiled into a preliminary codebook.¹⁴ Preliminary coding inconsistencies were resolved by consensus and a third investigator, who reviewed select transcripts. This iterative process resulted in a finalized and condensed codebook, which was reapplied to all interview transcripts. The web-based coding tool, Dedoose,¹⁵ was used. Participants were assigned pseudonyms as reported in the results.

RESULTS

Demographics

Twenty-five participants were interviewed, including 14 with perinatally acquired HIV and 11 with behaviourally acquired HIV. Interview recordings lasted approximately 40 min (range: 13–78 min). Participants were 17–25 years old (median ages: 21 for perinatally acquired and 23 for behaviourally acquired). Persons were identified as Black and/or

Hispanic (Table 1). The median age of HIV disclosure for participants with perinatally acquired HIV was 12 years and diagnosis for behaviourally acquired HIV was 18 years. For young women with perinatally acquired HIV, caregivers and/or medical providers informed them of their HIV status; disclosure refers to the age they were first made aware of their status. Participants with behaviourally acquired HIV through heterosexual transmission. Twelve young women were in sexual and romantic relationships at the time of the interview. Most had experienced penile–vaginal penetrative sex (including 12/13 perinatally acquired HIV) and most were in heterosexual relationships. Women with behaviourally -acquired HIV experienced more lifetime pregnancies and had more living children than did women with perinatally acquired HIV. All but one participant desired future pregnancy, yet few were trying to conceive at the time of the interview. Experience with contraception was common—10 (77%) perinatally acquired, 8 (73%) behaviourally acquired, and injectable progestin was the most common method used. Most had disclosed their HIV status to sexual partners—11 (85%) perinatally acquired and 9 (82%) behaviourally acquired. None reported perinatal transmission to their children.

Cross-cutting themes

The following themes were present across the sample:

Managing HIV medically was essential to parenting, sexual and reproductive health—Women consistently valued their access to antiretroviral therapy, relying upon it to maintain their general health, avoid hospitalization and remain free of opportunistic infections, although some cited a dependence on medication as a constant reminder of their diagnoses. Even despite regular access to care, struggles with side effects, historic nonadherence and recurrent hospitalizations were cited as regular challenges. Furthermore, these challenges were cited as barriers to the ability to parent. The following testimony gives a first-hand account:

I was gonna sign myself into a nursing home... called ICC, it's for basically teenagers... my son was a year and a half at the time and I was really, really sick. I haven't been taking my medicines for about a year at that time...I wasn't gonna be able to take care of him if I couldn't take care of myself, so I had to get myself strong in order for me... to take care of him. (Odessa, age 22 years, perinatally acquired)

Despite challenges with adherence, parenthood was viewed as motivation to remain healthy and superseded potential lapses in HIV care:

[My daughter] likes to help me crush it up cause I can't swallow the pills... she even reminds me sometimes, *mommy, you have to take your medicine*, and I'm like, *yes baby, right now I'm doing it*. She's...my reminder to keep myself going. (Jaclynn, age 24 years, behaviourally acquired)

Young women with perinatally acquired HIV were treated by paediatric infectious disease doctors, many described a lifelong relationship with their providers:

It was just me and my sister and my mom helping me through the process [of pregnancy] and of course my doctors and stuff. (Odessa, age 22 years, perinatally acquired)

Women with perinatally acquired HIV often had access to peer groups, support staff including social workers, and subsidiary benefits provided by their care centres. Conversely, women with behaviourally acquired HIV were often treated in adult infectious disease clinics, by rotating physicians (and reported a lack of continuity with care providers) and in environments that take care of predominantly older demographic:

I've been here since day one... they've gone through a lot of doctors and social workers, but as far as like the original team that was here when I came in, they really helped me get through it. (Marisol, age 25 years, behaviourally acquired)

The burden of disclosure—HIV disclosure across groups was 'that borderline' to overcome when in a sexual relationship, and was associated with a variety of stressors. Fears regarding disclosure and/or experience with rejection, judgement or public persecution as a result of their status were cited by many women in both groups—8 (62%) perinatally acquired and 6 (55%) behaviourally acquired. This stigma led many participants to no longer disclose to sexual partners or persons in their social networks:

