Providers Caring for Adolescents with Perinatally-Acquired HIV: Current Practices and Barriers to Communication About Sexual and Reproductive Health

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Abstract

The population of adolescents and young adults (AYA) with perinatally-acquired HIV (PHIV) present challenges to HIV healthcare providers (HHCPs). Originally not expected to survive childhood, they are now living well into young adulthood. Little is known about the type of sexual and reproductive (SRH) information/ services offered to AYA with PHIV by HHCPs. HHCPs (n=67) were recruited using snowball sampling, and completed an online survey. Providers' most frequently endorsed SRH topics discussed with both male and female patients included condom use (77.3%), STD prevention (73.1%), and screening (62.1%). Providers' reports indicated that females received significantly more education about SRH topics overall. The most frequently noted barriers to SRH communication included more pressing health concerns (53.0%), parent/ guardian not receptive (43.9%), and lack of time during appointment (43.9%). Provider-reported SRH conversations with HHCPs were highly focused on horizontal transmission and pregnancy prevention. Salient social aspects of SRH promotion for AYAs with PHIV (e.g., managing disclosure and romantic relationships) were less commonly discussed, though such conversations may serve to reduce secondary transmission and enhance the overall well-being of AYA with PHIV. Findings indicated that further work must be done to identify strategies to address unmet SRH needs of the aging population of AYA with PHIV.

Introduction

PPROXIMATELY 9100 ADOLESCENTS and young adults A (AYA; age 14-24 years) in the United States are growing up with perinatally-acquired HIV (PHIV).¹ PHIV was first publicly recognized in the US in 1983, and the incidence of infections in infants rose until 1992 when antiretroviral drug regimens decreased the risk of motherto-child transmission from 25% to 5%.^{2,3} Historically, HIVinfected infants were not expected to live past childhood. In the US, medical advances have enhanced the long-term survival of individuals with HIV, decreasing the mortality rate by 90% since the 1990s. Many youth are living well into young adulthood due to more effective antiretroviral treatment.⁴ The characteristic difficulties associated with adolescence are made especially complex for those living with PHIV, due to the possibility of horizontal transmission and requirements to disclose a highly stigmatized illness status to sexual partners. Evidence suggests that AYA with PHIV engage in intimate relationships and share similar sexual behaviors with their uninfected peers, and that many desire children in the future.^{4–7} AYA with PHIV are able to maintain perinatal and postpartum health, and give birth to uninfected infants.⁸

AYA with PHIV have typically been engaged in medical care for most of their lives and developed long-standing relationships with their providers. The challenges of transition to adult care for the population, partly due to the nature of their relationships with providers, are well-documented, and many stay in pediatric care into their early 20s.⁹ Prior research suggests that the sexual debut among AYA with PHIV is only slightly later than their uninfected peers, meaning that they may stay in pediatric care long after their sexual debut. As well, some research indicates that they have low knowledge of sexual transmission risk factors. Despite low risk knowledge, Wiener and Battles found that the population with PHIV reported higher condom usage rates than their uninfected peers, though 41% of respondents were uncertain whether they would be able to correctly use a condom during every sexual encounter, with one-fifth of participants

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reporting unplanned pregnancies.⁴ This highlights the importance of broad sexual and reproductive health (SRH) education across the healthcare settings in which AYA with PHIV engage, including those social aspects of SRH such as disclosure strategies that may not be routine in pediatric or general healthcare settings. Little is known about the nature of reproductive information offered to AYA with PHIV by their medical care providers.

Medical settings are appropriate for addressing aspects of sexual and reproductive health education specific to HIV infection. Federal and clinical guidelines for the care of adolescents AYA with HIV emphasize the importance of sexual and reproductive care for this population including gynecologic care for females and access to contraception.¹⁰⁻¹² However, Drainoni et al. (2009) found that adult HIV care providers described a lack of knowledge and training surrounding the initiation of SRH conversations with adult patients.¹³ Research suggests that patients themselves rarely initiate SRH discussions with their physicians or medical providers, but anticipate that their providers will engage in conversations about aspects of HIV unrelated to medical management.¹⁴ Additionally, evidence suggests that minority or low-income women with HIV perceive a higher risk of MTCT than is accurate.¹⁵ The significant challenges for patients' maintenance of sexual and reproductive health-such as stigma, disclosure, socioeconomic status, and lack of knowledge of risk reduction strategies-are nevertheless recognized by providers.16,17

