



# Congruence of Transition Perspectives Between Adolescents With Perinatally-Acquired HIV and Their Guardians: An Exploratory Qualitative Study

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Youth with perinatally-acquired HIV infection (PHIV) routinely survive into adulthood requiring transition to adult care. Research underscores the importance of assessing transition perspective congruence between adolescents and guardians. Interviews focused on transition decisions were conducted with 18 adolescents with PHIV and their guardians recruited from a southeastern US pediatric infectious disease clinic. Transcribed responses were coded as congruent or divergent. Adolescents and guardians held congruent views that the transition process had not started. Fewer dyads agreed upon the level of adolescent and guardian involvement in transition decisions. Providers should assess congruence of adolescent and guardian perspectives regarding transition-related decisions.

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PRIOR TO ADVANCEMENTS in HIV care, youth with perinatally acquired HIV (PHIV) did not historically survive childhood (Maturó et al., 2011). However, the introduction of highly active antiretroviral therapy (HAART) led to increased rates of survival for youth with PHIV (CDC, 2008), and the ability to interrupt mother-to-child-transmission has resulted in a precipitous decline in the number of youth with PHIV (Nesheim, Harris, & Lampe, 2013). For this generation of youth and their families, surviving into adulthood necessitates the transition from pediatric to adult care settings (Dowshen & D'Angelo, 2011), a relatively recent phenomenon. Previous research suggests that transition to adult care can be associated with declines in medication adherence as adolescents struggle with increased demands of self-management (Naar-King et al., 2009; Wiener, Kohrt, Battles, & Pao, 2011). An unsuccessful transition is especially concerning since poor adherence to antiretroviral therapies can result in significant individual and public health repercussions (Centers for Disease Control and Prevention (CDC), 2008; Descamps et al., 2000). Further,

young adults seen in adult infectious disease clinics are significantly more likely to miss appointments and fall out of care (Rayscavage, Anderson, Hutton, Reddy, & Taiwo, 2011). Therefore, facilitating successful transitions for adolescents with PHIV is important.

There is currently no consensus on the definition of a successful transition to adult care settings. However, previous literature focused on children with special health care needs (CSHCN) has identified several important components of a successful transition including: assessing transition readiness based on chronological age (Rosen, Blum, Britto, Sawyer, & Siegel, 2003) or developmental maturity (Maturó et al., 2011; Wiener et al., 2011), encouraging autonomy and self-management in medical care (Giarelli, Bernhardt, Mack, & Pyeritz, 2008; Miles, Edwards, & Clapson, 2004; Sawyer, Drew, Yeo, & Britto, 2007; Vijayan, Benin, Wagner, Romano, & Warren, 2009), and promoting coordination and communication between adult and pediatric providers (Maturó et al., 2011; Miles et al., 2004; While et al., 2004). Early planning and preparation for transition has been highlighted as a way to overcome potential barriers to transition (Blum, 1995; DHHS et al., 2001; Lotstein, McPherson, Strickland, & Newacheck,

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2005). In addition, the importance of caregivers' involvement in the adolescent's transition has been well documented in the literature as integral to a successful transfer (Fair, Sullivan, & Gatto, 2010; Reiss, Gibson, & Walker, 2005).

Transition perspectives of CSHCN and guardians have been studied (e.g., Fredericks et al., 2011; Geerts, Van de Wiel, & Tamminga, 2008; Rutishauser, Akre, & Suris, 2011). However, difficulty in discerning whether adolescents or their parents provide a more accurate representation of the adolescent's health (Bethell et al., 2002) has led chronic illness researchers to frame their understanding of adolescent and guardian perspectives by separately examining transition perspectives, and most recently, analyzing the congruence of perceptions. Separate analyses of adolescents and guardian transition perspectives reveal that parents expect and value a strong parent-provider relationship as an essential component of transition for CSHCN (Scal & Ireland, 2005). Other studies have found a similar trend when examining the perceptions of youth with HIV who indicated a need for increased communication with parents and providers (Bundock et al., 2011; Wiener et al., 2011) and continuity of care with a medical provider (Miles et al., 2004).

Research on congruent perspectives has pointed to several reasons why it may be important to simultaneously consider the perceptions of CSHCN and their parents or guardians. Some studies have investigated whether disagreement between adolescent and parent representations of illnesses may influence adolescent psychological well-being (Law, 2002). Youngblade and Shenkman (2003) found that adolescents identify special health care needs less often than their parents. Fredericks et al. (2011) studied congruence between adolescent transplant recipients and their parents who both reported having given little thought to transition planning or initiation. Other findings have suggested that compared to their adolescent, parents report greater frequency of planning (Knapp, Huang, Hinojosa, Baker, & Sloyer, 2013) and more distress and concern about transitioning to adult care (Boyle, Farukhi, & Nosky, 2001; Geerts et al., 2008). The previously mentioned studies indicate that congruence may indeed be an important construct and further research is warranted.

The transition of adolescent with PHIV has received increasing attention within the literature including the identification of barriers and possible benefits of transition to adult care. Vijayan et al. (2009) identified several transition challenges for adolescents with PHIV barriers, such as the family's understanding of HIV, experiences with related stigma, low levels of adolescent self-management skills, and hesitancy to relinquish long-term relationships with pediatric providers. Miles et al. (2004) studied a small group of adolescents who had already transitioned to adult care. Findings indicated that individual transition readiness, HIV-related stigma, and encounters with adult patients with HIV may contribute to a delayed or difficult transition for adolescents with HIV. Benefits of transition included increased autonomy and responsibilities. Wiener et al.

(2011) found that transitioned adolescents with HIV suggested improved communication between relevant parties and preparing youth for the differences in the adult environment would facilitate the transition to adult care.

Although these studies offer valuable insight, they do not directly examine the congruence of transition expectations of adolescents living with PHIV and their guardians. Previous PHIV transition research has examined caregivers' expectations of transition (Fair, Sullivan, Dizney, & Stackpole, 2012). However, the guardian's transition perspective has mostly been considered separate from or alongside of the perspective of their adolescent. The current project explores the ways in which transition perspectives of adolescents with PHIV youth converge or diverge from those of their caregivers.

## Methods

### Participants

The current study focuses on a subpopulation of 18 adolescents with PHIV and their guardians, drawn from a larger study of 40 adolescents (Fair et al., 2012 for further information). Participants were recruited from a pediatric disease clinic in the southeast United States and were eligible for the study if they were over 14 years of age, aware of their HIV status, and did not have cognitive impairments that would interfere with their ability to answer the interview questions. All guardians who were present at the clinic visit were invited to participate resulting in 18 guardian-adolescent unique dyads. No siblings participated.

### Procedure

This qualitative study was reviewed and approved by the institutional review boards of both the first author's institution and the medical center. The social worker from the pediatric infectious disease clinic (Author RD) approached all eligible families during regularly scheduled visits about participation in the study. Adolescents and guardians were interviewed separately by author CF as well as two other trained interviewers who were senior undergraduate research students. Author CF worked as a social worker and/or researcher for more than 20 years with children with HIV and their families, some of whom were engaged in care at the clinic from which most participants were drawn. CF trained all other interviewers on qualitative data collection and semi-structured interviewing.

Participants were offered a gift card worth \$15 to compensate them for their participation. Interviews were recorded and later transcribed.

### Interviews

Questions were embedded in a larger study that explored adolescents' (n = 40) and guardians' (n = 18) expectations of transition included in anticipated potential benefits and concerns/losses associated with transition. Only those adolescents whose guardians also participated in the study are included in the current project. Transition was defined as

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