He told me *okay, well I have to think about my kid at the end of the day, and the thing is if I wanted to be with you and I wanted to have a kid with you, I don't know if I could accept that my kid was to come out like that.* And I was like *okay, no problem, definitely.* (Jaclynn, age 24 years, behaviourally acquired)

For others, disclosure was navigated only after a relationship had gained a threshold level of intimacy, commitment or duration:

I won't sleep with them right away, and I'll try to get to know them a little bit and kind of make them fall for me... first try to feel out... how closed-minded or open-minded they are, like you have to like feel a person out first. But if somebody that I'm just like sleeping with and really don't want anything with, I'll just use protection and just leave it at that. (Marisol, age 25 years, behaviourally acquired)

So as to mitigate disclosure-related anxiety, in both groups some women remained in relationships longer than they might have otherwise because a new relationship meant a new obstacle of disclosure to another person:

I want to fix this relationship with me and him... if somehow we could just talk and work things out, if not then I'll just like, wait a while... maybe try to find somebody that will maybe have the same thing as me so I don't have to go through explaining and misunderstanding and go through the whole process again. (Shantelle, age 22 years, perinatally acquired)

Perinatally acquired themes

The following themes emerged predominantly within the perinatally acquired group:

Motherhood as a path to redemption—Motherhood repeatedly surfaced as an opportunity to rewrite one's own parenting script, a chance to succeed and claim self-worth. Multiple women described complex and often strained relationships with their mother or caregiver: 10 women living with perinatally acquired HIV (77%) were not raised by their biological mothers, in contrast to 3 women with behaviourally acquired HIV (27%). Multiple women with perinatally acquired HIV stated they are striving to parent in a way that their own mother could not:

I didn't have a motherly bond with my mom, so I want my son to have a mother, I want my son or daughter to have a mother. (Destiny, age 22 years, perinatally acquired)

The blessing is...you about to give birth to a wonderful life, and even though like if your life wasn't what you want it to be you can make your child's life...like a new start. (Desiree, age 21 years, perinatally acquired)

Motherhood was found to be a positive and powerful source of pride, accomplishment and life purpose.

The kid's gonna be looking to you for a bunch of things you know like nurture, and food, and attention, and that...would mean the most to me 'cause then I'll feel like, okay I have a purpose'. (Tiffany, age 21 years, perinatally acquired)

The concepts of parenting and pregnancy were identified as valued roles that fit within a framework of life accomplishments, aspirations and goals.

I wanna finish my education and get a good job, get married, then it will come. And [my parents are] just like, *I didn't do that when I had you*, and I'm like, well that's you, but...I wanna have a father for my son or my daughter, you know? Have a home, you know. (Tonya, age 19 years, perinatally acquired)

Current medicine will minimize HIV risk—While fleeting concerns of vertical transmission remained, all but one young woman with perinatally acquired HIV stated the unlikely risk would not change plans for pregnancy and parenthood. Furthermore, women were knowledgeable that advances in HIV treatment were a crucial component of their ability to succeed in achieving pregnancy and minimizing the risk of transmission to their children:

Back in 1992 I don't think I'd be talking about... having a child because medications... weren't what they are now, so you know odds of a kid coming out with HIV would've been extremely high, and I don't think I'd wanna put that on a child. But now that...it can be prevented, yeah it's an exciting thought. (Tiffany, age 21 years, perinatally acquired)

Advances in HIV care have further changed the paradigm for how persons living with perinatally acquired HIV think about their fertility, families and identity.

