

Youth and HIV: The Epidemic Continues

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HIV INFECTION CONTINUES TO INCREASE AMONG SEXUALLY ACTIVE adolescents and young adults, who account for half of all new HIV infections in the United States and worldwide. However, only a fraction of these young people are actually aware of their HIV serostatus, and an even smaller number have been successfully linked to vital medical care and social services.

It's all about "Gettin' Busy." The medical establishment, Dr. Donna Futterman argues, has much "Gettin' Busy" to do. Now, more than ever, there is a great need to identify at-risk adolescents, to introduce them to counseling and testing as a component of HIV prevention, and to bring HIV-infected young people into care. "Gettin' Busy"—a term that refers to having sex—also has enormous significance in the discourse of young people and it is something teenagers and adolescents are clearly doing. In the process, however, they are engaging in behavior that increases the risk of contracting or spreading sexually transmitted diseases, including HIV.

In order to stem the tide of STDs and new HIV infections among adolescents—and to get those who are already infected into care—it's important to take a look at some of the many epidemiologic, psychosocial, and medical issues that are unique among young people. This article touches on a number of these issues discussed by Dr. Futterman at the October 2002 meeting of the Physicians' Research Network—a lecture that proved to be one of the most inspiring presentations that PRN has ever hosted.

The Epidemiology of HIV in Adolescents

THERE IS NO SHORTAGE OF STATISTICS INDICATING THAT YOUTH CONTINUE to be the most vulnerable group of individuals to HIV infection. Every year, more than 50% of all new infection in both the United States and the rest of the world occur among young people between the ages of 13 and 24. At least two-thirds of young people with HIV contracted the virus sexually and three-quarters of HIV-positive youth are racial and ethnic minorities.

The U.S. Centers for Disease Control (CDC) estimates that 40,000 new cases of HIV transmission occur every year. "If half of these infections are in young people between the ages of 13 and 24," Dr. Futterman said, "we're essentially looking at 20,000 new HIV cases a year among U.S. youth. That comes to two young people infected every hour."

Additional reports estimate that 25% of the 40,000 new infections that occur annually are in adolescents under the age of 22. This is supported by data showing that 19% of AIDS cases in the United States are among young adults in their 20s which, given the 10-year average from the time of HIV infection to the development of reportable AIDS-defining circumstances, suggest that most of these infections likely occurred during adolescence.

The majority of adolescent HIV infections result from sexual transmission of the virus. Most young women are infected through heterosexual sex (75%), whereas many young men between the ages of 13 and 24 are infected through same-sex encounters.

Dr. Futterman also pointed out that with the advent of more effective treatment strategies, there is a growing number of perinatally infected youth who are living to see teenage and young adult years. "There are now young people born fifteen to twenty years ago with HIV who have managed to survive," she commented. "For many of these young people, HIV was considered a death sentence. Indeed, we all thought that pediatric HIV infection was not going to be a long-term survival issue. But these kids are now facing adolescence, and all of the issues that come along with it, such as peer identification, sexuality, the drive for independence, as well as HIV-related issues such as disclosure, planning a future, and dealing with medications." Interestingly, a recent case series reviewed by the CDC has found approximately 20 young people who themselves were born with HIV who have now had children. "So we're potentially talking about a third generation of this epidemic in the United States alone."

The connection between sexually transmitted diseases (STDs) and HIV is well understood by epidemiologists but is underappreciated by many clinicians and youth and is of particular concern when it comes to sexually active adolescents. Of the 12 million cases of STDs reported in the United States each year, approximately 3 million (25%) occur among teenagers. Dr. Futterman also noted that two-thirds of all STDs are acquired by age 25. Of central concern are ulcerative STDs, including syphilis, herpes, and chancroid, and inflammatory STDs, such as gonorrhea, chlamydia, and trichomoniasis—all of which can increase the risk of HIV transmission. "Given the high incidence and prevalence of STDs among young people," commented Dr. Futterman, "it becomes increasingly apparent how significant the risk of HIV infection really is for adolescents."

Understanding the Risk Factors

WHY IS IT THAT AMERICAN YOUNG PEOPLE ARE MORE VULNERABLE TO STDs AND HIV? To help answer this question, Dr. Futterman turned her attention to a 1997 report published by the Institute of Medicine (IOM). This report examined various behavioral, biological, and socioeconomic data—especially those pertaining to young women—that are believed to be associated with greater susceptibility to HIV and other STDs among young people (Institute of Medicine, 1997).

