Facing Adult Life with HIV
Lori S. Wiener, PhD, DCSW and Emilie Steffen-Smith

Adolescence is a period marked both by experimental behavior and by the development of skills needed for adulthood. For HIV-positive adolescents who were infected at birth or as children, extraordinary stressors complicate this developmental process. These young people confront the same challenges as their childhood and adolescent peers, but they do so in the context of a life-altering and highly stigmatizing disease. This context compounds the young person’s difficulty in making choices about life goals, intimate relationships, and sexual activity.

The physical and medical consequences of HIV itself, concerns about disclosure and transmission, and the impact of loss and stigma all add to the psychosocial stressors these adolescents face. Further, two transitions to adult life are particularly affected by the illness: vocational and other future planning and adjusting to the adult system of medical care.

Mental Health of Youth with HIV

Since the advent of HIV antiviral treatment, survival among HIV-positive children has increased significantly. Along with this increased life expectancy, however, many young people experience emotional and behavioral disorders and psychiatric illnesses. A 2006 review of the literature found high rates of anxiety, depression, and attention deficit hyperactivity disorder in HIV-positive children 4 to 7 years old when compared to rates of these disorders within the general population of children. High rates of depression, in particular, raise medical concerns because of the strong relationship between depression and HIV antiviral treatment nonadherence. A 2004 study suggests that children with HIV are hospitalized for psychiatric reasons more often than HIV-negative children. Leading the reasons for hospitalization were depression, behavior disorders, and suicidal ideation or attempts.

HIV-positive children are also given psychotropic medications more often than HIV-negative children. A recent cross-sectional study at the National Cancer Institute found that over a four-year period, almost half of all HIV-positive pediatric patients were prescribed at least one psychotropic medication (often antidepressants or stimulants), a number much higher than in the general population.

Physical Effects and Their Psychological Impact

HIV disease causes particular psychological and social stressors as children enter adolescence. Commonly, new physical symptoms present, medication regimens lose effectiveness, and sustaining medication adherence and medical appointment schedules becomes more challenging. For most adolescents, the clinical course of HIV infection follows the adult course, but the impact of changes on body image and social interactions can be heightened. Many of these teens are smaller in stature than their peers and they often struggle with lipodystrophy, recurrent thrush, and herpes. In addition, HIV-positive young people often experience pain from abdominal distress, muscular swelling, and headaches, as well as from invasive procedures, medication side effects, and opportunistic infections. These physical problems—and an adolescent’s emotional reactions to them—can lead to actual or feared rejection from peers, resulting in social isolation.

Adolescents must navigate the same maze of illnesses, medications, and medical treatments as adults, but for teens this process can be especially grueling. They often experience conflicts between adherence to a specific plan of care and other competing demands. Among these competing demands are the desire to keep their HIV status secret, pressure to keep
Recently, I’ve read in several places that “half of all new HIV infections in the United States occur among youth.” It’s easy to think of reasons why this statement might be true. Adolescence is a time of experimentation—with sex, sexuality, drugs, and identity—and the developmental appropriateness of adolescents’ experimentation does not shield them from risk.

But when we dig a little deeper, questions emerge. First, is the statistic accurate? As Jennifer Galbraith of the Centers for Disease Control and Prevention writes in this issue, recently published data suggest that youth may actually represent closer to 15 to 30 percent of new HIV infections.

Second, what age range defines “youth”? Statistics often lump 13-year-old teens in with adults in their twenties. Does a ninth grader share the same prevention concerns as a young adult?

Third, are all youth equally at risk? As Galbraith reminds us, young men who have sex with men and young Black women who have sex with men account for most new cases of HIV among young people. Her report suggests that in these subpopulations, HIV incidence is indeed at very high levels.

Lori Wiener and Emilie Steffen-Smith’s article also highlights a significant population of HIV-positive youth: young people who were infected perinatally. In the United States and other developed nations, the miracle of prenatal testing and HIV antiviral treatment has nearly eliminated mother-to-child transmission, although UNICEF estimates 1,800 children are infected each day worldwide.