The crazy thing about it is that me and my younger sister have the same parents... and it's crazy to me ... how can we both come from the same two people and I'm

the only one who has it... medicine makes a big difference in the world. (Odessa, age 22 years, perinatally acquired)

I was born in '93, so back then they didn't have nowhere near the as far as like the knowledge of prevention and...passin' it on to the baby...so my mother was just worried that... with the baby...of course she'll have [HIV], and basically I'll be in the same situation... But...I really wasn't worried about that, because I was doing what I had to do and to prevent her from getting it ...she was just worried that like I wasn't givin' her the medicines and stuff, and it was no problem. (Ebony, age 21 years, perinatally acquired)

Behaviourally acquired themes

The following themes emerged in the behaviourally acquired group:

The loss of the 'natural' fecund, sexual self—Nearly half of women living with behaviourally acquired HIV perceived their status as a major obstacle to sexual intimacy and conception:

I don't want anybody to go through what I went through, becoming positive, so I wouldn't put anybody at risk of becoming positive just so I can have a family. So for me, being positive kinda made it feel like...that was the end, that there was no family planning, there was none of that. (Xenia, age 25 years, behaviourally acquired)

Other women with behaviourally acquired HIV lamented that even with a healthy pregnancy outcome, there would be a difference in parenting experience because of HIV. They cited the need to medicate their infant with antiretroviral therapy, the inability to breastfeed (so as to reduce the risk of maternal transmission) and concerns about whether to disclose their HIV status to their children as factors that impacted their reproductive and family goals:

I liked the breastfeeding of my daughter that was something I loved doing. If I was to have a kid and it came out just fine, I couldn't do that. So think that would like break the bond between me and my child, but like I would still love my kid no matter what, but... it really did bother me. (Jaclynn, age 24 years, behaviourally acquired)

HIV interferes with making a baby naturally—Assisted reproductive technology, to reduce the risk of transmission in serodiscordant partners, was addressed in five (45%) of behaviourally acquired interviews. Technologies were described as 'turkey basters' and some stated that medical providers recommended these techniques. All participants with behaviourally acquired HIV found these methods to be unnatural, unpleasant, financially inaccessible or restigmatizing:

It's invasive. Like it's different opening your legs to have sex, like even when I go to the GYN, I feel a little awkward to... have somebody in my vagina, and still talking to me at the same time? It's different to having sex, and you know enjoying the moment, you know you're in it...this is not sex. (Shanice, age 23 years, behaviourally acquired)

Scepticism about artificial insemination prevailed:

It's been hard for me to get pregnant...let's say I wanna get pregnant, get inseminated...what is there out there that my insurance will pay for? It's not out there...you have to see a doctor, and your doctor don't even know, you have to see a different doctor, or get a referral to someone else. (Marisol, age 25 years, behaviourally acquired)

Some women with behaviourally acquired HIV reported receiving information about 'naturally' conceiving or pursuing pregnancy 'the regular way' (via condomless sex) from peers living with perinatally acquired HIV from support groups.

I went on a retreat...with kids who were positive, were born by it, and they have kids, and I'm like *yo how'd you do it*, they was like, *I just had regular sex and I make sure to stay on my meds*. (Shanice, age 23 years, behaviourally acquired)

One woman, who acquired HIV through a previous partner, described how having HIV led her to choose a seroconcordant partner for conception:

I met [my baby's] dad. And then it was more of a push to say we can have a family, we can have a normal healthy child, and if I'm gonna try with anybody I would rather try with somebody that's in the same situation that I'm in. I don't have to worry about bringing them something new or, anything like that. And that plays like such a huge difference, especially when you feel like...your world is over. (Xenia, age 25 years, behaviourally acquired)

Decreasing risks by having fewer children—Substantial anxiety regarding HIV transmission persisted even when women with behaviourally acquired HIV reported that they were educated by providers that the risk of maternal and sexual transmission remains <1% with adequate medical therapy:

Throughout my whole pregnancy I prayed like yo, I...hope she doesn't get it, and even when... I gave birth, they gave her medicine for like six weeks to make sure, right on time I would give it to her all the time, all the time to make sure. (Carla, age 20, behaviourally acquired)

Women living with behaviourally acquired HIV reconciled their family planning goals using a variety of mental and behavioural modifications. Some planned to have smaller families than they would otherwise, reasoning that fewer pregnancies conferred a more acceptable risk profile:

I think it's a very slim chance that I have like of regular family and a baby... I was thinking maybe two to three... And I was like okay that would be my little family, but now it's like *ah* you'll be lucky if you have one child... now if I don't have a child, then I don't have to worry about anything going wrong or happening. (Rashelle, age 19 years, behaviourally acquired)

Some women with behaviourally acquired HIV demonstrated concern that each future pregnancy substantially increases the cumulative possibility of giving birth to an infant with

HIV. This was further associated with the belief that women living with HIV who pursue multiple pregnancies are ‘selfish’ for knowingly placing children at presumed elevated risk.

[I want] one more, um because... the risk factor for the child is still there, [my daughter is] completely negative and super healthy, but it’s still something that’s a possibility, so I think I’d be selfish to wanna have more than two. (Xenia, age 25 years, behaviourally acquired)

DISCUSSION

In this article, we describe the reproductive perspectives of young women living with HIV and their beliefs regarding sexual intimacy, pregnancy and parenting (Figure 1). Furthermore, we identify how these findings may be informed by their mode of HIV acquisition (perinatally acquired vs. behaviourally acquired). While a previous study of providers for individuals with perinatally and behaviourally acquired HIV suggest that there are differences in identity, sexuality, and adeptness in accessing health care,¹⁶ this paper is unique in that participants were young women living with both perinatally and behaviourally acquired HIV, allowing for first-hand testimonies and comparisons.

Like other studies of women with HIV, disclosure to sexual partners is a topic of paramount anxiety and concern;¹⁷ concerns regarding transmission caused many of our participants to either selectively disclose their HIV status or refrain from sexual relationships altogether. Women with perinatally acquired HIV consistently expressed confidence in antiretroviral medications, such that sexual and maternal–infant transmission can be minimized if women ‘do the right thing’, supporting previous publications regarding this group.^{7,18} Many women further reported pregnancy and parenting as important aspects of their HIV care, a finding consistent with prior literature demonstrating high antiretroviral adherence in pregnancy.^{19,20} Indeed, the ability to conceive, gestate and parent was a tremendous measure of self-worth and success among participants with perinatally acquired HIV. This association of motherhood with personal fulfilment specific to our perinatally acquired group is consistent with other literature⁸ and emphasizes that a strength-based, patient-centred preconception counselling and sexual health service model will be well received in this population.

Women living with behaviourally acquired HIV, conversely, expressed heightened concerns about transmission risk to children. Their HIV status unhinged their reproductive trajectory, with perceived risks of transmission and the impaired ability for ‘natural’ conception at the forefront of discussions of sexual identity. Fear of maternal–infant transmission remains a critical factor in pregnancy planning for women with behaviourally acquired HIV.^{21,22} In our sample and other published literature, these fears were associated with ‘risk overestimation’, with transmission risk being labelled as a ‘50/50 chance’ with each pregnancy,^{22,23} despite the actual risk being less than 1:100 000 with appropriate medical interventions.²⁴ The concept of increasing risk with each pregnancy was found within our behaviourally acquired group, who further believed that exposing a pregnancy to even minor transmission risk is a ‘selfish’ decision.

Despite the intense anxiety about maternal transmission among participants with behaviourally acquired HIV, most resolved that they would still want to become pregnant and parent in the future. This conceptual dissonance was reconciled or mitigated by persons who accepted a smaller family size and/or a seroconcordant partner. As in previous research, many of our young women with behaviourally acquired HIV cited assisted reproductive technology techniques, such as insemination and timed intercourse, as unnatural, expensive and ineffective.²⁵

Some differences in perspectives among acquisition groups regarding the efficacy of medication and risk of transmission may be partially informed by their relationships with their medical providers (paediatricians vs. adult medicine), duration of living with HIV, exposure to/experience with therapy, stigma associated with mode of acquisition and access to peer social support groups. Despite a paucity of research comparing care for women with perinatally and behaviourally acquired HIV, evidence outlines the clear benefits that adolescent and paediatric persons with HIV receive from multidisciplinary clinic services, maintaining treatment team continuity and easy access to various providers.²⁶ With a high census of young women and age-appropriate reproductive health services, facilities that mainly serve adolescents with perinatally acquired HIV may better address the reproductive and developmental needs of adolescents with behaviourally acquired HIV.

