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Transitioning HIV-Positive Adolescents to Adult Care: Lessons Learned From Twelve Adolescent Medicine Clinics

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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.

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

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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; Maturo et al., 2011, 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; 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 (26%), outreach workers (23%), social workers (9%), case managers (8%), and other clinical staff (e.g., psychologists and HIV testers) (11%). Notably over 50% of participants had been working in the field since the pre-HAART era (i.e., 1996) thus had extensive training and experience. Participants at certain sites (e.g., large teaching hospitals) also captured medical providers 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 (Muhr, Atlas, Scientific Software Development, 2004); 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.