In this country, pediatric HIV providers often have the gratifying task of providing care to perinatally infected youth who are now reaching adulthood. But even this happy fact masks a more complex reality. Because many youth with HIV were not expected to survive past childhood, their families and providers have not always prepared them for the choices they now face: about having sex as HIV-positive people, their educations and vocations, and transitioning to the adult medical system. Rather than offering easy conclusions, both articles in this issue challenge providers to look beyond the headlines to focus on the specific prevention and care needs of the youth they serve.

### References


### Responding to the Impact of Physical Effects

Providers should be alert to physical and neurological effects and an adolescent’s emotional response to these effects. They can assess both the client’s cognitive development (including an adolescent’s level of understanding about his or her illness) and his or her psychological distress. In particular, providers should listen for personal crises such as a family fight, a breakup with a girlfriend or boyfriend, problems in school, and HIV-related body changes. Each of these situations can undermine psychological well-being and health-affirming behaviors, such as medication adherence.

Providers may find that many adolescents respond better to expressive techniques, such as art therapy and journal writing, than to more traditional “talk therapies.” Even medically stable adolescents may experience concerns about future health that increase anxiety and impair psychological adjustment. These concerns can also thwart relationships when adolescents avoid disclosure and feel isolated or do disclose and are rejected.
Disclosing HIV Status to and by Young People

In 1999, the American Academy of Pediatrics recommended that a child be told his or her HIV status as soon as such disclosure was appropriate—taking into consideration the child’s cognitive ability, developmental stage, clinical status, and social circumstances. A recent review of the literature, however, was unable to offer clear direction on proper timing of disclosure. While most parents disclose HIV-positive status to their children when they reach the age of 10 or 11, only one study has examined whether disclosure prior to adolescence is optimal. In this study, researchers found no relationship between age of disclosure and psychological adjustment, social support, or the adolescent’s own decision to disclose his or her HIV status to others.

Studies have found that adolescents who disclose tend to have fewer symptoms of posttraumatic stress disorder (PTSD), perceive themselves as more competent, and report a greater likelihood of disclosure to romantic and sexual partners. It is unclear whether these outcomes are due to disclosure or whether young people who have PTSD or perceive themselves as less competent are simply less likely to disclose. Providers can use their clinical understanding of the young person’s developmental stage, cognitive functioning, and emotional readiness to help the adolescent weigh the value of disclosure against the potential for rejection and other negative outcomes.

Sexuality and HIV

Dating and sexual exploration are important elements in adolescent development. Adolescents infected as children have similar rates of sexual behavior and substance use as their HIV-negative peers. For the HIV-positive teen, the process of integrating sexuality into his or her identity can add considerable stress to an already turbulent developmental stage of life.

Providers, including those in medical settings, are in a unique position to listen, educate, and help these adolescents make thoughtful decisions about their sexual activity. Even sexually experienced adolescents often have significant gaps in knowledge about their own bodies and sexuality. Non-judgmental listening can reduce adolescents’ feelings of embarrassment and lead them to share anxieties about their bodies and sexuality that they may be withholding from family members. Neutrality is particularly important for these adolescents, who already face stigma because they are HIV-positive.

Once a trusting therapeutic alliance is established, providers can talk with adolescents about preventing HIV transmission and pregnancy. Today, providers can communicate a sense of optimism to these clients regarding both their medical prognosis as HIV-positive people and the future option of becoming parents themselves.

Family members also need support around an HIV-positive adolescent’s developing sexuality. Some parents are unaware of—or opposed to—their child’s sexual activity and, therefore, feel it is unnecessary to discuss issues of partner disclosure and transmission risk. Providers can encourage and even facilitate open communication on these topics, thereby reducing parental discomfort, guilt, and shame, and paving the way for future discussions.

