Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: Using adolescent and adult providers' insights to create multi-level solutions to address transition barriers

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Abstract:

HIV-infected adolescents have disproportionately low rates of care retention and viral suppression. Approximately half disengage from care while transitioning to adult clinics, in part due to fragmented care systems and lack of streamlined protocols. We conducted 58 qualitative interviews with social service and health care providers across 14 Adolescent Trials Network clinics (n = 28) and 20 adult clinics that receive transitioning adolescents (n = 30) from August 2015–June 2016. We used the constant comparative approach to examine processes, barriers, and facilitators of adult care transition. Transition barriers coalesced around three levels. Structural: insurance eligibility, transportation, and HIV-related stigma; Clinical: inter-clinic communication, differences in care cultures, and resource/personnel limitations; and Individual: adolescents' transition readiness and developmental capacity. Staff-initiated solutions (e.g., grant-funded transportation) were often unsustainable and applied individual-level solutions to structural-level barriers. Comprehensive initiatives, which develop collaborative policies and protocols that support providers' ability to match the solution and barrier level (i.e., structural-to-structural), are sorely needed. These initiatives should also support local systematic planning to facilitate inter-clinic structures and communication. Such approaches will help HIV-infected adolescents transition to adult care and improve long-term health outcomes.

Article:

Introduction

Healthcare transition (HCT) is the planned and purposeful movement of adolescents from child-centered to adult-centered care; successful HCT is defined as having a non-pediatric provider, insurance, recent healthcare visit, and no treatment delay (Gilliam et al., [14]). In the next decade, 25,000 HIV-infected adolescents will need HCT. HIV-infected adolescents frequently transition in their early twenties, mostly commonly by age 24 (Centers for Disease Prevention and Control, [4]; Cervia, [5]). Adolescents' use of healthcare services declines significantly during HCT (Lotstein et al., [19]), and only 50% of recent HCT HIV-positive adolescents remain in care after one year (Ryscavage, Macharia, Patel, Palmeiro, & Tepper, [27]).

Research along HIV care continuum stages identifies multi-level challenges to adolescents' progression. While research has explored care linkage and engagement for newly diagnosed adolescents, little work has examined adolescents' HCT-related barriers. At the structural level, newly diagnosed adolescents struggle with HIV-related stigma (Fielden, Chapman, & Cadell, [11]), poverty (Kempf et al., [16]), housing (Gardner et al., [13]), insurance eligibility (Lillie-Blanton et al., [18]) and limited transportation options, factors that likely impact adolescents' HCT (Kempf et al., [16]). Research from initial linkage and other chronic diseases suggests that HCT obstacles at the clinic level could include a lack of inter-clinic communication, (Gilliam et al., [14]) adolescent providers' unwillingness to relinquish care, (Valenzuela et al., [33]) and adult providers' limited adolescent-specific training (Reiss, Gibson, & Walker, [25]). In comparison to adolescent clinics, adult clinics tend to be less flexible (e.g., with missed appointments), provide minimal case management (Reiss et al., [25]), and are HIV-specific (Dowshen & D'Angelo, [7]; Tanner et al., [29]). At the individual level, adolescents' development stage can complicate HCT (Philbin et al., [23]; Wiener, Kohrt, Battles, & Pao, [35]).

HCT-focused research primarily addresses individual level issues but structural barriers may be more imperative to successful HCT as they determine factors related to insurance eligibility, transportation access, and even adolescents' willingness to attend care (e.g., HIV-related stigma). Fragmentation across clinical systems is particularly relevant for adolescents without support to negotiate engagement across multiple care systems (Mugavero, Norton, & Saag, [21]). The American Academy of Pediatrics ([2]) recently emphasized the need for HCT-related protocols (AAP, [2]), and this paper outlines HCT-related barriers and participants' potential solutions to help inform integrated service delivery, direct appropriate resources, and address needs at adolescent and adult clinics.

Methods

Data for the Comprehensive Assessment of Transition and Coordination for HIV-positive Youth as they Move from Adolescent to Adult Care (CATCH) study, were collected from 14 Adolescent Medicine Trials Network (ATN) clinical sites in the U.S. who treat adolescents aged 13–24, which meets the standard medical definition of adolescence. Data were also collected from 20 adult clinics to which the ATN transitioned youth (Table 1). Two researchers trained in qualitative methods conducted 58 semi-structured interviews from August 2015–June 2016 with

medical and social service providers who transitioned adolescents from ATN sites ($n = 30$) or received adolescents at adult clinics ($n = 28$). Interviews lasted approximately 45 min (range = 22–78 min) and were conducted over the phone, recorded, and professionally transcribed. Field notes were drafted after each interview. Providers were contacted via email and/or phone. Purposive sampling was employed to choose individuals whose role included supporting youth through HCT. Of the eligible ATN staff 28/36 agreed to be interviewed. We contacted 39 adult clinic providers based on ATN Staff referrals of whom six were not eligible and five did not respond despite multiple contacts.

