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The Reproductive Health Behaviors of HIV-Infected Young Women in the United States: A Literature Review

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Abstract

HIV-infected young women in the United States have important reproductive health needs that are made more complex by their HIV status. We searched Pubmed and relevant bibliographies to identify 32 articles published from 2001 to July 2012 that described the prevalence, correlates, and characteristics of the sexual activity, relationships, pregnancy intentions, HIV status disclosure, and contraceptive and condom use among US HIV-infected adolescents and young women. Our synthesis of those articles found that, like youth not infected with HIV, substantial proportions of HIV-infected youth were sexually active, and most sought romantic or sexual relationships, though their serostatus may have affected the pace of physical and emotional intimacy. Disclosure was difficult, and large proportions of HIV-infected youth had not disclosed their serostatus to recent partners. A few studies suggest that most HIV-infected young women hoped to have children in the future, but many wanted to avoid pregnancy until later. Only one study described contraceptive use among this population in detail and found that condoms were a primary method of contraception. The results point to substantial gaps in published research, particularly in the areas of pregnancy intentions and contraceptive use. Much more needs to be done in research and health services to better understand and meet the complex health needs of HIV-infected young women.

Introduction

In the United States, as in most of the world, HIV remains a priority public health issue. At the end of 2009, over 1.1 million persons were estimated to be living with HIV in the US, and approximately 50,000 people become infected each year. While infections among women have declined recently, an estimated 9500 new HIV-infections occurred in women in 2010, and women comprised approximately 25% (over 250,000) of people living with HIV in the US^{2,3} These trends are marked by stark racial/ethnic disparities. For example, in 2010, the rate of new infections among black women was 20 times that of white women and five times that of Hispanic women, and similar racial/ethnic disparities are seen among HIV-infected youth. The 2010 National HIV/AIDS Strategy (NHAS) highlights the pressing need to address these disparities.

The NHAS also advocates for a stronger focus on HIV-infected individuals, as part of the strategy for addressing the nation's HIV epidemic. "Prevention with positives" now encompasses not only behaviors related to transmission risk

such as condom use and serostatus disclosure, but also testing, linkage to care, and support for optimal adherence to antiretroviral therapy (ART). Moreover, HIV is viewed by many as a chronic illness that needs to be managed over a long time. One of many implications of this lifelong focus on well-being of HIV-infected individuals is a need to consider their broader health needs further, particularly those that are closely intertwined with HIV infection and ART.

Reproductive health, as related to preventing unintended pregnancy and supporting planned pregnancy, is one such area that is especially relevant to HIV-infected young women. Reproductive health behaviors and intentions have different meaning in the presence of HIV infection. Condom use is more urgent; contraceptive method choices and use are different; relationship dynamics are more complicated, as are pregnancy and childbearing. Importantly, while this population has demonstrated high competence and resilience in the face of their disease, various studies demonstrate that many HIV-infected young women must manage substantial additional challenges to their well-being. These include mental health issues or HIV-related cognitive deficits, ^{6,7} a history of

abuse, ⁸ homelessness, ⁹ and other constraints born from difficult socioeconomic circumstances. ¹⁰ Many are factors that put them at high risk of HIV infection in the first place and also may put them at higher risk of unintended pregnancy and related reproductive health outcomes. For all these reasons, some of the social and economic circumstances and consequences associated with teen pregnancy in the US are likely magnified among HIV-infected teens. ^{11,12} Finally, with survival into adulthood now a realistic expectation for HIV-infected young women, many will want to, and do, seek to have children and start a family.

Studies show that both first and repeat pregnancies are common among HIV-infected teens and young women. ^{13–15} In one study, the pregnancy rate for HIV-infected teens who had become infected behaviorally (e.g., through sexual behaviors or intravenous drug use, as opposed to perinatally through their mother) was five times that of adolescents nationally, a finding likely related to many of those teens' history of unprotected sex and other high-risk behaviors. ¹⁶ Many also discover their HIV infection through their pregnancy consultations, due to widespread prenatal screening for HIV. ¹⁴

It is important to address the reproductive health of HIV-infected adolescents and young women, to ensure they can navigate adolescence and lay a solid foundation for adult-hood. However, despite substantial research focused on preventing sexual transmission to partners and infants, and despite the fact that family planning is a pillar of the global strategy to prevent perinatal transmission, ¹⁷ much less is known about the antecedents of pregnancy among HIV-infected young women. As part of a larger project to assess the reproductive health needs of HIV-infected young women in the US, we sought to summarize previous research on these issues and identify additional areas for research and service development for this vulnerable population.

Literature Search

We focused on some of the proximate behavioral determinants of pregnancy, with a particular interest in summarizing what was known about HIV-infected young women's pregnancy intentions and contraceptive use (including condoms). We broadened the scope of our search to include information on the context of their sexual relationships that likely affected those: characteristics of their sex partners and disclosure of HIV status. We also included information we found about sexual activity, in order to provide a more comprehensive portrait of reproductive health behaviors. In this way, this review also highlights some of the common threads between the fields of HIV prevention and reproductive health.

