

# The HIV Experience: Youth Identified Barriers for Transitioning from Pediatric to Adult Care

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**Objective** The aim of this study was to explore the experiences of youth living with HIV who transitioned from pediatric to adult care. **Methods** Semi-structured telephone interviews were conducted with 59 youth (mean age = 22 years) living with HIV about the transition experience, demographics, and health status. **Results** Of youth who transitioned to adult care, immune function (CD4) trended downward, 45% found the transition more difficult than anticipated, and 32% could not find emotional support services. Youth identified the need for increased continuity of care, assistance with logistics, improved communication with providers and caregivers, and individualized management of their transition process.

**Conclusion** Without adequate preparation, the transition process can be compromised with potentially serious health consequences. Youth living with HIV seek adult providers that can provide developmentally appropriate transition interventions that address loss, disclosure, and sexual behavior along with medical needs.

**Key words** adolescents; healthcare; HIV/AIDS; transition; young adults.

## Introduction

As advances in technology and better training of pediatric healthcare providers have improved the prognosis for children living with chronic illness, an increasing number of children born with HIV are living into adulthood. Embedded in this heartening finding is an inherent paradox. Children living with chronic illness may not be prepared for independent living, nor are their primary caregivers or pediatric healthcare providers necessarily prepared to let them transition to independently monitored adult care (Peter, Forke, Ginsburg, & Schwarz, 2009; Viner, 1999). When transition to adult care occurs, adult providers are sometimes insufficiently trained in the comprehensive care of their childhood onset illnesses (Reiss, Gibson, & Walker, 2005). The health and well-being of youth with chronic illnesses, particularly HIV/AIDS, hinges on uninterrupted and successful transition to adult care (American Academy of Pediatrics, 2002; Blum, 2002; Turkel, & Pao, 2007; Canadian Paediatric Society, 2007); therefore, examining the factors that improve transition to adult care is essential.

The recent literature on the transition process for children with chronic illness has yielded invaluable information on common barriers to transition success (Binks, Barden, Burke, & Young, 2007; Lotstein et al., 2009; Rosen, Blum, Britto, Sawyer, & Siegel, 2003; Scal & Ireland, 2005). Research has highlighted economic, logistical, educational, and psychosocial barriers to successful transition (e.g., Hilden, Himmelstein, Freyer, Friebert, & Kane, 2001; Ginsberg, Hobbie, Carlson, & Meadoes, 2006; Heller & Solomon, 2005; Miles, Edwards, & Clapson, 2004; Reiss et al., 2005). Many of these barriers are intertwined, making it difficult to parse apart which barriers play the largest role in either the success or failure of transition; in addition it is unclear whether or not barriers identified for one chronically ill population generalize to all adolescents and young adults with chronic illnesses. This is especially salient in the case of pediatric HIV infection, as transitioning to adult care is associated with confrontation of the discrimination, and intra-/inter-personal complications associated with a communicable and socially stigmatized chronic disorder (Miles et al., 2004;

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Remien & Mellins, 2007). The following section briefly reviews what the current literature states regarding economic, logistical, and psychosocial barriers to transition, highlighting the specific transition challenges unique to the concomitant medical and psychosocial factors associated with HIV infection.

### **Economic and Logistical Barriers**

#### **Access to Insurance Coverage**

Research has found that young adults are two times more likely to be uninsured than children or adults (Callahan & Cooper, 2007) and chronically ill young adults may have even more difficulty obtaining insurance due to insurance policies that exclude pre-existing medical conditions. Over half of young adults with chronic illnesses report gaps in insurance coverage, with an average gap of 15 months (Callahan & Cooper, 2007). Individuals with fewer socioeconomic resources are over-represented in the HIV epidemic (Remien & Mellins, 2007). While many state and federally supported AIDS drug assistance programs exist, even a brief gap in coverage can have significant health consequences for individuals with HIV in terms of drug resistance and reduced medication effectiveness (García et al., 2002).

#### **Lack of Communication**

All of the barriers described thus far have an effect on the quality of communication between the patient, his or her family, and the healthcare professionals in both pediatric and adult care. Communication between pediatric and adult providers is also often lacking (Peter et al., 2009), leaving young adults feeling as though they need to fully communicate their entire treatment history all over again. For HIV-positive youth, describing (without another adult present) how they acquired their disease, their medication history, history of illnesses and hospitalizations, and related events can be very stressful as well as potentially incomplete or inaccurate.

### **Psychosocial Barriers**

#### **Developmental Readiness**

In most cases, the transition from pediatric to adult care has been guided by age limits rather than the achievement of developmental milestones, with most children transferring to adult care beginning at the age of 18 and completing the transition process by the age of 21 (Reiss et al., 2005). This can result in adolescents aging out of care prior to being emotionally or cognitively ready. Youth with cognitive deficits may be at particular risk for difficulty with the transition. Malee et al. (2008) found that IQ scores of children and young adults with HIV tended to fall

in the low average range, and that 16% of these individuals could be classified as cognitively impaired (FSIQ < 70), as compared to 5% in the general population. In addition, for those who are not classified as impaired, subtle neuropsychological deficits are still prevalent (Aylward, 2002). Cognitive impairments can not only have effects on academic functioning but can also complicate medication adherence, ability to communicate healthcare needs, and healthy disease-related decision-making (Malee et al., 2008). The confluence of general risk due to having a chronic illness coupled with HIV-related neurocognitive impairment can result in a cohort of youth who are unprepared to address their own healthcare needs (Suris, Michaud, & Viner, 2004).

