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Factors Informing HIV Providers' Decisions to Start Antiretroviral Therapy for Young People Living with Behaviorally Acquired HIV

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Abstract

Purpose—Young people with behaviorally acquired HIV (BHIV) are less likely than adults to initiate antiretroviral therapy (ART) despite meeting treatment criteria. We explored critical factors involved in healthcare providers' decision-making regarding ART initiation for young people with BHIV (ages 12–24).

Methods—Semi-structured interviews were conducted with 23 HIV providers from diverse training backgrounds caring for youth with BHIV at 4 adult clinics and 1 pediatric clinic in a high prevalence urban city. Interview domains probed clinical and non-clinical patient characteristics, the role of adherence, and provider attitudes working with youth to establish decision-making priorities for ART initiation. The constant comparative approach was used to develop grounded theory on providers' decision-making on ART initiation.

Results—Clinical criteria, particularly the CD4 count, and the public health implications of HIV transmission determined the urgency for ART initiation. However, patient-related concerns regarding treatment readiness and adherence hampered the decision to initiate, especially at higher CD4 counts. Providers who acknowledged developmental characteristics of youth (e.g. evolving adult identity and self-efficacy around health management) appeared more cautious in assessing future ART adherence and responded with intensive clinical support. Extensive involvement of

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IMPLICATIONS AND CONTRIBUTION

Young people with behaviorally acquired HIV engage in care at adult and pediatric-centered clinics with experienced HIV providers who may have limited training in youth-targeted approaches to care. Identifying strategies that support youth-friendly services across all clinic settings where youth with HIV engage in care may enhance outcomes for this population.

multidisciplinary teams was identified as an important strategy to retain youth in care, whereas strengthening youth-targeted approaches may be an unmet need in adult clinics.

Conclusion—Evaluation of providers' awareness of the developmental features of youth and characteristics of youth-targeted approaches in clinics caring for youth with BHIV may inform interventions to increase youth engagement in care and subsequent decisions to successfully initiate ART.

Keywords

HIV; adolescent health services; antiretroviral therapy; guideline adherence; medication adherence

INTRODUCTION

Young people ages 13–24 years with behaviorally acquired HIV (BHIV) infection represent 26% of all new HIV infections in the United States¹. Nearly 40% have initial CD4 counts below 350 cells/mm³ and therefore meet criteria to start antiretroviral therapy (ART) upon entry into care².

With increasing attention on reducing the gaps in the continuum of services identified by the HIV “treatment cascade”³, it is important to recognize that younger people may require age-appropriate approaches to care in order to address their poorer rates of retention⁴, delayed initiation of ART⁵, and lower rates of virologic suppression once on ART⁶ compared to older adults.

Unlike young people with perinatally acquired HIV who are typically already in care at pediatric clinics from an early age, youth who may have acquired HIV behaviorally are frequently at a transitional age when they may enter care at either adult or pediatric-centered clinics. The proportion of young people with BHIV who are in care in either setting is unclear; however, in the HIV Research Network (HIVRN), a national consortium of 18 pediatric and adult clinics, nearly 80% of young people with BHIV infection were enrolled at adult sites⁷, suggesting that a significant number receive care at adult-centered clinics in the U.S.

Differences in the culture and models of healthcare delivery between adult and pediatric-centered clinical settings have been well-documented, however most literature comparing these differences have been in the context of adolescents transitioning from pediatric to adult care for chronic illnesses diagnosed during childhood^{8–11}. In contrast, young people newly diagnosed with HIV may be presenting into regular care for the first time and often face challenges in many ways distinct from adolescent and young adult survivors of perinatally acquired HIV¹².

Understanding the clinical decision-making approaches HIV providers use to successfully prepare, initiate, and sustain ART for young people with BHIV is critical to improve care for this population, but little is known about providers' training and attitudes with regards to working with youth. In this qualitative study, we focus on exploring the factors HIV providers consider when deciding to initiate ART in order to examine the disparities in ART

initiation noted between adults and youth. This study aims to provide formative data to generate hypotheses that will inform future interventions to improve timely ART initiation and, ultimately, outcomes for young people with BHIV.