Coping with Multiple Losses

Loss and bereavement remain critical psychosocial issues for HIV-positive youth. Many have lost at least one parent to HIV and have outlived HIV-positive peers. Survivor guilt and mourning are compounded by the tremendous stigma still surrounding HIV infection. These young people may feel they cannot openly acknowledge and discuss the death of family members or peers, ultimately intensifying their feelings of anger, guilt, isolation, depression, and low self-esteem.

Young people manifest loss and grief in a variety of ways. Some exhibit classic signs of anxiety, depression, guilt, or complicated grief reactions. Others show diminished academic performance, difficulty in making decisions, or have a general feeling that they are “lost.”

Providers can help adolescents process these losses by assessing the client’s grief reactions, encouraging individual and group discussions, and making referrals to bereavement-related social support. However, many teens either do not have access to or are reluctant to attend traditional support groups. In these cases, providers can work with the young person individually, supporting the adolescent’s sense of humor and life purpose, as well as his or her ability to stay mentally active, as such qualities can offer resilience in the face of loss. In addition, the simple act of helping HIV-positive youth plan for their futures...
can reduce depression and anxiety and encourage healing.

Planning an Adult Life

Children born in the 1980s and early 1990s were not expected to live past childhood. Thus, many of these youth were not prepared to face the challenges of adolescence or the skills necessary for independent adult living.

Little is known about how HIV and its treatment affect a young adult’s vocational preparedness. HIV care providers can begin talking with adolescents upon entering high school about their occupational interests, aptitudes, and limitations, and help them to identify educational and career goals. They can also refer young people to HIV-specific skill-building programs.

One such program, Camp Heartland, offers HIV-positive adolescents the opportunity to discuss a range of young adult issues in a peer support setting. Topics include obtaining insurance, creating résumés, and balancing checkbooks, as well as more complex subjects such as disclosing HIV status and negotiating safer sexual activity. Campers also discuss another important shift in their lives: the transition to the adult system of medical care.6

Transition to Adult Health Care

Between 18 and 23 years of age, young people usually begin seeing adult medical providers. This transition is a critical step in the development of HIV-positive adolescents. The shift is not only medically appropriate; it also contributes to a young person’s sense of independence and allows the satisfaction of being treated as an adult. Some individuals transition to adult care in an uninterrupted manner; others drop out of care and do not return to treatment until a medical problem arises—increasing the likelihood of serious illness and death.

Transition can be difficult for young clients, their families, and their medical providers. Many adolescents have received medical care in the same pediatric clinic throughout childhood and are hesitant to make the change. Families may be reluctant to let go of control over the young person’s medical care, and may create barriers to a successful transition. Providers, too, may be emotionally attached to the young person and ambivalent about the change. This ambivalence can further confuse the young person, who may already be unsure about the transition.

Providers can facilitate the transition by starting to talk about it well in advance—around the time the young person reaches 13 years of age. As adolescents mature, it is important for providers to increasingly include these patients in the decision-making process regarding care and to help them resolve problems that arise. In this way, providers can enhance their patients’ sense of competence and mastery. Providers can also foster a sense of responsibility and self-efficacy in small, simple ways, such as encouraging young people to use calendars for appointments and teaching them how to obtain their prescriptions. These small steps also allow the provider the opportunity to assess and address resistance or barriers to the transition.

Conclusion

A growing number of children born with HIV are actively pursuing dreams and plans that would have been impossible just 10 years ago. Some have already become our teachers, counselors, and health care providers. It is up to providers who care for these young people to recognize and nurture their individual strengths so that they can create loving connections with others and live productive and fulfilling lives.

References


HIV Prevention for Young People: An Epidemiological Review
Jennifer S. Galbraith, PhD

HIV infection continues to be a troubling epidemic in the United States, and its impact on youth persists. New estimates suggest that 15 percent to 30 percent of all HIV cases occur among individuals younger than 25 years, in particular among young men who have sex with men and among young Black women.

