



CLINICAL REPORT

Psychosocial Support for Youth Living With HIV

abstract

FREE

This clinical report provides guidance for the pediatrician in addressing the psychosocial needs of adolescents and young adults living with HIV, which can improve linkage to care and adherence to life-saving antiretroviral (ARV) therapy. Recent national case surveillance data for youth (defined here as adolescents and young adults 13 to 24 years of age) revealed that the burden of HIV/AIDS fell most heavily and disproportionately on African American youth, particularly males having sex with males. To effectively increase linkage to care and sustain adherence to therapy, interventions should address the immediate drivers of ARV compliance and also address factors that provide broader social and structural support for HIV-infected adolescents and young adults. Interventions should address psychosocial development, including lack of future orientation, inadequate educational attainment and limited health literacy, failure to focus on the long-term consequences of near-term risk behaviors, and coping ability. Associated challenges are closely linked to the structural environment. Individual case management is essential to linkage to and retention in care, ARV adherence, and management of associated comorbidities. Integrating these skills into pediatric and adolescent HIV practice in a medical home setting is critical, given the alarming increase in new HIV infections in youth in the United States. *Pediatrics* 2014;133:558–562

BACKGROUND

The US government released a National Strategy for HIV/AIDS in 2010, in which 3 common goals were stated: (1) to reduce the number of individuals who become HIV infected; (2) to increase access to care and improve health outcomes in HIV-infected individuals; and (3) to reduce HIV-related health disparities.¹ These goals reflect significant progress in treatment of HIV infection with effective combination antiretroviral therapy (cART). This approach requires an ever-vigilant approach to long-term antiretroviral (ARV) adherence ($\geq 95\%$) for optimal virologic suppression and to offset the emergence of drug-resistant HIV so that future treatment options remain viable. Unfortunately many HIV-positive youth are not consistently linked into or retained in care. Youth who miss clinic appointments are more likely to develop life-threatening opportunistic infections. Poor adherence to cART is also associated with increased secondary HIV transmission.²

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KEY WORDS

HIV, pediatrics, youth, psychosocial support, antiretroviral therapy

ABBREVIATIONS

ARV—antiretroviral
cART—combination antiretroviral therapy
LGBT—lesbian, gay, bisexual, and transgender

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The guidance in this report does 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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Epidemiology

HIV-infected youth consist of 2 distinct populations: those who acquired HIV infection perinatally and those infected horizontally either by transfusion of blood products or by risk behaviors, including sexual activity and intravenous drug use. As of 2010, there were an estimated 10 797 perinatally HIV-infected people in the United States and dependent areas, and 76% of those affected were ≥ 13 years of age at the time of the analysis.³ Recent surveillance data from 2009 and 2010 reveal that youth account for 26% of all new HIV infections in the United States. Nearly 75% and 46% of the 12 200 new HIV infections in youth were attributable to males having sex with males and African American adolescents and young adults, respectively.⁴ Stigma, discrimination,⁵ infrequent condom use, alcohol and drug use, and having sex with older partners⁶ contributed to an even higher risk for acquiring HIV infection, disproportionately affecting minority youth residing in the south and the north-eastern United States. An estimated 60% of individuals were unaware of their underlying HIV infection.⁷

Challenges to ARV Adherence Among HIV-Infected Youth in the United States

Poor adherence to ARV therapy has been documented for both perinatally and horizontally HIV-infected youth. Many children infected with HIV perinatally have survived into their second or third decade of life with cART. However, during adolescence a number of psychological and social factors influence decision-making and create challenges for effective ARV adherence. A retrospective multicenter study of adolescents who acquired HIV perinatally reported that adolescents and young adults had the highest risk for resistance to available ARVs secondary to poor drug adherence.^{8,9} Similar

findings among adolescents and young adults who acquired HIV horizontally are reported, with as few as 24% in 1 study achieving virologic suppression at 3 years after initiation of cART.¹⁰ Such observations reinforce the need to design, implement, and evaluate strategies to increase and sustain adherence to therapy in this group. Interventions must factor the adolescents' stage of development, education level, health literacy and coping ability, and structural environment.¹¹ Factors that have been implicated in poor levels of adherence and ARV efficacy include poverty, inadequate food access,^{12,13} unstable housing,⁸ limited educational attainment, lack of stable employment, substance abuse, denial, stigma, homophobia, and discrimination.¹⁴