#### **Access to Psychosocial Services**

Individuals undergoing transition have reported that it is difficult to locate adult providers who they feel are as skilled as their pediatric providers in addressing all aspects of their disease. In pediatric settings, the model of care is interdisciplinary in nature (Reiss et al., 2005). One domain critical to adequate care for youth with HIV is mental health. Studies show that nearly 30% of children living with HIV have diagnoses of ADHD (Remien & Mellins, 2007), as compared to 5–7% (in the general population) (Center for Disease Control and Prevention [CDC], 2002) while another 25% suffer from either anxiety disorders or depression (Scharko, 2006), as compared to 13 and 10%, respectively, for children in the general population (U.S. Department of Health and Human Services, 2009a,b). A higher rate of psychotropic medication use and of psychiatric hospitalizations in children living with HIV compared with HIV-uninfected controls has been reported (Gaughan et al., 2004). Chronic depression in young adults with HIV may be associated with faster disease progression, lower CD4 counts, higher viral load, and increased risk of mortality (Misrahi et al., 2004), and the presence of anxiety in this population is significantly related to nonadherence (Williams et al., 2006). While the need for case management and psychosocial services is not new to adult HIV care, the developmental, academic, and psychosocial needs are different for youth with HIV who have been in treatment since early in life than they are for adults who acquired their disease during adulthood (Remien & Mellins, 2007).

Furthermore, young adults with psychiatric symptoms are more likely to engage in sexual risk taking behavior and substance abuse (Remien & Mellins, 2007). Disease management for HIV includes the need to ensure developmental understanding of risky behaviors and of the behavioral steps required to avoid infecting others.

Disclosure issues—for both social networks and sexual partners—tend to emerge around the time of early adulthood, coinciding with the transition period (Taylor-Brown & Wiener, 1993). With increased interests in romantic and sexual relationships, youth who are HIV positive will likely need assistance in navigating when and with whom to disclose, and how to approach issues of physical and psychological safety for themselves and their respective partners (Remien & Mellins, 2007). Adult providers may be accustomed to treating individuals with behaviorally acquired HIV, for whom sexual activity is a routinely discussed topic. While adult providers must deal with issues of partner notification and disclosure with adults, they may be less well versed in broaching this topic for the first time with youth.

Likewise, transitioning to adult care in HIV yields a population change. An HIV positive child is often assumed to have acquired the disease either perinatally or through a transfusion. In adult care settings, most individuals acquired HIV through behavioral practices (Miles et al., 2004). Thus, some young adults experience transition as being viewed as victims of circumstance to being seen as responsible for their disease. These individuals report an increased sense of stigma upon moving to adult settings (Remien & Mellins, 2007).

#### **Hesitance by the Caregiver, Adolescent, or Pediatrician to Leave Pediatric Care**

The care transition process is marked by the same sense of loss and normal grief that occurs when going from one stage of life to another (Wiener, Zoble, Battles, & Ryder, 2007). Occasionally, pediatric providers are unable or unwilling to let go of their pediatric patients and youth and/or primary caregivers are highly resistant to the idea of transitioning to adult care. While pediatric providers may acknowledge that they are not best suited to discuss adult issues with their patients, they remain reluctant to initiate the transition process (Peter et al., 2009). This may be even more salient for pediatric providers caring for patients with HIV, as their care often begins at birth (Miles et al., 2004). While adolescents may also demonstrate resistance to transitioning, this change may be experienced more intensely for young adults living with HIV as many have already suffered the loss of important caregivers in their lives, including the death of one or both parents. The primary caregivers' role in the transition to adult care can be equally crucial. In pediatric care, treatment is family-centered and primary caregivers play an important role in managing their child's health. Primary caregivers are often excluded from decision-making once the young adult is transitioned to adult care. This is difficult for both the child, who is left

to make important decisions regarding their health without the support and guidance they are accustomed to, and for the primary caregivers, who often feel helpless and isolated when no longer able to share in treatment decisions (Shaw, Southwood, & McDonagh, 2004; Binks et al., 2007). This sense of helplessness may be particularly salient for parents when the disease was acquired via mother-to-child transmission (Pao & Wiener, 2008).

Thus the purpose of the present study was to take a step back from the advancing literature on transition from pediatric to adult care in order to re-examine the experience of a specific population of adolescents and young adults: those living with HIV. Between 1986 and 2005, 550 children/adolescents were evaluated for treatment in a pediatric HIV program at a large medical research facility. Youth who enroll on a clinical trial at this facility travel to and from their home community in order to participate in the research and to obtain their HIV treatment and care. Travel is provided for the youth and one primary caregiver. In December 2004, an administrative decision was made to close the program. To assess and assist with the transition of these youth to care in their home community, a transition readiness study was conducted (Wiener et al., 2007). The results of this study led to the identification of specific barriers to transitioning youth living with HIV to providers in the community and when appropriate, adult care. The program officially closed in October, 2005. The aim of the present study was to explore the transition experience of HIV-positive youth who were enrolled in a clinical trial or psychosocial protocol at the time of the program closure. Participants transitioned to adult or pediatric care in their home community. We were particularly interested in exploring whether individuals who transitioned to adult care providers would have equal or better health status post-transition and to better understand youth-identified key issues for a successful transition of care to occur.