METHODS

Study Design

Semi-structured interviews were used to examine provider decision-making for ART initiation. Interview domains were informed by a review of the literature and organized to probe clinical (e.g. CD4 count, viral load, comorbidities) and patient-related characteristics (e.g., mental health, housing/food instability, disclosure), the role of adherence in the decision to initiate ART, and providers' assessments of predicted ART adherence among young people with BHIV. Provider attitudes and preferences working with youth were also explored. Excerpts from the interview guide are listed in Table 1. Two pilot interviews were conducted to refine the interview guide and clarify ambiguous questions.

Study Setting and Participants

The study was conducted in Baltimore, Maryland, which has one of the highest rates of incident HIV infections among U.S. youth¹³. We selected clinic sites to represent the broad array of settings where young people with BHIV may receive care in Baltimore, with an emphasis on adult sites due to poorer outcomes noted in the literature among youth attending adult-centered HIV clinics. Of the five clinic sites, one adult-centered and one pediatric-centered clinic were based at an academic institution. The remaining three clinics were a large community-based practice recognized for providing comprehensive health care for people living with HIV, a community hospital-based clinic, and the local health department STD/HIV clinic, all of which were predominantly adult-centered and reflect the larger proportion of adult clinical settings available to young people with BHIV infection in Baltimore. Clinic managers were contacted prior to the study to confirm that care was provided to young people between the ages of 12 and 24 years, with adult-centered clinics reporting care primarily for youth older than 18 years.

Eligible providers were physicians, nurse practitioners, or physician assistants with at least 1 year of HIV clinical experience, who provided HIV care to at least 5 young people with BHIV, spoke English and were able to provide verbal consent for participation. Participants were recruited and enrolled until saturation of themes was achieved. The 60-minute interview was conducted face-to-face (n=21) in the participant's office at the clinical site or by phone (n=2) by the first author and were digitally recorded. Participants completed a brief demographic survey to describe professional training and experience working with youth living with HIV. A \$50 gift card was presented upon completion of the interview. Interviews were conducted between March 2011 and January 2012. This study was approved by the Johns Hopkins Institutional Review Board.

Data Analysis

Digital recordings of the interviews were transcribed and reviewed to verify content by the first author. Transcripts were analyzed using the constant comparative method to develop

grounded theory¹⁴ around provider decision-making for ART initiation among youth. An initial codebook of themes was generated by the first and last authors using a subset of transcripts and notes taken by the first author at the time of the interviews. The first and last authors read all of the transcripts and abstracted key ideas and themes, which were organized into major themes and subthemes that emerged through an iterative process. The coders met regularly to refine the themes and come to consensus on differences as they arose. Additional review for clarity of themes was provided by the second and third authors during the course of the analysis.

RESULTS

Provider and Clinic Characteristics

Table 2 summarizes the characteristics of all providers (n=23) from the 5 clinic sites. Among all providers, 14 (61%) were physicians and 5 (22%) were nurse practitioners from adult, pediatric, and combined specialties. All 4 (17%) physician assistants practiced in adult clinic settings. Additionally, 5 of 6 providers (83%) in the pediatric-centered clinic reported having any adolescent-specific training, defined broadly as clinical rotations, continuing medical education, or public health courses, and included 1 physician with subspecialty board certification in adolescent medicine. In contrast, 7 of 17 providers (41%) at the adult-centered clinics reported any adolescent training, none with adolescent medicine board certification.

Thematic Analysis

Table 3 illustrates the range of clinical and patient-related features that providers discussed. Six major themes (Table 4) emerged with regards to the decision-making factors for initiating ART among young people with BHIV. In this section, “most providers” represents more than 80% of the providers, “many” or “majority” represents 50–80%, “several” or “some” represents 20–50%, and “few” represents less than 20%.

Theme 1: Determining the Role of the CD4 Count in Deciding ART Initiation

Providers identified the CD4 count as the primary clinical indicator guiding ART initiation for patients at any age. Nearly all providers indicated they would consider ART initiation for youth at a CD4 count of 500 cells/mm³, consistent with current recommendations of the United States Department of Health and Human Services HIV Expert Panel guidelines¹⁵. However, adherence to the guidelines depended on a number of other clinical and psychosocial factors, resulting in the need to individually tailor the decision to initiate ART (Table 4, 1a).

