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Transitioning HIV-Infected Youth Into Adult Health Care
COMMITTEE ON PEDIATRIC AIDS
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POLICY STATEMENT

Transitioning HIV-Infected Youth Into Adult Health Care

abstract

FREE

With advances in antiretroviral therapy, most HIV-infected children survive into adulthood. Optimal health care for these youth includes a formal plan for the transition of care from primary and/or subspecialty pediatric/adolescent/family medicine health care providers (medical home) to adult health care provider(s). Successful transition involves the early engagement and participation of the youth and his or her family with the pediatric medical home and adult health care teams in developing a formal plan. Referring providers should have a written policy for the transfer of HIV-infected youth to adult care, which will guide in the development of an individualized plan for each youth. The plan should be introduced to the youth in early adolescence and modified as the youth approaches transition. Assessment of developmental milestones is important to define the readiness of the youth in assuming responsibility for his or her own care before initiating the transfer. Communication among all providers is essential and should include both personal contact and a written medical summary. Progress toward the transition should be tracked and, once completed, should be documented and assessed. *Pediatrics* 2013;132:192–197

INTRODUCTION

In the United States, the prevalence of HIV infection in adolescents and young adults continues to increase as a result of the improved survival of perinatally infected youth as well as those horizontally infected through adult risk behaviors.¹ The Centers for Disease Control and Prevention estimated that in 2009, there were approximately 77 000 HIV-infected youth between 13 and 24 years of age in the United States. Currently, HIV infection is the seventh leading cause of death in this age group. Youths accounted for 12 200 (25.7%) of all new HIV infections in 2010. More than one-half (59.5%) were unaware of their infection, the highest for any age group.²

The rate of new HIV infections is highest in African-American youth, including males who have sex with men (MSM) and females with heterosexual contact. HIV infection rates are sevenfold higher among non-Hispanic African Americans and 2.5-fold higher among Hispanic Americans than among non-Hispanic white Americans.³ AIDS rates nearly doubled from 1997 to 2006 in male subjects between 15 and 19 years of age, largely because of the dramatic increase in HIV infection among MSM from lower socioeconomic classes.⁴ In addition, female subjects between 10 and 14 years of age are at a higher risk of

COMMITTEE ON PEDIATRIC AIDS

KEY WORDS

adolescents, adults, HIV, transition, young adults

ABBREVIATIONS

AAP—American Academy of Pediatrics

ART—antiretroviral treatment

EHR—electronic health record

MSM—males who have sex with men

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The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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infection than similarly aged male subjects.² The disease disproportionately affects minorities and individuals residing in the South and the Northeast regions of the United States. Risk factors include sex with older men, lack of access to HIV prevention services, and lack of perceived personal risk despite frequent anonymous sexual encounters and unprotected anal intercourse. The HIV incidence rate for African-American women is nearly 15 times that of white women and nearly 4 times that of Hispanic/Latina women.⁵ Risk factors among these groups include poverty, stigma, limited access to health care, higher rates of concurrent sexually transmitted infections, and drug use.²

Adolescence is a developmental stage characterized by immature concrete reasoning often manifested by denial of illness, a sense of invulnerability reflected by risk taking, and behaviors that are strongly influenced by peer norms. These characteristics all have a direct negative effect on the ability to adhere to complex medical regimens. With the dramatic improvement in HIV care over the past 3 decades, the infected adolescent and his or her caregivers are now faced with managing a chronic illness. In addition to caring for the physical needs of the HIV-infected adolescent, it is important to recognize and address the psychosocial barriers to optimal health and enable delivery of uninterrupted, high-quality medically and developmentally appropriate health care as the individual transitions from adolescence to adulthood.⁶

The increasing incidence and prevalence of HIV infection affect the nation's youth at an age when individual psychosocial and physical developmental processes are evolving and maturing. Physically, the pubertal growth spurt is associated with hormonal and bodily changes reflected in secondary

sexual characteristics that influence adolescents' long-term self-image and self-esteem. Furthermore, the social environment and responses of peers and significant others have to be constantly integrated into an evolving identity. Among HIV-infected adolescents and young adults, these changes often occur on a background of denial, depression, marginalization and stigmatization, and medical comorbidities associated with HIV infection.⁶ Accompanying psychosocial stressors include parental loss, placement in foster care, poverty, homelessness, unemployment, discrimination, and abuse. HIV-infected youth may have less social support because of stigmatization associated with their infection and/or their sexual orientation. Planning for the transition to adult health care should consider potential cultural differences in different populations of infected youth.

