AIDS PATIENT CARE and STDs
Volume 27, Number 12, 2013

DOI: 10.1089/apc.2013.0253

Easing the Transition of HIV-Infected Adolescents to Adult Care

Joseph S. Cervia, MD, MBA, FACP, FAAP, FIDSA, AAHIVS

Abstract

The past two decades have witnessed dramatic reductions in HIV-related morbidity and mortality following the introduction of combination antiretroviral therapy (cART) for infants and children. Improved therapeutic outcomes have changed the face of the HIV epidemic and with it the needs of patients and families. Consequently, many perinatally- and behaviorally-infected adolescents are now transitioning to adult care. What follows is a brief review and commentary concerning original research, reviews, and clinical guidelines describing challenges and best practices in facilitating care transitions for HIV-infected youth to adult care. Over 25,000 HIV-infected US youth aged 13–24 years will require transition to adult care within the next decade. Transition planning must address issues of cognitive development and mental health, medication adherence, sexuality, reproductive, and gender identity, socioeconomic and health insurance status, stigma and disclosure, disrupted relationships with pediatric care providers, and communication. Clinical experience with HIV and other chronic illnesses supports a multidisciplinary, developmentally-sensitive approach to meeting the challenges inherent in care transition that begins early and is monitored with regular evaluation and revision. Specific clinical recommendations have been made by the U.S. Department of Health and Human Services and the New York State Department of Health AIDS Institute.

Introduction

Improved therapeutic outcomes with combination antiretroviral therapy (cART) have changed the face of the HIV epidemic and with it the needs of young patients and families.[1] As a result, many perinatally- and behaviorally-infected adolescents are now transitioning to adult care. This review is intended to describe some of the challenges faced by HIV-infected youth in transitioning to adult care, and to discuss some of the elements of family-centered, youth-friendly, multidisciplinary primary care with integrated HIV subspecialty services, and how such models of care may ease some of these transitional challenges.

Case Study 1: Tanisha

Tanisha is a 22-year-old perinatally HIV-infected woman, who has been a patient in your Pediatric and Adolescent HIV Clinic since birth. She attends clinic alone since the death 2 years ago of her maternal aunt and guardian. Tanisha has had experience taking numerous antiretroviral agents, at times with incomplete adherence; however, she has had undetectable viral loads for the past 12 months on tenofovir, emtricitabine, and ritonavir-boosted atazanavir, with CD4+ over 300 cells/μL. Your team has been working with Tanisha on a planned transition to the Adult HIV Center for the past 4 years, although she has expressed much distress at having to ultimately leave your care. Tanisha has been making steady progress, and demonstrates an understanding of her illness. She makes appointments with the assistance of her social worker, though she frequently misses appointments without calling or arrives late.

Last year, Tanisha was treated for genital gonorrhea and chlamydia. She admits occasional use of marijuana and alcohol, and has been treated for depression and anxiety by your team's child psychiatrist with daily escitalopram and alprazolam as needed with a favorable response.

Tanisha confides that her last menstrual period was 10 weeks ago, and a pregnancy test is positive. How might this development affect the transition plan?

Background

In the AIDS Clinical Trails Group (ACTG) 076 Study, pregnant women with mildly symptomatic HIV disease and no prior treatment with antiretroviral drugs during the

Department of Medicine and Pediatrics, Hofstra-North Shore LIJ School of Medicine, Manhasset, New York.

pregnancy, who received a regimen consisting of zidovudine given antepartum and intra-partum to the mother, and postpartum to the newborn for 6 weeks reduced the risk of maternal–infant HIV transmission by approximately two thirds, from 25.5% to 8.3%.[2] Since that seminal study and others demonstrating the safety and effectiveness of other cART regimens, perinatal HIV infections have decreased from 1000 to 2000 per year in the early 1990s to an estimated 138 per year in 2004, with corresponding declines in AIDS diagnoses.[3]

Nevertheless, as demonstrated by a pivotal long-term outcome study, ACTG 219, the use of cART has markedly reduced mortality among children and adolescents infected with HIV-1.[4] As a result, many perinatally-infected youth are surviving to adulthood and to the joys and challenges of parenthood.