In practice, most providers were comfortable deferring ART at CD4 counts greater than 350 cells/mm³ because of the lower likelihood for opportunistic infections (OIs) to occur at this stage. However, as the CD4 count decreased, particularly below 200 cells/mm³, most providers felt pressured to prescribe ART as the threat of clinical decline, OIs, and HIV-related comorbidities became more imminent (Table 4, 1b).

More than half of the providers also agreed that ART initiation should be considered for all individuals at any stage, however, this perspective was more frequently mentioned among adult providers (59%) compared to pediatric providers (33%). Some adult providers even reported initiating ART for patients irrespective of CD4 count, citing current evidence supporting the overall benefits of earlier treatment such as ameliorating the long-term inflammatory sequelae of HIV. In contrast, while all of the pediatric providers acknowledged they would consider early ART initiation if a young person was highly motivated, well-engaged in care, and had stable life circumstances (e.g. in school, strong support network), the majority of pediatric providers were less enthusiastic about advocating universal ART initiation due to concerns of poor adherence among youth (Table 4, 1c).

The public health benefit of early ART initiation demonstrated in the landmark HPTN 052 study¹⁶ was also cited by many providers, who indicated a willingness to initiate ART for individuals in serodiscordant partnerships or those engaging in risk behaviors such as commercial sex work (Table 4, 1d). However, most providers tempered their attitudes towards these trends by emphasizing the need to assess other patient-related factors that could affect their decision to initiate ART.

Theme 2: Balancing Tension Between Clinical Status and Concern for ART Non-Adherence

While the CD4 count was a critical decision-making factor, the actual decision to initiate ART balanced on the tension between an individual's clinical status and the potential ability to adhere to ART. Weighing these priorities for all individuals, whether young or old, was an important step for providers when deciding to initiate ART.

Concerns regarding the consequences of non-adherence, namely developing virologic resistance and its impact on future treatment options, appeared at times to result in conflict with the clinical need for ART. Given the detrimental, even deadly, consequences of late ART initiation, most providers were willing to accept the risks of potential non-adherence at low CD4 counts (Table 4, 2a). However, while a CD4 count threshold of 200 cells/mm³ or below was identified most frequently as the point at which providers would absolutely initiate ART, some providers reported they would not initiate ART at all if they had significant concerns for non-adherence (Table 4, 2b).

In order to assess the likelihood of adherence, providers explored non-clinical patient-related factors to identify potential obstacles. Although several providers expressed heightened concerns regarding adherence among youth (Theme 4), pediatric and adult providers evaluated similar patient-related factors including, but not limited to: mental health issues, substance abuse, sexual relationships and behaviors, psychosocial stability, social support, and serostatus disclosure. Exploring these factors provided opportunities to anticipate and troubleshoot potential adherence challenges prior to ART initiation (Table 4, 2c). Most providers also evaluated past engagement with medical care to anticipate future ART adherence and to determine whether or not to initiate ART (Table 4, 2d).

Theme 3: Defining “Patient Readiness” and the Impact on ART Initiation

Although no single patient-related factor emerged as an insurmountable barrier to ART initiation, nearly all providers discussed “patient readiness” as an important decision trigger

for initiation. Several dimensions developed within the concept of patient readiness across all providers: 1) an individual's acknowledgement and acceptance of the diagnosis, 2) insight into the needs and benefits of treatment, 3) ability to consistently engage in care and navigate the health system, and 4) a willingness to take medications (Table 4, 3a). For most providers, these features signaled the potential ability to successfully adhere on ART, though some providers acknowledged this was not always the case (Table 4, 3b).

For patients who were not ready for treatment, a few providers expressed futility in starting ART, even at very low CD4 counts. Under these dire circumstances, providers were not likely to start ART or would start as a reflection of a doubtful hope rather than true confidence that a patient would start the medications once leaving the office (Table 4, 3c).

Theme 4: Identifying Youth-Specific Adherence Concerns

While many providers did not report significant differences in their decision-making approaches on when to initiate ART for young people with BHIV compared to other age groups, greater concerns for non-adherence among youth and unique challenges to assess readiness emerged.

For most providers, a past history of adherence to medications and to regularly scheduled appointments were useful predictors for future ART adherence. However, several adult providers identified the lack of experience with managing a chronic illness to be a challenge when assessing a youth's potential ability to adhere to ART (Table 4, 4a).