HIV Disclosure to Perinatally HIV-Infected Youth

As perinatally HIV-infected children approach adolescence, disclosure of their serostatus becomes essential for personal health maintenance and secondary HIV prevention. The first longitudinal study to examine the impact of disclosure of HIV status on health-related quality of life outcomes documented a median age at disclosure of 11 years. There were no significant changes over time in general health perception, psychological status, physical functioning, social/role functioning, or health care use domains. There was also no significant difference between time trends in quality of life scores before and after disclosure of HIV status, suggesting that diagnostic disclosure to children should not be delayed for fear of a negative impact on quality of life.¹⁵ Disclosure prior to sexual activity is also a public health issue affecting secondary HIV transmission.

Stigma and Disclosure in Horizontally HIV-Infected Youth

Horizontally HIV-infected youth have historically experienced rejection,

violence, and discrimination following disclosure of their HIV status. These experiences reflect prevalent societal stigma toward individuals who have acquired HIV through perceived risk behavior. The detrimental effect of HIV stigma on youth is often reported as more significant than the disease itself⁹ and negatively impacts ARV adherence. In one study, individuals who have HIV who reported high levels of HIV stigma were 3 times more likely to report problems with adherence.⁸ In contrast, when youth reported high levels of satisfaction with health care providers, this ameliorated the negative impact of stigma on adherence to treatment.¹⁶

Children and Youth Who Are in Foster Care or Homeless

Children who have HIV infection are often placed in foster care. Provision of medical services, including hospitalization, can be initially complicated by limited acquisition and communication of medical information. Eliminating barriers to sharing confidential information between medical providers, mental health case managers, and the foster care agency can improve care of the child or adolescent living with HIV.¹⁷ Institutional confidentiality and privacy policies guiding the care of HIV-infected youth should be developed.¹⁸ Samples of confidentiality policies can be found in *Bright Futures*.¹⁹ A complete medical history may be unavailable at the initial visit, and physicians must be prepared to document the circumstances surrounding the unavailability of previous medical records and provide service with limited knowledge of the youth's family, past medical or ARV history, or immunization status.²⁰

Studies indicate that youth aging out of foster care at 18 years of age and those who are lesbian, gay, bisexual, and transgender (LGBT) are especially susceptible to homelessness.²¹ The former, particularly minority youth,

have limited experience in independent living and lack the financial and social supports required to become independent.^{22,23} Many are at increased risk for sexual victimization, school dropout, substance abuse, and mental health comorbidities. Homeless adolescents and young adults frequently engage in prostitution in exchange for money, food, or shelter. The literature estimates that nightly in the United States, homeless youth can number between 1.6 and 2 million, including those living in shelters, on the streets, or in other temporary accommodations. Significantly, LGBT youth account for 20% to 40% of all homeless youth in the United States^{24–26} and are 6 to 12 times more likely to become HIV infected than other youth.²⁷ Homeless youth are 7 times as likely to die from AIDS and 16 times as likely to have HIV infection diagnosed as the general youth population.²⁶ These youth experience high rates of trauma and abuse before and during their experience of homelessness. Violence is reported in many forms, including physical (50%–82%), sexual (26%–39%), and family abuse (50%).²⁸

Acceptance of an HIV Diagnosis and Self-Disclosure to Others

Studies have revealed that youth who have chronic and/or terminal illness experience similar difficulty adjusting to their diagnosis, predominantly with medical management.^{29–32} However, HIV-infected youth have the unique difficulty of also living with stigma, which can interfere with their ability to adjust and cope.^{33,34} Significant stressors include acceptance of their diagnosis and rejection by others following disclosure.³⁵ Many fail to keep their medical appointments and present much later with opportunistic infections.

