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Transitioning adolescents with HIV to adult care: Lessons learned from twelve adolescent medicine clinics

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Abstract

Purpose—To maximize positive health outcomes for youth with HIV as they transition from youth to adult care, clinical staff need strategies and protocols to help youth maintain clinic engagement and medication adherence. Accordingly, this paper describe transition processes across twelve clinics within the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) to provide lessons learned and inform the development of transition protocols to improve health outcomes as youth shift from adolescent to adult HIV care.

Design and Methods—During a large multi-method *Care Initiative* program evaluation, three annual visits were completed at each site from 2010–2012 and conducted 174 semi-structured interviews with clinical and program staff (Baseline n=64, Year 1 n=56, Year 2=54).

Results—The results underscore the value of adhering to recent American Academy of Pediatrics (AAP) transition recommendations, including: developing formal transition protocols, preparing youth for transition, facilitating youth's connection to the adult clinic, and identifying necessary strategies for transition evaluation.

Conclusions—Transitioning youth with HIV involves targeting individual-, provider-, and system-level factors. Acknowledging and addressing key barriers is essential for developing streamlined, comprehensive, and context-specific transition protocols.

Practice Implications—Adolescent and adult clinic involvement in transition is essential to reduce service fragmentation, provide coordinated and continuous care, and support individual and community level health.

Keywords

HIV; transition; adolescents; young adults; healthcare

Many youth living with HIV, especially those with co-occurring issues (e.g., substance use, insecure housing, and mental health), disengage at some point from care. The stages through which a person living with HIV is expected to progress includes linkage, engagement, medication prescription, adherence, and viral suppression, which are collectively known as the HIV Care Continuum (Zanboni & Mayer, 2014). One significant point of disengagement occurs during the transition from pediatric/adolescent to adult clinics. Interruptions of care at this point may reverse improvements in health status associated with HIV medical treatment and increase transmission risk if viral loads are unsuppressed (Crowley, Wolfe, Lock, & McKee, 2011). With approximately 25,000 youth with HIV scheduled to transition from adolescent to adult care in the next decade (Cervia, 2013), identifying effective approaches to transition is needed in order to support care retention and continued effective treatment in adult HIV care settings. The movement from adolescent-focused to adult-focused care for individuals with chronic conditions (e.g., congenital heart conditions, cystic fibrosis, diabetes mellitus) is clearly challenging for youth, families, and providers (Chu, Maslow, von Isenburg, & Chung, 2015; Oswald et al., 2012). Indeed, successful transition is reported for only 21.6% of youth with diverse chronic conditions (Oswald et al., 2012). The transition from adolescent-specific to adult HIV care may have even lower rates of successful transition (Hussen et al., 2015).

The little research that exists on HIV transition reports the perspectives of adolescents (primarily perinatally infected youth) and clinic providers to examine challenges associated with navigating between adolescent and adult HIV care systems (Nehring, Betz, & Lobo, 2015). These studies identify a range of issues including: youths' developmental readiness, Medicaid eligibility due to age, and providers' reticence to relinquish care (Gilliam et al., 2011; Valenzuela et al., 2011; Vijayan, Benin, Wagner, Romano, & Andiman, 2009). Youth clinic providers, in particular, perceive adult providers as lacking training in treating youth, the provision of less flexible services (e.g., accommodating missed appointments), and greater likelihood to be located in HIV-specific clinics (Dowshen & D'Angelo, 2011; Fair, Sullivan, Dizney, & Stackpole, 2012; Gilliam et al., 2011; Schwartz et al., 2013; Tanner et al., 2014). Further, adult HIV clinics may provide less anonymity than adolescent clinics and serve patients who appear more visibly ill, making the transition process even more challenging for adolescents accustomed to youth-focused clinics (Gilliam et al., 2011; Tanner et al., 2014).

Although patient and provider perceptions are important, little is known about the actual processes associated with how adolescents are transitioned to adult HIV care and few studies describe the existing approaches to transition in centers of expertise (for exceptions see: Bundock et al., 2011; Mauro et al., 2011; Mauro et al., 2015; Wiener, Kohrt, Battles, &

Pao, 2011). In 2013 the American Academy of Pediatrics (AAP) released recommendations for transition to adult HIV care that include four steps: (1) development of written policies to guide transition; (2) joint creation of a transition plan by youth, family and providers; (3) planned facilitation of youths' connection to adult clinics as transition is initiated; and (4) communication between adolescent and adult clinics during the transition process for quality assurance review (Committee on Pediatric AIDS, 2013). Understanding applications of these guidelines could inform approaches to enhance transition planning and improve transition outcomes. Accordingly, the purpose of this paper was to describe transition processes across twelve Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) sites to highlight lessons learned and inform the development of future protocols to improve adolescent transition and health outcomes.