Some adult providers also noted that young people with BHIV appeared to lack communication skills to convey their needs compared to older adults (Table 4, 4b), further limiting a provider's ability to recognize when additional support with adherence might be required. Several providers also observed that a young person's stated desires to take medications sometimes appeared incongruent with health engagement behaviors demonstrated over time (Table 4, 4c). Although a young person might express intent to engage in care, the subsequent inconsistencies in behavior contributed to concerns for potential non-adherence and were more likely to discourage providers from initiating ART.

Additionally, several providers identified variability in schedules and the mobility and instability of a young person's social circumstances to be particularly characteristic of the adherence challenges for youth (Table 4, 4d). Although such variability did not prevent ART initiation, providers emphasized the importance of reviewing barriers to adherence due to the frequent changes occurring in the lives of young people with BHIV.

Theme 5: Being Aware of the Developing Youth

In their observations of young people with BHIV, many providers recognized some characteristic features of adolescence such as the importance of body image, the influence of peer relationships, and expressions of personal autonomy. However, compared to nearly all pediatric providers, only one-third of adult providers (35%) observed that what appeared to be erratic health-seeking behaviors could in fact represent a young person's evolving capacity to plan and make decisions for the future, while establishing adult identities and acquiring skills necessary for adulthood (Table 4, 5a). Adult providers who discussed the

developmental changes occurring through adolescence and young adulthood appeared sensitive to the contexts of a young person's life experiences and occasionally described using these experiences to engage youth and create opportunities for discussions around health (Table 4, 5b).

Some providers in the pediatric clinical setting also described a "light bulb moment" when a young person who previously had difficulty engaging in care would begin to demonstrate consistent engagement and adherence to medications (Table 4, 5c). However, this process did not appear to be consistent or predictable among youth.

Theme 6: Working Effectively with BHIV Youth in Care

Nearly all providers reported that they enjoyed working with youth. For many, building relationships during a period of transition into adulthood provided a rewarding opportunity to impact future health behaviors and outcomes (Table 4, 6a). Several adult providers also acknowledged that the relatively fewer medical comorbidities and oftentimes rapid immunologic recovery allowed for time to counsel around other important health issues including mental health, substance use, and sexual risk reduction compared to older adults (Table 4, 6b).

Across all clinical sites, a comprehensive care approach using an interdisciplinary team was important. Team members focused on concerns especially around adherence, but most pediatric providers and some adult providers also emphasized that building patient-provider relationships and providing a support system were equally important in the care of youth with BHIV. Among adult providers, a few identified intensive provider or clinic-initiated follow-up as a strategy to build relationships, which also provided opportunities for clinical teams to maintain contact and retain youth in care. (Table 4, 6c).

Although many providers in adult clinic settings recognized certain features of adolescent development and reported greater concerns for non-adherence among young people, most adult providers described using similar approaches to assess the likelihood of adherence and to gauge patient readiness with their younger and older patients, as adherence challenges were seen among older adults as well. Additionally, most adult providers reported that youth-specific programs were not available at their clinics. Although many adult providers felt comfortable working with youth, a few identified the limited availability of youth-specific services at adult clinics as a potential barrier for young people to successfully engage in care and perceived pediatric clinics to be better equipped to tailor care to the developing youth (Table 4, 6d).

DISCUSSION

In our study, we found that diversely trained providers care for young people with BHIV and assess very similar clinical and non-clinical patient-related factors to decide when to initiate ART. Concerns about patient readiness to initiate and adhere with therapy were strong and reoccurring themes for both pediatric and adult providers. However, many providers, including some in adult clinic settings, recognized key differences in caring for youth that distinguished the unique period of transition from adolescence into adulthood.

With 75% of new HIV infections among young people occurring in the 20–24 year age group¹⁷, there is a high likelihood that a significant number of youth newly diagnosed with HIV will be linked to care at adult-centered clinics. Although there is limited national data characterizing the providers who care for young people with BHIV, nearly 80% of the young people with BHIV enrolled in one geographically diverse network of HIV clinics are in care at an adult-centered site⁷. A search of an online directory of a popular consumer-oriented website for people living with HIV (www.poz.com) reveals that among the 3384 organizations listed with a primary function of “Clinic”, 1799 (53%) listed youth services as a feature, but only 122 (4%) served children and adolescent populations¹⁸. The limited availability of clinics serving a pediatric population may be representative of the relatively low proportion of pediatric and adolescent-oriented HIV clinics available in the U.S. In this study, we purposively sampled more providers at adult-centered clinics to reflect the greater availability of adult HIV clinics accessible to youth seeking care in Baltimore. Our study suggests that regardless of specialty training, clinicians practicing across a variety of settings, including pediatric and adult care settings, evaluate similar clinical and patient-related criteria prior to initiating ART.

