

YouthLens

on Reproductive Health and HIV/AIDS

HIV-Infected Youth

Youth need medical, psychological, and social support, but programs rarely address their specific needs.

Half of all new HIV infections are among 15- to 24-year-olds, with young women particularly at risk.¹ Youth infected with HIV need not only medical care, but also psychological and social support. Yet, as the number of HIV-infected youth continues to rise, care and support programs rarely address their specific needs, and young women in particular lack access to services.

By the end of 2003, less than 10 percent of all people who needed antiretroviral (ARV) drugs worldwide had access to this treatment.² Efforts to expand access to ARVs, including the “3x5” initiative of the World Health Organization (WHO) and the U.S. President’s Emergency Plan for AIDS Relief, do not specifically allocate funds for treating adolescents or children. However, they could offer opportunities to design programs that meet the broader care and support needs of HIV-infected youth.

Needs of HIV-Infected Youth

The natural course of HIV infection in youth differs from the pattern of progression usually seen in HIV-infected adults. Young people infected after the onset of puberty generally develop symptoms and become ill more slowly than adults. In contrast, children infected at birth who survive into adolescence usually have advanced disease.

HIV-infected youth whose immune systems are not yet compromised enough to require antiretroviral

treatment still benefit from counseling, nutrition interventions, and preventive treatment to help avoid opportunistic infections, which can slow the progression from HIV infection to AIDS and postpone the need for ARVs. Eventually, infected youth will need ARVs, which require strict adherence to dosing regimens to ensure treatment efficacy and to prevent development of viral resistance. Regular treatment counseling is also important to help young people adapt their lifestyles to accommodate daily, often complicated pill-taking schedules and cope with side effects.

In one of the few studies on ARV adherence in young people, among 161 HIV-infected adolescents from 13 U.S. cities, only 41 percent reported taking all their prescribed medications.³ Pilot ARV treatment programs in Cambodia, South Africa, and Uganda have achieved short-term adherence rates of about 90 percent, largely among adult patients.⁴

Even less is known about the psychological and social needs of young people coping with HIV infection. Research from the United States suggests that certain developmental characteristics of adolescents, such as their sense of invulnerability and difficulty in deferring gratification, may present obstacles to acceptance of an HIV diagnosis, adherence to treatment, and use of HIV prevention measures. The process of integrating sexuality into self-identity that occurs during adolescence is





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much more complex for youth living with an infection that can be transmitted sexually.⁵

In a few developing countries, qualitative research has identified challenges for HIV-infected youth, including disclosure, stigma, physical development, and sexuality. Children infected with HIV before puberty experience slower growth than their peers and delayed pubertal development. In Côte d'Ivoire, for example, physical development was a primary concern among 19 HIV-infected adolescents ages 13 to 17 receiving medical and psychological care through the Yopougon Child Programme in Abidjan. Girls who had not reached puberty were unable to participate in traditional rituals and worried that they could never marry or have children. Other girls were preoccupied with avoiding signs of HIV-related disease, such as weight loss, which could signal their serostatus to others. Seven of the 19 young people had parents who were not prepared to tell them that they were infected. Sexual development and sexual feelings were forbidden topics in all the families.⁶

Several qualitative studies describe the challenges facing Brazilian youth infected with HIV. For 12- to 19-year-olds interviewed at four health centers in São Paulo, Brazil, learning that they were HIV-positive represented a dividing marker between life as a “normal” person and a new identity yet to be formed.⁷ Parents and caregivers of the HIV-infected adolescents and children receiving services at two of the centers requested help with such disclosure, fearing that youth could blame parents as the possible source of their infection and could experience discrimination.⁸

In-depth interviews with 22 HIV-infected adolescents ages 13 to 20 receiving care at six different AIDS treatment centers in São Paulo and 13 of their caregivers identified stigma and discrimination as the most important challenges in living with HIV.⁹ The study found gaps in the adolescents' knowledge about sex and condoms. Most of the

youth had dated after learning their HIV serostatus, and five reported being sexually active. However, their caregivers said the young people were not ready to talk about sex and thought initiating such conversations might encourage sexual activity. All 22 adolescents feared discrimination and delayed disclosing or did not tell sexual partners and dates about their HIV infection.¹⁰

Programmatic Challenges

As access to HIV testing expands in many countries, thousands of young people will learn that they are infected with HIV but will have no symptoms. A major programmatic challenge is to keep these youth connected to care and support systems that can meet their needs for emotional support, counseling, and prevention education while monitoring needs for medical care, nutrition interventions, and ARV treatment. Other youth need access to ARVs right away, as well as referrals to related support services. Various strategies are emerging to meet these needs.

In Uganda, Kenya, Haiti, and other countries, voluntary counseling and testing centers are beginning to provide services for youth who test positive for HIV, experimenting with post-test clubs, referral systems, and on-site follow-up counseling. In South Africa, the National Adolescent-Friendly Clinic Initiative (NAFCI) is including ARV treatment and monitoring. Casa Alianza, a nongovernmental organization (NGO) serving homeless children and adolescents in Guatemala, Honduras, Mexico, and Nicaragua, has developed referral networks of adolescent-friendly HIV/AIDS service providers for a growing number of HIV-infected clients. In Tanzania, the Coordinating Committee for Youth Programs, a group of 60 representatives of youth-serving organizations, government ministries, and donors convened and coordinated by YouthNet, is advocating to include youth in new programs providing ARVs in regional and district hospitals and is mobilizing support for youth-friendly HIV/AIDS treatment and care services.