The challenges of providing SRH education to the general population of AYA are well-documented. Among other factors, the developmental stage of adolescence, inconsistent engagement in care, and patient or parent/guardian reticence to discuss SRH affects pediatric providers' ability to adequately address SRH needs.¹⁸ A complicating factor for pediatric clinicians in the provision of thorough SRH education for AYA with PHIV is that they are often faced with preparing patients for transition to adult care while also addressing other developmental and HIV-related needs.⁹ The increased prevalence of medical and psychiatric disorders among AYA with PHIV may also impede provider counseling about SRH and SRH outcomes.⁸ Providers' concerns about a lack of support for the sexual and reproductive health education needs of AYA with PHIV within adult clinics have been documented, and researchers have called for special attention to the SRH needs of the aging population of AYA with PHIV.^{19,20} This study describes reported communication about SRH by healthcare providers of the aging population of AYA with HIV in order to identify unmet needs.

Methods

Participants

Snowball sampling was used to recruit HIV care providers including doctors, nurses, social workers, and other clinicians between May and June 2012. Providers in the southeast US who offered care to a previous study population,⁵ comprising AYA with HIV, were initially contacted to complete the online survey, and asked to send the survey to other HIV care providers, who in turn were asked to do the same. The projected sample size was 50 participants, and this number was reached and surpassed within 2 months. Eighty-one individuals started the online survey and provided consent. Fourteen were excluded for incomplete responses, having no contact with individuals with PHIV, and/or non-completion after consenting to participate. All those included in the final sample of 67 respondents had experience working with adolescents living with PHIV. The survey protocol was adapted from previous studies conducted by Nostlinger et al.¹⁶ and Akers et al.,²¹ and explored the nature of SRH services offered to adolescents with PHIV as well as barriers to service provision. Participants were asked to indicate which topics were routinely covered from a drop down menu which included options within the broad topics of pregnancy/STD prevention, reproductive health and psychosocial aspects of relationships/childbearing (Table 1). Participants were also asked to indicate which topics related to mother-to-child transmission were routinely covered from a drop down menu, which included the topics such as role of viral load, rates of transmission, and use of C-section (Table 2). Other survey items included questions eliciting information about perceived

<i>Topic</i> (n=66)	Discussed with males n (%)	Discussed with females n (%)	Discussed with both males and females n (%)
I. Contraception and sexual risk reduction			
Contraception	37 (55.2)	54 (80.6)	37 (55.2)
STD/STI prevention	51 (76.1)	53 (79.1)	49 (73.1)
HPV vaccination	35 (52.2)	49 (73.1)	34 (50.7)
Referral to a reproductive health specialist	7 (10.4)	23 (34.3)	6 (9.0)
STD/STI screening	45 (67.2)	47 (70.1)	41 (61.2)
Condom use	53 (79.1)	54 (80.6)	51 (76.1)
Importance of Pap smears	1 (1.5)	48 (71.6)	1 (1.5)
II. Psychosocial aspects of sexual health			
Romantic relationships (general)	37 (55.2)	38 (57.6)	34 (50.7)
Including partner in appointments	34 (50.7)	42 (63.6)	33 (49.3)
Disclosure issues	51 (77.3)	51 (77.3)	48 (71.6)
Sexual violence	17 (25.4)	30 (45.5)	15 (22.4)
Average score(scale 0–4)	2.07	$2.40^{\rm a}$	

TABLE 1. PROVIDER-REPORTED DISCUSSIONS ABOUT SEXUAL HEALTH

^aDifference between total number of topics provided to males and females significant at p < 0.05.