Despite the similarities, adult providers identified concerns related to the inexperience and lack of self-efficacy of young people with BHIV around management of chronic health conditions, such as navigating health systems and planning around medications. These concerns reflect expectations of adult health-seeking and self-management behaviors, and may not take into consideration the developmental context of young people with BHIV and their need to acquire skills for managing a chronic illness¹⁹. In our study, only 41% of adult providers reported any adolescent-oriented training, compared to nearly all of the pediatric providers. Currently, adolescent-oriented training is not a required component of graduate medical education for physicians in adult primary care specialties (internal medicine and family practice), whereas all physicians training in pediatrics are required to have a minimum 4-week clinical experience in adolescent medicine. This discrepancy may have important implications for adolescent health training across all primary care disciplines, but especially for providers in adult settings who will inevitably care for youth as they transition into adult care. Determining the impact of provider-targeted interventions focusing on effective competencies for adolescent health care may be an important step towards improving care for young people with BHIV.

Across all settings, providers in our study also described tension when the clinical need for ART conflicted with behaviors and social situations that could interfere with adherence. Our findings are consistent with a recent study by Gagliardo et al. demonstrating that providers commonly identified patient-related factors as large barriers to earlier ART initiation in young people with BHIV²⁰. These concerns are well-founded on studies demonstrating behavioral and structural risk factors associated with suboptimal adherence to ART (e.g. low self-efficacy, social support, environmental challenges, mental health^{21–24}) and the serious consequences of poor adherence on future treatment options and overall clinical outcomes^{25,26}.

However, providers in our study also recognized recent trends favoring earlier ART initiation and referenced studies highlighting the public health benefits of using treatment as

prevention^{16,27}. These advantages were factored against adherence concerns and the potential to develop and transmit resistant virus²⁸, further complicating the decision to initiate ART, particularly among youth. Our study suggests that strategies to intensify provider or clinic-initiated support for young people with BHIV may be necessary to avoid further exacerbating the consequences of treatment failure in this population as clinical practice shifts towards earlier ART initiation. Additional work to determine provider attitudes and practices with respect to initiating treatment as prevention for youth is necessary in order to implement these strategies safely and effectively for young people with BHIV and their partners.

Patient “readiness” emerged as an important indicator of future adherence that prompted providers to initiate ART. Efforts to conceptualize and define patient readiness for treatment have been previously described^{29–31}, but a cohesive framework that illustrates the components of patient readiness for treatment remains poorly defined. A few studies have evaluated tools to assess readiness among individuals with HIV^{29,32,33}, however studies among adolescents and young adults are limited³⁴. As both pediatric and adult providers in our study identified patient readiness as an important trigger in their decision to initiate ART, further work to determine the characteristics of patient readiness within a developmental context for adolescents and young adults may help providers recognize the necessary steps required to facilitate young people’s readiness to initiate ART.

Several providers in this study recognized key features of the developing youth and many identified youth-specific adherence concerns, but this did not significantly change their approaches to care for youth, particularly among adult providers. Although adult providers were familiar with assessing similar factors that raise adherence concerns in both young and older adult populations (e.g. housing and food instability, substance use, mental health concerns), our study suggests that fewer adult providers may recognize the effectiveness of tailoring patient-provider communication and interactions to sufficiently meet the needs and expectations of young people. These observations are important to the overall care of youth since provider communication and behavior styles have been associated with patient satisfaction, treatment adherence, and understanding of medical information among youth³⁵. Studies reveal that a provider’s willingness to answer questions, their respect and understanding about teens, and the responsiveness of a clinic’s social and physical environment towards youth are all associated with young people’s intentions to seek and engage in care^{36–38}. Developing clinical skills and structures to provide adolescent-friendly care in all settings where young people with BHIV receive care may be an important step towards reducing disparities in youth outcomes between adult and pediatric HIV clinics.