With respect to behavioral factors, there is one central common denominator: young people are having sex. According to the IOM report, between 50% and 70% of adolescents have had sexual intercourse by the time they complete their senior year of high school. A sizeable percentage (16%) of adolescents also report having had more than four sexual partners prior to finishing high school. Only half of adolescents reported using condoms during their last sexual encounter.

In this context, it's also important to consider that some subpopulations of adolescents are at a higher risk for HIV infection than others. As explained by Dr. Futterman, young men who have sex with men (YMSM), transgendered young people, and adolescents who are homeless, runaways, drug users, incarcerated, in the foster care system, or have been physically or sexually abused are of particular concern, giv-

en the greater likelihood of being exposed to the virus in their social networks and the greater likelihood of being isolated from youth-friendly prevention and care.

There are several important biological factors associated with increased vulnerability to HIV infection, particularly among young women. First is the physical development of the cervix during puberty. Over the course of puberty, the single-layer columnar cells, which are more susceptible to various STDs, are replaced by a multi-layered epithelium, which is less susceptible to infection. Second, women are also more likely than men to experience asymptomatic STDs. “Chlamydia can often go unnoticed,” Dr. Futterman said. “So can syphilis, if a chancre forms high up in the vagina. This generally means that women are less likely to come in to the clinic for screening and treatment and, in turn, are at a higher risk for persistent STDs and susceptibility to HIV infection.” Third is the basic fact that HIV and other STDs are more efficiently transmitted from men to women than from women to men. “We see this as a surface-area issue,” Dr. Futterman explained. “In transmission involving women to men, it is believed that HIV enters through the urethral opening, whereas in male-to-female transmission, we’re dealing with a much larger susceptible surface area, including mucosal tissues of the vagina and the cervical epithelium.”

Finally there are socioeconomic factors to consider, with the two most important being poverty and limited access to health care. Dr. Futterman pointed out that teenagers are the least likely to be insured among all age groups in the United States. Children’s health programs have greatly increased young people’s access to health care, but these benefits are typically halted once a child reaches the age of 18 or 19. In turn, adolescents without adequate insurance turn to walk-in clinics and emergency departments for their immediate medical needs—health-care programs that aren’t usually equipped to deal with the long-term support requirements of at-risk young people. “Most young people fall off health insurance if they’re not in college, covered by their employer, or by the age of 21 if they were covered as a child under a parent’s insurance policy,” Dr. Futterman said. “There’s health insurance for young children. There’s health insurance for working adults. There’s health insurance for older people. But adolescents are frequently left out and this prevents many young people from accessing the health-care services they need.”

A lecture unto itself is the lack of sex education that young people so desperately need to make informed, healthy, and empowered decisions regarding sexuality. “The parties in power are now focusing on abstinence-only educational programs,” Dr. Futterman wryly commented. “Abstinence is an important component of STD prevention, but it’s definitely not the only option to discuss.” And there are confidentiality issues to consider as well. “Teenage studies have shown over and over again that young people will not access sensitive health-care services, unless they can be assured of confidentiality and that their parents will not be told. It’s the basic principal of taking care of teenagers, yet many teens

and providers aren’t aware of the fact that their confidentiality is protected by state laws and, as a result, avoid needed health care.”

Race, Gender, and Age

HIV/AIDS IN THE UNITED STATES HAS DISPROPORTIONATELY AFFECTED communities of color, and this is particularly true among teenagers. As is illustrated in Figure 1, African Americans make up 15% of the U.S. population, yet they account for 47% of all AIDS cases. Even more startling are demographic data indicating that roughly two-thirds of 13- to 19-year-olds with AIDS are African American. The proportion of Latinos with AIDS is also higher than their percentage of the population.

The AIDS incidence by gender shows similarity disparities among young people (CDC, 1999). As shown in Figure 2, 24% of all AIDS cases are in women. However, among young adults diagnosed with AIDS between the ages of 20 and 24, women make up 40% of the cases. And among adolescents between the ages of 13 and 19, more than 50% of new AIDS cases are female. As for the incidence of HIV infection among adolescents, there are some data indicating that nearly two-thirds of all new documented cases are women. “However, we may have a reporting bias here,” added Dr. Futterman. “Women, including adolescent women, who are pregnant will be screened for HIV as part of a comprehensive prenatal care program. There are no parallel programs that involve screening young men.”