To be included, the studies had to present descriptive results from quantitative or qualitative studies pertaining to those aspects of reproductive health. Because our purpose was largely to inform future research, we limited the literature search to articles published since highly active antiretrovirals were widely available, about 1998. We included articles that were published in English up to July 2012 and that focused on HIV-infected adolescents or young adults, generally defined between ages 10 and 24 years. Studies could involve behaviorally infected youth ("BHIV") or perinatally infected ("PHIV") youth. Studies that included both adolescent and older women but did not disaggregate findings by age were

excluded. We focused on findings presented for females, but also refer to studies that included both females and males.

We identified articles in various ways. First, multiple authors conducted concurrent searches in PubMed using various combinations of search terms such as HIV-infected, HIV seropositivity, adolescent, young adult, sexual behavior, reproductive behavior, contraception, and pregnancy. For major, well-known studies pertaining to adolescents with HIV, or reports from researchers frequently publishing on adolescent HIV, we conducted additional searches using specific author or study names [e.g., Reaching for Excellence in Adolescent Care and Health (REACH)]. We also selected articles from publication lists posted by the Adolescent Medicine Trials Network for HIV/AIDS Intervention (ATN), a large NIH-funded research network that has conducted, since 2001, research on HIV-infected youth and uninfected at-risk youth under the age of 25. Finally, we examined the bibliographies of articles identified through these means.

Though comprehensive, this process did not constitute a formal systematic review. We did not conduct a systematic review because we knew that the published literature on HIV-infected young women in the US was limited, and we believed that broad search strategies would yield few additional studies, with little gain for our aims. Using a standard spreadsheet template, we summarized each article's study design, methodology, and main findings related to reproductive health behaviors and then synthesized those across studies. As our purpose was to describe the reproductive health behaviors of this population, we did not formally grade the strength or weakness of the evidence presented. In the presentation below, we summarize the key themes and findings across the articles identified, in each of our primary areas of interest.

Results

Set of manuscripts

We identified 30 articles that contributed to the synthesis below, as well as two review articles, ^{7,18} one of which (15) was not specific to youth. Eight studies (Table 1) came from research conducted under the auspices of the ATN ^{8,9,19–24} and four came from ATN's precursor, the REACH study, ^{25–28} an NIH-funded research network that recruited BHIV and HIV-uninfected at-risk youth ages 12–18 years, from 16 clinical care sites across the US between 1996 and 1999. Other studies came from intervention research samples (e.g., Adolescent Impact Study^{29,30}) and other research cohorts [e.g., Women's Interagency HIV Study (WIHS), ³¹ LE-GACY³²].

Most reports involved the analysis of cross-sectional survey data from a single time point. Four studies were qualitative. 8,33–35 Nine studies had HIV-uninfected counterparts as part of the analytic sample to serve as a comparison group. 14,25,28,31,36–40 Ten studies focused on samples of only young women, 8,9,14,19,25,28,31,33,39,41 while the remainder had samples that included both young men and women. Eight studies included only BHIV. 8,9,19,21,25–28 Because of a recently published review article on PHIV adolescents, 7 we only included eight articles focused on just PHIV. 33,35–38,40–42 Those were published since the review or were outside the scope of the review; one was included in the review, but is highlighted here from a different perspective. 41 The remaining studies

Table 1. Studies Summarized in the Review of the Reproductive Health Behaviors of HIV-Infected Young Women in the US^a