What to do

While continuing to receive primary care in the Pediatric and Adolescent HIV Clinic, Tanisha should be referred to an appropriate OB provider, experienced in the care of pregnant HIV-infected adolescents and young adults. After the birth of her infant, Tanisha and her baby should both be followed for at least 6 weeks at the Pediatric and Adolescent HIV Clinic until the HIV status of infant is known. During this time, both Tanisha and her infant can be followed by her current team, while at the same time Tanisha's care is gradually transitioned to an adult service.

Case Study 2: Dominique

Dominique is a 21-year-old gay man who has been your patient in the Adolescent Clinic since testing positive for HIV after some injection drug use and a high-risk sexual encounter 3 years ago. Although he has remained clinically asymptomatic, with CD4+ lymphocyte counts above 500 cells/μL, and viral loads of 25,000–45,000 copies/mL without commencing antiretroviral therapy, you have counseled him regarding current standards for HIV prevention and antiretroviral therapy. Dominique has not disclosed his sexual orientation or HIV status to his parents and family, and remains very reluctant to do so. While Dominique admits occasional use of marijuana and alcohol, he has been free of injection drug use and consistent in making and keeping appointments over the past 3 years.

Dominique has just been offered an unpaid internship in a studio across the country, and would like to transition his care to an adult provider there when he moves next month. What would you advise?

Background

Currently, in the United States, there are 1.1 million individuals living with HIV/AIDS, and some 50,000 new HIV infections annually. While there have been approximately 40,000 adolescents diagnosed thus far since the start of the epidemic, it is now estimated that 13% of all new infections are occurring in young persons aged 13–24 years. In that age group, male-to-male sexual contact is the leading risk factor for transmission.[5] Thus, there are now approximately 25,000 young people aged 13–24 living with HIV (nearly one-third perinatally infected), who will require transition to adult care within the next decade.

What to do

After discussing the importance of disclosure to his close support network, as well as exploring options for health care coverage in his future home town, Dominque should be referred to an established HIV care program experienced in providing care in the area where he will be relocating. Complete medical records, current treatment requirements, and a comprehensive care plan should be forwarded and reviewed with Dominique's accepting provider well before his planned move.

Special Challenges for Transition in HIV Care

Transition in care is the purposeful, planned movement of children and adolescents with special health care needs from child-centered to adult health care. Across the spectrum of chronic illnesses, there is general agreement that transition programs should be continuous, coordinated, culturally appropriate, compassionate, and family-centered; however, little data exist as to what strategies are most effective.[6]

Many children growing up with HIV infection in the United States have become accustomed to family-centered, child-friendly, multidisciplinary primary care with integrated HIV subspecialty services, offered by teams optimally consisting of pediatricians, pediatric nurse practitioners, nurses, social work case managers, child life therapists, psychologists, nutritionists, chaplains, and other dedicated caregivers. These team members have often developed long-standing and intimate bonds with patients and family members. Ironically, it is the very strength of these bonds, which have been forged by shared struggle against demons such as poverty, social stigmatization, drug use, and often the concurrent illness and death of multiple family members, that may render transitioning all the more painful and difficult. One recently published survey indicated that many adolescents did not know what to expect in a transition to adult care.[7] Young patients sometimes dread having to disclose anew their diagnoses and complex medical and psychosocial histories in unfamiliar, larger, and adult-oriented clinics that ordinarily have not given transitional issues a great deal of systematic attention.[8]

In their state of the art review of this topic, Dowshen and D'Angelo described many of the unique transitional challenges facing HIV-infected youth in the process of care transition as issues related to cognitive development and mental health, medication adherence, sexual, reproductive, and gender identity, socioeconomic and health insurance status, stigma and disclosure, disrupted relationships with pediatric care providers, and communication.[9]

As illustrated by the first case study, higher rates of mental health issues (e.g., anxiety, depression, ADHD, PTSD) are experienced by HIV-infected young people like Tanisha, than by their HIV-negative counterparts. Whereas many pediatric centers have integrated mental health providers on the multidisciplinary care team, some adult care models have fragmented medical and psychosocial services. As a result, providers surveyed have expressed concern that young patients with mental health and substance use issues may be lost to care during transition.[10]

In addition, 50% of perinatally-infected youth report adherence difficulties following transition, citing psychosocial concerns and insurance lapses, as well as depression and substance use.[11] Far from uncommon, substance use histories

such as those of both Tanisha and Dominiqe are a special cause for concern in care transitions. With elaborate support mechanisms often employed in pediatric care centers becoming unavailable in transition, the burden of adherence is shifted. And, whereas high-level (>95%) adherence with cART is often necessary to maintain optimal virological response, the consequences of poor adherence are more severe than for many other chronic conditions.