## **Methods**

### ***Procedure and Participants***

This study was approved by the NIH Office of Human Subjects Research. Between September through December, 2008, the Principal Investigator contacted youth over the age of 18 by telephone, using the phone number provided at their last clinic visit. Each individual was asked whether they would be interested in participating in a study designed to assess their experience or feelings about transitioning from pediatric to adult HIV care. They were informed that the study consisted of a 5–10 min phone interview during which they would answer

questions pertaining to their current HIV care, health status, transition experience, recommendations for pediatric and adult providers about the transition to adult care, and demographic information. Of the 94 youth who were enrolled in a study at the time of the program closure, four patients had died, six telephone numbers were no longer in service, two numbers had no answer, and two calls were not returned. No significant differences were found in CD4 [ $t(86) = 1.1, p = .29$ ], gender [ $X^2(1) = .09, p = .77$ ], mode of transmission [ $X^2(2) = .68, p = .71$ ], or race [ $X^2(3) = .81, p = .85$ ] from those who participated in the study and those who were unable to be contacted.

Data were collected from 80 participants, yielding a response rate of 89%. Data concerning transition needs and experiences of minor participants were obtained

from the primary caregiver. The focus of this paper is those who transitioned to adult care. Of the 80 participants, 59 were age 18 years or older and were the subject of the current analysis.

## Measures

### Transition Questionnaire

The transition questionnaire was designed by investigators to obtain information on factors identified in the literature and our earlier studies as obstacles to a successful transition (Hauser & Dorn, 1999; Rettig & Athreya, 1991; Wiener et al., 2007). First, it was determined whether HIV care was currently being obtained and if so, whether a pediatric or an adult provider was providing the care. Other questions pertained to (1) current health status

1. Are you currently receiving medical care for your HIV infection?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. Do you get your medical care from a doctor or program for adults (rather than a pediatrician or pediatric clinic)?	<input type="checkbox"/> Yes	<input type="checkbox"/> No (Skip to #3)
2a. How easy or hard was it to change from pediatric to adult health care?	<input type="checkbox"/> Very easy (Please explain)	<input type="checkbox"/> Easy (Please explain)
	<input type="checkbox"/> Difficult (Please explain)	<input type="checkbox"/> Very difficult (Please explain)
2b. Please describe the transition experience for you.		
2c. Was the transition to adult care:	<input type="checkbox"/> As expected	<input type="checkbox"/> Better than expected
	<input type="checkbox"/> More difficult than expected	
2d. What would have made the transition from pediatric to adult care easier for you?		
2e. Since transitioning to adult care, have you had:		
	<input type="checkbox"/> Difficult time being adherent to the medications prescribed (taking the medications as instructed)	
	<input type="checkbox"/> Having more medical needs or complications	
	<input type="checkbox"/> Not been able to find support services at home.	
2f. If yes, please specify:		
	<input type="checkbox"/> Emotional support services	<input type="checkbox"/> Financial support services
	<input type="checkbox"/> Other type of support	
3. Are you currently taking medications to treat your HIV infection?	<input type="checkbox"/> Yes	<input type="checkbox"/> No (please explain)
4. What medications are you currently taking?		
5a. What was your latest CD4 count? _____	When was this taken? _____/____	
5b. What was your latest viral load? _____	When was this taken? _____/____	
6. Since your treatment at XXX, have you ever been hospitalized?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
6a. If yes, what were you hospitalized for:		
	<input type="checkbox"/> An infection	<input type="checkbox"/> Start new medications
	<input type="checkbox"/> Depression	<input type="checkbox"/> Other (Specify)
7. Do you currently have medical insurance?		
	<input type="checkbox"/> Yes What type of insurance do you have?	<input type="checkbox"/> No, I don't have medical insurance
8. Do you currently live:		
	<input type="checkbox"/> Alone	<input type="checkbox"/> W/ roommate/friend/partner
	<input type="checkbox"/> W/ parents	<input type="checkbox"/> W/ other relatives
	<input type="checkbox"/> Other	
9. Are you:		
	<input type="checkbox"/> Single, never married	<input type="checkbox"/> Married
	<input type="checkbox"/> Widowed	<input type="checkbox"/> Separated/Divorced
	<input type="checkbox"/> Committed relationship	
10. Do you have any children? <input type="checkbox"/> Yes <input type="checkbox"/> No		
10a. If yes, a. how many children do you have? _____		
10b. Are they your biological children? <input type="checkbox"/> Yes <input type="checkbox"/> No		
10c. What is the HIV status of each child? _____		
11. Are you working or going to school:		
	<input type="checkbox"/> Full time job	<input type="checkbox"/> Part time job
	<input type="checkbox"/> Full time student	<input type="checkbox"/> Part time student
	<input type="checkbox"/> Not working or in school	
12. What is the highest level of education you have finished?		
	<input type="checkbox"/> 8 <sup>th</sup> grade or less	<input type="checkbox"/> Some high school
	<input type="checkbox"/> Finished high school/GED	<input type="checkbox"/> Some college
	<input type="checkbox"/> Associate's (2 year) college degree	<input type="checkbox"/> Bachelor's (4-year) college degree
	<input type="checkbox"/> Post-graduate degree	<input type="checkbox"/> Other
13. Is your biological mother still living? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Biological father still living? <input type="checkbox"/> Yes <input type="checkbox"/> No		
14. Other thoughts about leaving a pediatric program and transitioning to adult care: _____		