Citation				Citaco	.; Polic co				Study design and sample characteristics	eristics	
Lead author,				011.38	sections cited in					I	Includes HIV-
year, reference number	Sexual activity	Sexual Pregnancy activity Relationships Disclosure intention	s Disclosure	Pregnancy intention	Contraceptive Condom use use	ondom	Study design	Study source (recruitment dates)	Analytic sample	PHIV, BHIV, or both	uninfectea comparison group?
Batterham (2005) [48]			×			J	Cross-sectional analysis of survey data	Clinical care sites in 4 cities (2 cohorts, 1994–1996 and 1999–2000)	Ages 13–24 years (N=351 and N=253); 28%/30% female (Pre-HAART/Post-HAART)	Not noted, but included many BHIV	Š
Bauermeister (2009) [36]	×						Cross-sectional analysis of survey data, medical chart abstractions of HIV+study participants	Project Child and Adolescent Self- Awareness and Health Project (CASAH), 4 clinical care sites in 1 city (2003–2007)	Ages 9–16 years, N=316, 50% female, 60% HIV+	PHIV	Yes
Bauermeister (2012) [37] & Elkington (2012) [38]	×					×	Longitudinal analysis of survey data	Combined sample using Risk and Resilience in Youth With HIV+ Mothers (R&R, 1998–2000) and CASAH (2003–2005)	Ages 9–16 years, Combined sample N=417 and 420, respectively, 50% female, 39% HIV+	PHIV	Yes
Belzer (2001) [25]					×	J	Cross-sectional analysis of survey data	REACH study (1996–1999)	Ages 13–18 years old, N =216 participants with 648 study visits, 100% female, 66% HIV+	BHIV	Yes
Clum (2009) [8]		×				J	Qualitative study	3 ATN sites (year not noted)	Ages 18–24 years, $N=40$, 100% female	BHIV	No
Clum (2012) [19]		×				×	Cross-sectional analysis of survey data	5 ATN sites (2003–2004)	Ages 18–24 years, <i>N</i> =118, 100% female	BHIV	Š.
D'Angelo (2001) [26]			×			Ü	Cross-sectional analysis REACH study of survey data, lab (1996–1999) studies, chart review	REACH study (1996–1999)	Ages 14–19 years, <i>N</i> =203, 70% female	BHIV	N _o
Dempsey (2012) [20]		×	×			×	Cross-sectional analysis of survey data	5 ATN sites (2005–2006)	5 ATN sites (2005–2006) Ages 16–24 years, <i>N</i> =146, 48% female	Both (87% BHIV)	S _o
Ezeanoule (2006) [41]				×		J	Cross-sectional analysis of survey data	FXB clinic, University of Ages 13–24 years, Medicine & Dentistry N =57, 100% female of NJ (2003–2004)		PHIV	No
Fair (2012) [35]		×	×			Ŭ	Qualitative study	2 clinics (2011–2012)	Ages 15–30 (mean 20.7 years), N=35, 66% female	PHIV	No (continued)

Table 1. (Continued)

	Includes HIV-	uninfected comparison group?	No	Yes	No	Yes	No	Š	No	No	Yes	Yes	(continued)
teristics		PHIV, BHIV, or both	BHIV	Both (44% PHIV)	BHIV	BHIV	Both (60% PHIV)	Not stated	Both (60% PHIV)	PHIV	Not noted but 75% BHIV	PHIV	
Study design and sample characteristics		Analytic sample	Ages 13–24 years, <i>N</i> =130, 100% female	Ages 15–24 years, <i>N</i> =401, 100% female, 11% HIV+	Ages 13–24 years, N=176, 100% female (sample of 177 MSM also surveyed)	Ages 13–21 years, <i>N</i> =147, 100% female, 42% HIV+	Age 13–21 years, <i>N</i> =166, 53% female	Ages 16–25 years, <i>N</i> =66, 49% female	Ages 13–24 years, $N=20$, 75% female	Ages 12–16 years, $N=20$, 100% female	Ages < 20 to over 50 years, total sample = 2784 with 71 women under age 20, 100% female, 31% of women under age 20 were HIV+	Ages 10–16 years, N=349, 50% female, 68% HIV+	
		Study source (recruitment dates)	5 ATN sites (2003–2004)	Combined sources: Neighborhood Influences on Adolescent and Adult Health (NIAAH) household- based survey + convenience sample of patients from 1 clinical care site (2004–2008)	15 ATN sites (2003–2004)	Perinatal Guidelines Evaluation Project 4 sites (1997–1999)	Adolescent Impact Study, 5 clinics in 3 cities (2002–2005)	1 urban site (2002–2003)	HIV clinics in 1 urban area (2007)	Clinical care site in 1 city (year not noted)	Women's Interagency HIV Study or WIHS (1994–2005)	Pediatric HIV/ AIDS Cohort Study or PHACS, 15 sites (2007–2010)	(-1)-
		Study design	Cross-sectional analysis of survey data	Cross-sectional analysis of survey data	Cross-sectional analysis of survey data	Cross-sectional analysis of survey data and chart abstraction	Cross-sectional analysis of survey data, chart review	Cross-sectional analysis of survey data, chart review	Qualitative study	Qualitative study	Longitudinal analysis of survey data	Cross-sectional analysis of survey data	
		Condom use					×			×		×	
	Sections cited in	Contraceptive use									×		
:	Sections	Pregnancy intention	×	×		×							
		Disclosure					×	×	×				
		Sexual activity Relationships Disclosure			×	×				×			
		Sexual activity					×					×	
Citation	Lead author,	year, reference number	Finger (2012) [9]	Finocchario- Kessler (2012) [39]	Jennings (2009) [21]	Koenig (2007) [14]	Koenig (2010) [29]	Lam (2007) [46]	Leonard (2010) [34]	Marhefka (2011) [33]	Massad (2007) [31]	Mellins (2011) [40]	