Methods

The research team collected transition data during a large *Care Initiative* program evaluation. The *Care Initiative* originated in a formal partnership between the NICHD, CDC, and the ATN, and was developed to improve care linkage and engagement for adolescents with HIV by facilitating collaboration with local health departments and community organization partners, and by providing linkage to care coordinators (for details see Tanner et al., 2013).

The 12 ATN sites were located in academic or community medical centers that serve youth with HIV. Most sites were in southern states (n=8) and were either adolescent-specific (n=5) or served both pediatric and adolescent patients (n=5); only two were HIV-only (see Philbin et al. 2014 and Tanner et al., 2013 for more site specific details). Two researchers conducted 174 semi-structured interviews with clinic staff during three annual site visits from 2010–2012 (Baseline n=64, Year 1 n=56, Year 2=54). At all sites, interviews were conducted with medical providers (e.g., physicians (13%), nurses (8%), physician assistants (2%)), care linkage coordinators (27%), outreach workers (23%), social workers (9%), case managers (8%), and other clinical staff (e.g., psychologists and HIV testers) (11%). Participants at certain sites (e.g., large teaching hospitals) also captured psychiatrists and/or physicians who treated both adolescent and adult patients. Interviewing all the staff involved in care linkage and transition allowed for an opportunity to answer questions regarding transition processes, the role of formal and informal protocols, and comprehensively assess different strategies employed across sites.

The Baseline and Year 1 site visits illuminated challenges related to transition; during the Year 2 site visit questions were asked that explicitly addressed transition processes with a focus on one aspect of transition - transfer of care. Interview questions were developed using prior transition research (HIV and other chronic disease) and built off of emerging themes from the previous site visits. These questions focused on site-specific transition protocols and strategies (e.g., Can you describe your transition protocol? How was it developed? How do you define a successful transition?), descriptions of typical transition cases (e.g., Can you provide an example of a recent transition case?), and recommendations for care engagement during transition (e.g., What advice do you have for keeping youth engaged in care during transition?). Interviews were digitally recorded, professionally transcribed, and managed using Atlas ti 6.2; field notes were written following each interview. Average interview

length was 68 minutes (range=32–118 minutes). The Institutional Review Boards at the Johns Hopkins Medical Institutions and all ATN sites approved study protocols.

Data were analyzed using a Creswell & Plano Clark's (2011) process to examine alignment with the American Academy of Pediatrics (2013) transition guidelines and distinguish similarities and differences across sites. First, a data dictionary was created to summarize and refine codes based on existing transition literature (HIV and chronic disease more generally), interview questions, and preliminary readings of transcripts (Creswell & Plano Clark, 2011). Then a site matrix was created to compare site similarities and variation in transition protocols (e.g., formal versus informal, differences in receiving adult clinics and transition staff responsibilities) (see Table 1). Two researchers applied the finalized structure to all transcripts; there was high consistency between raters (88%) and discrepancies were resolved via discussion.

Results

All healthcare and social service providers and program staff emphasized the importance of a seamless transition to maintain care continuity and health (e.g., viral load suppression) for both behaviorally and perinatally infected youth; they also noted frequent challenges. One participant highlighted a frequently discussed distinction between adolescent and adult care: “Adolescent care means that we are going to hold their hand a little longer than if they walk into an adult [clinic], the [adult providers] are not going to have this patience” (Site N). Participants discussed this distinction as important for creating transition protocols that provide adolescents the structure and skills to succeed in an adult clinic. Other barriers to a successful transition were youth-specific (e.g., substance use, mental health), provider-specific (e.g., hesitancy to transfer youth), and system-specific (e.g., insurance coverage). Sites created and implemented transition protocols—albeit to varying degrees—to prepare youth by focusing on a variety of elements. Table 1 summarizes the descriptive data related to the similarities and differences that exist across sites. The results are further presented in four sections that correspond to the AAP (2013) transition recommendations (described above) highlighting the ways some sites had already integrated these recently documented transition plan elements (see Table 1). Variations in participants' responses were primarily at the individual level (e.g., staff with longer histories of relationships with youth tended to report more transition specific challenges than those with shorter relationships). The responses were not significantly different across types of participants (e.g., physicians vs. case managers).