Figure 1. Transition follow-up interview.

and medication regimens; (2) whether participant had medical insurance, and (3) if transition to adult care had occurred, whether the transition was as expected, better than expected or more difficult than expected. Participants were also asked whether they had faced any challenges or difficulty obtaining services or adhering to a medication schedule or regimen since the transition occurred (Figure 1). Demographic information included age, gender, race, living arrangements, education, academic and work status, and whether biological parent(s) were still living. Physical health status (immune function) was measured by participants' CD4 count obtained during their last clinic visit prior to program closure (chart review) and self-report of their most recent CD4 count. Participant reporting of measured viral load units from multiple laboratories was not thought to be comparable so only CD4 counts are reported. Interviews lasted approximately 10 min and responses were hand-recorded.

### **Analysis**

This study utilizes a mixed methodology framework to provide descriptive information on both the status and functioning of the transitioned sample in order to explore personal narratives regarding patient recommendations for improving the transition experience. Univariate analyses are utilized to present descriptive information. Paired samples *t*-tests were utilized to compare CD4 counts from pre- to posttransition within the same participants. Independent samples *t*-tests were utilized to compare differences in CD4 count from pre- to posttransition or in posttransition scores alone between two groups of participants.

### **Qualitative Analysis Procedure**

To further elucidate the experience of transitioning health-care in this population, participants were asked to describe the transition experience and to identify what they believe would have made the transition from pediatric to adult care easier for them. While there is a lack of research on the transition process of HIV-positive youth, the depth of research on transition in general allowed us to utilize a content analysis approach to the analysis of data. Qualitative content analysis allows for "interpretation of the content of text data through the systemic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). The directed approach is useful when some theoretical concepts have emerged and the researcher seeks to validate or build upon these initial themes (Hsieh & Shannon, 2005).

For consistency purposes, the primary investigator conducted all interviews. Responses were transcribed

verbatim and uploaded into NVivo8.0 qualitative software. Computer-assisted qualitative data analysis (CAQDA) was utilized to aid in the organization of the responses. The use of CAQDA in this manner is highly recommended in the literature to improve the trustworthiness, transparency, and rigor of analysis (Welsh, 2002). Two psychology research fellows utilized an open coding procedure to identify themes of the responses using NVivo. In an attempt to reduce researcher bias, the individuals that conducted the analyses were not involved in the care or the interviews of participants. Open coding is a technique of naming and categorizing phenomena based on a careful examination of the data itself (Seidel & Klaus, 1995). Themes were collapsed into a higher order set, or family, under which similar responses were grouped. Responses could be coded into as many categories as were applicable. When themes differed between raters, they met with each other and the primary investigator for discussion in order to reach full consensus.

### **Results**

The 59 participants in this study have been living with HIV an average of 20 years; the majority were relatively healthy, with 86% having self-reported CD4 counts over 200. The average age was 22 (range 18–31) and 51% were male. Less than 40% had a biological mother still living. Eighty-eight percent ( $n = 52$ ) of the individuals were single (never married). Of the 15% ( $n = 9$ ) who had a biological child, all had HIV negative children. Only one participant was living with the child's other biological parent. Academically, 68% ( $n = 40$ ) had finished at least high school or obtained a GED, and 25% ( $n = 15$ ) reported neither working nor being in school. Thirty-six percent ( $n = 21$ ) reported having been hospitalized since the program closed, with 29% ( $n = 6$ ) of those reporting having been hospitalized since the program closed for psychiatric reasons (Table I).

Ninety-three percent ( $n = 55$ ) of participants were receiving HIV care, with 71% ( $n = 42$ ) having made the transition from pediatric to adult care. The following results apply only to those 42 participants who were receiving adult care. Forty-five percent ( $n = 19$ ) reported the transition was more difficult than expected. Eighty-six percent ( $n = 36$ ) were on antiretroviral (ARV) medication at the time of the interview and 45% ( $n = 19$ ) reported challenges adhering to a medical schedule/regimen. Of the six individuals off ARV medication, three were not taking them due to nonadherence and three for lack of insurance. Fifteen percent of individuals ( $n = 9$ ) who had transitioned to adult care were receiving psychopharmacological