Citation				Castiana	in Police				Study design and sample characteristics	acteristics	
Lead author,				Sections	Sections cited in						Includes HIV-
yeur, reference number	Sexual activity	Relationships Disclosure	Disclosure	Pregnancy intention	Contraceptive use	Condom use	Study design	Study source (recruitment dates)	Analytic sample	PHIV, BHIV, or both	uninjecieu comparison group?
Murphy (2001) [27]	×					×	Longitudinal analysis of survey data	REACH study (1996–1999)	Youth mean age 17 (SD 1.1), <i>N</i> = 323, 74% female	BHIV	No
Nugent (2010) [22]						×	Cross-sectional analysis of survey data	5 ATN sites (year not noted)	Ages 16–24 years, N=122, 43% female	Not noted but likely many BHIV	No
O'Brien (2003) [47]			×				Cross-sectional analysis of survey data	2 clinical care sites in 1 city (2000)	Ages 18 and older, N=269 overall, N=28 for those ages 18-22 years, 48% female	Both but mostly PHIV (91%)	No
Orban (2010) [30]			×				Cross-sectional analysis of survey data, chart review	Adolescent Impact Study, 5 clinics in 3 cities (2002–2005)	Ages 13–21 years, <i>N</i> =166, 53% female	Both (60% PHIV)	No
Outlaw (2010) [23]						×	Cross-sectional analysis of survey data	4 ATN sites and 1 one non-ATN site (year not noted)	Ages 16–24 years, <i>N</i> =186, 48% female	Both (83% BHIV)	No
Setse (2011) [32]	×						Chart abstraction, one point in time	Longitudinal Epidemiologic Study to Gain Insight into HIV/AIDS in Children and Youth or LEGACY, 22 cities (2006)	Ages 13– 24 years, N=752, 56% female	Both (76% PHIV)	°Z
Sturdevant (2001) [28]		×	×			×	Cross-sectional analysis of survey data	REACH study (1996–1999)	Ages 13–19 years, <i>N</i> =243, 100% female, 63% HIV+	BHIV	Yes
Tanney (2010) [24]						×	Cross-sectional analysis of survey data	4 ATN sites+1 non-ATN site (year not noted)	Youth with mean age 20.4 (SD 2.46), N=352 (screener data), 42% female	Both (80% BHIV)	No
Wiener (2006) [42]			×				Cross-sectional analysis of survey data, chart review	Patients seen at 1 National Cancer Institute clinical care site (2003)	Ages 13–24 years, <i>N</i> =40, 62% female	PHIV or tranfusion- infected only	N _o
Total:	^	8	11	4	2	11					
E											

^aTwo additional review articles are not included in this table: Koenig 2011 [16] and Eustace 2010 [15]. BHIV, Behaviorally-infected youth; HAART, Highly-active anti-retroviral therapy; PHIV, Perinatally-infected youth.

included both PHIV and BHIV, or did not state explicitly the distribution of participants by mode of transmission.

Sample sizes ranged from 20 to over 700 HIV-infected youth; however, most involved samples of about 100 to 200 youth. Reflecting the HIV epidemic among youth today, most study samples included high percentages of African Americans (about 60–80%), with the only exception being the study supported by the National Cancer Institute. Age ranges varied, with some studies including youth as young as 8 years and as old as 25 years, but most included older teens and/or young adults, up to age 24. For purposes of this article, the term "adolescents" is used to refer to persons between ages 13–19, and "young adults" refers to individuals ages 20–25. "Youth" and "young women" are used as more general terms that include individuals in both age groups (e.g., 18–22 or 13–24 years olds).

Current sexual activity

Among the studies we identified, few focused on the prevalence of current sexual activity among young HIVinfected women, but results from eight studies with mixedsamples provided some indications. By definition, most behaviorally-infected adolescents are sexually experienced or active; in one study, for example, 89% of BHIV youth had sex during the previous year.^{32*} Among samples of PHIV, a smaller proportion were sexually experienced, but the proportion increased with age (as is also the case for HIV-uninfected youth), with estimates ranging from 27% to 46% among samples of youth ranging in age from 13 to 24 years.⁷ In a set of recent studies that compared PHIV adolescents with HIVuninfected but perinatally exposed adolescents (i.e., with an HIV-infected mother), PHIV initiated sexual activity of any kind (e.g., kissing) at an earlier age than HIV-uninfected youth, but initiated penetrative sex (vaginal or anal) at a slower rate ^{37,38} However, some studies found largely similar percentages between those two groups in the percent reporting experience with oral sex³⁷ and penetrative sex.^{36,40}

A large proportion of HIV-infected youth reported being sexually active at the time of survey. In one study of 105 sexually experienced HIV-infected youth (ages 13-21 years; 38% PHIV), 72% were sexually active in the 3 months preceding survey.²⁹ Similarly, in the REACH cohort of BHIV adolescents, 68% reported, at the first study visit, being sexually active in the preceding 3 months. That proportion was virtually unchanged after 6 study visits spanning 15 months.²⁷ Statistically significant, positive correlates of recent sexual activity among sexually-experienced HIV-infected youth included acquiring HIV behaviorally (as compared with perinatally), drug and alcohol use, and greater HIV knowledge; those with very low or very high CD4 counts (vs. mid-level counts) were less likely to be currently sexually active.²⁹ In another study that focused on mental health correlates among BHIV adolescents, physiological anxiety was positively associated with recent sexual activity, while having high health-related anxiety was negatively associated.²⁷