Topic	Discussed with males n (%)	Discussed with females n (%)	Discussed with males and females n (%)
I. Medical aspects of fertility/reproduction			
Effects of STDs on fertility	16 (23.9)	33 (50.0)	14 (20.9)
Effects of HIV on fertility	9 (13.4)	20 (30.3)	5 (7.5)
Abortion	4 (6.1)	27 (40.9)	4 (6.0)
Medications safe during pregnancy	4 (6.1)	46 (69.7)	4 (6.0)
Referral to reproductive health specialist	7 (10.4)	23 (34.8)	6 (9.0)
Preventive role of decreased viral load	45 (66.2)	13 (19.7)	11 (16.4)
Sperm washing	19 (28.8)	19 (28.8)	14 (20.9)
Artificial insemination	12 (18.2)	44 (66.7)	11 (16.4)
Use of rhythm method	3 (4.5)	4 (6.1)	0(0.0)
Transmission routes during/around delivery	20 (30.3)	45 (68.2)	18 (26.5)
C-section as prevention	6 (9.1)	5 (7.6)	1 (1.5)
Risk of transmission through breastfeeding	15 (22.7)	44 (66.7)	14 (20.6)
Percent change of transmission	28 (42.4)	33 (50.0)	22 (32.4)
Average score(scale 0–13)	2.81	6.01 ^a	
II. Future-oriented/social aspects of fertility and	childbearing		
General discussion about having children	30 (45.5)	44 (66.7)	30 (44.8)
Abortion	4 (6.1)	27 (40.9)	4 (6.0)
Responsibilities of parenting	28 (41.8)	35 (53.0)	28 (41.8)
Average score(scale 0–3)	0.93	1.58 ^a	

TABLE 2. PROVIDER-REPORTED DISCUSSIONS ABOUT FERTILITY AND CHILDBEARING

^aDifference between total number of topics provided to males and females significant at p < 0.05.

barriers to SRH education, and barriers to the maintenance of SRH for their patients (Table 3).

Survey participants were entered into a drawing for one of four \$50 gift cards in appreciation of their time. Elon University's Institutional Review Board approved this study.

Results

Sample characteristics

55.2%) or medical (n = 30, 44.8%).

Data analysis

Data were entered into SPSS version 6.0, a quantitative data analysis program. Descriptive statistics were used to describe reported SRH services offered to AYA. Chi square for categorical variables and *t*-tests for continuous variables were used to test associations between features of providers, patients, and services offered. When appropriate, analyses included a comparison of two categories of healthcare pro-

Of the 67 HIV care provider survey participants, most were female (n = 55), white (n = 44, 64.7%), with an average of 12.0 years of experience working in the field of HIV care. More than half (56.7) practiced in settings located in the southeastern US. The sample included a variety of professionals in HIV care settings, including physicians, nurses, social workers/case managers, and researchers. Most providers engaged in multiple roles in their interactions with AYA with PHIV, including clinical care (68.7%), risk reduction counseling (67.2%), and

viders, who were identified as either social service (n=37,

Provider-identified barriers to communication about SRH (n=66)	Medical providers (n = 30) n (%)	Social service providers (n=37) n (%)	Total n (%)
More pressing health concerns to address during appointments	18 (60.0)	17 (45.9)	35 (53.0)
Not part of job description	1 (3.3)	1 (2.7)	2 (3.0)
Patient not receptive	2 (6.7)	5 (13.5)	7 (10.6)
Parent/guardian not receptive	14 (46.7)	15 (40.5)	29 (43.9)
Lack of time during appointment	10 (33.3)	15 (40.5)	25 (43.9)
Provider(s) not trained to discuss	12 (40.0)	10 (27.0)	22 (33.3)
Uncomfortable with SRH discussions	1 (3.3)	2 (5.4)	3 (4.5)
Different health professional's job	3 (10.0)	6 (16.2)	9 (13.6)
Not enough knowledge about referral services	1 (3.3)	2 (5.4)	3 (4.5)
Waiting for patient to bring it up	2 (6.7)	1 (2.7)	3 (4.5)
Expect the patient to have a reproductive health medical provider	1 (3.3)	3 (8.1)	4 (6.1)
Personal reservations about discussing SRH	10 (33.3)	15 (40.5)	25 (37.9)
Age of patient	4 (13.3)	10 (27.0)	14 (21.2)

No significant differences between perceived barriers to communication about SRH among social service and medical providers.

adherence counseling (62.2%). The majority of participants worked in hospital-based pediatric or adolescent clinics. Refer to Table 4 for further details about provider demographics and affiliated clinic characteristics.

