

## The Intersection Between Women's Reproductive Desires and HIV Care Providers' Reproductive Health Practices: A Mixed Methods Analysis

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### **Abstract:**

*Background:* HIV-positive women in the United States can have healthy pregnancies and avoid transmitting HIV to their children. Yet, little is known about the extent to which HIV care providers' reproductive health practices match women's pregnancy desires. Accordingly, we explored young HIV-positive women's pregnancy desires and reproductive health behaviors and examined reproductive health information offered by HIV care clinics. *Methods:* A mixed-method analysis was conducted using data from a 14-site Adolescent Medicine Trials Network (ATN) study. We conducted descriptive statistics on data from 25 HIV-positive women (e.g., demographics, pregnancy desires, and sexual- and health-related behaviors). Qualitative interviews with 58 adolescent and adult clinic providers were analyzed using the constant comparative method. *Results:* About half of the women reported using reproductive health care services (i.e., contraception and pregnancy tests) (n = 12) and wanted a future pregnancy (n = 13). Among women who did not desire a future pregnancy (n = 5), three used dual methods and two used condoms at last sexual encounter. Qualitative themes related to *clinics' approaches to reproductive health* (e.g., "the emphasis...is to encourage use of contraceptives") and *the complexity of merging HIV and reproductive care* (e.g., "We [adolescent clinic] transition pregnant moms from our care back and forth to adult care"). *Discussion:* Despite regular HIV-related medical appointments, HIV-positive women may have unaddressed reproductive health needs (e.g., pregnancy desire with providers focused on contraceptive use). Findings from this study suggest that increased support for young HIV-positive women's reproductive health is needed, including supporting pregnancy desires (to choose when, how, and if, to have children).

**Keywords:** HIV | Young women | Reproductive health | Pregnancy

### **Article:**

## **Significance**

To help reduce the high rates of unintended pregnancy among young HIV-positive women, it is critical to understand and support their reproductive desires and behaviors. While current biomedical HIV treatment strategies allow HIV-positive women in the United States to give birth to healthy (HIV-negative) children, healthcare providers may be underprepared to discuss pregnancy desires, intentions, and options with their HIV-positive patients. Primary HIV care represents an important, but often-missed, opportunity for obtaining reproductive health services. Thus, increased support for young HIV-positive women's reproductive health is needed, including supporting pregnancy desires (to choose when, how, and if, to have children).

## **Introduction**

In the United States (U.S.), about 19% of newly diagnosed cases of HIV are among women, with an increasing proportion among women of reproductive age (Centers for Disease Control and Prevention 2017). The majority (87%) of transmissions are through heterosexual contact (CDC 2017) with a quarter of women diagnosed with HIV during pregnancy (Loutfy et al. 2013). HIV-positive women have higher rates of unintended pregnancies (52–85%) (Rahangdale et al. 2014; Sutton et al. 2014) compared to women nationwide (45%) (Finer and Zolna 2016). Despite advances in biomedical HIV treatments to reduce vertical transmission, HIV-positive women continue to have pregnancies without clinical consultation, increasing their risk for adverse outcomes for both women and infants (Loutfy et al. 2009). To help reduce the high rates of unintended pregnancy among young HIV-positive women, it is critical to understand both young women's reproductive desires and behaviors and providers' approaches to supporting the reproductive health of women living with HIV (Jones et al. 2017).

Given the frequency of HIV-related care visits (e.g., quarterly), HIV care presents an important, but often-missed, opportunity for provision of reproductive health services, including pre- and inter-conception care (Loutfy et al. 2009). However, the way in which care and training is divided (e.g., HIV care through infectious diseases specialists and reproductive health through obstetrics/gynecology specialists), such service integration poses many challenges. For instance, HIV providers may be underprepared to discuss pregnancy desires and options with HIV-positive female patients (Coll et al. 2016), despite CDC recommendations that HIV care include comprehensive reproductive health counseling and services (CDC 2014; Masur et al. 2014). In 2013–2014 about half (49%) of U.S. HIV care providers reported offering comprehensive reproductive health counseling to HIV-positive women; some providers used condom discussions as a proxy for addressing pregnancy (Gokhale et al. 2017). Using prevention methods as a proxy to address pregnancy desires places the responsibility on HIV-positive women for initiating discussions about their reproductive options (Coll et al. 2016) and few (about 25%) HIV-positive women report sharing fertility desires and goals with their HIV providers (Finocchiaro-Kessler et al. 2012).