Finally, some adult providers identified the lack of youth-targeted approaches in adult clinical settings as a possible barrier despite the fact that interdisciplinary and comprehensive teams are used in both adult and pediatric-centered clinics. Important domains of youth-friendly healthcare have been previously reported, but operationalizing approaches to care for this population are necessary^{39,40}. Exploring the barriers and facilitators to provide developmentally appropriate youth-targeted services in adult-centered HIV clinics may be important to optimize treatment outcomes and maintain long-term engagement among young people with BHIV seeking care in adult clinics.

There are several limitations to this study. The findings may not be generalizable, but were rather intended to generate hypotheses for potential areas of further study. Due to the small sample size limited to providers in Baltimore, additional work among a larger set of providers from other locations, including additional adolescent medicine HIV providers, may be necessary to further explore the study findings. Finally, social acceptance or moderator acceptance bias was also possible.

In conclusion, with significant numbers of young people living with HIV in the U.S. and abroad, evaluating strategies to improve outcomes among youth are critical. The trends toward earlier ART initiation and using treatment as prevention highlight the importance of addressing the disparities around ART initiation and the quality of care for young people with BHIV. Recognizing the clinical care and support needs of youth from a developmental context through provider and clinic-targeted interventions, particularly at adult clinic sites, may enhance outcomes in this population.

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List of Abbreviations

ART	Antiretroviral therapy
HIV	Human immunodeficiency virus
BHIV	Behaviorally acquired HIV
OIs	Opportunistic infections

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Table 1

Excerpts from Interview Guide to Explore Providers' Decision-making Factors for ART Initiation

Domains	Example Core Questions and Probes
Clinical “rules of thumb” for decision-making	<ul style="list-style-type: none"> • What are the most important clinical features you consider in starting/not starting HAART in young patients? • Are there any clinical criteria that prompt you to always initiate or not initiate HAART in a young person? • What might push you to start HAART for patients with higher CD4 counts? Lower CD4 counts?
Patient-related “rules of thumb” for decision-making	<ul style="list-style-type: none"> • Generally speaking, are there any specific patient factors or behaviors that you consider critical in your decision to initiate or not initiate HAART in young patients? • Does a patient's young age change your usual approach in deciding when to initiate HAART? In what ways? • How do you prioritize these factors when making your decision about whether or not to initiate HAART?
Adherence issues and decision-making	<ul style="list-style-type: none"> • How do you decide that patients will/will not be adherent? • Are there situations where you have been surprised (i.e. expected patients to do well and they did not and vice versa)? Tell me about those situations. • At the end of the day when deciding to initiate HAART for an adolescent/young adult, which is more important, CD4 count or whether your patient is going to be adherent?
Involvement of young patients in decision-making	<ul style="list-style-type: none"> • How do you involve your patients in decision-making? • Are there any differences in your approach between younger and older patients? What are they?
Attitudes and preferences working with young people	<ul style="list-style-type: none"> • Generally, how would you rank your preferences in working with children (ages 0–11), adolescents (12–17), young adults (18–24/5), or older adults? • How do you feel about working with adolescents and young adults? • How does your work with adolescent and young adult populations differ from other populations?

Table 2

Baseline characteristics and professional training of study participants

Gender	N=23	
Male	8	34.8%
Female	15	65.2%
Race/Ethnicity		
Hispanic	0	0.0%
Asian	3	13.0%
Black/African American	8	34.8%
White	10	43.5%
Other	1	4.3%
Declined	1	4.3%
Median Age (years)	41	32–63
Median Duration in Practice (years)	13	(3–26)
Professional Degree and Specialty		
Physician	14	60.8%
Internal Medicine	8	
Medicine-Pediatrics	2	
Family Practice	2	
Pediatrics	2	
Nurse Practitioner	5	21.7%
Adult	2	
Family Practice	1	
Pediatrics	2	
Physician Assistant	4	17.4%
Adolescent Training*	13	56.5%
Pediatric-centered clinic (6 providers)	5	
Adult-centered clinic (17 providers)	7	

* Broadly defined as a clinical rotation, continuing medical education, public health course, or subspecialty fellowship

Table 3

Clinical and patient-related features considered during decision-making to initiate ART