**Table I.** Demographic Characteristics of the Sample ( $n = 59$ )

Demographic	$N$ (%)
Male gender	30 (51.0)
Mode of acquisition	
Vertical	48 (81.4)
Transfusion	10 (16.9)
Sexual	1 (1.7)
Mean age (range)	22 (range 18–31)
Education	
Less than high school/GED	19 (32.2)
Finished high school/GED	19 (32.2)
Some college	15 (25.4)
4-year degree/some post-graduate work	6 (10.2)
employment status <sup>a</sup>	
Full time job	10 (16.9)
Part time job	9 (15.3)
Full time student	25 (42.4)
Part time student	6 (10.2)
Not working or in school	15 (25.4)
Race/ethnicity	
Caucasian	26 (44.1)
African American	24 (40.7)
Hispanic	5 (8.5)
Other	4 (6.8)
Marital status	
Single/never married	52 (88.1)
Separated/divorced	1 (1.7)
Committed relationship	2 (3.4)
Married	4 (6.8)
Living arrangements	
With parents	30 (50.8)
With other relatives	8 (13.6)
With friend/roommate/partner	11 (18.6)
Alone	6 (10.2)
Other	4 (6.8)
Have children	9 (15.3)
Biological mother	
Alive	23 (39.0)
Deceased	35 (59.3)
Unknown	1 (1.7)
Biological father alive	
Alive	29 (49.2)
Deceased	19 (32.2)
Unknown	11 (18.6)
Geographic location	23 states and District of Columbia
Have insurance	50 (85.0)

<sup>a</sup>Categories not mutually exclusive.

medication and 32% reported not being able to find emotional support services at home.

Of the 59 total participants, 52 had CD4 values from pre- and posttransition, with pretransition CD4 mean equal

to 575 ( $SD = 396$ , range = 12–2,449) and posttransition CD4 mean equal to 504 ( $SD = 293$ , range = 45–1,702). The mean decrease in CD4 counts was 71 ( $SD = 388$ ; range, 1,002 decrease to 1,549 increase); however, this trend did not reach statistical significance [ $t(52) = 1.4$ ,  $p = .18$ ]. Those who transitioned to adult care and had both of their CD4 counts recorded experienced a mean 115 point drop in their CD4 count from pre- to posttransition [ $t(38) = 1.8$ ,  $p = .08$ ] vs. a 72-point increase among those who did not transition to adult care [ $t(14) = .76$ ,  $p = .46$ ]. Despite what appear to be substantial differences between those who transitioned to adult care and those who did not, the difference in change scores between these two groups only approached significance [ $t(52) = 1.6$ ,  $p = .13$ ].

### Qualitative Results

All 59 participants provided recommendations for improving the transition process. Responses fell into eight general domains, which are summarized below. Participants could provide responses that fell into multiple domains, or could make more than one comment within the same domain. Therefore, percentages were obtained by seeing how many responses, out of the total number of responses, fell into the following categories, rather than the number of participants who reported said recommendation. This is useful in order to both maintain the open coding system and to help determine the frequency and intensity of the recommendation. Themes from the respondents are provided in italics. The number and percentage of specific responses under each larger domain are provided in Table II.

(1) *Increase continuity and quality of care* (17.7%). The importance of having a rapport with the physician or healthcare team was mentioned by 22 of the participants. The standard of care for pediatric HIV providers tends to be personalized and intimate, and many respondents reported the continuation of such individualized care could have improved the transition process.

H, 24: *(I) just want nice people who are willing to take the time to talk to you and ask about your life and not just the virus. They should be friendly and call me by my name.*

In addition, participants stated that seeing the same doctor at each visit would greatly improve transition by allowing them to develop a relationship with their provider more akin to that which they had with their pediatric physician.

B, 30: *I need consistency. I haven't seen the same doctor twice. Doctors change, and there is no person for support.*

(2) *Provide assistance with the logistical aspects of transition* (16.9%). A number of participants reported needing assistance in managing the multiple dimensions of care, specifically logistical issues. Examples included help in locating an adult provider.

L, 19: *... do not make referrals to places that won't really take us or are not really available. Ped(iatric) program needs to stay up-to-date on appropriate HIV referrals, especially when kids don't have insurance.*

A few participants also described how their transition would have been simpler had their pediatric provider released their medical records to them and helped them to

J, 23: *... practice being able to tell my health history. Starting new can be stressful.*

Help with paperwork was seen as a simple way to ease the transition process. Many individuals did not feel prepared to competently navigate all of this information by themselves.

S, 20: *(I) need help to be prepared for all of the paperwork & forms to fill out myself. It can be overwhelming.*

Help getting to appointments was a concern for a few individuals, as was accessing and maintaining appropriate insurance or other financial resources to cover treatment.

K, 22: *Unfortunately, the only time I had amazing doctors was when my parents had a really good insurance plan. Am currently seeing a Nurse Practitioner and have never met the doctor because he is always busy.*

(3) *Improve communication between all parties involved in transition* (14.5%). Eighteen participants highlighted a need for improved communication. For some, this communication was lacking between the pediatric and adult provider.

Z, 24: *It would help if the doctors from pediatrics and the adult center talk to each other so they know what I am taking and what I went through, medically & socially.*

Other responses demonstrated that communication needed to be improved between the patient and their pediatric provider so as to better understand what challenges would occur during the transition. These individuals stated that they would feel better if they knew that communication with the pediatric provider did not need to end entirely following transition.

D, 27: *Knowing there are still people at (pediatric provider) to talk to if I need medical or emotional help/guidance would make things easier.*

Finally, some individuals also mentioned that it would be helpful if adult providers communicated more with their primary caregivers.