This is not to say that some frightening numbers do not exist for young men, most notably YMSM. The Young Men’s Survey, sponsored by the CDC, was a cross-sectional survey conducted from 1994 through 1998 (Valleroy, 2000). The surveys were conducted at 194 public venues frequented by young MSM in seven cities (Baltimore, Dallas, Los Angeles, Miami, New York, San Francisco, and Seattle) and a total of 3,492 15- to 22-year-old MSM provided consent to be interviewed and tested for HIV.

The prevalence of HIV infection was high (7.2%) and increased with age, from 0% among 15-year-olds, to 6% among 15- to 19-year olds, to 9.7% among 22-year-olds. Fourteen percent of all young African-American men surveyed were found to be HIV-positive. Most startling were data indicating that 82% of the HIV-positive men surveyed did not know they were infected until they were tested as a part of the study. “Only 15% of the kids in this study were receiving care for HIV,” Dr. Futterman added. “There is a huge population of young men who have sex with men and young HIV-positive men who are not receiving appropriate medical care. This is where the system has failed. We need to find ways to let them know their status and bring them into care.”

Approximately 80% of the young men surveyed reported having anal sex, at least once, with another man. What’s more, 41% reported having unprotected anal sex within six months prior to being interviewed and 61% had reported ever having sex with a woman. “Sex is quite fluid in young men and women,” Dr. Futterman said. “There are a lot of young

Figure 1. AIDS Cases by Race/ Ethnicity

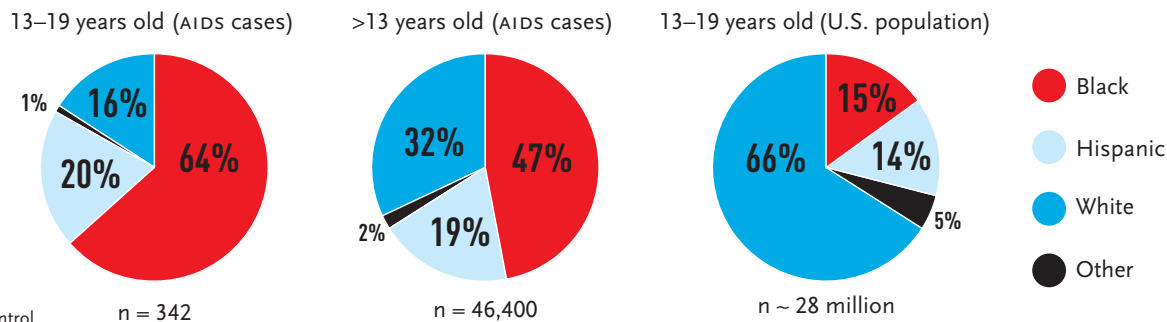
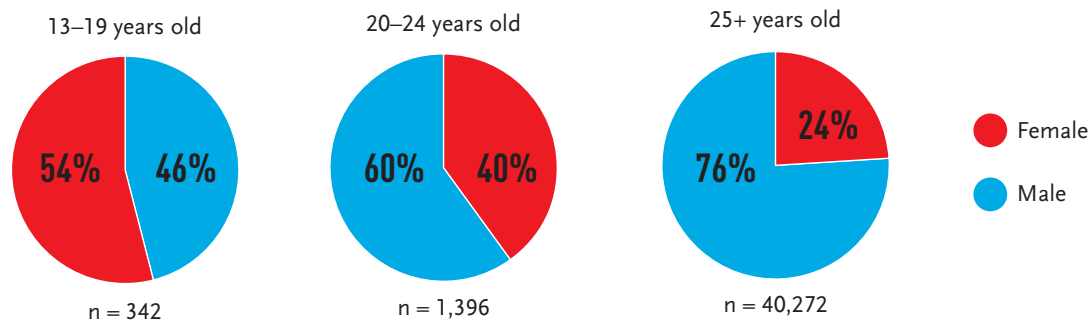


Figure 2. AIDS Cases by Gender



Source: U.S. Centers for Disease Control

men who are having sex with both men and women and a number of young women who say they are lesbians, but are also having sex with men. We're really seeing that identity is not the same as behavior. It's behavior that we really need to be discussing with these young men and women."

Treatment Issues

ALTHOUGH THE CLINICAL COURSE OF HIV INFECTION FOR MOST ADOLESCENTS follows that of adults, distinctive features may exist for adolescents compared with adults and children. Summarizing data from studies conducted over the past five years, Dr. Futterman explained that adolescents likely have residual thymic function, which has led to the hypothesis that HIV-infected young people have a greater potential for immune reconstitution than their adult counterparts. "This is certainly an argument in favor of initiating antiretroviral therapy early in the course of HIV infection in adolescents," Dr. Futterman said. "But the fact is, we often see HIV-positive adolescents who do not enter care until moderate-to-severe immune dysfunction has occurred. Again, it's important to emphasize the need to identify HIV-positive adolescents soon after infection and get them into necessary care."