Clinical Features	Patient-related Features
CD4 count	“Patient readiness”
Viral load	Mental health
Opportunistic infections	Substance use
Pregnancy	Past history of medication adherence
HIV-related nephropathy	Engagement in medical care
Hepatitis coinfection	Housing or other social instability
Other HIV/AIDS-related comorbidity	Sexual behaviors
	HIV serodiscordant partnership
	Patient’s desire to start ART
	Social support/disclosure status

Table 4

HIV providers' decision-making factors and priorities for ART initiation among young people with behaviorally acquired HIV

Theme 1: Determining the Role of the CD4 Count in Deciding ART Initiation	
1a	<p>"I think there's guidelines and then there's the patient...Decisions are still individual decisions and I try to include the patients...It's not like [a CD4 count of] 500 is a magic number. I think there are a lot of other factors that go into that decision."</p> <p style="text-align: right;"><i>Physician, Internal Medicine</i></p>
1b.	<p>"I think everybody should be on antiretroviral therapy but, you know, the urgency of that is dependent on CD4. So someone below 200 I think absolutely needs it quickly; somebody in the 200–350 range needs it soon, 350–500 needs it...but I would be willing to wait if I was concerned about adherence and, above 500, would view it as being an option for people who are motivated and likely to be adherent."</p> <p style="text-align: right;"><i>Physician, Internal Medicine</i></p>
1c.	<p>"I think personally I would not do that [start ART for everyone]...we're talking about somebody who's probably not adherent and not going to be taking medicines, or on and off, developing a resistant virus, who then will be transmitting this resistant virus to others... personally to me, that trade-off is not very well balanced."</p> <p style="text-align: right;"><i>Physician, Medicine-Pediatrics</i></p>
1d.	<p>"I've had patients [with] normal T-cells...[who] just didn't want there to be a possibility...to pass onto his partner if the condom were to break or anything like that...If there's high-risk sexual activity, sex workers...if there's no other barriers to adherence and they're going to take it the way they're supposed to, then I'd like to get them started too, to prevent transmission."</p> <p style="text-align: right;"><i>Physician, Family Practice</i></p>
Theme 2: Balancing Tension Between Clinical Status and Concern for ART Non-Adherence	
2a	<p>"If they have AIDS, you know, then I think that they would probably benefit from therapy even if they're not completely adherent...I don't think I would make them prove to me that they can be adherent...The higher the CD4 count is...the more I focus on, you know, making sure the patient is adherent before I start the therapy. So it varies depending on their stage."</p> <p style="text-align: right;"><i>Physician, Internal Medicine</i></p>
2b	<p>"No, if someone can't take their meds, we don't give them their meds, no matter what their CD4 is. No matter if they've had pneumocystis. Because it doesn't help them. They just give resistance. Just makes the doctor feel like she's doing something."</p> <p style="text-align: right;"><i>Physician, Family Practice</i></p>
2c	<p>"Is there anybody you've told about your HIV?...Does the person have any place stable to sleep? Do they have...food? Are they...in and out of jail?...In terms of HAART, it's stuff that's going to completely get in the way of them being able to adhere to a HAART regimen."</p> <p style="text-align: right;"><i>Physician, Pediatrics</i></p>
2d	<p>"So if they're good at taking their birth control pills, or they can take a vitamin every day...then I'm willing to start the process of getting them on HAART...Do they even keep the appointment with the pharmacy adherence team? If they don't keep that appointment, then we may need to reconsider starting them because they're not showing that they're up to their medical care."</p> <p style="text-align: right;"><i>Physician, Family Practice</i></p>
Theme 3: Defining "Patient Readiness" and the Impact on ART Initiation	
3a	<p>"When a patient comes in saying, 'I'm really ready to get started on medications. I want to take them every day... I don't want to risk getting sick...I've been really adherent with my other medicines. I never miss any doses.' That kind of language...That's a patient who's ready to start."</p> <p style="text-align: right;"><i>Physician Assistant, Adult Practice</i></p>
3b	<p>"You think someone's ready, [but] I got burned a couple of weeks ago with one of our youth...very articulate, educated guy...He's able to really convince you that he understands what's going on, he understands the gravity...Guess what? He took Atripla and two months into it...find out his viral load is 62,000. So again, it's a judgment call, that's why they call it an art... You become convinced and you're not right."</p>

Physician, Medicine-Pediatrics

- 3c “Somebody who I just can’t get to come into clinic despite all of our best efforts, who just sort of shows up out of the blue once a year, I mean, I just don’t see how writing them a prescription is going to help... But even in the setting where I feel like there’s no way in hell they’re going to take this medication at all on a regular basis, that severe immunosuppression or recent severe illness has made me just try it anyway. [Interviewer: And what have you found those outcomes tend to be?] Horrible. So, in the end, I’m treating myself in some ways more than them, I think.”