AAP Transition Guideline 1: Develop formal transition policies and protocols

Four ATN sites had formal, written protocols and two had work-in-progress plans. The remaining six sites articulated informal (although detailed) transition processes. Protocols were largely determined by where youth would transition for adult care, for example a new physical clinical space (n=7 sites), a different clinical location within same medical system (n=2), or a new provider in the same clinic (n=3). Four of six sites with formal or work-in-progress protocols transitioned youth to new sites. Other core clinical differences included

the preparation of youth for transition, the relationship and communication between adolescent and adult clinics, and the potential for quality assurance assessment.

AAP Transition Guideline 2: Creation of transition plans to prepare youth for transition

The majority of sites (n=11) employed staff – primarily social workers and case managers – whose responsibilities included developing transition plans and facilitating transition. The staff worked to prepare youth for transition and often began with discussions a few years before planned transition, typically around age 22 (range 21–25 years old). Staff focused on life skill development both formally (e.g., budgeting seminars) and informally (e.g., medication management discussions). Program staff identified these skills as imperative in supporting youths’ abilities to take more responsibility for care, with less of the “handholding” offered at adolescent clinics.

At our clinic, our nurses will hold your child while you're giving blood. At adult care, you're an adult, put your kid in day care. So many ‘kid glove’ things that we do provide even though some of our kids are older and they're 24 and 25, is not something that happens in adult care. (Site E)

Thus, adolescent clinic staff worked to prepare youth for the different approaches at they would encounter at the adult clinic. Other services and activities, such as transition support groups, celebrations, and certificates were discussed as helpful in supporting and demonstrating to youth that they were ‘graduating’ to another level of care and independence.

While participants often had connections with adult clinic providers and staff, most adult clinics did not have a transition-focused staff member: “I’m certain that we do lose some [adolescents] because you’re not going to find another [care linkage coordinator] on the other end of this spectrum for 25 and older.” (Site M). Participants reported that a dedicated transition staff member at the adult clinic would be particularly helpful in completing transition:

A pivotal [adult clinic] person...will tell them all about that clinic and how to navigate it and then help them make their first appointment, help them navigate it, be there for reminders and then be able to also do some short-term follow up to make sure that they transition. (Site H)

AAP Transition Guideline 3: Planned facilitation of youths’ connection to adult clinics as transition is initiated

To provide youth with a specific connection to the adult clinic, three sites scheduled adolescent clinic visits with an adult provider, starting approximately one year prior to transition. Other sites introduced youth to adult providers when they did not have to change clinical space (n=2), conducted visits to adult clinics (n=4), or had adolescent clinic staff attend the youth’s first adult medical appointment (n=2).

Participants also discussed how clinical space affected efforts to link, retain, and transition youth. For instance, adolescent clinics were described as more youth friendly and rarely HIV-specific. Thus, youth’s shift to an adult HIV clinic had implications for contact with

older, sicker patients and more overt HIV-related stigma; “Every time [they] come into the building it’s a reminder and when [they] leave [they] can put that aside. When [they] come here, [they] can’t escape that.” (Site A). That sentiment was supported by another participant: “a large majority [of youth] are choosing to transition to a system of neighborhood clinics that are not HIV-specific” (Site H). Thus, staff worked with youth to determine what would help them succeed and developed individualized transition plans accordingly.

For sites that treated both adolescents and adults (n=3), the transition was easier, even when clinics were HIV-specific: “Once they’re used to going there, I mean, it’s an HIV clinic, how much worse can you get? And they know everybody there and people are friendly” (Site M). New adult clinical space meant new people (e.g., providers and receptionists) with whom youth were required to share their medical and social histories. Compared to having to transition to new space, youth staying in the same space had more consistency in interactions:

The provider and the nursing people change but the phlebotomist's the same person, the dentist is the same person, your social worker's the same person...so it makes it a little bit easier for them to continue to maintain their care. (Site C)

Sites worked within their existing infrastructure to connect youth to adult clinics and providers in order to improve chances of transition success.

