



# Transitioning Adolescents and Young Adults With HIV Infection to Adult Care: Pilot Testing the “Movin’ Out” Transitioning Protocol

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**Background** Advances in care and treatment of adolescents/young adults with HIV infection have made survival into adulthood possible, requiring transition to adult care. Researchers have documented that the transition process is challenging for adolescents/young adults. To ensure successful transition, a formal transition protocol is needed. Despite existing research, little quantitative evaluation of the transition process has been conducted.

**Purpose:** The purpose of the study was to pilot test the “Movin’ Out” Transitioning Protocol, a formalized protocol developed to assist transition to adult care.

**Method:** A retrospective medical/nursing record review was conducted with 38 clients enrolled in the “Movin’ Out” Transitioning Protocol at a university-based adolescent medicine clinic providing care to adolescents/young adults with HIV infection.

**Results:** Almost half of the participants were able to successfully transition to adult care. Reasons for failure to transition included relocation, attrition, lost to follow-up, and transfer to another adult service. Failure to transition to adult care was not related to adherence issues,  $\chi^2(1, N = 38) = 2.49, p = .288$ ; substance use,  $\chi^2(1, N = 38) = 1.71, p = .474$ ; mental health issues,  $\chi^2(1, N = 38) = 2.23, p = .322$ ; or pregnancy/childrearing,  $\chi^2(1, N = 38) = 0.00, p = .627$ .

**Conclusions:** Despite the small sample size, the “Movin’ Out” Transitioning Protocol appears to be useful in guiding the transition process of adolescents/young adults with HIV infection to adult care. More research is needed with a larger sample to fully evaluate the “Movin’ Out” Transitioning Protocol.

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ADVANCES IN THE care and treatment of children and adolescents with HIV infection over the last 20 years has resulted in increased survival into late adolescence and young adulthood. This includes those that were infected perinatally via vertical transmission, as well as those who contracted HIV infection behaviorally via horizontal

transmission (Rakhmanina & Phelps, 2012). Increased survival results in a number of psychosocial issues and stressors for adolescents and young adults with HIV infection. Adolescents and young adults have reported that the transition to adult care is a source of stress and uncertainty (De Santis, Garcia, Chaparro, & Beltran, 2014).

This relevant topic was the subject of The Committee on Pediatric AIDS (2013) position statement. This Committee developed a number of recommendations to assist healthcare

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providers in transitioning adolescents/young adults with HIV infection. These recommendations include the development of a written policy for transition, an assessment of readiness to transition with an individualized plan for each client. The Committee also recommended documenting, tracking, and evaluating each client's progress in the transition process. Monitoring a client's progress during the transition process is essential to not only monitor morbidity, but also that mortality does not occur (Fish et al., 2014).

Transition for the chronically ill from pediatric care to adult care has been studied by various disciplines within the context of different chronic illnesses. A recent systematic review that included 10 U.S. studies and 25 international studies that focused on a variety of pediatric chronic illnesses deduced that the transition process is complex, and that those clients who are transitioning want to be included as a part of the transition process to ensure that their healthcare needs are met (Betz, Lobo, Nehring, & Bui, 2013). The systematic review included two U.S. studies (Valenzuela et al., 2011; Weiner, Kohrt, Battles, & Pao, 2011) and one international study (Bundock et al., 2011) that were focused on adolescents and young adults with HIV infection.

A number of research studies have been conducted with adolescents/young adults' experiences with transition to adult care. This topic has global implications as evidenced by the fact that it has been studied in Australia (Bundock et al., 2011), sub-Saharan Africa (Pettitt, Greifinger, Phelps, & Bowsky, 2013), Thailand (Tulloch et al., 2014), and the United Kingdom (Fish et al., 2014), in addition to the U.S. (e.g., Fair, Sullivan, & Gatto, 2011; Fair, Sullivan, Dizney, & Stackpole, 2012; Newman, Persson, Miller, & Cama, 2014; Sharma, Willen, Garcia, & Sharma, 2014; Vijayan, Benin, Wagner, Romano, & Andiman, 2009).

A critical review of the available research on transitioning adolescents/young adults with HIV infection to adult care revealed a few gaps in the literature. First, the majority of studies evaluated the transition process qualitatively (Fair et al., 2012; Sharma et al., 2014; Vijayan et al., 2009; Weiner et al., 2011). Two quantitative studies were conducted, but both contained small samples of 12 adolescents/young adults and their caregivers (Weiner, Zobel, Battles, & Ryder, 2007), and 19 HIV-infected adolescents/young adults (Bundock et al., 2011).

Second, three studies were conducted that evaluated the transition process from the perspectives of clinicians providing care to adolescents/young adults with HIV infection (Fair et al., 2011; Newman et al., 2014; Tulloch et al., 2014). It is important to note that a study by Tulloch et al. (2014) also included both caregivers of children/adolescent orphans with HIV infection. Although perspectives of clinicians and caregivers are important and add pertinent information to the evaluation of the transition process, failure to include the unique perspectives of those experiencing the transition process firsthand probably does not fully evaluate the transition process.

Third, all available research studies on transition of adolescents/young adults with HIV infection have focused on perinatally-acquired HIV infection. Little if any research on

transition to adult care for those adolescents/young adults with behaviorally-acquired HIV infection has not been conducted.

## Purpose of the Study

Despite the body of knowledge on the transition of HIV-infected adolescents/young adults to adult care, a significant gap in the knowledge base has been identified. No study to date has used a systematic method to evaluate the transition process. Therefore, to address the gap in the knowledge base, the purpose of this pilot study was to pilot test the effectiveness of the "Movin' Out" Transitioning Protocol that guides the transition process of adolescents/young adults with HIV infection to adult care.

## The "Movin' Out" Transitioning Protocol

The "Movin' Out" Transitioning Protocol was developed by a multi-disciplinary team of physicians, nurse practitioners, social workers, and peer advocates of the University Of Miami Miller School Of Medicine's Special Adolescent Clinic (SAC) as a guide to assist adolescents/young adults with HIV infection to transition to adult care. Two factors promoted the development of the "Movin' Out" Transitioning Protocol. The first was the multi-disciplinary healthcare team that wanted to provide a guide for both healthcare providers and transitioning clients that detailed the transition process. The second factor was that the multidisciplinary team anecdotally noted that attrition rates were nearly 100% in adult care after clients left the SAC and were transitioned to adult care. This formalized protocol allowed members of the multi-disciplinary team to track each client's progress through the transition process. The "Movin' Out" Transitioning Protocol consists of five distinct phases that start with discussions about transition (phase one) and ends with a 1-year follow-up after transition (phase five). A more detailed description of the protocol, the protocol's development, and its specific phases, can be found in Maturo et al. (2011), and a summary of the protocol can be found in Figure 1.

## Method Study Design

After obtaining approval by the university's institutional review board as an exempt study, a retrospective chart review was used to collect data. The retrospective chart review process was based on a modified version of procedures developed by Gearing, Miam, Barber, and Ickowicz (2006).

## Participants

The medical records of 38 adolescents and young adults who were transitioned using the "Movin' Out" Transitioning Protocol were reviewed. The sample consisted of 34 participants who were behaviorally infected, and four participants who were perinatally infected. Using the Centers for Disease Control criteria (1993) six participants (15.8%) were classified as AIDS, while 84.2% were classified as HIV infection. Among the 34 participants who were behaviorally-infected, mean age at

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