E, 22: *(I want) doctors who listen to my mom and for her to hear what they say.*

(4) *Acknowledge the developmental level of the patient and use this to individualize the amount of autonomy granted to the patient* (12.1%). Numerous respondents felt that the pediatric provider, the adult provider, or both, failed to take into consideration their developmental level and competencies when initiating and carrying out the transition process. Participants discussed how the transition from pediatric to adult care led to an assumption that they were prepared to assume responsibility for their own care. These individuals stated that they would have preferred to not be treated as adults immediately, and that physicians had been more sensitive to their developmental competencies.

B, 18: *I am still not all grown up and don't accept/understand all the bad things that can happen because of the disease.*

In order to help circumvent many of the problems that occur when individuals may be "old enough" for transition but developmentally still in need of additional supports, a few participants recommended having programs specifically designed for young adults.

R, 26: *Where I am being treated now, they have an adolescent/young adult program. I have been able to meet others my age.*

(5) *Have adult providers learn skills specific to the treatment of youth with HIV* (11.3%). A lack of perceived competency among adult providers in regards to the specific health and psychosocial needs of HIV-positive adolescents and young adults was often described. Participants felt that

**Table II.** Recommendations for Improving Transition

Recommendation	N	%
1. Increase continuity and quality of care	22	17.7
• Provide more personal/intimate care	17	
• Have patient see same provider/team consistently	5	
2. Provide assistance with the logistical aspects of transition	21	16.9
• Have providers more conveniently located	7	
• Help with paperwork	4	
• Help patient locate adult providers	3	
• Help secure insurance	3	
• Release medical records	2	
• Provide or help locate transportation	1	
• Provide or help to access financial support	1	
3. Improve communication between all parties involved in transition	18	14.5
• Between providers	8	
• Between patient and pediatric provider	3	
• Have pediatrician help patient to learn how to communicate needs to adult provider	3	
• Between patient and adult provider	2	
• Between parent and adult provider	2	
4. Acknowledge the developmental level of the patient and use this to individualize amount of autonomy granted	15	12.1
• Give patients more autonomy while in patient care	7	
• Do not overestimate young adult's capabilities in assuming own care	5	
• Have programs specifically designed for young adults	2	
• Give strict age limit for transition	1	
5. Have adult providers learn skills specific to the treatment of youth with HIV	14	11.3
• Adult providers should be aware of and sensitive to concerns specific to HIV youth	7	
◦ Disclosure issues	4	
◦ Developmental disabilities	2	
◦ Pregnancy and parenting	1	
• Adult providers should have experience with all ages of HIV-infected individuals	4	
• Adult providers should work more closely than parents	3	
6. Provide interdisciplinary service, specifically mental health and case management	12	9.7
• Mental health/socio-emotional support	9	
• Case management and job training	3	
7. Prepare patients for changes in atmosphere at adult settings	12	9.7
• Address changes in atmosphere and population in adult settings	5	
• Discuss behaviors expected of patients by adult providers	5	
• Provide peer support to ease discomfort in adult settings	2	
8. Pediatric providers should encourage transition, not impede it	10	8.1
• Pediatric providers more willing to let go	5	
• Pediatric providers give patients more autonomy while in pediatric care	5	

all doctors who treat persons with HIV should have experience across the developmental continuum.

D, 27: *(It was) difficult finding an HIV specialist that is knowledgeable in pediatric and adult care and all the social stuff that goes along with it.*

Participants felt that the inclusion of primary caregivers in decision-making and treatment planning was critical, especially directly following transition from pediatric care, and particularly with youth with special developmental needs.

E, 22: *They (doctors) need to engage parents for longer and be sensitive to how complicated some of our care has been.*

(6) Provide interdisciplinary services, specifically mental health and case management (9.7%). A number of respondents described a change in the provision of interdisciplinary supports and stated that adult providers often do not address all of the patient's needs—specifically concerns about sexual activity, pregnancy, and issues of disclosure.



J, 29: *(I) needed to have someone to talk to like I had in the pediatric program and that wasn't there. Would have been helpful to have the medical care and the support if I had problems at home, with girls, disclosing, etc.*

(7) *Prepare youth for changes in atmosphere at adult settings* (9.7%). While having more intimate and personal care was mentioned previously as a means of increasing patient comfort, participants also discussed how the atmosphere in adult settings can be jarring and lead to increased anxiety around transition.

D, 27: *Pediatric providers need to prepare their patients that they will not be treated as a kid anymore. Adult providers are not tactful- (one said to me) 'I'm surprised you are not dead'. We are talked to as adults with no special treatment.*

T, 26: *In adult program, as long as you are not sick, you are "not a problem". The care is more hands off. It's a different culture . . . get in, get out.*

In addition to the actual environmental differences, participants described how the population of individuals with HIV infection seeking treatment from adult providers is very different from those seeking treatment from pediatric providers.

B, 30: *The toughest transition was going from "this is no fault of yours" to people who were infected by their own actions and a lot of anger ('my spouse cheated on me').*

(8) *Pediatric providers need to encourage transition rather than impeding it* (8.1%). To ease the transition to adult care, some participants discussed wishing they had been given more responsibility while still in pediatric care, where they could make mistakes, but also learn to build the necessary competencies for self-management of care.

J, 25: *Pediatric providers need to prepare their patients that they will not be treated as a kid anymore and to take more responsibility. Adult docs don't put up with teen stuff. More "tough love" is needed in pediatric/adolescent programs . . . need to toughen us up so kids are not so dependent—not prepared for the real world.*

Participants acknowledged that part of the reason they might not develop said competencies necessary for

transition is due to pediatric provider's lack of willingness to surrender their care to an adult provider.