Limitations of this study include the exclusion of young men living with HIV, underrepresentation of women in same-sex relationships and the sampling of participants from medical facilities who were already engaged in care. Additionally, some participants shared clinics, providers and/or peer groups and may therefore express similar perspectives. Future studies should include views of young men, transgender and gender-nonconforming individuals, as well as nonheterosexual participants who desire families. Cohorts of adolescents with perinatally and behaviourally acquired HIV are not as common in the US when compared to many other nations that carry the highest burden of HIV morbidity. The results of this manuscript may not be generalizable to a setting where persons do not have access to antiretroviral therapy, prenatal care or contraception.

CONCLUSION

Our findings suggest that the mode of HIV acquisition may influence reproductive goals and intentions. Every effort should be made to expand comprehensive care and support models to include all adolescents living with behaviourally acquired HIV so as to combat stigma, support outreach, coordinate referrals, support groups, and continuity of care. Sexual and reproductive care should be offered to adolescents living with HIV to address fertility, intimacy and parenting goals. It is critical that providers communicate that with adherence to adequate therapy, persons with HIV can become pregnant with a very low risk of transmission to a serodiscordant partner or an infant. Barriers to the use of assisted reproductive technologies include cost and stigma.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

REFERENCES

1. World Health Organization. Summary of the Global HIV Epidemic, 2020. World Health Organization; 2020.
2. Hall HI, An Q, Tang T, et al. Prevalence of diagnosed and undiagnosed HIV Infection—United States, 2008–2012. *Morb Mortal Wkly Rep.* 2015;64(24):657–662.
3. Centers for Disease Control and Prevention. HIV Among Pregnant Women, Infants, and Children. Centers for Disease Control and Prevention; 2017. <https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html>
4. Hatfield-Timajchy K, Brown JL, Haddad LB, Chakraborty R, Kourtis AP. Parenting among adolescents and young adults with human immunodeficiency virus infection in the United States: challenges, unmet needs, and opportunities. *AIDS Patient Care STDS.* 2016;30(7):315–323. doi:10.1089/apc.2016.0067 [PubMed: 27410495]
5. Munjal I, Dobroszycki J, Fakioglu E, et al. Impact of HIV-1 infection and pregnancy on maternal health: comparison between perinatally and behaviorally infected young women. *Adolesc Health Med Ther.* 2013;4:51–58. [PubMed: 24600295]
6. Mellins CA, Malee KM. Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. *J Int AIDS Soc.* 2013;16(1):18593. doi:10.7448/ias.16.1.18593 [PubMed: 23782478]
7. Fair CD, Albright JN. “I definitely want kids, but I think the risks are pretty high”: fertility desires and perinatal HIV transmission knowledge among adolescents and young adults with perinatally-acquired HIV. In: Liamputtong P, ed. *Children and Young People Living with HIV/AIDS.* Springer; 2016:191–206. doi:10.1007/978-3-319-29936-5_10
8. Fair CD, Albright JN. “Someone needs to carry on the legacy of my family”: childbearing perceptions among adolescents and young adults with perinatally-acquired HIV. *Int J Sex Health.* 2015;27: 457–468. doi:10.1080/19317611.2015.1038677)
9. Zandoni BC, Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS.* 2014;28(3):128–135. doi:10.1089/apc.2013.0345 [PubMed: 24601734]
10. Finocchiaro-Kessler S, Bastos FI, Malta M, et al. Discussing childbearing with HIV-infected women of reproductive age in clinical care: a comparison of Brazil and the US. *AIDS Behav.* 2012;16(1): 99–107. doi:10.1007/s10461-011-9906-1 [PubMed: 21359541]