Since HIV-positive women are connected to the health care system through HIV care, combining general HIV care with reproductive health care (e.g., cervical cancer screening, sexually transmitted diseases testing, screening for relationship violence, screening for sexual dysfunctions, pre- and inter-conception planning) could help meet these women's reproductive

health needs (Fakoya et al. 2008; Huynh et al. 2017; Jones et al. 2017; Loutfy et al. 2013; Nancy et al. 2007; Ndlovu et al. 2009), including during the healthcare transition process (HCT) from pediatric/adolescent to adult HIV care. HCT is especially crucial for the health and wellbeing of HIV-infected young women including maintaining a low viral load and adhering to ART medication, all factors important reduce vertical transmission (Crowley et al. 2011). Research documents successful HCT can be challenging for youth, where only 50% of youth who had a successful HCT remained in adult care past 12 months (Hussen et al. 2017; Ryscavage et al. 2016), due to both individual (e.g., drug use) (Philbin et al. 2014; Tanner et al. 2018), clinical (e.g., inter-clinic communication) (Gilliam et al. 2011; Tanner et al. 2016, 2018) and structural (e.g., housing) (Gardner et al. 2009) factors. With a few exceptions (Coll et al. 2016; Gokhale et al. 2017), little is known about HIV care providers reproductive health practices, and the extent to which women's reproductive health desires and behaviors are aligned with, and supported in, HIV clinical settings, particularly during HCT. Accordingly, this brief report explored young HIV-positive women's reproductive health desires and behaviors; and examined the strategies clinics used to provide reproductive health information and services to women within HIV care during HCT.

## **Methods**

### Study Overview

We performed a mixed-method analysis using data from the Comprehensive Assessment of Transition and Coordination for HIV-positive Youth as they Move from Adolescent to Adult Care (CATCH) Study conducted across 14 Adolescent Medicine Trials Network (ATN) sites [methods described in detail elsewhere (Philbin et al. 2017)]. The Institutional Review Boards at the University of North Carolina, Greensboro and participating ATN sites approved the study protocol. All participants provided informed consent and had the opportunity to receive an incentive for participation (17 providers refused).

### Quantitative Methods

Baseline Audio Computer-Assisted Self-Interviews (ACASI) data were collected from 135 HIV-positive youth (the 25 women were included in the current analysis) from August 2015 to February 2016. Variables of interest included: demographics (e.g., age, race/ethnicity, sexual orientation, relationship status, education, and housing stability), any disclosure of HIV status, sexual behaviors, contraceptive use, pregnancy history, pregnancy desires, and discussions about preconception care and prevention methods with their HIV care providers. Descriptive statistics were conducted using SPSS version 24 (Armonk, NY).

### Qualitative Methods

Presentation of qualitative methods and findings are in accordance with the consolidated criteria for reporting qualitative research (COREQ) criteria (Tong et al. 2007). Fifty-eight semi-structured telephone interviews were conducted from August 2015 to June 2016 with adolescent (n = 30) and adult (n = 28) clinic medical and social service providers at 34 clinics (14 adolescent and 20 adult clinics). We used purposive sampling to recruit adolescent and adult clinic staff who

work with HIV-positive youth who are eligible for HCT from pediatric- to adult-specific care; 15 medical and social service providers refused to participate. Two female doctoral-level graduate student research assistants conducted the interviews; both were women of color and had 3 years of qualitative research experience. Interviews averaged 45 min (range 22–78 min), and were professionally transcribed. A semi-structured interview guide addressed HIV and reproductive health counseling and services, and how pregnancy and parenting facilitates or hinders HIV care engagement. A checklist describing each clinic’s services (including preconception care) was also completed. Field notes were completed following each interview.

**Table 1.** Demographic characteristics of HIV-positive women (N = 25)

	n	Percent
Age		
24 years old	22	88
Less than 24 years old	3	12
Hispanic		
No	23	92
Yes	2	8
Race		
Black alone	24	96
Mixed race (black and white)	1	4
Sexual orientation		
Straight	20	80
Gay/lesbian	2	8
Bisexual	3	12
Relationship status		
In a relationship for 6 months or more	6	24
In a relationship for 6 months or less	4	16
Single/other	15	60
Education		
Less than high school	6	24
High school or greater	19	76
Currently employed		
No	13	52
Yes	12	48
Annual income		
More than \$12,000	5	20
Less than \$12,000	19	76
Missing	1	4
Ever homeless		
No	18	72
Yes	7	28
Disclosed HIV status (at least one person)		
No	7	28
Yes	18	72

The constant comparative method (Buetow 2010; Glaser and Strauss 1967) was used to examine how providers described reproductive health services. Two qualitatively trained researchers (B.D. Chambers and A. Ma) independently read and manually coded each transcript to create a codebook which was summarized into a coding matrix based on existing literature for inclusion of theory-based and emergent concepts and other team members’ feedback (MacQueen et al. 1998). Two graduate student researchers independently applied the finalized codes to all

transcripts using Atlas.ti 6.2, with greater than 90% inter-rater agreement. Coding disagreements were resolved through consensus of the research team.