HIV-infected youth consist of 2 distinct populations: those who acquired HIV infection perinatally and those infected horizontally through risk behaviors including consensual or nonconsensual sex. Although the course of the infections in these populations may differ, the challenges faced can be similar, including the stigma of HIV infection and the resulting need for confidentiality, which conflicts with the need for disclosure of their infection status to sexual partners.⁷ Youth with horizontal acquisition of HIV may be reluctant to disclose an abusive relationship or sexual exploitation to parents and authorities. Differences between the clinical and psychosocial presentations of youth with perinatally and horizontally acquired HIV infection influence the acceptance of illness, self-efficacy, and antiretroviral treatment (ART) adherence. Among young MSM, unique stressors include homophobia and discrimination, which can lead to a cascade of adverse outcomes, including homelessness and unemployment,

and directly affect clinical follow-up and adherence to life-saving medications. Adolescents with newly diagnosed infection may present with an opportunistic and/or sexually transmitted infection associated with advanced immunosuppression. The development of individual disease management skills may be essential for adherence to ART and treatment of associated comorbidities. However, these expectations may be incongruous with the developmental stage of the individual newly diagnosed with HIV along with the complex social situations in which these teenagers may find themselves. Many perinatally infected children have survived into adolescence with multiple courses of combination ART not infrequently associated with periods of poor adherence, often reflecting treatment fatigue, leading to viral resistance.⁸ With HIV resistance, therapeutic options become limited, necessitating increasingly more complex treatment regimens. Such regimens can be particularly difficult to implement in treatment-weary adolescents with challenges such as stunted growth, delayed puberty, and physical disabilities arising from earlier complications of perinatal HIV infection or from long-term ART.

Adolescents who have chronic health conditions are often followed up in pediatric or adolescent clinics through adolescence or into young adulthood, although the upper age limit varies. Seamless and successful transition from pediatric- to adult-oriented health care is dependent on these youth acquiring skills to allow them to be responsible for the management of their own health care.⁹⁻¹² In situations in which youth have both a primary care provider (medical home) and a subspecialty HIV care provider, both primary care and HIV care will need to be transitioned to adult providers. This situation could allow for the transition of

primary care and subspecialty care at different times. With good communication and careful planning, this strategy could help smooth the transition and improve retention in care.

HIV-infected youth face many of the same challenges in transitioning to adult health care as do individuals with other chronic health conditions.¹⁰ These include the loss of close and supportive relationships with their individual pediatric/adolescent/family medicine providers. The neurocognitive delay and behavioral problems commonly experienced by HIV-infected youth may pose additional challenges for the adult health care provider.^{6,13,14} The adult care site may not provide the level of support and encouragement to which the youth is accustomed in his or her pediatric medical home. At 1 site, HIV-infected youth aged 17 to 24 years who received care in an adult health clinic had poorer outcomes than did older adults in the same clinic, with lower rates of viral suppression and nearly 4 times the rate of loss to follow-up.¹⁵ However, increases in CD4+ T-lymphocyte counts were similar in the 2 groups. High rates of substance use and mental health problems, difficulties in adjustment, and reduced emotional support may lead to loss to follow-up and disease progression.^{15,16} In addition, in many states, youth who have received public health insurance coverage become ineligible at 18 to 21 years of age, limiting their access to care and medications. Among HIV-infected youth older than 18 years who transitioned from National Institutes of Health clinical research protocols to adult care, 15% reported not having health insurance.¹⁶ Protocols and linkages to care in anticipation of the transition can help avert such consequences.