11. Centers for Disease Control and Prevention. Vital signs: teen pregnancy—United States, 1991–2009. *MMWR Morb Mortal Wkly Rep*. 2011;60(13):414–420. [PubMed: 21471949]
12. Millery M, Vazquez S, Walther V, Humphrey N, Schlecht J, Van Devanter N. Pregnancies in perinatally HIV-infected young women and implications for care and service programs. *J Assoc Nurses AIDS Care*. 2012;23(1):41–51. doi:10.1016/j.jana.2011.05.008 [PubMed: 21820325]
13. Agwu AL, Jang SS, Korthuis PT, Araneta MRG, Gebo KA. Pregnancy incidence and outcomes in vertically and behaviorally HIV-infected youth. *JAMA*. 2011;305(5):468–470. doi:10.1001/jama.2011.79 [PubMed: 21285423]
14. Boyatzis R. *Transforming Qualitative Information: Thematic Analysis and Code Development*. SAGE; 1998.
15. SocioCultural Research Consultants, LLC. Dedoose (Version 7.0.23), 2016. <https://www.dedoose.com>
16. Fair CD, Albright JN, Varney O. US provider perceptions of differences in the sexual and reproductive health needs of adolescents with perinatally acquired and behaviorally acquired HIV: a mixed methods study. *AIDS Patient Care STDS*. 2019;33(10):440–448. doi:10.1089/apc.2019.0108 [PubMed: 31524504]
17. Greenhalgh C, Evangeli M, Frize G, Foster C, Fidler S. Intimate relationships in young adults with perinatally acquired HIV: a qualitative study of strategies used to manage HIV disclosure. *AIDS Care*. 2016;28(3):283–288. doi:10.1080/09540121.2015.1093594 [PubMed: 26444656]
18. Ezeanolue EE, Wodi AP, Patel R, Dieudonne A, Oleske JM. Sexual behaviors and procreational intentions of adolescents and young adults with perinatally acquired human immunodeficiency virus infection: experience of an urban tertiary center. *J Adolesc Health*. 2006;38(6):719–725. doi:10.1016/j.jadohealth.2005.06.015 [PubMed: 16730601]
19. Nachega JB, Uthman OA, Anderson J, et al. Adherence to antiretroviral therapy during and after pregnancy in low-income, middle-income, and high-income countries: a systematic review and meta-analysis. *AIDS*. 2012;26(16):2039–2052. doi:10.1097/QAD.0b013e328359590f [PubMed: 22951634]
20. Mukose AD, Bastiaens H, Makumbi F, et al. What influences uptake and early adherence to option B+ (lifelong antiretroviral therapy among HIV positive pregnant and breastfeeding women) in central Uganda? A mixed methods study. *PLoS One*. 2021;16(5):e0251181. doi:10.1371/journal.pone.0251181 [PubMed: 33951109]
21. Craft SM, Delaney RO, Bautista DT, Serovich JM. Pregnancy decisions among women with HIV. *AIDS Behav*. 2007;11(6): 927–935. doi:10.1007/s10461-007-9219-6 [PubMed: 17323122]
22. Haddad LB, Machen LK, Cordes S, et al. Future desire for children among women living with HIV in Atlanta, Georgia. *AIDS Care*. 2016;28(4):455–459. doi:10.1080/09540121.2015.1114996 [PubMed: 26702869]
23. Kirshenbaum SB, Hirky AE, Correale J, et al. “Throwing the dice”: pregnancy decision-making among HIV-positive women in four U.S. cities. *Perspect Sex Reprod Health*. 2004;36(3):106–113. doi:10.1363/psrh.36.106.04 [PubMed: 15306272]
24. Nesheim SR, Wiener J, Fitz Harris LF, Lampe MA, Weidle PJ. Brief report: estimated incidence of perinatally acquired HIV infection in the United States, 1978–2013. *J Acquir Immune Defic Syndr*. 2017;76(5):461–464. doi:10.1097/QAI.0000000000001552 [PubMed: 28991886]
25. Ngure K, Baeten JM, Mugo N, et al. My intention was a child but I was very afraid: fertility intentions and HIV risk perceptions among HIV-serodiscordant couples experiencing pregnancy in Kenya. *AIDS Care*. 2014;26(10):1283–1287. doi:10.1080/09540121.2014.911808 [PubMed: 24779445]
26. Lam PK, Fidler S, Foster C. A review of transition experiences in perinatally and behaviourally acquired HIV-1 infection; same, same but different? *J Int AIDS Soc*. 2017;20(suppl 3):21506. doi:10.7448/IAS.20.4.21506 [PubMed: 28530044]