Schooling

Graduating from school is a major milestone for all youth. Youth living

with HIV infection are most concerned about disclosure to peers causing HIV stigmatization and adversely impacting social functioning. Youth living with HIV infection report changing grades after being given their diagnosis, with some ultimately dropping out of school. Like many youth who have chronic disease, HIV-infected youth in school have the added stress of skipping classes for medical appointments, which can negatively affect their grades.³⁵

THE RESPONSE TO IDENTIFIED PSYCHOSOCIAL NEEDS

1. Youth-Friendly Services

HIV Disclosure, Confidentiality, and Stigma

- (a) Confidentiality and privacy policies should be implemented. Given that homophobia, discrimination, and violence often affect HIV-positive LGBT adolescents and young adults, better outcomes are reported in health care settings where there are confidentiality and privacy policies that are discussed during enrollment and at subsequent clinic visits.^{18,36,37} Standard forms for and policies on confidentiality as well as policies on privacy for youth are available and can be modified as state or local jurisdictions legally permit.³⁸
- (b) HIV stigma should be addressed within a developmentally appropriate unit offering comprehensive medical services like a medical home,¹⁶ with patients engaged in trusting relationships with health care providers and being kept well informed of the status of their illness.^{16,39}

Denial and Coping With the Diagnosis of HIV Infection

- (c) Services should address how youth can cope with their HIV

diagnosis. Infrastructure in the medical home that promotes coping through family, peer groups, and spiritual groups as well as professional involvement can improve adherence to clinic appointments and ARV therapy.¹⁶

Case Management and Multidisciplinary Care in the Medical Home

- (d) The sole provision of medical treatment is not sufficient to engage and retain HIV-infected youth in care. Service models that include consideration of gender, race and ethnicity, developmental stage, mental health, family composition, peer reference groups and relationships, economic resources, sexuality, and sexual behaviors are more likely to improve outcomes.⁴⁰
- (e) Effective medical treatment should be inclusive of flexible scheduling and a multidisciplinary team approach that includes aggressive case management and care coordination.^{41,42}
- (f) Patients should be assigned to a physician-led medical home team that can regularly provide all of the medical services and continuity of care.⁴¹
- (g) Medical care services should facilitate prompt access to mental health services.
- (h) Regular multidisciplinary team meetings should be scheduled to include all providers involved in the patient's care.

2. Structural Program Elements

- (a) Addressing barriers to health care use may assist youth in improving disease self-management. Perceived needs in 1 study of 107 HIV-infected youth included access to mental health services (45%), alcohol and drug treatment (14%), transportation to health care

settings (40%), and housing (47%). Youth who expressed these needs were unable or unwilling to “focus on accessing” HIV comprehensive health care.^{41,43}

- (b) Youth buddies are peer advocates who conduct peer-to-peer counseling. When youth buddies are used as part of the comprehensive medical services team, they can be effective in engaging and retaining youth in care.⁴¹

3. Social Media

Health Insurance Portability and Accountability Act-compliant secure messaging through the Internet, mobile phones, and social media can be used for improving appointment and medication adherence. Almost all adolescents and young adults have used the Internet

and mobile phones in their daily lives.⁴⁴ Ninety-five percent of youth report using the Internet and are avid users of social media, with 90% of 13- to 17-year-olds reporting its use, 80% reporting a current profile on a social network site, and 22% having a Twitter account.^{45–50}

4. Advocacy

Pediatricians should advocate for resources that are necessary to provide optimal care for HIV-infected adolescents and young adults to include social support, rehabilitation, education, and access to basic necessities, including stable housing, without which the best medical care may prove ineffective. Pediatricians can advocate at the community and legislative/public policy levels (<http://www.aap.org/en-us/advocacy-and-policy/Pages/Advocacy-and-Policy.aspx>).

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