Table 1. Adolescent and adult clinic staff descriptive statistics.

Characteristics and roles	Adolescent clinic n (%)	Adult clinic n (%)	Combined n
Gender			
Male	4(14.3)	6(21.4)	10
Female	24(85.7)	22(78.6)	46
Occupation or role in Adult clinic			
MD or MD/Professor	6(21.4)	11(39.3)	17
NP	7(25)	2(7.1)	9
Social Worker	8(28.6)	5(17.9)	13
Case Manager	2(7.1)	3(10.7)	5
Linkage to care/patient coordinator or supervisor	2(7.1)	4(14.3)	6
Other	3(10.7)	3(10.7)	6
Time worked in clinic			
Years	8 (range 1–25)	9 (range 2–25)	

Interviewers used a semi-structured interview guide to address topics including: transition processes and protocols; HCT facilitators, barriers, and solutions; and inter-clinic relationships. Guides were informed by HIV care linkage and engagement and HCT for other chronic diseases research. Participants received $25 Amazon gift cards for their time. Institutional Review Boards at the University of North Carolina Greensboro and participating ATN sites approved the study. All interviewees provided verbal consent and all data were stored on password-protected computers or in a locked storage cabinet.

Data were analyzed using the constant comparative method (Buetow, [3]; Glaser & Strauss, [15]) to examine how providers described HCT, with focus on HCT facilitators and barriers. Team members independently read and manually coded each transcript to create a codebook. Thematic codes based on existing literature were subsequently added to ensure that theory-based and emergent concepts were included. This codebook was reviewed and amended by other team members (MacQueen, McLellan, & Kay, [20]). Codes were summarized and refined within a data table (Glaser & Strauss, [15]), and incorporated into a matrix to compare clinics' descriptions of HCT processes. The coders independently applied the finalized codes to all transcripts using Atlas.ti version 7 with 90% inter-rater agreement. Coders then searched transcripts and field notes for negative cases regarding barriers- and solutions-related themes, modifying the coding matrix as needed, and returned to the transcripts for additional comparisons (Glaser & Strauss, [15]). Coding disagreements were resolved through consensus of the entire research team.

Results

HCT-related barrier themes coalesced around three levels – structural, clinical, and individual. Participants also provided suggestions to improve the HCT process (Table 2).

Table 2. Barriers and solutions to adolescent transition.

Level	Current barriers	Currently employed solutions
Structural	*Insurance eligibility* - Youth lose their insurance coverage and need to re-enroll - Adult clinics lack funding to cover initial visits without insurance	- Establishing insurance coverage prior to transition - Fast-track process for ADAP (AIDS Drug Assistance Program)
	Transportation - Complexity or complete lack of public transportation systems	- Grant-funded transportation (e.g., bus tokens)
	HIV-related stigma - Adult clinics named as HIV clinics - Having to disclose to additional providers	
Clinical	*Lack of inter-clinic communication* - Weaker relationships between adolescent and adult clinics in different health care systems - Lack of between-site data sharing	- Creating transition-specific protocols (e.g., guidance about starting transition, assessment of transition readiness, and provision for staff to attend the first adult clinic appointment)
	Differences in care cultures - Adult clinics described as less friendly than adolescent clinics - Differences in expectations of patient behavior - Adolescents' reluctance to leave providers they trusted	- More flexibility, allowing adolescents to adjust (e.g., ease them in, make the rules less stiff) - Youth connect with someone at adult clinic prior to transition - Adolescent staff accompany a patient to their first adult clinic - Adult provider conducts first appointment in adolescent clinic - Work with adolescent clinics before transition to identify struggling adolescents - Transition-specific staff
	Resource/personnel limitations - Adult clinics less often had co-located services to address housing instability and unemployment, as well as fewer staff to help navigate these - Transition services are rarely financially supported (e.g., sexual health counseling, empowerment training, motivational interviewing)	- Additional funding for transition services
Individual	*Adolescents' transition readiness/willingness* - For those perinatally-infected, switching from the same doctor they've had their entire life - Youth are reluctant to leave a clinics with higher levels of services and support	- Develop wraparound services (e.g., mental health, housing support) - Adolescent providers refer patients to outside services prior to HCT to avoid treatment gaps and help navigate insurance claims - Adolescent providers try to maintain contact during HCT to facilitate care retention and, if necessary, to allow patients to briefly return to the adolescent clinic
	Adolescents' developmental capacity - Difficulty with adolescents obtaining referrals from insurance company - Lack of HIV/AIDS-related knowledge (e.g., that HIV is a precursor to AIDS, how to approach safer sex, and/or the importance of taking medication daily)	- Delay transition for adolescents viewed as particularly vulnerable (e.g., not initiating HCT at a specific threshold age) - Begin transition-related discussions earlier