This article reviews epidemiological data on HIV and AIDS among young people to help identify the subpopulations most affected and the cofactors likely to lead to infection. This information can aid in determining the best use of resources for HIV prevention approaches delineated by the Centers for Disease Control and Prevention, including HIV counseling, testing, and referral services; prevention activities directed at people at high risk for acquiring or transmitting HIV; and prevention efforts focused on improving the health of people living with HIV and preventing further transmission.

The New Data on Youth
From 2001 through 2004, in the 33 states with long-term, confidential name-based reporting, 17,824 people 13 to 24 years old received a diagnosis of HIV/AIDS, representing 11 percent of people given a diagnosis during these years. Of these, 62 percent were male and 38 percent were female. In addition, approximately 10,000 children who were perinatally infected are entering adolescence, adding to the number of young people living with HIV.

Maria Rangel and colleagues analyzed HIV diagnoses among adolescents and young adults 13 to 24 years old that had been reported to the national HIV/AIDS Reporting System. Five-year trends in HIV diagnoses from 1999 through 2003 from 33 states with long-term, confidential name-based reporting showed that HIV rates were highest among Black youth (63 per 100,000) and youth living in the South (22 per 100,000) and the Northeast (18 per 100,000). Among young women, the number of diagnosed HIV cases decreased from 1,611 cases in 1999 to 1,454 in 2003.

Among young men, the number increased significantly from 1,763 in 1999 to 2,443 in 2003, primarily among young men who have sex with men. Results of one study, conducted in seven participating cities from 1994 to 1998, showed that, among men aged 15 to 22 years who have sex with men, 14 percent of Black and 7 percent of Hispanic men had HIV infection. Sexually active young people are not likely to know their HIV status. They are also more likely than older adults to be recently infected and hence have less time to have an opportunity for testing. Data from the National HIV Behavioral Surveillance system show that of the 18- to 24-year-old men who have sex with men surveyed, 14 percent were HIV-positive, and 79 percent of these participants were unaware of their infection (compared with 70 percent of men 25 to 29 years old and 49 percent of men 30 to 39 years old). Limited interaction with the health care system, the desire to conceal sexual and drug-using behaviors that put them at risk, and the youth-unfriendly design of some clinical settings all may make HIV testing less accessible to young people.

Sex as Key Transmission Category
The two most common transmission modes for young people are heterosexual contact and male-to-male sexual contact. Almost all of the young women in the 35 areas with long-term, confidential name-


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Based HIV reporting (includes 33 states, the U.S. Virgin Islands, and Guam) were infected through heterosexual contact. A variety of factors may place these young women at risk, including inequality in relationships—due to financial dependency or the older age of partners—and lack of knowledge about the activities in which their partners engage. Further, because the cervix is not fully matured, sexually active young women are biologically more susceptible to chlamydia and gonorrhea, placing them at greater risk for HIV infection.

For young men, the most common transmission category was male-to-male sexual contact. Many young men who have sex with men do not disclose their same-sex behavior. Although most studies have not demonstrated increased HIV risk behavior related to nondisclosure, young men who do not disclose their sexual orientation are less likely than men who do disclose to use HIV testing services and to know their status. Men who do not disclose may also be more likely than men who do disclose to have female partners. Further, prevention messages targeting young gay men might not seem relevant to young men who do not identify as such.

**Risk Factors**

HIV infection disproportionately affects young people of minority races and ethnicities. These youth are more likely to face challenges associated with risk for HIV infection, including early age of sexual initiation, multiple partners, higher rates of sexually transmitted infections (STIs), and poverty.