Sexual risk reduction and pregnancy prevention

Survey data indicated that for both male and female patients, the most commonly reported discussions by healthcare providers about sexual health were focused on condom use and STDs (Table 1) Few referrals to reproductive health specialists for males (10.4%) or females (34.3%) were reported. As indicated in Table 1, providers indicated that overall, more

TABLE 4. PROVIDER DEMOGRAPHICS AND CLINIC CHARACTERISTICS

Variable (n=67)	
Age (years) Years of experience working with PHIV + adol.	Mean (range) 42.3 (23–67) 12.0 (1–30)
Females	n (%) 55 (82.1)
Ethnicity Black/African American White Hispanic Asian Mixed race	12 (17.6) 44 (64.7) 3 (4.4) 3 (4.4) 5 (7.4)
Work setting Hospital-based pediatric clinic Hospital-based adolescent clinic Community-based pediatric or adolescent clinic Adult clinic (hospital or community-based)	31 (45.6) 39 (57.4) 15 (22.1) 6 (8.8)
Region/location Northern US Southeastern US Southwestern US Western US International: African countries	13 (19.4) 38 (56.7) 4 (6.0) 8 (11.9) 6 (9.0)
Areas served Urban Suburban Rural Number of patients in setting (n=61)	Mean % (range) 78.3 (5–100) 18.4 (1–60) 17.8 (1–75) 50.3 (3–200)
Modes of HIV acquisition Perinatally-acquired Behaviorally-acquired Transfusion-acquired Unknown	Mean % (range) 60.1 (1–100) 30.7 (0–25) 0.5 (0–25) 3.3 (0–5)
Providers who observed pregnancies among AYA with PHIV (%) Females Males who got someone pregnant	73.1 (<i>n</i> =49) 31.3 (<i>n</i> =21)
Pregnancy outcomes Live birth Miscarriage Abortion	Mean (range) 55.8 (0-00) 3.4 (0-33) 9.5 (0-50)

sexual risk/pregnancy prevention topics were discussed with female patients than with male patients (p < 0.05).

Psychosocial support for sexual health

The most commonly reported types of discussions initiated by healthcare providers regarding psychosocial aspects of sexuality included disclosure issues (71.6%) and romantic relationships (50.7%). Approximately 25.4% of providers discussed sexual violence with male patients, compared to almost one-half (45.5%) who discussed the topic with their female patients. Respondents who indicated that their role in the care setting involved anticipatory guidance, a term that refers to a proactive approach to health counseling, discussed significantly more (p < 0.05) social aspects of sexual health overall compared to other providers. In general, social service providers more frequently reported discussions about the psychosocial aspects of sexual health than did their medical provider counterparts. As a whole, healthcare providers gave male and female AYAs significantly different total content of education about the psychosocial aspects of sexual health, although providers indicated that all patients were engaged in discussions about disclosure issues in similar frequencies (77.3%). See Table 1 for further detail.

Medical aspects of reproduction/fertility

In conversations with both male and female patients about the medical aspects of fertility, providers indicated that they most frequently discussed the risk of MTCT (33.3) and transmission routes during/around delivery (27.3). When comparing reported information offered to patients of different sexes, the reported total content of information related to medical aspects of reproduction and fertility given to females was significantly higher than for males (p < 0.05). Healthcare providers indicated that males were most likely to receive information about the preventive nature of decreased viral load in MTCT (66.2%), while females were most likely to have received information about medications safe during pregnancy (66.7%). Half of all healthcare providers provided information about the risk of MTCT to females and 42.4% discussed risk of MTCT with male patients. Additional details can be found in Table 2.