Structural-level barriers

Insurance-related barriers to HCT were widespread, particularly since adolescents often switched insurance carriers once at the adult clinic. One adult-site doctor (X-A) noted that, "*The biggest challenge is the insurance coverage ... A number of youth every year lose their insurance and then have to reenroll and that can be destructive to the transition process*." Adult clinics often

lacked funding to provide initial visits to patients without insurance, and approval processes could take months. Insurance status had to be addressed prior to HCT to ensure a seamless process.

Providers repeatedly emphasized the complexity – or complete lack of – public transport systems. One adolescent physician (T-B) noted that patients relied on clinic support because, "*Public transportation is actually quite limited. Transportation is definitely a big barrier for many of our patients.*" Unreliable transport systems challenged consistent care engagement; adult sites often rescheduled if patients were more than 15 min late. Adolescent clinics provided transportation tokens, but these relied on grant funding or specific insurance coverage, hampering the utility of this approach. For example, a physician (Q) stated: "*We apply for grants and have some limited additional funding for transportation ... that can be an issue in* [*adult*] *clinics.*"

Providers consistently described how "*intense issues around the stigma of HIV can challenge them* [*adolescents*] *to actually engage in their medical care*" (adult social worker, Site Q-B). Adult clinics often were named as HIV-specific clinics, exacerbating HIV-related stigma, and transition required adolescents to disclose to additional providers.

Solutions for structural barriers

Insurance issues during HCT were often solved through unsustainable individual-level workarounds like delaying HCT until insurance processed or using research grants to cover care. Adult providers suggested that the adolescent clinic should ensure patients have stable health insurance prior to transition, and adolescent staff suggested a fast-track process for ADAP (AIDS Drug Assistance Program). Adolescent sites had some resources for services such as housing and employment, although these were often difficult to access because the waitlists were long. However, adult clinics less often had co-located services to address housing instability and unemployment and fewer staff to help adolescents navigate these; few adult clinics applied for grants to support transportation (e.g., bus tokens).

Clinic-level barriers

Adolescent and adult clinics within the same health care system were described as having strong relationships, often using the same medical record system. Weaker inter-clinic relationships were described for clinics in different systems, particularly in larger cities where adolescent sites could refer to multiple adult clinics. Lack of between-site data sharing hindered care through the HCT process: "*As far as having kind-of that close working relationship, not much, and so I would say there's less comfortability on our part*" (adult nurse, W-B).

Adult clinics were frequently described as less friendly than adolescent clinics. An adolescent nurse (P-A) explained, "*Some adult patients are kind of scary to youth in their physical appearance ... something about what their future holds. So those things hold them back from the adult clinic.*" Adolescent providers described these aspects of HCT as disorienting to adolescents, and transition was often delayed for this reason.

All providers described differences in expectations of patient behavior as potential barriers. Adult providers expected independent, proactive, and adherent patients, especially around missed visits. As one adult physician (X-A) noted: "*If you're lucky, you'll get a reminder the day or two before, an automated machine, and that's pretty much all the assistance you have.*" Adolescent staff, however, felt that this approach complicated HCT because of the abruptness of change in clinical care philosophy. Moreover, some adult staff emphasized that HCT taught adolescents important new skills:

> They miss that mothering that happened without them having to do anything. That's the hardest transition for them, and it's the hardest for us, because their expectations of us are to continue what the adolescent program had started, and we can't. And I don't think it's fair if we try to do it, because that's not what we're supposed to be doing, and they're supposed to kind of grow (adult pharmacist, N-A).

Another barrier to HCT was adolescents' reluctance to leave providers they trusted. As one adolescent case manager (U-C) noted, "*It's really kind of a loss. It's a loss for the youth who's transitioning, and it's also a loss on the part of the provider, because it's such a relationship that's been formed over those years.*" Indeed, both adult and adolescent providers noted that adolescent providers were often reluctant to transition patients, additionally delaying HCT.