Overall, Black and Hispanic students in grades 9 through 12 are more likely than White students to have ever engaged in sexual intercourse (67.6 percent and 51.0 percent versus 43.0 percent); initiated sexual intercourse before 13 years of age (16.5 percent and 7.3 percent versus 4.0 percent); and had sexual intercourse with four or more persons during their lives (28.2 percent and 15.9 percent versus 11.4 percent). Early sexual behavior and higher numbers of partners are both associated with increased rates of HIV and STIs which increases the chances of contracting HIV. Of the approximately 19 million new STIs that occur in the United States each year, almost half are thought to be among young people 15 to 24 years old.

Poverty is associated with lack of access to high-quality health care and dropping out of school. Out-of-school youth are more likely to become sexually active at younger ages. Further, since most HIV education for youth is conducted in schools, out-of-school youth are less likely to receive HIV prevention messages.

Finally, both casual and chronic substance use are associated with high-risk sexual behaviors in young people. Young people who exchange sex for drugs and money are also at increased risk for HIV infection.

**Implications**

To strengthen HIV prevention for young people, programs must make HIV testing routine and more accessible. For example, program planners should seek to make testing more readily available in locations that are accessible to youth at highest risk, for example, those in adolescent drug treatment programs, juvenile justice facilities, and runaway and homeless youth facilities, and those attending “youth-friendly” health clinics.

A number of behavioral interventions have been rigorously evaluated and have demonstrated efficacy in reducing HIV-related risk behaviors or promoting safer behaviors among young people. The potential impact of successful HIV prevention programs is reduced, in part, because these interventions are not being widely used. Several CDC projects, including Prevention Research Synthesis, Replicating Effective Programs, and Diffusion of Effective Behavioral Interventions, attempt to promote and facilitate widespread utilization of effective programs. Currently, the CDC disseminates four packaged interventions specifically targeting young people at highest risk and is in the process of replicating three of these interventions. The need for packaged efficacious HIV prevention interventions is especially great for young people of color, particularly young men who have sex with men.

Adolescence and young adulthood is a critical time to provide prevention messages, not only because this is a time when people can and do contract HIV, but also because this is a period when people establish patterns of health behavior. If adolescents and young adults adopt healthy behaviors early on, they are more likely to sustain these behaviors throughout adulthood.

**Comments and Submissions**

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rob.marks@ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
Recent Reports

Mental Health of HIV-Positive Children


In their overview article, Lori Wiener and Emilie Steffen-Smith explore the variety of mental health challenges, including anxiety and attention deficit disorders, that children with HIV often face. The two studies below—one from Columbia University and the other from Harvard University, both with samples comprised primarily of Black and Hispanic subjects—further support the conclusion that HIV-positive children often struggle with these mental health conditions as well as with medical and social concerns. The following excerpts were taken from the cited articles and their abstracts:

The Columbia University sample of 47 perinatally infected young people, ages 9 to 16, had very high rates of psychiatric disorders, primarily in the anxiety and behavioral domains.

Investigators recruited subjects and their primary caregivers from a pediatric HIV clinic. They interviewed participants using standardized assessments of youth psychiatric disorders and emotional and behavioral functioning; they also measured caregiver mental health.

According to either the child’s report or the caregiver’s report of the child, 55 percent of young people met criteria for a psychiatric disorder. The most prevalent diagnoses were anxiety disorders (40 percent), attention deficit hyperactivity disorders (21 percent), conduct disorders (13 percent), and oppositional defiant disorders (11 percent). The majority of both children and their caregivers, however, scored in the normative range on the symptom questionnaires measuring emotional and behavioral functioning. Researchers concluded that when symptom checklists are used alone, psychopathology may be underestimated. None of the demographic or child health variables or measures of caregiver mental health was significantly associated with presence of a child psychiatric disorder. However, caregivers experiencing anxiety and depression were significantly more likely to report child behavioral problems.

The Harvard University study, which compared the quality of life of 1,847 perinatally infected HIV-positive children and adolescents with that of 712 HIV-negative young people, found that HIV infection was associated with poorer scores on several quality of life dimensions.