While the challenges imposed by HIV infection are multidimensional, it remains particularly critical to address HIV as a sexually-transmitted disease. As such, it is important to ensure that lesbian, gay, bisexual, and transgender (LGBT) youth are transitioned to care in compatible programs. Perinatally and behaviorally infected young women like Tanisha have also recommended the integration of pregnancy and parenting education and services in transition planning. Interestingly, although pregnancy presents many of its own challenges to health care transition, 50% of adolescent providers in one study reported that young women who had been pregnant often had easier transitions to adult care later, citing experience working with alternate providers during pregnancy and increased access to insurance coverage.[10]

Indeed, socioeconomic factors and the availability of continuous health insurance coverage prove substantial hurdles for many young people. HIV-infected adolescents and young adults are less likely to have health insurance than other age groups, more likely to experience poverty than their uninfected counterparts, and are more likely to experience delays in accessing an adult provider due to difficulty navigating an insurance referral system. As in the case of Dominique, youth in transition may be more likely to suffer gaps in health coverage and other economic or transportation barriers, resulting in missed visits, viral rebound, and ART-resistance; and may be less likely to access care due to disclosure issues with parental primary health insurance beneficiaries.[12]

Disclosure is particularly problematic given the continued social stigma associated with HIV. Many HIV-infected adolescents and young adults report experiencing rejection, violence, or discrimination. The majority young adults with perinatally-acquired HIV participating in one recent survey have struggled with disclosure of their HIV status in intimate partner relationships.[13] Concerns about stigma and disclosure are prevalent in both perinatally and behaviorally infected youth and among their adolescent providers. This is often an important issue underlying delays in transition as pediatric/adolescent HIV care may be perceived as more likely to afford anonymity.[10]

Fears related to disclosure are often accompanied by the dread of disrupted close relationships with pediatric care providers. Many perinatally-infected youth like Tanisha describe leaving their pediatric care team as similar to the loss of a family member.

Like Dominique, behaviorally-infected youth may experience similar feelings, particularly those who may have disclosed their diagnosis to few others besides the adolescent care team. Compounding the challenges posed by such feelings, pediatric care providers may also have difficulty letting go of their long-term patients.[14]

In the midst of these challenges, HIV care providers, youth living with HIV, and their families all identify communication as a pivotal transition issue. Patient–provider communication regarding transition and expectations for adult care should begin early and include adult providers whenever possible. Communication between pediatric and adult providers may help prevent lapses in effective care, and may spare young patients some of the stress and trauma of recounting every aspect of their often lengthy and involved care histories.[15]

A Way Forward

With few data to guide us, clinical experience with HIV and other chronic illnesses supports a multidisciplinary, developmentally-sensitive approach to meeting the challenges inherent in care transition that begins early and is monitored with regular evaluation and revision. Toward that end, specific clinical recommendations have been made by the U.S. Department of Health and Human Services and the New York State Department of Health AIDS Institute.

U.S. DHHS Recommendations for Promoting Successful Transition

The Panel on Antiretroviral Guidelines for Adults and Adolescents of the U.S. Department of Health and Human Services has offered a series of recommendations to promote successful transitions in care. These include optimizing provider communication between adolescent and adult care settings, and addressing patient and family resistance. The panel also emphasized the importance of prepare youth for life skills development (e.g., appointment management, symptom recognition and reporting, medication management, insurance). Acknowledging geographic and cultural differences, DHHS urged providers to identify an optimal clinical model for a given setting, and to implement ongoing evaluation. The panel encouraged regular multidisciplinary case conferences, including adolescent and adult providers, and the implementation of interventions associated with improved outcomes (e.g., support groups, mental health services, and family planning).[16]