Solutions for clinic-level barriers

To streamline and routinize the HCT process, adolescent clinics developed transition-specific protocols – nine had formal protocols and five had informal protocols. Among adult clinics, four had formal protocols, 14 had informal protocols, and two had no protocol. Protocols included guidance about starting transition, assessment of transition readiness, and provision for staff to attend the first adult clinic appointment.

Adolescent providers facilitated inter-clinic relationships through meetings and phone calls, but frequently maintained only a few close relationships with adult sites. Even with strong relationships, providers faced consistent challenges in data sharing and follow up post-HCT. As an adult provider (X-A) noted, "*The more you can data share across entities that are pretty possessive, the more that the clinical staff would be aware that there are kids out there and where they are, and then could reach out to them.*"

Adolescent staff stressed the need for more flexibility at the adult clinics, allowing adolescents to adjust:

> It's on us to better prepare them by not letting patients show up six, seven hours late for their appointments, but it could also be on the adult clinic to kind of ease them in a little more slowly and not make the rules as stiff. (adolescent nurse W-B)

Adolescent staff suggested training adult clinics; "*maybe getting adult providers more acquainted with what it means to care for an adolescent ... more education for adult providers*" (adolescent provider, Site I). However, some adult providers disputed the need for this: "*No. In fact, I think we're at a point of overkill, honestly*" (adult nurse, K-A).

Participants stressed the importance of relationship building and, "*connecting with someone at the adult site prior to transition so they're already building rapport*" (social worker, Z-B). Adolescent staff often accompanied a patient to their first adult clinic visit, and in some cases (e.g., adolescents transferred within the same medical system) the adult provider would conduct the first appointment in the adolescent clinic. Adult clinic staff also discussed working with adolescent clinics before transition to identify fragile adolescents who were struggling in order to provide additional attention and services.

All providers stressed the importance of transition-specific staff: "*If money weren't an object, having one staff person specifically devoted to the youth ... So, sort of have a transition within the transition when they transition to here*" (adult social worker, R-A). However, few adolescent or adult clinics had transition-focused staff.

Individual-level barriers

Nearly all providers mentioned individual-level HCT barriers specific to adolescence; the most commonly cited issues was developmental stage. For example, an adult social worker (Q-A) noted, "*We might ask you to get a referral from your insurance company, and not do it for you. And some adolescents, if they're not developmentally ready for that, just don't do it. And they fall out of care.*" Adolescents' willingness to transition was repeatedly mentioned as an issue, particularly for perinatally-infected adolescents. An adult provider (W-A) explained:

> The majority of the ones that drop out of care were perinatally infected. They've had the same doctor from birth if they're age 24. And then, to have to now go to a new clinic ... they reported, 'I'm not going. I didn't know those people'.

Adolescents often lacked the HIV/AIDS-related knowledge that could help them understand the need for seamless transition and care continuity, including the potential individual- and community-level health implications. For example, some adolescents did not know that HIV is a precursor to AIDS, how to approach safer sex, and/or the importance of taking medication daily.

Solutions for individual barriers

Adolescent providers described the transition process as lengthy, especially for adolescents reluctant to leave a clinic where they had often been treated for years. This meant that some staff would delay transition for adolescents deemed particularly vulnerable. One adolescent physician (I-A) did not initiate HCT at a specific threshold age, "*because I don't want all the good work that we've all done to be destroyed because somebody wasn't quite ready to make it there. So sometimes I do see the patients until they're a little bit older.*" Both adolescent and adult providers noted that transition services are rarely financially supported: "*We just need more money* [*for*] *sexual health counseling, empowerment training, motivational interviewing ... there really isn't support around that*" (adult pharmacist N-A).

Adolescent clinics developed other wraparound services (e.g., mental health and housing support) to support adolescents in these aspects during HCT. Some adolescent providers referred

patients to outside services prior to HCT to avoid treatment gaps. Adolescent providers also reported trying to maintain contact during HCT to facilitate care retention and, if necessary, to allow patients to briefly return to the adolescent clinic.