Characteristics of sex partners and relationships

Eight studies highlighted aspects of young HIV-infected women's sex partners or relationships. Partner characteristics were examined in these studies in order to identify risk factors for HIV/STD transmission and condom use, but relationship

qualities also pertain to pregnancy intentions and pregnancy prevention among HIV-infected young women, as they do among young women who are not HIV-infected. 43 In the REACH cohort, which included a sample of matched HIVuninfected controls, the age difference between female participants and their recent partners was significantly larger for BHIV girls than their uninfected counterparts, though both groups had partners who were on average older than they were (6 years older, vs. 4.7 years older, respectively).²⁸ In that same study, similar proportions of HIV-infected and HIV-uninfected girls (76%) described their partners as "main" partners, and the average length of their relationships was approximately 11 months, with no differences between the two groups. In a study comparing pregnant, HIV-infected young women with pregnant, HIV-uninfected counterparts, the two groups were similar in many relationship characteristics, but the HIV-infected group reported more supportive male partners. 14 In a qualitative study of romantic relationships among 20 PHIV adolescents, girls wanted and sought romantic relationships just as their HIVuninfected counterparts did. However, their HIV status led some girls to delay some sexual practices such as intercourse and made condom use decision-making even more complicated for them, given issues related to disclosure and transmission risk.³³ Another qualitative study of PHIV young adults found that they were also generally more cautious with trust and physical intimacy in their romantic relationships, and expressed optimism that they and other PHIV would find loving, supportive partners (see also "disclosure" below).35

Four studies described physical, sexual, and/or emotional abuse within the past and current relationships of HIV-infected young women. In a survey of 118 BHIV young women, 89% reported childhood victimization (physical or sexual abuse, neglect, or witnessing violence as a child) and 50% reported experiencing or witnessing violence as an adult.¹⁹ Older studies also documented high prevalence of childhood sexual abuse among young women with HIV.44,45 In-depth qualitative interviews with 40 HIV-infected young women with a history of past sexual or physical abuse identified various ways that those experiences factored into their sexual relationships.⁸ For example, some women felt they could not trust men any more or faced other barriers to intimacy, and others experienced sexual dysfunction. Among a sample of BHIV young women, 14% reported ever having been forced by their recent partners to have sex (oral, anal, or vaginal) without a condom.²¹ In a study of HIV-infected pregnant young women, 9% (4/44) reported that their current partner was physically or emotionally abusive; this figure was significantly lower than that reported by HIV-infected, pregnant older women (22%).14

Concurrent or multiple partnerships were an issue in many of the relationships of HIV-infected young women. In the REACH cohort, about half (43%) of BHIV adolescents thought that their male partners were having sex with other women (not significantly different from the 55% reported by HIV-uninfected girls). ²⁸ In two other studies, the percent of BHIV young women who thought their male partners were also having other partners ranged from 22% to 36%. ^{19,21} These two studies also found sexually active HIV-infected young women to have a mean of 1.9 and 1.8 partners in the previous three months. ^{21,28}

According to results from another two studies, serosorting also factored into partner selection for some HIV-infected young women. About 28% of the recent partners of BHIV adolescent girls were themselves reportedly known to be HIV infected, compared with 6% of partners of HIV-uninfected adolescents;²⁸ a similar figure (29%) was found in another study that included young men and women.²⁰ About a quarter of BHIV young women in one study reported ever having a male partner who they knew or believed to be HIV infected; however in that study, it is not clear if some of those partners were those who initially transmitted HIV to the participants.²¹

Serostatus disclosure to sex partners

Eleven studies described disclosure of serostatus to sex partners among HIV-infected youth. Disclosure of a positive HIV status to partners is clearly relevant to HIV transmission and presumably is also related to reproductive health decision-making. Disclosure likely affects the formation of, and communication about, pregnancy intentions with a partner, as well as the use of condoms and other contraceptives. Disclosure is itself a complex process, involving the interplay of social context, personal experiences, and relationship characteristics with decisions about whether/how/when/to whom to communicate one's HIV status, and related issues. 18 Disclosure has been labeled a "major hurdle" for youth living with HIV,³⁴ and doing so with sex partners is consistently cited as a major concern of theirs, particularly for BHIV. 30,42,46 Studies in primarily BHIV youth populations have reported prevalence of nondisclosure to recent sex partners of 40%²⁰ and 48%. 26 In another study, 12 of 22 youth had not disclosed to their main sex partner. 47 In a study of PHIV and BHIV youth, about 80% of both groups had not yet disclosed to their recent sex partners.29