NYS DOH AIDS Institute Guidelines

Guidelines established by the New York State Department of Health AIDS Institute propose an individualized approach, identifying capable and willing adult care providers, ensuring communication between adolescent and adult providers, and beginning the process early. Providers are urged to develop and follow an individualized and flexible transition plan, employing a multidisciplinary transition team, which may include peers who have successfully transitioned to adult care. Such teams, which should be trained in best practices for transitioning, are viewed as best able to address needs comprehensively, including medical, psychosocial, and financial. Importantly, these guidelines promote the critical importance of allowing adolescents to express opinions and to participate actively in the transition process. Some key steps in enhancing this process are discussed below.[17]

Preparing for transition

It is never too early to begin preparing for care transitions. As most transitions in HIV care occur between ages 21–24 years, it is important to develop a transition plan several years prior, and to update it regularly. Pediatric and adolescent providers should ensure that HIV-infected youth understand their illness and its management, as well as the skills needed

to negotiate care in an adult care setting. This includes an assessment of each individual's understanding and skills, as well as individual barriers (e.g., developmental delays, anxiety, PTSD, family or transient living conditions). As preparations progress, it is essential to prepare and discuss a comprehensive medical history with the patient, including previous hospitalizations and allergies that may have occurred in infancy or early childhood.

Developing the transition plan

The best transition planning represents collaboration with the patient and family to develop concrete goals and a reasonable timeline. Optimally, this should begin at least 3 years before the transition, with plans updated regularly. Disclosure should be a primary goal for any adolescents who may not yet know their HIV status, or have communicated it to close family members and friends. Every effort should be made to arrange to have transitioning adolescents meet their new providers well in advance.

Several important differences between perinatally- and behaviorally-infected adolescents should be considered in the development of transition plans. Perinatally-infected youth are more likely to be in advanced stages of HIV disease, with opportunistic infection risk requiring prophylaxis or treatment, more likely to have multi-drug resistant virus, more complex cART histories, and more likely to suffer physical and developmental disabilities. As a result, this group of young people, like Tanisha, are at higher risk of transmitting HIV to offspring and of suboptimal immune response to immunizations. In contrast, behaviorally-infected youth are more likely to be in early stages of HIV disease, with higher CD4+ and fewer opportunistic complications, less likely to manifest cART resistance, and so are able to benefit from simpler cART regimens. In addition, this group suffers fewer physical and developmental delays, less risk of perinatal transmission, and enjoys better response to immunizations.

Education and skills training

Successful transitioning requires that adolescent care teams should ensure that HIV-infected youth understand their illness, and offer training and practice in skills necessary for actively participating in their adult care. This includes knowing when and how to seek care, identify and describe symptoms, schedule appointments, arrive on time, and request necessary prescriptions and refills. In negotiating care within complex, changing, and often confusing payment systems, young people must also understand how to evaluate, select, obtain, and renew health insurance, understand entitlements and how to access them, and actively collaborate with a case manager.

Importance of responsive multidisciplinary care

Referring pediatric providers should identify adult providers and care teams experienced with transitioning HIV-infected adolescents and young adults, who are willing to communicate, collaborate, and accept the patient's health insurance. Ideally, it may be possible for such a provider to divide time between pediatric and adult clinics, and to be part of multidisciplinary teams, who can provide mental health, psychosocial, and gynecological services. Med–Peds trained physicians may be uniquely well suited to lead such multidisciplinary care teams.

Role of the adult care provider

In the interests of facilitating care transitions, adult providers should become knowledgeable about the challenges of transitioning, and how these pertain to individual patients. They would be well advised to meet with patients and family members before the change in care, and communicate with pediatric providers, assigning one staff member as a liaison or point of contact. Adult care settings should have an orientation plan in place, addressing all anticipated needs (e.g., medical, OB/GYN, mental health, substance use, housing, employment, education, insurance, home-based services, transportation). It is also important that all caregivers regularly reassess the ability of individual patients to care for their health, and help to identify and overcome barriers.

When to transition

Optimally, the transition plan should be implemented when the youth demonstrates an understanding of the disease and its management, demonstrates the ability to make and keep appointments, knows when and how to seek medical care for symptoms or emergencies, and is clinically and psychosocially stable. That stated, for young patients like Tanisha, pregnancy poses some unique challenges. Adolescent care providers should have referral agreements with obstetrical services that can provide prenatal care to HIV-infected youth during transition. Since adolescent or pediatric providers may be needed to provide individual support and advocacy for pregnant youth who are unprepared for transition to obstetrical services, it is often the case that these caregivers consider remaining the primary care providers for HIV-infected adolescents during pregnancy.