Discussion

The study results describe structural-, clinical-, and individual-level barriers to, and currently employed solutions for, HCT for HIV-infected adolescents. Similar transition studies have focused primarily on individual clinics – versus a network – and most research on care linkage and engagement is focused on newly diagnosed youth, not during HCT. Differences in professional cultures consistently affected HCT: adolescent providers approached transition-aged adolescents from a perspective of vulnerability and inexperience, while adult providers expected self-sufficiency and responsibility for meeting health care system requirements (Fegran et al., [10]). Adolescent staff felt that adult providers failed to appreciate HCT challenges while many adult providers rejected the need for additional HCT training. Adolescent staff described adult clinic visits as transactional and less likely to address adolescents' concerns such as sexuality, substance use, and psychosocial issues. Adult HIV providers described adolescent providers in ways that aligned with HCT research on other chronic diseases: as over-involved and slow to transition patients (Peter, Forke, Ginsburg, & Schwarz, [22]). Adult providers believed this decreased adolescents' autonomy and diminished their ability to successfully transition (Clarizia et al., [6]).

Several other key points emerged. Providers' solutions to HCT barriers were often *ad hoc* and provided limited short-term solutions. Similar to newly diagnosed youth, health insurance was a powerful barrier to HCT (Fair, Sullivan, Dizney, & Stackpole, [9]; Reiss et al., [25]) and long-term care engagement (Ulett et al., [31]). Transportation was also a consistent barrier, which aligned with other studies on adolescent care linkage (Fortenberry, Martinez, Rudy, & Monte, [12]; Philbin et al., [23]). Lastly, similar to other students that documented the impact of HIV-related stigma in care retention for adults (Duffy, [8]; Fielden et al., [11]), this study found that stigma was particularly salient for transitioning adolescents as adult clinics were often HIV-specific and required additional transportation and disclosure for needed adjunctive services.

Strong inter-clinic relationships and data sharing are key elements of successful HCT (Ryscavage et al., [27]; Tanner et al., [30]). However, even with such advantages, HCT was complicated by insufficient resources and lack of a systematic HCT infrastructure (Mugavero et al., [21]). Providers identified adolescents' familiarity with a 'one-stop-shop' clinic model as a barrier to HCT because adult clinics lacked comparable on-site services to support care engagement, meaning such services had to be accessed elsewhere (Wiener et al., [35]). Although guidelines exist many clinics – particularly adult clinics – lacked formal HCT protocols. Failure to implement HCT protocols can result in *ad hoc* transfers that involve limited contact between clinics, with little feedback about successes and failures (Lee & Hazra, [17]; Roberta, [26]). While age has been a factor in care linkage and engagement for newly diagnosed adolescents (Philbin et al., [24]), providers rarely described it here, most likely because adolescents often delayed transitioning until the last possible moment (i.e., age 24).

These challenges demonstrate the need for multi-level solutions. First, it would require changes in national guideless, such as those suggested by the American Academy of Pediatrics (AAP, [2]; White, Cooley, & McAllister, [34]) that mandate transition protocols and processes, and provide adequate funding for transition-focused personnel (AIDSinfo, [1]). However, solutions will also require local systematic planning and collaboration that supports an approach that can be tailored to match local programs.

Limitations

Several limitations should be considered. First, the participating sites represented urban areas with relatively high HIV prevalence among adolescents. HCT may be affected by different issues in lower prevalence cities, or for adolescents in rural areas (Straub et al., [28]). We only interviewed staff at ATN clinics, and the adult clinics to which they referred patients. This could mean that some types of clinics were not represented. However, given the geographic diversity of the ATN sites, findings illustrate a wide array of experiences. Transitioning adolescents were not interviewed, although some studies have already addressed those perspectives on HCT (Fair et al., [9]; Wiener et al., [35]). In addition, providers had varying clinical roles and experiences in transitioning adolescents, which could differentially impact their perspectives. It is possible that some clinicians may not know of all social services offered in their clinic, because it would come from a social worker or case manager. Lastly, as this is a qualitative study, its results cannot be generalizable to all clinic populations, though a major strength of this study is that it occurred through an extensive network of geographically dispersed clinics.

Conclusions

Funding and programing have increasingly focused on ensuring that all HIV-infected individuals progress through the continuum of care and maintain viral suppression to limit further transmission and achieve, for example, the 90-90-90 goals outlined by the United Nations (UNAIDS, [32]). However, these goals rarely identify how central HCT is to success. Providers across all 34 clinics expressed agreement about the challenges to HCT and how these might be addressed. Yet, clinics frequently lacked the resources to sustainably address barriers, or to facilitate structural-level changes that would alleviate the need for the current 'stop gap' measures. This suggests the need to develop policies and funding initiatives to facilitate structural-level approaches in ways that will complement clinics' current solutions and match the level of barrier with the level of solution (i.e., structural-to-structural). Only then will we be able to meet the National goals to end the HIV epidemic and help HIV-infected adolescents successfully transition to adult care.

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