

YouthLens

on Reproductive Health
and HIV/AIDS

HIV-Infected Youth

HIV-infected youth need age-appropriate prevention, care, and treatment programs.

Young people ages 10 to 24 who are infected with HIV present unique challenges to policymakers, program planners, and health care providers. Approximately 5.4 million young people ages 15 to 24 live with HIV worldwide,¹ and there is likely to be a growing number of infected 10- to 14-year-olds, although data on this group are lacking. Still, some experts believe that the needs of HIV-infected youth often are neglected in favor of approaches that focus on younger children and adults.²

Many young people with HIV contract the infection as adolescents or young adults, most often through sexual contact or injecting drug use. Others have been infected since birth. In the past, these perinatally infected infants often did not survive. However, improved care and treatment, including access to antiretroviral therapy, has enabled many to live into their teenage years and beyond. As the number of HIV-infected youth increases, more programs are needed to provide age-appropriate care and treatment, psychosocial support, reproductive health counseling, and advocacy.

Care and treatment needs

Young people who are infected with HIV when they are adolescents (and diagnosed promptly) are likely to be in a relatively early stage of infection. This makes them good candidates for counseling, health interventions, and behavior change efforts.³ These interventions can address risky sexual

behavior and drug use, the most common ways that youth can infect others.

For HIV-infected infants, new World Health Organization (WHO) guidelines recommend provision of antiretroviral therapy in their first year of life, regardless of clinical or immunological stage.⁴ Treatment approaches based on the guidelines could help perinatally infected youth live longer. But if young people are infected perinatally and are not diagnosed until they begin to suffer from opportunistic infections in adolescence, their chances of long-term survival are diminished.

Early diagnosis and treatment are crucial, but barriers can prevent the testing and treatment of infants exposed to HIV. Fear of stigma and discrimination discourages some HIV-infected women from giving birth in a hospital or clinic, so their babies do not receive tests or drugs that can reduce HIV transmission immediately after birth. Also, the equipment needed for early testing is not universally available.

Several studies support the assertion that perinatally infected infants are not being tested in a timely manner. A 2007 study of HIV infection among 32 symptomatic HIV-infected youth (8 to 19 years old) in Harare, Zimbabwe, found that the median age at which they received their first HIV test was 11. The median delay between contracting their first HIV-related illness and receiving their first HIV test was 3.5 years. All of these youth were





found to be in late stages of HIV infection. The advanced stage of disease in these youth, coupled with a high incidence of parental and sibling mortality, suggest that these young people were probably infected via mother-to-child transmission and had not received appropriate early interventions.⁵

A study was conducted in 2006 among HIV-infected youth ages 10 to 19 attending Jamaica's Kingston Paediatric and Perinatal Programme. Sixty-eight percent had been infected through perinatal transmission, yet many were "slow progressors" who presented with symptoms for the first time in late childhood or early adolescence. Others of those perinatally infected were asymptomatic and were only diagnosed because their parents became ill and were found to be HIV-infected.⁶

Regardless of when they are infected, all young people on antiretroviral therapy must maintain strict dosing regimens. Adherence of greater than 95 percent is needed to achieve the best health outcomes,⁷ but adherence among youth tends to be low. WHO found that 41 percent of service providers surveyed said that adherence to medication was the most pressing challenge for HIV-infected adolescents.⁸ Adolescents may miss taking their drugs because of concern about side effects, the inconvenience of taking so many pills, forgetfulness, or the feeling that medications reinforce the reality of being HIV-infected.⁹ HIV-infected youth need regular counseling to help them adapt to daily pill-taking and cope with side effects.

Psychosocial support needs

The psychosocial needs of HIV-infected youth can be complex, depending on the point at which a young person learns of his or her infection; the progression of the disease; and the young person's age, marital status, and presence or absence of sexual activity. Those who are perinatally infected may be facing not only their own illness, stigma, and isolation, but may also have parents who are ill or who have died. Orphaned adolescents are generally more vulnerable to risky sexual behaviors, have less access to education and health care, and face greater degrees of neglect and abandonment.¹⁰

Questions of disclosure for youth can pose ethical dilemmas for parents (when to tell a child that he or she is HIV infected) and for youth (when to disclose their status to peers and teachers). U.S.-based studies suggest that children who are told their diagnosis have better self-esteem, improved adherence, and better long-term health and emotional well-being.¹¹

In a 2008 worldwide study of psychosocial support interventions for HIV-infected youth, service providers said they considered the most significant problems facing HIV-infected youth to be lack of support networks, difficulty disclosing their status to others, anxiety about having children, isolation, trouble coping with their diagnosis, and stigma and discrimination. In Africa, heading households was mentioned as a concern.¹²

Children who are living with HIV are often treated as "innocents," while adolescents are blamed for risky behavior, which can increase the stigma they face.¹³ A recent book, *Teenagers, HIV, and AIDS: Insights from Youths Living with the Virus*, argues that service providers should not over-emphasize the biomedical aspects of a teenager's HIV infection because psychosocial needs are just as important. Effective health services for HIV-infected youth must be comprehensive and holistic.¹⁴

Recent programs in Uganda are addressing the psychosocial support needs of HIV-infected youth. At the Paediatric Infectious Diseases Clinic and the Adult Infectious Diseases Clinic at Kampala Hospital, a 2003 needs assessment of 100 HIV-infected 10- to 19-year-olds revealed that youth preferred to be treated differently from children and adults. As a result, a peer support group began addressing the psychosocial needs of that age group. Currently, more than 250 adolescents attend peer support meetings twice a month. The emphasis is on living successfully with HIV/AIDS and anticipating productive adult lives.