Successful transitions occur when patients have understood and accepted their illness and are oriented toward future goals, including long-term survival. They must have learned the skills required to negotiate appointments and multiple providers in the adult setting, and achieved independence, assuming responsibility for treatment and decision-making. Pediatric/adolescent and adult care providers must communicate and agree on a comprehensive, individualized plan for each young person. Mental health and psychosocial services should be transitioned simultaneously with medical services, and life skills (e.g., educational, vocational, parenting) must be addressed, ensuring that young patients living and maturing with HIV receive uninterrupted comprehensive health care. When key transitional challenges are addressed in a systematic and comprehensive manner, the vast majority of young people growing to adulthood with HIV express satisfaction with the process.[18]

Author Disclosure Statement

No competing financial interests exist.

References

1. Cervia J. The changing face of HIV infection in children. The PRN Notebook 2004;9:20–27. Available online at: http://www.prn.org/prn_nb_cntnt/pdf/cervia.pdf. Accessed August 7, 2013.

2. Connor EM, Sperling RS, Gelber R, et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. N Engl J Med 1994;331:1173–1180.
3. Pediatric HIV Surveillance (through 2011). http://www.cdc.gov/hiv/library/slideSets/index.html. Accessed August 7, 2013.
4. Gortmaker S, Hughes M, Cervia J, et al. Effect of combination therapy including protease inhibitors on mortality among children and adolescents infected with HIV-1. N Engl J Med 2001;345:1522–1528.
5. HIV Surveillance in Adolescents and Young Adults (through 2011). http://www.cdc.gov/hiv/library/slideSets/index.html. Accessed August 7, 2013.
6. Blum RW, Garrell D, Hodgman CH, et al. Transition from child-centered to adult healthcare systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. J Adolesc Health 1993;14:570–576.
7. Fair CD, Sullivan K, Dizney R. et al. "It's like losing a part of my family": Transition expectations of adolescents living with perinatally acquired HIV and their guardians. AIDS Patient Care STDs 2012;26:423–429.
8. Cervia JS. Transitioning HIV-infected children to adult care. J Pediatr 2007;150:E1.
9. Dowshen N, D'Angelo L. Health care transition for youth living with HIV/AIDS. Pediatrics 2011;128:762–771.
10. Gilliam PP, Ellen JM, Leonard L, et al. Transition of adolescents with HIV to adult care: characteristics and current practices of the Adolescent Trials Network for HIV/AIDS Interventions. J Assoc Nurses AIDS Care 2011; 22:283–294.
11. Weiner LS, Kohrt BA, Battles HB, et al. The HIV experience: Youth identified barriers for transitioning from pediatric to adult care. J Pediatr Psychol 2011;36:141–154.
12. Callahan ST, Cooper WO. Continuity of health insurance coverage among young adults with disabilities. Pediatrics 2007;119:1175–1180.
13. Fair C, Albright J. "Don't tell him you have HIV unless he's 'the one' ": Romantic relationships among adolescents and young adults with perinatal HIV infection. AIDS Patient Care STDs 2012;26:746–754.
14. Vijayan T, Benin AL, Wagner K, et al. We never thought this would happen: Transitioning care of adolescents with perinatally-acquired HIV infection from pediatrics to internal medicine. AIDS Care 2009;21:1222–1229.
15. Tuchman LK, Slap GB, Britto MT. Transition to adult care: Experiences and expectations of adolescents with a chronic illness. Child Care Health Dev 2008;34:557–563.
16. US Department of Health and Human Services, Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. www.aidsinfo.nih.gov/contentfiles/adultandadolescentgl.pdf. Accessed August 7, 2013.
17. Transitioning HIV-infected adolescents into adult care. New York State Department of Health AIDS Institute. www.hivguidelines.org. Accessed August 7, 2013.
18. Bundock H, Fidler S, Clarke S, et al. Crossing the divide: Transition care services for young people with HIV-Their views. AIDS Patient Care STDs 2011;25:465–473.

Address correspondence to:
Joseph S. Cervia, M.D., M.B.A., FACP, FAAP, FIDSA, AAHIVS
Department of Medicine and Pediatrics
Hofstra-North Shore LIJ School of Medicine
400 Community Drive
Manhasset, NY 11030

E-mail: jcervia@nshs.edu