Researchers used quality of life measures to assess subjects in three age cohorts: 6 months to 4 years old, 5 to 11 years old, and 12 to 21 years old (but included no HIV-negative comparison group for this last cohort). All study participants, both HIV-positive and HIV-negative, had HIV-positive mothers. Investigators also evaluated the impact of infection status on quality of life.

Among children in the youngest cohort, HIV infection was associated with significantly worse mean adjusted functional status scores. For children 5 to 11 years old, being HIV-positive was associated with significantly poorer health perceptions, physical resilience, physical functioning, and social/role functioning. The parents of HIV-positive 5- to 11-year-olds also reported lower mean quality of life scores than the parents of HIV-negative children even though it was the HIV-negative 5- to 11-year-olds who reported significantly worse psychological functioning than their HIV-positive counterparts.

Researchers in one small New York study found that 55 percent of HIV-positive participants aged 9 to 16 met criteria for a psychiatric disorder.

Reaching Youth in Poor Communities

In her article, Jennifer Galbraith discusses the association between poverty and HIV risk...
for young people and urges the dissemination of successful behavioral interventions to assist youth most at risk. The study below compared two interventions and a control group among young people living in several low-income housing developments. The following excerpt was adapted from the cited article and its abstract:

A large, randomized, controlled study found that a community-level intervention was more effective at reducing transmission-related risk among adolescents than a skills-building intervention or an educational group.

Researchers recruited adolescents between the ages of 12 and 17 living in 15 low-income housing developments in five U.S. cities. Investigators conducted risk assessments with 1,172 participants at baseline, 865 participants at short-term follow-up, and 763 participants at long-term follow-up. The developments were randomly assigned in equal numbers (five developments) to each of three conditions: experimental community-level intervention; "state of the science" skills-training workshops; and a control group that received a community AIDS education session including an informational videotape and discussion.

The skills-building workshop intervention included two 3-hour workshops on sexual negotiation, condom use, and avoiding unwanted sexual activity. The community-level intervention combined all of these components with follow-up sessions, the participation of community opinion leaders, activities to create social and environmental supports for HIV risk avoidance, and workshops for parents.

At long-term follow-up, 85 percent of the adolescents in the community-level intervention group who had never had intercourse had remained abstinent. This compared with 78 percent in the skills-building workshop developments and 76 percent in the control group developments. Participants who received either the community-level intervention (77 percent) and the skills-building workshop (76 percent) were more likely to use a condom at last intercourse than those in the control group (62 percent).

Substance Use and HIV-Related Risk


As Galbraith notes, substance use is often associated with sexual behaviors that place young people at risk for HIV. The Johns Hopkins University study below clarifies which substances may be most associated with unprotected insertive and receptive anal sex for young men ages 15 to 22. The following excerpt was adapted from the article's abstract:

A large sample of young men in seven cities found that a recent history of alcohol, marijuana, amphetamine, or cocaine use was associated to varying degrees with unprotected anal intercourse. Researchers concluded that prevention messages should be tailored to an individual’s drug of choice.

Researchers interviewed 3,492 young men who have sex with men through the Young Men’s Survey, an anonymous, cross-sectional, multi-site, venue-based survey. The survey ran from 1994 through 1998 at 194 public venues frequented by 15- to 22-year-old men who have sex with men. The majority of young men who have sex with men reported both receptive and insertive anal intercourse, and, of these, approximately half reported not using condoms.

Unprotected receptive anal intercourse at least once in the prior six months was associated with being under the influence of alcohol, cocaine, amphetamines, or marijuana during sex. For instance, the odds of having unprotected insertive anal sex were 1.5 times higher for men who reported amphetamine use than for those who had not reported use (odds for the other substances ranged between 1.2 and 1.6). Unprotected insertive anal intercourse at least once in the prior six months was also associated with being under the influence of these drugs except marijuana. The analysis adjusted for respondent’s demographics (including age, race, city of residence), number of male partners, and HIV status.
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