Practitioner points

- Providers must acknowledge that young women living with human immunodeficiency virus (HIV) have basic sexuality concerns as well as pregnancy aspirations.
- Providers should recognize and communicate that, with the right immunovirologic parameters, women living with HIV can become pregnant with a very low risk of transmission to a serodiscordant partner and/or infant.
- HIV providers, particularly those caring for patients with behaviourally acquired HIV, should address the stigma that their patients may experience, and provide education and support when addressing disclosure, sexual activities and family planning goals. Consider referral to perinatal HIV centres, which may be more focused on a holistic approach to HIV care for young women.

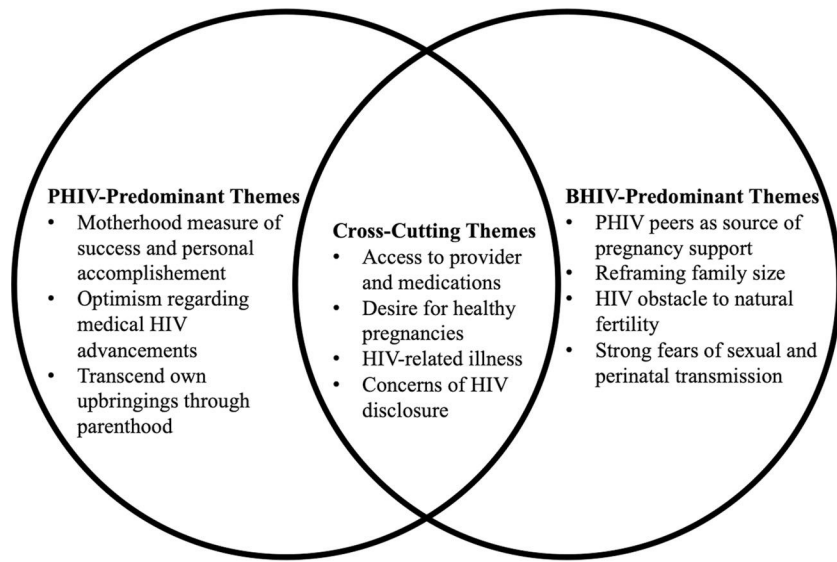


FIGURE 1. Predominant themes found among young women with perinatally acquired HIV (PHIV) and behaviourally acquired HIV (BHIV)

TABLE 1

Demographic characteristics of participants with perinatally acquired HIV and behaviourally acquired HIV

	Perinatally acquired HIV (<i>n</i> = 13)	Behaviourally acquired HIV (<i>n</i> = 11)
Age ^a	21 (17–23)	23 (19–25)
Race ^{b,c}	Black 77% (10)	Black 73% (8)
	Hispanic 23% (3)	Hispanic 27% (3)
HIV-related factors		
Age at HIV disclosure/ diagnosis ^a	12 (5–16)	18 (15–22)
Years lived aware of HIV status ^a	9 (5–16)	4 (1–8)
Reported HIV-related illness and/or hospitalization ^c	46% (6)	45% (5)
Reproductive profiles		
In current sexual relationship ^c	54% (7)	45% (5)
Ever pregnant ^c	46% (6)	73% (8)
Total children	4	6
Total pregnancies	8	16

Abbreviation: HIV, human immunodeficiency virus.

^aMedian (range).^bRace was self-reported by study participants, and race categories (Black and Hispanic) were defined by investigators. Racial information was included to provide sociodemographic information for our participants.^cPercentage (number of participants).