Future-oriented, psychosocial conversations about SRH

Healthcare providers reported relatively fewer discussions about future-oriented aspects of fertility and family planning than prevention-oriented topics (Table 2). With males, 45.4% of providers had discussed childbearing, and with females, 66.7%. Four (6.1%) medical providers discussed abortion with males; and less than half had such conversations with females (40.9%). Similar numbers of providers indicated that they engaged males and females in discussions about the responsibilities of parenting (41.8 and 53.0%, respectively). The total number of future-oriented conversation topics reported by healthcare providers was higher for females than males.

Barriers to patient-provider communication about SRH

The most commonly cited barriers to discussing issues of SRH with adolescents living with PHIV included more pressing health concerns (53.0%), parent/guardian not receptive (43.9%), and lack of time during appointment

(43.9%). See Table 3 for further details. There were no significant differences between the number or types of barriers cited by medical and social service providers.

Discussion

Providers reported focusing on more sexual risk behaviorrelated topics during communication about SRH with AYA living with PHIV than on psychosocial aspects of sexual health and romantic relationships. Sexual risk-related topics such as condom use and STD prevention were most frequently reported. Encouragingly, according to providers in this study, disclosure was also a commonly discussed topic within the context of SRH-related discussions. Previous research has found that among the population of AYA with PHIV, consistent condom use and disclosure to partners is low.⁵ Further, HIV disclosure is one of the most challenging components of engaging in romantic relationships and is fraught with anxiety.^{22,23} There is evidence to support the efficacy of disclosure-oriented counseling from providers in increasing the likelihood of disclosure in romantic relationships among adults with HIV as well as the disclosure to children.24,25

Most providers (73.1%) reported pregnancies among female patients with PHIV at their clinics (Table 4). This indicates the importance of broader conversations about pregnancy to supplement prevention-focused discussions with support for patients trying to conceive or who may become pregnant unintentionally despite contraceptive use/knowledge. Providers may interpret discussions about pregnancy prevention as inclusive of childbearing topics, but it is important to note that this approach may neglect content related to fertility planning and parenting. Future research should employ qualitative or observational methodology to determine the nature of pregnancy prevention and childbearing-related conversations for a better understanding of how providers themselves categorize such education.

Encouragingly, of those pregnancies reported by providers that resulted in a live birth, all but one offspring were HIVnegative. The low incidence of infants born with HIV among this population may be indicative of connection to HIVappropriate obstetrical care for AYA with PHIV who become pregnant. More providers in this study reported having discussions about pregnancy prevention than aspects of fertility and family planning with both genders (in particular, percent chance of transmission risk and general discussion about childbearing), but more than half had discussed MTCTrelated topics such as medications safe for pregnancy, artificial insemination, transmission routes during/around delivery, and breastfeeding with their female patients. In previous studies, perceived high risk pregnancies among women with HIV has been associated with hesitance to seek prenatal care and to inform medical providers about pregnancies.²⁶ This population, who have typically received long-term care from HIV providers, may experience more comfort with reporting pregnancies, receive more consistent and early information about sexual and reproductive health topics, and thus more quickly engage in prenatal care. Nonetheless, receiving comprehensive education about mother-to-child transmission is not only important for patients to make educated decisions about childbearing, but also to encourage seeking appropriate care. The right of HIV-positive women to make their own

decisions about fertility and to receive comprehensive information about their ability to bear children has been recognized internationally.²⁷ Still, evidence suggests that some women with HIV have experienced stigma in medical or social service settings that has contributed to regretted abortion or sterilization.^{28,29} Broad reproductive health education for people living with HIV includes information about methods of safer conception, the risk of MTCT, and specific medical interventions that support reduced transmission risk for both males and females.

The American Academy of Pediatrics and Society for Adolescent Health and Medicine recommends that providers address sexual health topics including healthy and safe relationship dynamics with patients, attain a comprehensive sexual history, and begin sexual health education in childhood so as to increase exposure to such topics.^{30,31} These guidelines apply to both male and female patients, but evidence suggests that males receive quantitatively less and qualitatively different SRH education than females.³² The significant differences found between information provided to male and female patients were unsurprising, given this observation in the general population of AYA. Recently, researchers and practitioners have called for broader education for AYA males: specifically, to prioritize conversations about contraception for females (to offer support for partners), effective relationship communication, and sexual violence.^{32–34} For the population of male AYA with PHIV, holistic discussions about SRH will help ensure optimal health as they age. Information about the SRH of HIV-positive females should not be excluded from conversations with males with HIV, particularly since evidence suggests some HIVpositive individuals may actively seek out sero-concordant partnerships³⁵