## **Results**

### **Women and Provider Characteristics**

The majority of women reported being Black (n = 24) with one (n = 1) who reported mixed race (Black and White). Two women (n = 2) also reported their ethnicity as Hispanic/Latino. Women identified as straight (n = 20), lesbian (n = 2), and bisexual (n = 3). Three (n = 3) women reported being less than 24 years old, with all others being 24 years old (n = 22). Seven (n = 7) women reported ever being homeless. Most women reported: having a high school degree or higher (n = 19), being single (n = 14), being unemployed (n = 13), making less than \$12,000 annually (n = 19), and disclosing their HIV status to at least one person (n = 18). Table 1 summarizes women's characteristics.

The majority of the 58 clinic staff were female (n = 48) and represented diverse occupational roles: physicians (n = 18), nurse practitioner (n = 9), social worker (n = 13), case manager (n = 6), care linkage/patient coordinator (n = 7), and other (n = 5). Staff had occupied their roles at clinics on average for 8.5 years (range 1–25 years).

### **HIV Clinics' Reproductive Health Information**

All 14 adolescent clinics indicated that staff discussed and provided information related to preconception care with female patients, while 17 out of 20 adult clinics reported staff discussed this information. All adolescent (n = 14) and adult (n = 20) clinics specified staff discussed STI/cervical cancer prevention with female patients. Women's data supported clinics' reports related to the discussion of reproductive health information during HIV care. The majority of women reported discussing issues related to preconception care (n = 23) and STI/cervical cancer prevention (n = 22) with their adolescent care providers. All women who discussed these issues with their HIV care providers reported the discussions were helpful.

### **Women's Pregnancy Desires and Providers Approaches to Reproductive Health**

Most women desired a pregnancy at some point in the future (n = 13), while five did not want a future pregnancy and three were ambivalent. Of the 13 women who desired a(nother) pregnancy, five reported using dual methods, three condoms, four hormonal contraception, and one no method. All five of the women who did not want a pregnancy reported a protected last sexual event; three used a dual method and two used condoms (see Table 2).

Despite the range in women's pregnancy desires, providers mostly described HIV care as a place to promote pregnancy prevention. For instance, one adult clinic physician (Site V) reported: "We've been working really hard to try to get girls [on] the Nexplanon [implant], if they're agreeable...but sometimes they don't always agree and then they turn up pregnant."

**Table 2.** HIV-positive women's reproductive health desires and behaviors (N = 25)

	<b>n</b>	<b>Percent</b>
Received birth control or pregnancy testing from clinic		
No	13	52
Yes	12	48
Contraception use (at last sex)		
Condom only	9	36
Dual methods	9	36
Hormonal only	4	16
No method	3	12
Pregnancy desire		
No	5	20
Yes	13	52
Ambivalent	3	12
Missing	4	16
Ever pregnant		
No	9	36
Yes	15	60
Pregnancy not planned	12	80
Pregnancy planned	3	20
Missing	1	4
Contraception use (at last sex) by pregnancy desire		
Want a future pregnancy (n = 13)		
Condom only	3	23
Dual methods	5	38
Hormonal only	4	31
No method	1	7
Do not want a future pregnancy (n = 5)		
Condom only	2	40
Dual methods	3	60
Hormonal only	0	0
No method	0	0
Ambivalent (n = 3)		
Condom only	1	33
Dual methods	1	33
Hormonal only	0	0
No method	1	33
Missing pregnancy desire (n = 4)		
Condom only	3	75
Dual methods	0	0
Hormonal only	0	0
No method	1	25

The adolescent clinics approach to reproductive health often emphasized the challenges of parenthood as described by a case manager (Site S):

...[we discuss] what it means to go through a pregnancy, and of course to raise a child, 'cause, you know, they're still pretty young at this point, and usually not in a place where they're...I would say they're not totally ready. Or they're struggling, maybe, to take care of themselves.

Some providers were more directly supportive of women's pregnancy desires as reported by an adult clinic family advocate (Site W):

Now, if...a young lady comes in, who wants to be a parent, then we schedule an appointment with Dr. [J], so he can do a consultation with her...he tells her ways to become pregnant that would be less likely for her to transmit the virus to someone else.

While providers were willing to discuss reproductive health, adolescent and adult providers reported that, in general, women initiated most of these discussions. One adolescent physician (Site U) explained: “Preconception care is discussed after someone has clearly articulated...that they would not like to use contraception...So the emphasis of myself and other clinic staff is to encourage use of contraceptives unless someone is serious about having a child.” Women-initiated conversations about pregnancy can be problematic given that a large portion of women (n = 15) women reported being pregnant at least once in their lifetime; three of these pregnancies were planned and nine women were HIV-positive during their pregnancy.