Physician, Pediatrics

Theme 4: Identifying Youth-Specific Adherence Concerns

- 4a “I’m not sure if it’s because [older people] are used to going to the doctor, whereas the new generation or the younger generation, this may be their first time in a doctor’s office since their pediatrician...the older patient population...understand health a little bit better...they’re just usually overall more adherent.”

Nurse Practitioner, Adult Practice

- 4b “I find it’s like with some of the young ones, communication is the issue. They don’t communicate well or they don’t have the foresight because they don’t have the experience of even taking medications before, much less a chronic medication.”

Physician Assistant, Adult Practice

- 4c “They say all the right things, they want to be treated; they’re very gung ho, and then I never see them again...that’s a much more common scenario to me than older people and so I’m always a little careful to not believe everything I hear. It’s true for everybody, but a young person can really be there at one moment and then move onto something else pretty quickly.”

Physician, Internal Medicine

- 4d “I think the primary thing I’ve noticed is just more of an erratic schedule for younger patients compared to someone who is older and has more of an established routine. And maybe more tendency to travel and potentially forget medications at home, things of that nature and maybe trying to hide things from friends or family because they’re not totally comfortable even in their own skin.”

Physician, Internal Medicine

Theme 5: Being Aware of the Developing Youth

- 5a “The young adult is a different host altogether, because they’re still growing and still experimenting and testing the waters, so that makes it a little difficult in honing in on whether you would treat or not to treat... they don’t have the life skills onboard...and like any child they don’t look beyond yesterday, or tomorrow’s not even in the equation. It’s today, here and now, and trying to get a young person to understand that taking this [medicine] makes a difference and tomorrow is different.”

Nurse Practitioner, Adult Practice

- 5b “I find they’re learning about dating, they’re learning about drinking, they’re learning about drug use, they’re learning about sex, they’re learning about all those kinds of things...I had a kid, 22-year-old...in his first relationship... And I tossed the whole plan for that visit out the window to deal with that, because I thought it was huge for him...you’ve got to dig a little bit for it...help them peel the onion a little bit and pull it down, see what’s going on.”

Physician Assistant, Adult Practice

- 5c “Then there was just a turning point, for him, personally. He wanted to be more mature and he wanted to start medicines...And so we started him on medicines and he’s done fine since then, you know?...Maybe it was just him coming to a point where he felt mature enough to take medicines.”

Physician, Medicine-Pediatrics

Theme 6: Working Effectively with BHIV Youth in Care

- 6a “I like the fact that I’m working with them as they emerge into adulthood to figure out who they are... I see these kids who come in just disasters and destined for what looks like bad outcomes, who just really manage to bit-by-bit pull it together, often with a lot of support from our team. To be able to talk to them, get to know them, see them mature and to progress over that time is really gratifying.”

Physician, Pediatrics

- 6b “I think they have a greater ability to adapt and change... It feels good to work with them because you can help optimize their health for the long term where, sometimes in the older adults, they have a lot of other comorbidities, and you can control their HIV but it’s hard to manage all their other comorbidities.”

	<i>Physician, Internal Medicine</i>
6c	<p>“I think the ones that we’ve stayed on top of and trying to make sure that they get into their visits...the case managers calling them, making sure that we’re arranging for transportation to get into their clinics is big...Almost like that hypervigilant follow up is key...Also when you’re able to do the comprehensive care...making sure everybody is taking care of them and has a pulse on how they’re doing can make a big difference.”</p> <p style="text-align: right;"><i>Physician Assistant, Adult Practice</i></p>
6d	<p>“I enjoy working with young patients, but for the ones who are truly still kind of adolescent in their development, I don’t feel like I have a great deal of expertise, and I --probably unlike a true adolescent expert --tend to expect them to behave like adults, and when they don’t, I don’t do a whole lot of the kind of modification that might happen in a pediatric clinic.”</p> <p style="text-align: right;"><i>Physician, Internal Medicine</i></p>