AAP Transition Guideline 4: Communication between adolescent and adult clinics for quality assurance and evaluation

No standard approach was identified in terms of before-transition communication, after-transition follow-up, or between-clinic data sharing. Evaluating transition success (e.g., appointment adherence) was easier when youth stayed in the same clinic (or in a system with shared medical/health records) compared to youth attending new clinics. The sites that shared data and information could more easily assess transition outcomes for youth engaged in adult care and work toward continuous quality improvement.

Inter-clinic communication and data sharing was identified as essential to efficiently evaluate transition outcomes and conduct quality assurance reviews. Transitions were more effectively managed when pre-transitions communications occurred between clinics. Direct communication also facilitated follow-up to determine status of adult clinic appointment adherence: “The nice thing is we have good relationships with our adult providers so if they haven’t seen some of our clients, they’ll call us and say have you talked to them” (Site J). However, limited communication between adolescent and adult clinics was common and identified as an issue that affected transition outcomes as well as evaluation and quality assurance processes.

Discussion

Our results add to the limited data on transition to adult care for youth living with HIV. Specifically, the results highlight core components of transition (identified in the recent American Academy of Pediatrics guidelines) that may fail in practice (Committee on

Pediatric AIDS, 2013). Although transition clearly depends, at least in part, on individual patient characteristics such as co-morbidities (e.g., substance use and mental health), concurrent transitions such as evolving independence (e.g., moving out of parents' home), education (e.g., high school to college/vocational training), and changes in peer relationships also affect transition (Philbin et al., 2014; Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014). Thus, approaching transition to adult care as a process rather than a one-time event needs to be a key practice.

Consistently successful transition programs clearly require additional attention on providers and service delivery systems at both the adolescent and adult clinics. Our finding that adult HIV clinics are perceived as less supportive and require increased patient responsibility raises questions about the qualities of a "transition-friendly" adult clinical space and approach. Youth acceptance of loss of a supportive environment is seen as tacit cost of "growing up." However, attention to transition issues through physical space and receptive and supportive staff could decrease those lost to care during transition (Douglas & Douglas, 2005; Fair, Sullivan, & Gatto, 2011; Fegran et al., 2014; Tanner et al., 2013). This approach could extend HIV patient navigator models used to organize care linkage for newly diagnosed persons with HIV (Bauman et al., 2013; Bradford, Coleman, & Cunningham, 2007; Higa, Marks, Crepaz, Liau, & Lyles, 2012).

Results indicated that data sharing and communication between clinics was mostly low, and often explained by insufficient resources and time to make contacts or follow-up about specific adolescents. This suggests that consistently successful transition requires appropriate resources in addition to programmatic infrastructure and quality assurance assessments. Full implementation of the Affordable Care Act (US Department of Health and Human Services, 2010) will affect insurance coverage with benefits (e.g., ability to stay on parent's insurance until 26) and challenges (e.g., adolescents' ability to choose how and whether to actively disclose to family given risk of inadvertent disclosure from insurance bills). Thus, integrating data sharing into the changes will, ideally, facilitate consistency in coverage. Finally, data sharing can assist with the evaluation of transition protocols and outcomes necessary for continued program quality improvement and sustainability.

Limitations

Given the variation across ATN clinical sites (e.g., geography and patient populations) an overview of the key elements of transition protocols was provided without providing complete details. Further, the study focused on transfer of care, which is a singular aspect of the transition process. The study design also relied on a purposive sample of adolescent program and clinical staff perspective, without speaking to all adolescent staff or to adult clinic staff (with the exception of clinics serving adolescent and adult patients), families/guardians, or youth (Fair et al., 2015). Participants had diverse training, skill sets, and time practicing in clinic, which may have influenced their perspectives on transition and thus affected the study results. Determining the effectiveness of transition protocols was not possible given the limitations of data sharing, HIPAA, and resource constraints. This means that additional work is needed to comprehensively understand the most effective and efficient processes for transitioning youth with HIV to adult care.

Future Research

Future research needs to evaluate the effectiveness of transition outcomes (e.g., engagement, viral suppression, patient satisfaction) (Dowshen & D'Angelo, 2011; Fair et al., 2011). Longitudinal and prospective work is also needed for a thorough understanding of youths' transition experiences and to examine transition trajectories (Fair et al., 2011). Further, research is needed to examine adult clinic transition protocols (if they exist) and how adult and adolescent protocols might be integrated. The role of the adult clinic in transition processes has been largely ignored but is crucial for developing a streamlined process (Nehring et al., 2015; Tanner et al., 2013). Exploring adult providers' attitudes and comfort in treating adolescents, who are often dealing with other challenges (e.g., developmental stage), will be essential to ascertain training gaps and needs. Future efforts should include adult clinic staff, as their insight into factors affecting transition and the tools they employ will allow for continued improvement in care continuity. This continued exploration could help identify how the key elements work together to develop and refine transition protocols that build on the American Academy of Pediatrics recommendations (Committee on Pediatric AIDS, 2013). The creation of successful transition programs requires an explicit focus on providers and systems at both the adolescent and adult clinics.