Standardized treatment recommendations for adolescents—at least in the eyes of the U.S. Department of Health and Human Services (DHHS)—are identical to those for HIV-positive adults (DHHS, 2002). Dosing, however, is based on the Tanner staging of pubertal development. "There are five Tanner stages," Dr. Futterman reminded PRN's clinician audience. "We look for breast development and penile and scrotal enlargement to determine which Tanner stage an adolescent falls under. You can't use the absolute age. There are some sixteen-year-olds who are still in the early stages of puberty. Similarly, there are some considerably younger adolescents who have finished puberty."

Pediatric dosing of antiretroviral agents should be used for adolescents who have not yet initiated puberty or are in the early stages of puberty (Tanner stage I or II). Dosing for adolescents who are in the middle of puberty (Tanner stage III or IV) should be based on whether they have completed their growth spurts. Adolescents who have completed puberty (Tanner stage V) should be given adult doses.

The best regimens for adolescents are those that fall under the slogan *KISS*: keep it simple and safe. Adherence is, in short, a major issue for adolescents. Dr. Futterman stressed that "practice regimens," perhaps using vitamins, are useful in terms of helping youth acclimate to treatment and to figure out ways around adherence obstacles—before actual medications are used. Once- or twice-daily regimens are likely most applicable to young people. Dr. Futterman also mentioned that protease inhibitor-sparing regimens are considered by many adolescent-treating clinicians to be useful in first-line regimens, given the difficulty of achieving excellent adherence the first time around and the risk of cross resistance among the protease inhibitors.

Psychosocial Issues

THE EFFECTIVE CARE AND TREATMENT OF ADOLESCENTS NECESSITATES AN understanding of the psychosocial issues that pertain to adolescent development. "Young people with HIV are a vulnerable group with multiple risks," Dr. Futterman said. "There are barriers to treatment, all of which need to be acknowledged and dealt with accordingly."

For starters, many adolescents with HIV have histories of sexual and/or physical abuse. Numerous HIV-positive adolescents also have a concurrent diagnosis of mental illness, whether it's depression, borderline personality disorder, or substance abuse problems. "Failure to identify and address these comorbidities can prevent young people from coping with their HIV infection, including adherence to antiretroviral therapy," Dr. Futterman commented. "There is a major role for mental health services in the care of these adolescents, including individual, group, family, and peer counseling."

Abilities to cope with HIV will vary considerably, in accordance with an individual patient's emotional development. In general, Dr. Futterman explained, maturity enhances adherence. "Sometimes, a young person who is straight-forward can do very well. There are no questions involved. They simply do as they're told, which makes things very easy." However, cognitive barriers can make a difference in the day-to-day coping mechanisms of HIV-positive adolescents.

Many adolescents are concrete thinkers, in the sense that they see things as black-and-white issues. One example provided by Dr. Futterman is the fact that many adolescents simply do not understand the concept of taking medications while they are feeling fine. In light of this, it is important for HIV-positive young people to grasp the significance of viral load and CD4+ cell testing, to help them better understand the basic principles of treatment—including what the treatments are and how they work—and the good it can do.

Dr. Futterman also explained that many adolescents have an altered sense of their future orientation. On one hand, there is a pervasive sense of immortality and invincibility among many adolescents, including those infected with HIV. As suggested by Dr. Futterman: "Many adolescents believe, 'I'm going to live forever.' 'I feel fine, so how can HIV kill me?'" On the flipside, there are numerous young people with more fatalistic points of view: "I'm going to die tomorrow. What's the point of taking these medications? I can't even make it out of my neighborhood." All of these somewhat naive notions can make it difficult for adolescents to recognize the importance of medication adherence.

There are also issues of disclosure that can impede adherence to medical care and treatment, along with an adolescent's much larger support/social network. "In an ideal world," Dr. Futterman said, "our adolescents would reach out to an adult, preferably a parent, for support. However, we have numerous adolescents who choose not to disclose their status because they fear losing the love of their parents, or being kicked out of their house, or being physically abused. And for a number

of young people, disclosing their HIV status also means disclosing the fact that they are gay or abusing drugs.” This, Dr. Futterman believes, might mean having to hide medications, which can be seen as a challenge to treatment adherence, and a general breakdown of trust and communication when it is needed most.