O, 29: *Pediatric clinics hold the kids so close, they don't even know what their needs are until they get to an adult program and no services exist.*

## Discussion

To our knowledge, this is the first report to examine both the experience of transition from pediatric to adult care and medical outcomes in an HIV cohort several years post-transition. This is critical as potentially serious health consequences can occur when transition is compromised and care is interrupted. In addition, this study looks at the transition process through the eyes of the youth who lived through the experience. This allows for greater insight into needs that can potentially lead to optimal healthcare. Despite living with HIV an average of two decades, children who acquired HIV in the 1970s and 1980s are relatively healthy but not without medical and psychosocial challenges. Almost a third of this sample has been hospitalized over the past 3 years demonstrating that close medical and psychiatric monitoring is vital. Almost a quarter of the participants over the age of 18 are not working or in school. This finding suggests that preparation for transition should include an assessment of vocational needs, educational plans, encouragement of work experiences, and a vision for future employment along with life skills training. As many children born with HIV early in the epidemic were not expected to survive to adulthood, becoming academically or emotionally prepared for independent living or independent decision-making was not a priority for most primary caregivers or providers. With the advent of highly active antiretroviral therapy (HAART), survival is now expected. The need to help these youth "catch up" academically and emotionally by reducing dependence on their families has become necessary for day-to-day living as well as for transitioning care (Battles & Wiener, 2002). This theme was highlighted by participants who reported difficulty with relaying their own medical history, their expressed desire to keep their primary caregivers involved in their care, and reluctance by either primary caregivers or pediatricians to give up control of their healthcare.

The interplay between HIV and psychiatric symptomatology also contributes to the complexity of the transition process. Twenty-nine percent of those hospitalized were admitted for psychiatric reasons, and a third of participants that transitioned to adult care identified a lack of emotional

support services. With almost 10% of the total cohort reporting having had a psychiatric hospitalization over the past 3 years, and the high use of concurrent psychotropic medications, the availability of mental healthcare appears to be a critical component to a successful transition. Furthermore, once HIV treatment is initiated, anticipating and monitoring psychotropic–antiretroviral drug interactions require special expertise (Ferrando, 2009).

In addition to addressing mental health issues, approximately a quarter of the youth interviewed stated that adult providers seemed to have limited understanding of the psychosocial issues of this age group. Adult providers need to address common concerns of young people including sexuality, substance use, and other health promoting and harming behaviors (Rosen et al., 2003). As noted earlier, 15% of this cohort has biological children of his or her own. While it is encouraging that all of the children born are HIV negative, these were unplanned pregnancies and safe sex was not practiced. The need to incorporate secondary prevention messages into primary care for this population is crucial. If these youth become disengaged from the healthcare system, or have an adult provider with whom they are not comfortable discussing issues associated with sexual behavior, the opportunities to provide prevention messages and to achieve prevention goals are lost, an alarming situation given the public health implications of potential transmission of a multi-drug resistant virus by heavily treatment-experienced youth (Rice, Batterham & Rotheram-Borus, 2006; Wiener, Battles, & Wood, 2007).

In terms of disease parameters, a trend was found toward lowered CD4 counts for participants who transitioned to adult care. While one could anticipate that CD4s might decline with age and with duration of therapy, this finding is most probably associated with poor adherence as 44% of these youth reporting challenges with adhering to a medication schedule. Persons living with HIV who do not maintain consistently high levels of adherence to HAART regimens may experience therapeutic failure and deterioration of health status as well as develop multi-drug resistant HIV that can be transmitted to others. Poor medication adherence can occur when youth prematurely assume responsibility for their care (Naar-King et al., 2008). Drug palatability, drug side effects including body changes in fat distribution, disclosure issues, peer relationships, difficult social conditions, substance use, psychological distress, depression, complications with day-to-day routines, and family perception of the value of the medication regimen also potentially negatively impact adherence (Bryne et al., 2002; Murphy et al., 2003). With fewer medical appointments and less personal “engagement” in the

adult setting, it is not surprising that adherence challenges were reported. In order to maximize adherence during the transition process, strategies are needed that consider young adults’ cognitive capacities, emotional maturity, reduced dependence on adult caregivers for supervision and administration of medications, and personal beliefs about the long-term effects of HAART.

The qualitative results of the study demonstrated that many of the barriers to successful transition that were identified in the literature for youth with chronic illnesses were also prevalent in the voices of youth with HIV; however, some important differences exist. The first consists of a perceived change in stigma upon transitioning to adult care. The adult care setting typically has a more diverse client base including persons who typically acquired their HIV infection behaviorally rather than vertically. Newly transitioning young adults would benefit from being prepared for coming into contact with people whose age, sexual orientation, mode of transmission, and severity of illness may be different from their own.

How the barriers to transition are conceptualized also differs. A useful addendum to these findings are provided by Reiss et al., (2005), who separate barriers to transition into systemic and relational barriers. Systemic barriers are those occurring in the healthcare system such as difficulty in securing health insurance and funding, availability of care, and practice differences. Relational barriers are those occurring within the relationships formed between the patient, caregiver, and provider(s) and include communication failure, changes in family involvement, attachment of pediatric providers, and resistance from primary caregivers and youth. In this study, three of the four most frequently endorsed barriers are relational in nature: the need for more personal and consistent care, improved communication, and consideration of developmental level. Subsumed within the relational barriers is the willingness of the pediatric provider to let go.

