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Do confidentiality concerns impact pre-exposure prophylaxis willingness in emergency department adolescents and young adults?

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PrEP – Pre-exposure Prophylaxis; HIV – Human Immunodeficiency Virus; AYAs – Adolescent and Young Adults; HIPAA – Health Insurance Portability and Accountability Act; STI – Sexually Transmitted Infection; ED – Emergency Department

Daily oral pre-exposure prophylaxis (PrEP) is recommended to reduce the risk of human immunodeficiency virus (HIV) infection in adolescents and young adults (AYAs). [1] National electronic pharmacy data suggest that emergency department (ED) providers provide approximately 12–21% of PrEP prescriptions to AYAs. [2] The ED may be a key access for PrEP given the risk profile of the population served. [3,4] Yet, there have been limited studies to examine what factors impact willingness to take PrEP in ED settings.

Lack of confidentiality protections may decrease AYA's willingness to seek sexual health services. [5–7] Confidentiality breaches may exist for AYAs on their parents' health insurance plans. While the Health Insurance Portability and Accountability Act (HIPAA) prevents release of information without written authorization, the insurer can provide the policy holder with information related to billing and payment in an Explanation of Benefits [EOB] which occurs more often in EDs where AYAs are more likely to seek care. [6,3]

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We sought to explore the relationship between confidentiality concerns and willingness to take PrEP in AYAs seeking care in EDs. We hypothesized that AYA confidential needs may contribute to decreased willingness to take PrEP.

Data were drawn from a web-based cross-sectional survey conducted in a mid-size urban emergency department. Patients 18 to 44 years old completed a 10-minute anonymous survey after registration and triage. This data focuses on 18 to 25-year-old HIV seronegative participants. The Johns Hopkins Medicine Institutional Review Board approved this study.

The survey questions included: demographic, sexual/drug use history; insurance status/source; confidentiality; HIV risk perception; and willingness to take PrEP. Confidentiality questions were developed from validated questions on contraceptive services. [8] Participants were asked whether they wanted their parents to know they were taking PrEP and likelihood of using PrEP if further discussions with parents were required. Responses were converted to a binary (likely/unlikely) due to aggregation.

Simple logistic regression was used to examine associations between parental insurance coverage, confidentiality factors, and willingness to take PrEP. Multivariable logistic regression was performed to examine associations between parental insurance coverage, confidentiality factors, factors associated with PrEP use as determined by existing literature and willingness to take PrEP. Analyses were conducted using StataSE 14 software.

Participants included 156 between the ages of 18 and 25 years. Sociodemographic characteristics are summarized in Table 1. Most participants were female, self-identified as African-American, heterosexual and reported having health insurance coverage. Nearly half were on parental insurance.

In bivariate analysis, age and STI diagnosis were significantly associated with parental insurance coverage. Older AYAs and AYAs with a prior STI diagnosis had a lower odds of being on a parent's insurance compared to younger AYAs. Not wanting a parent to know about PrEP use and being unlikely to use PrEP if required to discuss side effects with parents were negatively associated with willingness to take PrEP, whereas prior HIV testing was positively associated with willingness (Table 2). Parental insurance coverage approached significance in bivariate analysis with AYAs on parent's insurance having a lower odds of being willing to take PrEP.

In the final multivariate model, AYAs who indicated they would not want their parents to know they were taking PrEP had a lower odds of being willing to take PrEP. [Table 2, OR = 0.30 (95% CI: 0.11–0.85)] (Table 2).

This is the first ED study to examine parental insurance, confidentiality, and willingness to take PrEP. Parental insurance coverage was not a direct barrier to starting PrEP; however, parent-AYA confidentiality concerns were associated with lower willingness. HIV testing history was associated with greater willingness suggesting that ED PrEP programs will need to be paired with HIV testing services.

ED providers will need to guide AYAs around confidentiality protections that come with parental insurance coverage. This may require insurance companies to further elucidate their policies regarding protections around confidentiality and to establish protocols that prevent disclosure of sensitive information. HIPAA regulations allow for AYAs to request insurers send EOBs by alternative means, but prior studies suggest that insurance companies receive very few yearly requests likely because AYAs are unaware of this right. [6,8] A dialogue between AYAs, clinicians, and insurance companies may be needed to assure confidentiality. [9]

This study has potential limitations. Given the high prevalence of risky sexual behavior in ED-seeking AYAs [3], our findings may not generalize to AYAs seeking care in primary care settings. Participants may also have been unaware that they were on their parents' insurance.

This work suggests that AYAs in EDs are less likely to be willing to take PrEP if parents know about their use. In order to increase PrEP access for AYAs in EDs, further research is needed to understand how parental insurance and confidential protections impact access to PrEP. Such research is critical as PrEP for AYAs expands in settings, including EDs where AYAs are frequently seeking care.

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Table 1

Demographics, N=156

Characteristic	Mean (SD)	N (%)
Age, in years	22.1 (2.2)	
Insurance status		
Insured		143 (91.7%)
Under 26 on parent's insurance		71 (45.5%)
Race (N=116)		
White		20 (17.2%)
Undefined		14 (12.1%)
Black/African-American		82 (70.7%)
Gender identity		
Female		92 (59.0%)
Male		63 (40.4%)
Other		1 (0.64%)
Sexual Orientation		
Heterosexual		135 (86.5%)
LGBTQ ¹		21 (13.5%)
Sexual Behaviors		
Men who have sex with men		4 (2.6%)
Unprotected receptive anal sex		20 (12.8%)
Unprotected receptive vaginal sex		59 (37.8%)
STD/HIV history		
History of STI		38 (24.4%)
Have been tested for HIV		126 (80.8%)
Perception of HIV likelihood		3 (1.9%)
Drug use last 6 months		
Marijuana		84 (53.9%)
Other ²		7 (4.5%)

¹ Lesbian, Gay, Bisexual, Transgender, or Questioning² Methamphetamines, cocaine, or intravenous drug use.

Bivariate and multivariate comparisons among parental insurance coverage and willingness to take PrEP stratified by participant characteristics

Table 2:

Characteristics	Parental Insurance Coverage		Willingness to Take PrEP	
	Unadjusted OR	95% CI	Unadjusted OR	95% CI
Parental Insurance Coverage	----	----	0.52	0.25–1.07
Age				
–18–20	5.69**	2.74–11.82	1.11	0.53–2.37
–21–25	0.32**	0.15–0.68	0.93	0.42–2.05
Race				
–White	1.14	0.28–4.59	0.53	0.11–2.63
–Undefined	1.09	0.28–4.32	3.15	0.61–16.29
–Black	0.58	0.22–1.55	2.34	0.63–8.75
Previous HIV test	0.68	0.30–1.51	4.34**	1.24–15.15
History of STI	0.46*	0.21–1.00	2.00	0.92–4.34
Do not want parents to know that they're taking PrEP	1.26	0.65–2.45	0.32**	0.15–0.66
Unlikely to use PrEP if...				
– Needed to talk to parents about side effects of PrEP	1.00	0.46–2.17	0.44**	0.20–0.98
– Needed to talk about the sex they're having	1.69	0.67–4.25	0.45	0.18–1.11

* Indicate variable significantly associated at p-value =0.05.

** Indicate variable significantly associated at p-value<0.05.