
Attitudes Toward Transitioning in Youth With Perinatally Acquired HIV and Their Family Caregivers

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This study investigated the preparedness and views of patients with perinatally acquired HIV and their family caregivers about transitioning to adult medical care. Fifteen participants (ages 15–24 years) with perinatally acquired HIV and eight family caregivers participated in structured interviews. All interviews were recorded and analyzed for themes using qualitative research methodology. Three major themes emerged: (a) perceived lack of readiness for transition, (b) fear of change and anxiety about entering the adult health care system, and (c) burgeoning personal responsibility that comes with age. Participants also offered suggestions to improve the transition experience, including starting the process early with specific guidelines. All patients and family caregivers wanted early knowledge about transition; these individuals could be an important resource to find potential solutions to guide the transition process. Clinical outcomes must be assessed in patients undergoing transition to determine the effect on management of medical disease, and protocols must be developed.

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As medical care for people who are infected with HIV has improved, the length of survival has also

increased. The same is true for children who are infected with HIV at birth or in utero (Patel et al., 2008). However, perinatally acquired HIV impacts children differently than individuals infected with HIV later in life because these children were infected at a time when their immune systems and overall development were particularly vulnerable. Many perinatally infected patients suffer from cognitive issues, ranging from learning disabilities to severe mental retardation (Willen, 2006). They also may experience growth problems, including pubertal delay, which can result in a difference between

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a patient's mental age and his/her chronological/physical age and appearance (Knight, Mellens, Levenson, Arpadi, & Kairam, 2000). Because these children acquired the virus perinatally, they may also have one or more family caregivers who are living with HIV (Sherr et al., 2008). Finally, some patients will have developed resistance to first- or second-line antiretrovirals by the time they are adolescents due to factors such as poor or intermittent adherence (Descamps et al., 2000; Reddington et al., 2000).

At the University of Miami, the first cases of patients with perinatally acquired HIV were noted in 1981. By 2004, 310 children and adolescents had been cared for in the clinic and nearly half had reached the ages of 13 to 24 years. The clinic offers a comprehensive model that provides multilevel, wraparound services to cover all aspects of psychosocial as well as medical care. As the population has aged, specific adult health care issues such as hypertension, diabetes, and gynecological needs have become more prevalent. Pediatric health care providers in the clinic have reported feeling uncomfortable managing such conditions and, therefore, have had difficulty providing adequate care in these areas. Problems often arise when emergency department or inpatient admissions are required, as the pediatric units do not admit patients who are 21 years of age or older. In addition, pediatric clinic services end at 24 years of age and, for the first time, the clinic has been serving patients who would likely live beyond this age.

Health Resources and Services Administration Ryan White Part D grants fund many of the additional services in the pediatric clinic, such as nursing, nutrition, psychology, mental health, peer education, and psychosocial services, as well as access to research. On the adult side, funding for such resources does not exist, necessitating that patients act more independently in following up with appointments and taking medications. Additionally, the adult HIV clinic follows more than 3,000 patients, and adult practitioners may not have the time or resources to address the unique needs of patients with perinatally acquired HIV. For example, a 24-year-old patient with perinatal HIV infection may have severe developmental delays due to HIV-associated encephalopathy and may not be able to understand his/her

disease process or medication instructions. Anecdotally, pediatric clinical staff, as well as patients and families, have expressed concern about patients moving to the adult clinic given its size and fewer services to specifically address the needs of patients with perinatally acquired HIV infection.

Several studies have investigated the transition of adolescents with HIV to adult care. A few have involved patients with perinatally acquired HIV, or young adults with behaviorally acquired HIV who were asked to retrospectively reflect on the transition process (Bundock et al., 2011; Miles, Edwards, & Clapson, 2004; Valenzuela et al., 2011). Others have focused on health care providers' views about transition (Fair, Sullivan, & Gatto, 2010; 2011). Two other studies have reviewed existing transition programs, although there is little consensus among the sites regarding the specific elements of a successful program (Gilliam et al., 2010; Maturo et al., 2011).

Wiener, Zobel, Battles, and Ryder (2007) conducted a study with HIV-infected adolescent patients transitioning from their primary clinic. The study was prompted by the closure of the National Institutes of Health Pediatric HIV/AIDS Clinical Research Program. This necessitated transitioning adolescent patients from the referral center at the National Institutes of Health to community providers within 1 year. Although they used a scale to assess level of anxiety, transition readiness, and barriers to transition for patients, the study did not include family caregivers in the assessment. Another study by Fielden et al. (2006) evaluated children with HIV, their family caregivers, and their service providers and found that participants were concerned about the social stigma associated with HIV, future mental health needs, and the ability to have sexual relationships. Neither study asked questions about how to best develop a transition program to prospectively transfer patients to adult care.

In a paper by Vijayan, Benin, Wagner, Romano, and Andiman (2009), the authors conducted interviews with adolescents, their parents, and their clinic health care providers in a pediatric clinic devoted to the care of adolescents with perinatally acquired HIV. In the study, however, 12 of 15 parent participants were adoptive, so despite having a child with perinatal HIV, the extent to which other family

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