Based on results from five studies, disclosure to sex partners has been positively associated with: the partner being primary/main versus casual, the partner having or being perceived to have HIV;^{26,28,48} a greater number of sex acts with the partner;⁴⁸ a greater length of time since HIV diagnosis;^{42,48} disclosure to friends and family;⁴² and immunosuppression.⁴⁷ Factors negatively associated with disclosure have included higher number of sex partners,²⁰ and partner being HIV-negative⁴⁸ or of unknown serostatus.²⁰ In a study that included HIV-infected persons ages 18 and older, the youngest age group (ages 18–22) were less likely to disclose than older persons.⁴⁷

According to one qualitative study of 20 HIV-infected men and women aged 13–24, most disclosed to their partners to generate support and acceptance and to deepen a relationship. ³⁴ About half felt that disclosing their HIV status did not influence their dating behaviors or physical intimacy with a sex partner initially; however, they also believed that an HIV-negative partner would not be able to relate to what they were going through and that there might eventually be difficulties with physical and emotional intimacy as the relationship deepened. Although most felt it important to use a condom with an HIV-negative partner, some felt that if they did disclose, then unprotected sex was acceptable. Another qualitative study of 35 PHIV young adults found that many felt that serostatus disclosure was risky in more casual relationships, and essential in more serious ones; participants described

experiencing both rejection and support in response to disclosure.³⁵

Pregnancy intentions and desire

Two studies suggested that the majority of HIV-infected adolescents and young adults want children at some point in their future. In one study of PHIV young women and men, 70% wanted to have a child "now" or "in the future." In another study of young women, 80% of HIV-infected females wanted at least one child sometime in the future, a figure similar to that for their HIV-uninfected counterparts (85%). In a multivariable analysis, not having a child already, having more positive pregnancy motivations (e.g., agreeing with positive statements about having children, such as a child is someone to love), and believing one's partner would be happy or excited about a pregnancy were positively associated with a young woman's desire to have a child sometime in the future, while serostatus was not. 39

Two additional studies described recent or short-term pregnancy intentions. Among 61 HIV-infected, pregnant young women in one study (half of whom had received a diagnosis of HIV prior to the pregnancy), 83% reported that their current pregnancies were unplanned. In a study of 130 HIV-infected young women, 32% reported that they "maybe," "probably," or "definitely" wanted to get pregnant in the 6 months following survey. In multivariable analyses, having some desire or openness to pregnancy in the next 6 months was positively associated with having a history of sexual abuse, having disclosed to fewer people in one's family, and not having any children already.

Contraceptive use

We identified two studies that described the contraceptive use behaviors of HIV-infected young women. Data from the REACH cohort found that across all 344 study visits made by 154 adolescents with HIV, the most commonly reported contraceptive method being used during the 3 months preceding survey was condoms alone (51% of visits), followed by injectable contraceptives alone (21%), and using condoms plus either injectable or oral contraceptives (16%).²⁵ In addition, the distribution of contraceptive methods used was similar for BHIV adolescents as for their counterparts that did not have HIV. Exceptions were that HIV-infected adolescents were slightly more likely to report having used injectable contraceptives alone (21% vs. 15% of total visits). Although the proportion of females using condoms was similar among HIV-infected and HIV-uninfected youth, HIV-infected females were substantially more likely to report consistent condom use (73% vs. 46%, respectively). Overall, compared with HIV-uninfected young women, HIV-infected young women were more likely to report consistent use of effective methods over the course of a year (56% vs. 44%), which was defined by the authors as using "forgettable" contraception such as injectables, an intrauterine device, or sterilization; taking contraceptive pills daily; using condoms "all of the time"; or being abstinent. In multivariable analysis, this association remained statistically significant, and non-Hispanic African Americans were more likely than non-Hispanic whites and females of other racial/ethnic groups to be consistent users of effective methods. A number of other measures, including relationship status and parity, were not associated with consistent use of effective methods.

An analysis of contraceptive use among HIV-infected women in the Women's Interagency Health Study (WHIS) revealed that among younger women (age < 20) at risk of unintended pregnancy (e.g., not sterilized or not seeking pregnancy, yet not using other contraception), condoms were reported to be the method relied on for pregnancy prevention in about 40% of the semiannual visits over the years of the study, hormonal contraception was relied on in 40% of visits, and women reported using no method in about 15% of visits. Use of condoms and hormonal methods decreased as women aged into adulthood. ³¹

Condom use

We identified 11 studies and one review that characterized condom-use behaviors in this population. The review of research on PHIV youth found that across several studies, sex without a condom was not more common, and was often less common, for these HIV-infected youth than for their uninfected peers. At the same time, the proportion who engaged in unprotected sex was still sizable; in one recent study, 65% of sexually active PHIV had ever had unprotected sex. 40 One longitudinal analysis of unprotected sex across the adolescent years found increasing prevalence for PHIV, but the increase over time was not as steep as it was for most HIV-uninfected youth.37 A qualitative study of PHIV adolescent girls highlighted the complexity of condom use among this population, reporting, for example, that some girls become adamant, consistent (100%) condom users, while others struggled with disclosure of their status to partners and discussions about condom use.³³ Moreover, for some girls, disclosing their HIV status to partners led them to shift condom use decisionmaking to their male partners.