One promising approach to serving HIV-infected youth is family-centered care, which enables members of families who are affected by HIV to receive care at the same clinic on the same day. This makes services more convenient while encouraging disclosure and support within families, and it is also likely to be more cost-effective than serving adults and children separately. Members of the first 82 families enrolled in such a program at the Botswana-Baylor Clinical Centre of Excellence, a collaboration between the Baylor College of Medicine, based in Houston, Texas, USA, the Botswana Ministry of Health (MOH), and the Princess Marina Hospital in Gaborone, Botswana, said they preferred this model of care because it helped them cope together with the challenges of living with HIV/AIDS.¹¹

In October 2004, the Botswana center also established a special program for HIV-infected adolescents, which will offer life skills education and peer education training in addition to the other services the young people receive with their families. This mix of services may prove popular among youth. In other settings, HIV care and support services target youth alone. In Uganda, for example, Mulago Hospital instituted separate HIV services for adolescents at the request of these clients.

The introduction of ARVs at another Baylor-supported service for HIV-infected youth, the Romanian-American Children's Center in Constanta, Romania, has reduced the annual mortality rate from about 15 percent to 3 percent. As a result, many of the children have survived into adolescence. Center staff members have begun to prepare them for adult life by teaching them basic life skills, such as how to do their own laundry and balance a checkbook. The Romanian project is also collaborating with the Romanian MOH, the U.S. Agency for International Development, and seven local NGOs to design a program to improve reproductive health among HIV-infected adolescents and help them avoid transmitting the virus.

A project in Uganda is using a curriculum with 18 individual counseling and skill-building sessions to help HIV-infected youth prevent HIV transmission and improve the quality of their lives. The Ugandan project has added culturally relevant material on disclosure, stigma, nutrition, and reproductive health to a U.S. curriculum called *Choosing Life: Empowerment, Action, Results (CLEAR)*, which has helped reduce risk behaviors among HIV-infected youth in three U.S. cities.¹² *CLEAR* is based on the hypothesis that meeting the various needs of HIV-infected youth and helping them value their own lives will motivate them to protect others. The Uganda Youth Development Link, a local NGO, and the University of California at Los Angeles, which developed the curriculum, are conducting a randomized controlled trial of the adapted curriculum with 100 HIV-infected youth. Self-reported changes in sexual risk behavior, substance abuse, and quality of life will be used to evaluate the intervention and adapt it for broader use, with results expected in 2005.

RESOURCES ON WORKING WITH HIV-INFECTED YOUTH

HIV Counseling and Testing for Youth – A Manual for Providers

This easy-to-use desk-reference tool provides a guide to counseling young clients on HIV testing, prevention, care, and treatment, as well as related services such as contraceptive options and other STIs. Available at: <http://www.fhi.org/en/Youth/YouthNet/Publications/otherpubs.htm>.

Kids to Kids: Medication Dedication

This video featuring six HIV-infected children and adolescents is useful for HIV-infected youth who are starting antiretroviral treatment or are experiencing difficulties with treatment. An accompanying brochure is designed for older children, adolescents, and parents. To obtain a free copy of the video in English or Spanish, e-mail: ncalles@texaschildrenshospital.org.

Primary Care of Adolescents with HIV: Related Resources

This Web site from the University of California at San Francisco, Center for HIV Information includes links to guidelines for ARV treatment and HIV care for adolescents, resources on adolescents and HIV prevention for youth, HIV policy reports and papers, and Web sites for youth about HIV. <http://hivinsite.ucsf.edu/InSite?page=kbr-03-01-15>.

Where Do I Start? Talking to Children with HIV about Their Illness

This booklet for adults who care for children living with HIV offers advice on how to talk about the infection and the levels of information that may be appropriate at different ages, from early childhood to adolescence. Available at: <http://www.bhiva.org/chiva/protocols/supportdocs/talking-with-children.pdf>.

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A review of several U.S. demonstration projects that combine medical treatment for HIV-infected youth with psychosocial support and individual case management by multidisciplinary teams of providers found that they often had to help youth find shelter and food before gaining their trust and interest in HIV testing, treatment, and prevention. These experiences suggest that connecting youth with a support system facilitated treatment adherence and patient retention.¹³

In one of a series of studies on HIV and youth under way in Brazil, most physicians attending advanced HIV training agreed that the MOH should establish targeted services for HIV-infected youth. The Brazilian government offers free antiretroviral treatment to eligible patients, and 1,675 young people ages 10 to 19 were receiving ARVs in 2004. Nevertheless, linking HIV-infected adolescents to HIV care has proved difficult.¹⁴

Offering separate services for large numbers of HIV-infected young people in developing countries heavily affected by HIV may not be feasible because most have not yet been able to provide the minimum level of service to the majority of their HIV-infected citizens, concluded experts at a recent WHO meeting. Meeting participants recommended that countries strengthen existing health services to respond to the needs of HIV-infected youth.¹⁵ WHO is preparing standards for services for HIV-infected young people and training tools for health care workers.

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Note: The XV International AIDS Conference, Bangkok, Thailand, July 11-16, 2004, is cited as "2004 International AIDS Conference."

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