Several models of transition to adult health care have been proposed, with considerable variability among

institutions and individual providers. This variability is reflected in differences in addressing comprehensive care needs as part of the transition, including medical, psychosocial, and financial aspects of transitioning.^{17–21} In a survey of providers of pediatric HIV care in the United States, 81% had designated a transition coordinator, but few had established policies to define the details of the transition.²² One university-based program elected to begin the process at 23 years of age because of a high failure rate when initiated at 21 years of age.²⁰ Results of this strategy are not yet available. Most models are characterized by flexibility, allowing youth to move back and forth between stages of the transition with the anticipation of completing the process by 25 years of age.

Data are limited regarding the outcomes of HIV-infected youth after transition to adult health care.^{23,24} Fewer than one-half of children with congenital heart disease at 1 large pediatric center successfully transitioned to adult health care.²⁵ Qualitative studies emphasize the importance of an adult-based case manager and mental health providers to assist in the transition as well as an individualized approach to the transition process, including addressing health insurance, alcohol and drug treatment, housing, transportation, education, training, and employment needs.^{16,26} Predictors of a successful transition included good adherence to care²⁴ and effective management of psychiatric comorbidities^{6,27} before transition. Further studies to define the outcome of transition and identify the determinants of a successful transfer of care are urgently needed.

RECOMMENDATIONS

Guidelines for transitioning youth with chronic diseases to adult health care have been published by the Society for Adolescent Health and

Medicine (formerly known as the Society for Adolescent Medicine)²⁸ and the American Academy of Pediatrics (AAP [with endorsement by the American Academy of Family Physicians and the American College of Physicians]).^{10,29} Broad recommendations include the development of a formal, multidisciplinary, transitional program that involves individual youths and their families and the identification of an adult health care provider before the transition. These guidelines provide guidance on care planning and the transfer of medical information. Their conclusions remain widely accepted as a gold standard that can serve as a framework for the transition of HIV-infected youth. However, a national survey of AAP members revealed that pediatricians remain poorly informed about the conclusions of the AAP consensus statement and that most pediatric practices neither initiate transition planning early in adolescence nor offer transition support services.³⁰ Identified gaps included limited personnel and training of staff, limited time and workforce shortages, inadequate reimbursement, and anxiety on the part of treating clinicians, adolescents, and their parents about planning for future health care. Guidelines specific to transitioning HIV-infected youth are also available.^{20,21}

There are 4 major steps in the transition process:

1. The primary and/or subspecialty pediatric, adolescent, or family medicine HIV care team, in collaboration with adult HIV care providers, develops a formal written policy for transition of youth to adult health care. Written supporting documents, such as brochures and Web-based information, can be helpful in implementing the policy. The transition policy should describe the goals and timeline of transition and explain how the practice evaluates this process.

The policy should be shared with all members of the health care team and implemented with appropriate staff training. An important component of the plan is to establish a system, such as a registry, to identify and track youth as they approach and progress through the transition process because these youth may frequently change where they are living.

2. The patient and his or her family should be introduced to the concept of transition to adult health care early in adolescence, well in anticipation of the actual transfer of care. Although opinions differ regarding the appropriate age to first introduce the transition process, early adolescence is generally regarded as the most appropriate time. Many recommend beginning the discussion of transition by 12 years of age or at an appropriate time after the initial diagnosis, if it occurs at an older age.¹⁰ HIV infection status must be fully disclosed to the patient and explained before introducing the plan. Factors to consider in choosing the age to introduce the plan include individual developmental stage and neurocognitive abilities. Providers may use a readiness assessment tool to reveal areas of strength and weakness to which patient education can be focused to achieve self-management. Specific tools are available for downloading from the Internet, such as the New York State guidelines.²¹ It is important to encourage independence through personal ownership and management of health care. Particular attention should be paid to identifying and addressing behavioral, emotional, and mental health problems. In conjunction with the patient and family, the referring provider develops an individualized written

transition plan with realistic goals to delineate the process of transition to adult health care. The plan should emphasize education of all involved parties and empowerment of the HIV-infected youth to assume responsibility for his or her own health care. The plan should anticipate and address challenges that patients, parents, and caregivers encounter during transition, including the loss of an established provider. Patient education during office visits and peer group sessions can reinforce the value of independence and decision-making as part of the transition. The creation of a portable medical summary and an emergency care plan is an important component of the plan.