Aligning with these findings are those of studies including BHIV youth, which document that the occurrence of sex without a condom is substantial in this group. Among studies that only included young women (both PHIV and BHIV), unprotected sex over the 3 months preceding survey was reported by 42% with their main partner.¹⁹ and 59% with any partner.²⁸ Among studies that included both women and men, estimates of recent unprotected sex ranged from 40% to 63% across five studies.^{22–24,27,29}

Multivariable analyses of predictors of recent unprotected sex among HIV-infected young women have found positive associations with poorer partner communication about sex and the perception that the partner had other partners, ¹⁹ older partner age, greater age difference with the partner, longer relationship duration, and perception that the partner had HIV.²⁸ In similar analyses with mixed-gender samples, positive associations have been found with experiencing sexual abuse as an adolescent; greater level of knowledge about HIV;²⁹ more psychological distress, when sexual activity was mixed with drugs and alcohol;²² and depression.²⁷ In one study, consistent condom use was positively associated with motivational readiness and self-efficacy to use condoms.²³ In another study, disclosure was not significantly associated with unprotected sex in multivariable analysis. 20 However, in a different study, among BHIV adolescent girls who had not disclosed their HIV status to their partner, unprotected sex was more likely if they believed their partner to be HIV infected and if that partner were older; however, the same was not found for BHIV girls who had disclosed.²⁸

Discussion

Overall, we identified a relatively small, heterogeneous set of studies that collectively provided only a sketch of the reproductive health behaviors and needs of HIV-infected young women. Based on these studies, we can assume that large percentages of HIV-infected youth, especially BHIV, are sexually active. Condom use is far from universal among sexually-active HIV-infected youth, but use is somewhat higher and more consistent than it is among HIV-uninfected counterparts. Such findings indicate laudable efforts on the part of many HIV-infected youth to prevent infection in their partners, but they also indicate that others have a continuing risk of HIV transmission, as well as pregnancy and sexually transmitted infection acquisition. Disclosure is difficult and, among youth, complicates the developmental tasks of establishing and maintaining romantic and sexual relationships; studies show that large portions of youth have not disclosed their serostatus to recent sex partners. Some opt to delay sexual activity or restrain emotional intimacy in response to their serostatus and concerns about disclosure. No studies we identified discussed the relationship between serostatus disclosure and reproductive health decision-making beyond condom use. In the future, researchers may want to investigate whether and how disclosure factors into discussions between partners about pregnancy and contraceptive use.

In other areas with even fewer research findings, we are also left to speculate. The two studies that described the pregnancy intentions of HIV-infected young women suggest that nearly all will desire pregnancy at some time. Only one study assessed pregnancy intentions in the near future, a staple measure in reproductive health studies. It showed that some are interested in pregnancy in the near future. Additional research is imperative. It will be important to apply many of the concepts related to multiple dimensions of pregnancy intentions, ambivalence, 49 and pregnancy planning⁵⁰ to this population. Without more information on their short-term pregnancy intentions, it is difficult to estimate the need for pregnancy prevention and preconception health services for this population. Recent clinical guidelines from Canada for supporting pregnancy planning among HIV-infected men and women summarized relevant literature, but evidence is lacking in many areas, particularly in how best to help HIV-infected persons plan safer pregnancies. 51,52 There are also important behavioral questions about the interactions between HIV and reproductive health, after pregnancy. For example, new data suggest that some young women become infected during pregnancy, potentially compromising infant outcomes.⁵³ Not only do such findings call attention to CDC recommendations for repeat HIV screening in the third trimester for women at risk, 54 but they also reiterate the need for HIV prevention counseling among young women currently pregnant.

In terms of contraceptive use, only one study, from over 10 years ago, included sufficient measures to described in detail the mix of contraceptive methods used by HIV-infected youth, finding that their choices were not all that different from those of HIV-uninfected youth.²⁵ The dearth of published information about the most basic aspects of contraceptive use is problematic. Knowing more about this population's contraceptive knowledge, past and current experiences, barriers, and preferences, is essential to advancing

the reproductive health of this population. Future research can follow the lead of recent studies of older HIV-infected women, which are identifying important findings, such as high levels of sterilization regret, very low levels of longacting, reversible contraceptive use,55 and very high levels of unintended pregnancy.⁵⁶ Further clouding the contraceptive decisions that HIV-infected women make are questions about the biomedical interactions between hormonal contraception and the risk of HIV infection and transmission to partners.⁵⁷ The World Health Organization and the Centers for Disease Control and Prevention recently recommended continuing to offer HIV-infected women hormonal contraception without restrictions, but highlighted the fact that evidence on this interaction is inconclusive. 58 Other questions about contraceptive use in HIV-infected teens, relate to their long-term effects on bone and metabolic health, which need to be elucidated.⁵⁹ Such biomedical research is critical, particularly given the chronicity of HIV disease and its potential implications for the large population of HIV-infected young women worldwide. Table 2 summarizes some of the research gaps that this review highlighted.