HIV-infected youth (19 to 24 years) in Uganda also are benefitting from psychosocial support as they transition out of pediatric care. In 2008, the Infectious Diseases Institute launched a weekly

clinic for 480 HIV-positive adolescents moving from pediatric to adult care, with support and involvement from staff at the Paediatric Infectious Diseases Clinic. As of late July 2008, 160 youth had undergone baseline evaluation for enrollment and two youth-friendly clinic sessions had been held. Psychosocial support group meetings began at the end of August. While it is still too early to report results, institute staff say youth appreciate the services, with several expressing a desire to be more involved in developing programs.

Prevention needs

Because they tend to be just as sexually active or curious as other teenagers, HIV-infected youth need counseling about preventing infection of uninfected partners (secondary prevention) and preventing pregnancy.¹⁵ Research reveals significant levels of sexual activity among this group and low levels of condom use. A 2007 study of 29 male and 41 female HIV-infected youth between the ages of 16 and 25 in Thailand found that only 55 percent used condoms consistently at baseline. This number had not increased significantly at a three-month follow-up visit (58 percent).¹⁶ Unintended pregnancy is also a concern for these youth. In 2008, the Population Council and the AIDS Support Organization conducted a survey of 732 perinatally HIV-infected girls and boys 15 to 19 years old in Uganda. Forty-one percent of the sexually active, HIV-positive female adolescents had ever been pregnant.¹⁷

Youth who are not sexually active can be encouraged to delay sex. If youth are already sexually active and wish to remain so, providers should emphasize that they must use condoms to prevent further transmission of HIV but also inform them that there are more effective contraceptive methods. When condoms are used correctly and consistently, they can provide protection against both HIV infection and unintended pregnancy. But as condoms are *typically* used (that is, not correctly or consistently), about one in every eight girls or women will become pregnant.

One strategy is for youth to use two methods: condoms for preventing HIV infection and another method that is more effective at preventing pregnancy. Hormonal contraceptive methods—including oral contraceptives, injectables, and implants—are very effective, easy to use, and safe for young people with HIV or AIDS.¹⁸ The antiretroviral drug ritonavir reduces the effectiveness of some hormonal contraceptives, however, so providers should ask their clients about any medications they are taking. Another key counseling issue is ensuring that adolescents who do use two methods are using both of them consistently. Data are conflicting, but some studies suggest that the more effective a hormonal method is, the less consistently a couple uses condoms.¹⁹ Another option is to counsel youth to use condoms correctly, every time they have sex, as dual protection against HIV and unintended pregnancy but to use emergency contraception, if it is available, as a backup method for pregnancy prevention.

KEY ADVOCACY MESSAGES ABOUT YOUNG PEOPLE LIVING WITH HIV

Stakeholders who attended a global consultation by WHO and UNICEF agreed on the following ways to improve how the health sector responds to young people living with HIV:

1. Young people make important contributions to HIV/AIDS efforts, so their knowledge and experience should be respected.
2. Health workers should be sensitized to the needs and rights of young people living with HIV/AIDS. Service providers need more training in youth-friendly services, and stigma against young people needs to be better addressed.
3. Young people living with HIV need access to a full range of sexual and reproductive health services.
4. Health workers must remember that HIV-infected youth have different needs, including affordable and accessible care and treatment, age-appropriate information, and referrals to other services.
5. Approaches are needed to attract young people to health services and to encourage their continued use of these services. Recommendations include developing and implementing standards, providing a minimum care and treatment package, and training and supporting health care workers to strengthen the provision of services.
6. Stakeholders should improve the data collected on young people, ensure that policies and laws address the specific needs of young people living with HIV, and continue advocating for HIV-positive youth.

Adapted from: World Health Organization, UNICEF. *More Positive Living: Strengthening the Health Sector Response to Young People Living with HIV*. Geneva: World Health Organization, 2008.

Advocacy for HIV-infected youth

Advocates are working to ensure that international health organizations, governments, and health workers are sensitive to the needs of HIV-infected youth. For example, in November 2006, WHO and UNICEF convened a global consultation in Malawi to discuss how the health sector can better provide services to HIV-infected youth. Stakeholders from 18 countries took part, including health workers, youth infected with HIV, and representatives from United Nations agencies and nongovernmental organizations. See the box on key advocacy messages from the conference.²⁰

The Global Youth Coalition on HIV/AIDS, a youth-led network of 4,000 youth and adults, works to address HIV/AIDS in 150 countries. The coalition oversees a network called Living Positively, which has enabled HIV-infected youth to connect internationally and address decision makers on issues important to them. The coalition is also researching the health care needs of youth living with HIV/AIDS through a survey designed by HIV-infected youth. Survey findings will help WHO issue guidelines that will be used at the country level.

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