There are a number of reasons why relational barriers may be particularly salient to this population. The number of youth whose biological parents are deceased is unique to this population. Anxiety may be associated with having to break ties with providers with whom these youth have had close relationships and who may have known their parents before their death, which may compromise a successful transition. One young woman who lost her mother while under care in the pediatric program shared, “*it (leaving the program) was like losing another member of a family. I couldn’t just comfortably connect to someone new.*” The need to anticipate and work through this loss is an identified gap in the transition process. Furthermore, a new medical environment brings the expectation of new

relationships and the challenge of learning to trust all over again. Young adults also may be reluctant to confide in a new provider, fearing that the provider may disclose information to their primary caregivers or condemn their behaviors (Feldman-Winter & McAbee, 2002; Michaud, Suris, & Ciner, 2004). Such challenges must be overcome, as the development of a trusting and respectful relationship is critical for health management (Michaud et al., 2004). A coordinated approach, where communication between pediatric and adult providers takes place prior to and, if clinically indicated, after the transition takes place, can reduce the sense of loss and a feeling of abandonment. As almost a third of participants reported not being able to find emotional support services at home, having an individual maintain contact for several months after leaving the pediatric program, if feasible, may also reduce the anxiety and sense of loss.

The results of this study suggest that achieving transition readiness requires a proactive and developmental approach. Adolescence and young adulthood is marked by pervasive change and transitioning to adult care ideally takes place during a stable time when these young adults are chronologically, behaviorally, and psychologically ready (Michaud et al., 2004). To help youth navigate the adult healthcare setting, it is vital for them to be both permitted and encouraged to take an increasingly more active role in their healthcare (Reiss & Gibson, 2002). Early in adolescence, part of the office visit could be spent alone with the provider so an accurate assessment can be made of the youth's strengths, maturity, and knowledge of his or her health status and of sexual risk. Remembering past medical history and all the medications the youth may have received can be overwhelming so creating a healthcare summary document that includes their treatment summary, toxicities, allergies, hospitalizations, as well as relevant social and family history with the pediatric provider can empower the youth with knowledge about himself or herself. Psychologically, this becomes an important, useful, and symbolic "transitional object" from pediatric care to adult services as it can later be updated with the adult provider. As participants reported resenting the amount of time it takes to review their history and complete forms, this document can also help reduce the reassessment time across providers.

This study has several limitations including the brief telephone survey design. While telephone interviewing has a number of advantages over face-to-face interviewing, such as providing a focused, time sparing, and convenient way to obtain data from a geographically dispersed sample, the data only includes patient self-report, which is subject to recall bias. In particular, the self-reported CD4 counts are

not as reliable as the pretransition chart values. Second, we assessed adherence via self-report, as employing objective measures to validate adherence was not feasible. Therefore, the results should be viewed with some caution. Third, participant confirmation of qualitative results was not obtained; that is, answers were not sent back to the participants to ensure accurate understanding and interpretation of the comments provided. This presents some concern regarding examiner bias. While the division of interviewing, transcribing, and coding responsibilities prevented overlap between the researcher asking the question and the researcher interpreting it, future studies should not neglect this step of returning the results to the participants to ensure accuracy. Fourth, as this was a brief descriptive study of the transition process, we were not able to employ measures to assess mental health status or family environment and therefore could not address other potential predictors or indicators that can potentially influence the experience of transition. We were also restricted to conducting interviews only with participants' ages 18 and older. Future studies should include the concerns and thoughts of younger participants anticipating the transition process, the experience of youth whose transition timing is not based on a program closure, and those who do not need to travel great distances to obtain care. Fifth, is the single-institution setting. While the good response rate reduces the concern for selection bias, a more demographically representative sample of perinatally HIV-infected adolescents can help determine the extent to which our findings are generalizable to all youth seen in pediatric HIV programs. Lastly, the intention of this study was to learn about the experiences of those youth who have transitioned out of pediatric care. The data do not answer the question of how long the transition preparation should take or the best age to introduce or make the change, but rather highlights what the participants found most challenging and the importance for further work to be conducted on this topic. Future studies should consider determining an operational definition of a "successful" transition and may benefit from including the healthcare provider and family perspective to more accurately identify factors that can result in a successful and sustained transition to adult care.

The data obtained during this study provides clear insights into the concerns of youth living with HIV surrounding the transfer of care from pediatric to adult HIV oriented medicine. Some of these findings have been reported with other chronic illnesses, although the stigma, high percent of parent loss, and issues surrounding disease transmission are factors that make transition for these youth particularly complex. It is the role of the

pediatric provider to assess readiness, help foster autonomy, and ensure that a care provider is identified and records are transferred prior to transition. It is the role of the adult provider to recognize that a successful transition will require care that is as personal and flexible as possible, addresses mental health and specialty care needs, considers the youth's strengths as well as the losses already experienced, and is consistent. Most importantly, a commitment to the merit of transition planning by providers on both the pediatric and adult teams is of fundamental importance.

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