Across topics summarized, we identified many studies that did not disaggregate findings by sex or age, a fact probably driven at least in part by relatively small sample sizes. Regardless, this limited our ability to identify the behaviors of the unique population of young women. It equally prohibits opportunities to consider further the specific sexual and reproductive health needs of HIV-infected young men, who make up the majority of HIV-infected young people in the US.4 Relationship characteristics, disclosure, condom use, and related issues are most likely also complicated for them;⁶⁰ those who have sex with women also have a role in planning and preventing pregnancy. In most studies reviewed here, cross-sectional analyses of survey data were used, and were limited in the kinds of predictors or measures available for inclusion. Further, a limitation of this review is that it is likely that we missed a relevant study, statistic, or prevalence point. Nevertheless, our approach was comprehensive in that it involved multiple searches and redundancy. A recent NIHsupported Think Tank exploring the reproductive health decision-making of PHIV youth came to the similar conclusion that research in this area is thin and major gaps remain.⁶¹

Various efforts have been oriented towards identifying the clinical and behavioral interventions that can support HIVinfected youth effectively. Many involve multiple clinic-based sessions focused on increasing safer sex behaviors or improving mental health and adherence to HIV-related medications (e.g., Healthy Choices, Adolescent Impact, Project ACCEPT, among others). 62-66 There is evidence that such interventions are acceptable to HIV-infected youth and feasible to provide in the clinical settings that those youth already typically attend (ibid), as well as evidence of positive impact on key behaviors and psychosocial outcomes. 67-70 Such interventions, particularly if they improve condom use, would likely also reduce unintended pregnancies and could benefit other reproductive health outcomes and precedents (e.g., communication with sex partners). Nevertheless, we are unaware of any evaluations of interventions that have focused on the reproductive health behaviors of HIV-infected youth (women or men). There is a need to identify and evaluate best practices among practicing clinicians for addressing reproductive health behaviors of HIV-infected youth.⁷¹ For exam-

Table 2. A Selection of Remaining Research Questions Related to the Reproductive Health of HIV-Infected Young Women

Relationships and disclosure

- What is distinctive about the romantic/sexual relationships of HIV-infected young women?
- How does disclosure and HIV status factor into their relationship trajectories?
- How does disclosure factor into discussions between them and their partners about pregnancy and contraceptive use?

Pregnancy intentions

- What are the short-term pregnancy intentions of HIVinfected young women?
- How are their pregnancy intentions different, compared to HIV-uninfected young women?
- How do their HIV status and disclosure factor into their pregnancy intentions?
- What are their pregnancy prevention and preconception health service needs?

Contraceptive and condom use

- What is the contraceptive knowledge, including for dual protection (from STI/HIV and unintended pregnancy) of HIV-infected young women? What are their preferences?
- What methods do they use for contraception? What contraceptive experience do they have?
- What barriers do they face to contraceptive and condom use? How are they different from those that HIV-uninfected young women face?

Biomedical questions

- How does hormonal contraceptive use affect HIV transmission and the course of infection among HIV-infected young women?
- How does hormonal contraceptive use affect their metabolism?
- What are the interactions of hormonal contraceptive use and antiretroviral therapy in HIV-infected young women, locally in the genital tract and systemically?

Other service questions

- How do HIV interventions for HIV-infected young women affect their reproductive health outcomes, such as pregnancy and contraceptive use?
- How could health care services for HIV-infected young women better incorporate and support their reproductive health needs?

ple, in a recent qualitative study, many HIV-infected women reported having limited conversations with their providers about pregnancy planning, for reasons related to little rapport with the provider, inadequate provider training, and other issues, indicating a need for more standardized approaches to pregnancy-related counseling overall. Even in the absence of additional information on contraceptive use and pregnancy intentions of this population, clinical care for HIV-infected young women should continue to be assessed and improved, through targeted evaluations or quality improvement initiatives, to ensure their reproductive health needs are met.

More than anything, this literature search served to illustrate how little is known about the reproductive health behaviors of this population and how many research opportunities remain. Researching this population is not easy, and certainly many HIV-focused research questions still merit

research support. However, integrating reproductive health components into HIV research makes sense. Doing so would be worthwhile not only from a public health point of view, given the intersections between reproductive health and HIV transmission, but from the point of view of many HIV-infected young women, who have voiced a desire for more comprehensive, sexual health care. 73–75

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