### Complexity of HIV Care and Pregnancy

Across the 34 adolescent and adult HIV clinics, 15 clinics provides obstetric care on-site and 19 clinics provided obstetric care off-site. Providers described pregnancy and engagement with obstetric care as both a potential facilitator and barrier to HIV care engagement. An adolescent clinic social worker (Site Z) highlighted this complexity: “We [adolescent clinic] also transition pregnant moms from our care back and forth to adult care and sometimes several times because they might be in adult care, get pregnant, come and we share their care.” The adult social worker (Site Z) further illuminated this process:

They [the adolescent clinic] have a program [that] works mostly with the women clients or with partners that are trying to get pregnant...then they have another social worker at [adolescent clinic] who works with all the people that are pregnant or trying to get pregnant and gets them enrolled in that program.

Connection to prenatal care services was described as an opportunity to support women’s care engagement. One adolescent physician (Site V) reported “Actually, I think the ones who are pregnant is [sic] easier because they’re going to be doing prenatal care, and we send them to an obstetrician who does prenatal care.” Overall, adolescent and adult providers reported that during pregnancy women were more engaged in care.

### Discussion

Our results highlight that young HIV-positive women have diverse pregnancy desires and HIV providers’ approaches to reproductive health may not be meeting all their patients’ needs. Over half of the women in this study reported desire for future pregnancies. Compared to prior work, more women reported discussing preconception care with their providers (Finocchiaro-Kessler et al. 2012). Our qualitative findings revealed that discussions about preconception care are mostly limited to contraception so a more nuanced examination of the content of these interactions is warranted.

Similar to previous research, providers in our analysis reported pregnancy prevention as the primary reproductive health focus in HIV care settings (Coll et al. 2016). While pregnancy prevention is an important component in reducing unintended pregnancies (Rahangdale et al. 2014; Sutton et al. 2014), this approach may have significant implications for preconception and prenatal care utilization as well as increase the likelihood of vertical transmission (Huynh et al. 2017; Loutfy et al. 2013; Ndlovu et al. 2009). The goal of preconception care is to provide optimal health care to women to ensure their pregnancies (if chosen) are timely, and for HIV-positive women, to discuss plans to reduce the risk of HIV transmission to either an infant or non-infected partner (Nancy et al. 2007). To accomplish this, it is essential that HIV care providers be prepared to discuss fertility desires, contraceptive options, preconception and inter-conception planning, and prevention of vertical transmission.

Despite HIV-positive women's regular access to medical services through their HIV care, our results confirm that providers may be underprepared to provide women with comprehensive reproductive care (Lachat et al. 2006). Many providers recognized the importance of contraception and described adolescence as a challenging developmental period to add the responsibilities of pregnancy and parenthood to disease management. Yet, the primary burden of communication around pregnancy desires and intentions was placed on young HIV-positive women, challenging the dynamic of provider-patient interactions and potentially reducing the likelihood of these discussions occurring in a timely manner. These expectations may present substantial barriers for young HIV-positive women who desire family formation through pregnancies. This issue is especially relevant for young women during HCT from adolescent- to adult-oriented HIV care as they develop new relationships with adult clinic staff (Tanner et al. 2016, 2018), and identifies key areas where current HIV HCT planning may be inadequate.

### Limitations

A few limitations should be considered. National attention towards young HIV-positive women's unique reproductive needs may be limited given the U.S. epidemic disproportionately affecting men who have sex with men. While an important first step, the self-reported data came from a relatively small number of women and cannot be generalizable to the larger population. Additionally, we were unable to talk with women to get a better understanding of barriers and facilitators to preconception care they experience as an HIV-positive person. Clinics were also primarily located in urban areas which may not reflect the experiences of women in other areas (e.g., rural); however, women and providers were recruited from 14 geographically distinct clinics across the U.S.

### Conclusions

Young HIV-positive women have diverse pregnancy desires, therefore, incorporating reproductive health care within routine HIV care may improve care engagement and health outcomes by providing women with holistic care. Additional training for HIV care providers may improve their comfort and skills in offering comprehensive reproductive health information and services and initiating discussion related to fertility planning. Access to comprehensive reproductive health services may reduce unintended pregnancy rates, improve birth outcomes among HIV-positive women, and keep women engaged in HIV care (which is critical for the



health of women, their partners, and their potential children). Future, larger studies can build on this foundational work to inform innovative tools to assist with comprehensive reproductive health counseling and services for HIV-positive women. Ideally, integrated HIV care and reproductive health services will reduce unintended pregnancy rates, improve prenatal care utilization, improve birth outcomes, and support all HIV-positive women's pregnancy desires (to choose when, how, and if, to have children).

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