Ongoing discussions of the transition plan should occur at least annually at subsequent visits, with modification of the plan as appropriate. The health care coverage of the youth should be evaluated regularly to ensure that health care coverage and access to medications remains uninterrupted during the transition. The 2010 Patient Protection and Affordable Care Act health care reform legislation includes provision for children to remain on their parents' insurance until 26 years of age and eliminates insurers' ability to exclude coverage on the basis of preexisting conditions.

3. The actual transition to adult health care is initiated. The age at which this transition is initiated is generally between 18 and 25 years and can be influenced by the upper age at which health care is provided by the referring team and the comfort of the adult health care provider in caring for younger adults. Once a suitable adult HIV medicine provider is identified, a pretransfer visit to meet the adult health care provider can help to

establish a successful long-term relationship. The pediatric, adolescent, or family medicine provider should communicate directly with the adult health care provider and supply appropriate documentation, including a transfer letter; the portable medical summary, and/or electronic health record (EHR), before the initial encounter between the adult health care provider and the patient. The portable medical summary and/or EHR should address all medical and psychosocial needs, including advance directives. Ideally, the youth would be introduced to the adult health care provider personally by the pediatric, adolescent, or family medicine provider, either in the referring or adult clinic. It is likely that most youth will need ongoing support from the pediatric adolescent or family medicine health care team during the process for transition to be successful. This support could consist of periodic contact by a member of the referring health care team, such as a nurse or social worker. A peer support group may assist youth with dealing with anxiety resulting from the transition process.

4. The final step in the transition process is to document the completion of the transition and evaluate the outcome of the process. The referring health care provider should document that the young adult has established his or her care in the adult clinic and should be available to provide ongoing encouragement to maintain the youth in adult health care. The referring team should be available to the adult health care provider to serve as a resource during the immediate posttransfer period. However, once the youth has established ongoing care with the adult health care provider, it is appropriate for the

pediatric, adolescent, or family medicine provider to withdraw from providing care to prevent confusion in the patient and to reinforce the role of the adult health care provider.

CONCLUSIONS

A well-planned transition of HIV-infected youth from pediatric, adolescent, or family medicine clinics, often from a medical home to adult health care, enables them to optimize their ability to assume adult roles and activities. Transition planning should be a standard part of providing health care for all HIV-infected youth. Pediatricians and adolescent and family medicine providers have a pivotal role in facilitating seamless and effective transition at a very vulnerable and anxious time of life for both HIV-infected youth and their families. These essential transitional activities can improve health outcomes for HIV-infected adolescents.

Specific Recommendations

1. Pediatric, adolescent, and family medicine HIV care providers, in collaboration with suitable adult HIV care providers, should develop a formal process for transition of youth to adult health care.
2. The patient and his or her family should be introduced to the concept of transition to adult health care early in adolescence well in anticipation of the actual transfer of care. The youth should be informed of his or her HIV status before initiating the process.
3. There are 4 key steps in the transition process:

- a. The referring provider should develop written policies to define the process of transition of HIV-infected youth to adult health care. The plan should be shared with all pediatric/adolescent or family medicine providers, staff, and patients and their families with appropriate staff training. Written documents, such as brochures and Web-based information, can be helpful in implementing the policy. Providers should establish a system to identify and track youth as they progress through the transition process.
- b. The provider, the youth, and the family should jointly create an individualized transition plan well in anticipation of transition, which should include creation of a portable medical summary and/or EHR and an emergency care plan. Providers may use a readiness assessment tool, and the transition plan should be revised on the basis of these assessments.
- c. Transition to the adult HIV care provider should be initiated with appropriate communication, including a transfer letter and portable medical summary. A pretransfer visit by the patient to meet the adult health care provider can assist in establishing a successful long-term relationship.
- d. Completion of the transition should be documented, and the outcome of the process should

be evaluated. The referring health care team should be available to the adult health care provider to serve as a resource during the immediate posttransfer period.

4. The health care coverage of the youth should be evaluated regularly to ensure that health care coverage and access to medications remains uninterrupted during transition.
5. The transition process should ensure that the youth's health care, educational, vocational, and social service needs are discussed and addressed.

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