The barriers to providing SRH education cited by providers in this study were consistent with those described by other researchers who focused on adults in HIV care settings.¹³ Certain barriers to providing SRH education reported by providers reflect system-level issues, such as large patient loads that limit the length of one-on-one time with providers, and lack of training on how to effectively provide SRH education. Others speak to differences in individual providers or patient characteristics-some providers may feel uncomfortable discussing SRH, whether due to inexperience or due to religious/personal reservations. Some patients may similarly avoid such discussions due to discomfort or anxiety about parental involvement. Many providers indicated that parents/guardians of their patients were not receptive to SRH discussions, or that they themselves were uncomfortable discussing SRH. Each of these barriers points to a potential for dialogue within clinic teams about effective communication and personal reservations to identify providers who are most skilled and comfortable with such discussions.

The findings must be considered in light of several limitations. The generalizability of findings from this study is limited by the sampling approach and survey methodology. It is not possible to know how many healthcare providers eligible for the study may have received the survey but did not participate. The sample was recruited using snowball sampling, yielding a geographically disparate group of respondents. More than half of participants were located in the southeastern US, and a few were located internationally. Most providers (78.3%) served urban areas, so the information may be less generalizable to those clinicians in suburban or rural areas. Sample size limited the ability to make comparisons across different geographic regions. While a few participants were located in African nations, the generalizability of findings internationally is likely very limited, considering the demographic differences in populations of AYA with HIV.

For the purposes of this study, only survey items referring to AYA with perinatal HIV were included in analysis. The described communication about SRH does not offer insight into information offered to other groups of AYA living with HIV who may have acquired HIV later in life through sexual activity or intravenous drug use. Considering the current epidemiology of perinatal HIV in the US, it is likely that the majority of patients served were in their late teens or early 20s. However, some pediatric providers may care for exclusively much younger AYA, which may explain lower levels of SRH communication. Nonetheless, current adolescent care guidelines recommend that SRH education begin in early adolescence, so findings of infrequent or limited SRH education are still important to note, regardless of whether patients are younger adolescents or young adults. Finally, data were limited to self-report only, and most items offered closed-ended response options, which may have been interpreted differently among providers. In order to gain a more in-depth understanding of patient-provider communication about SRH, especially across different geographic settings and patient groups, larger scale studies and qualitative methodology must be employed to determine the nuances of responses given by providers.

Notwithstanding the aforementioned limitations, study findings that social service providers more frequently discussed psychosocial aspects of SRH than the medical professionals support a model of care that incorporates both social service and medical providers in SRH conversations. As gatekeepers to reproductive care and reliable sources of accurate medical information, HIV medical and social service providers play a critical role in enhancing the sexual and reproductive health of the aging population of AYA with PHIV, particularly considering the persistent context of HIVrelated stigma in which these young people are forging intimate relationships. The medical care appointment is one setting in which HIV-specific SRH topics can be addressed for patients who may not discuss issues related to their HIV status elsewhere by a variety of care providers. Interdisciplinary teams should draw upon the strengths of different practitioners and work collaboratively to offer AYA holistic SRH information.

Findings indicate a need for increased focus on quantity and quality of the SRH of the aging population of AYA living with PHIV. HIV care settings, often staffed by both medical and social service providers, are ideal for addressing social aspects of SRH, ranging from communication between partners to childbearing. Additional training for addressing difficult issues such as SRH may be beneficial for both sides of the patient–provider dyad: providers may feel more comfortable, and patients may feel more engaged in conversations that also attend to the psychosocial challenges of maintaining SRH while living with HIV. Finally, it is critical for providers to provide holistic SRH education that not only focuses on medical and transmission issues, but also strategies for educating partners about HIV, negotiating condom use, and disclosure. Comprehensive support for SRH has the

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Author Disclosure Statement

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