Conclusions

Successful transition for youth living with HIV is complex due to the coordinated medical and behavioral management required to reduce transmission risk and the co-occurring challenges of substance use, mental health issues, and associated stigma and discrimination (Fair et al., 2012; Gilliam et al., 2011; Koenig & Bachanas, 2006; Office of National AIDS Policy, 2012; Ryscavage, Anderson, Sutton, Reddy, & Taiwo, 2011; Vijayan et al., 2010; Wiener et al., 2011). Therefore, creating a seamless transition process for youth with HIV is especially important given the intersecting identities and stigmas often associated with the disease (CDC, 2012). The disproportionate impact of HIV on sexual, racial, and ethnic minority communities (CDC, 2010; Dowshen & D'Angelo, 2011; New York State Department of Health, 2011; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000) underscores how these issues further complicate youths' ability to prioritize their own health, address the more direct stigma confronted in adult clinics, and meet the different behavioral expectations of adult clinics. Ideally, adolescent clinics would be stepping-stones to adult care with staff on both sides providing necessary care and support. Transition to adult HIV care will be improved through developing formal, multidisciplinary transition plans that involve youth, their families/guardians, and adolescent and adult providers (Committee on Pediatric AIDS, 2013; Mauro et al., 2011; Mauro et al., 2015; NYSDOH, 2011). Recommendations for transitioning involve targeting youth-specific factors, while also addressing provider- and systems-level issues. Addressing core clinical factors to inform transition protocols and behavioral interventions will improve the coordination capacity of adolescent and adult clinics to provide uninterrupted, quality HIV-related care.

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Table 1

Overview of ATN site transition processes by adult clinic type

	Existence of formal transition protocols at the adolescent clinics (average age of transition)	Strategies to prepare adolescents for transition at the adolescent clinics	Methods used at the adolescent clinics to facilitate adolescents' connection to adult clinics	Process for transition outcome evaluation at the adolescent clinics
Sites where transition requires new providers and a new clinical space				
Site T	No formal protocol (25 years old)	Informal discussions to prepare youth for transition		Informal, follow up for 2 visits. Case manager will maintain contact with adolescents post transition
Site S	Formal protocol - in revision Based on a protocol that allergy/immunology uses with adolescents (24/25 years old)	Provides certificates to celebrate transition		None
Site R	Formal protocol - in revision (24 years old; cannot admit after 21)		Social worker takes youth to appointment	Informal – staff try to maintain contact even after youth transitions to adult clinic
Site Q	No formal protocol (24 years old)			Track for 3–6 months
Site O	Transition process; no formal protocol (21 years old; but can see older patients)			Informal – social worker tries maintain contact for up to one year
Site J	No formal protocol (25 years old)	Informal discussions to prepare youth for transition		Informal – staff will keep contact with youth
Site G	Formal protocol (24 years old)			Informal - trying to standardize a year follow-up (difficult with different adult sites)
Sites whose primary referral site is in the same medical system				
Site N	Formal protocol; all staff know of plan but it is not written up formally (25 years old; do allow youth to come back)	“Moving Up” ceremony to celebrate transition		Informal - follow-up for 2 visits at other place (easier if stay in system) Let them come back even at 25
Site I	Formal protocol (25th birthday)		Staff takes youth over to meet adult case manager	Same system but no consent (or funds) to follow
Sites that allow adolescents to stay in the same clinical space (but who may have new providers)				
Site P	Formal protocol – solidifying it (24–25 years old)		In same clinic – introduce to adult provider(s)	Tracks for 6 months
Site K	No formal protocol (24 years old)	Informal discussions to prepare youth for transition	In same clinic – introduce to adult provider(s)	Informal - get adult clinics' schedule (can see who's going); case manager still calls
Site H	No formal protocol (~23/24 years old)		In same clinic – introduce to adult provider(s)	In same clinic so easy (medical records)