Another psychosocial issue of concern is disclosure to sexual partners. “I don’t need to remind everyone about how small teenage and adolescent social circles are,” Dr. Futterman said. “Young people are often concerned about keeping their serostatus confidential. Disclosure can seem too great of a test of trust, so some teens cut themselves off from others, including sexual partners. ‘I’ll never have sex again,’ some adolescents say. But this simply isn’t realistic.”

Barriers to Prevention

THERE ARE A NUMBER OF SOCIETAL, INSTITUTIONAL, AND INDIVIDUAL barriers in the lives of teenagers and adolescents that effectively disrupt HIV prevention messages from taking root. “Understanding these barriers and the ways in which we can work around them has been a central goal of the Adolescent AIDS Program and Montefiore,” Dr. Futterman said.

One of the key societal barriers to HIV prevention is the fact that we live in a sexphobic society. “Teens simply aren’t supposed to be having sex and society wants nothing more than to prevent teenagers from having sex,” commented Dr. Futterman. “However, this simply isn’t the case and teens are often reluctant to talk about things they’re not supposed to be doing.” Adding to this is the fact that teenagers and adolescents who are at risk for HIV do not have a memory of the horrors of AIDS in the 1980s and 1990s and treatment advances have lessened the fears of HIV as a fatal disease. For many it remains a mythical disease that cannot readily be seen or comprehended, which can certainly lead to skeptical views as to what the fuss is really all about and denial of personal risk.

In terms of institutional barriers to prevention, Dr. Futterman reminded PRN members that the current political climate is that of “abstinence only,” which fails to reflect the fact that adolescence is a developmental period marked by discovery and experimentation, with sex being a significant part of this exploration. How difficult it must be for impressionable young people to sort through the mixed messages: politicians and public health officials preaching abstinence against the backdrop of a cultural landscape that glamorizes sex and recreational drugs in movies, television programs, and magazines.

Many churches and schools have set conservative agendas about sex, which further cuts off teens from getting the information they need. What’s more, many clinicians are still unaware of HIV risks in adolescents and many physicians are resistant to offer testing. “HIV is still considered to be exotic and testing is generally considered to be beyond the routine care of adolescents,” Dr. Futterman said. “Many physicians will only test their young patients for HIV if other STDs are diagnosed or if their patients talk openly about their sex lives. I think we’re missing a sizeable population if we limit testing only to adolescents who meet these criteria.”

Numerous individual barriers to prevention exist as well. Many teens do not perceive themselves to be at risk. For example, many prevention messages are aimed at gay and bisexual men. But many YMSM do not identify as being gay or bisexual, ultimately causing them to miss the gist of these otherwise important messages. Another issue to consider is the nature of short-term adolescent relationships. “These increase exposure risk,” Dr. Futterman explained. “The scenario often goes like this: ‘We’re celebrating our second anniversary,’ one will say to the other. ‘Yeah?’ ‘Yeah, we’ve been together for two weeks. Let’s have sex.’ Sure, they’re monogamous, but for the four weeks that the relationship lasts. And then they

move on to something else with somebody else.” It’s also important to recognize that many youth have multiple barriers, including poverty, discrimination, and broken families. Dr. Futterman also pointed out that many young people are simply not comfortable seeking services and addressing risk behaviors with adults.

Outreach and Social Marketing

TO HELP LINK AT-RISK ADOLESCENTS TO NECESSARY COUNSELING, TESTING, and care, Dr. Futterman and her colleagues have been working diligently over the past several years to implement outreach and social marketing programs that appeal to the sensibilities of young people. “The first initiative has been to link HIV-positive youth to care,” Dr. Futterman said. “We want to normalize HIV counseling and testing among sexually active youth, helping them to understand why testing is so important. Another component of this has been to routinize counseling and testing among health-care providers.”

Effective prevention messages geared toward sexually active young people must consist of appropriate style and substance. In terms of style, Dr. Futterman explained that messages must frankly address risk and prevention, without preaching or using scare tactics, using the imagery and vocabulary of urban youth. It’s also important that messages be designed and marketed with different populations in mind, conscious of racial and ethnic differences, age differences, and the different types of social and sexual relationships young people have. A major new HIV social marketing initiative of VIACOM and the Kaiser Family Foundation will hopefully break through much of the silence and growing complacency still surrounding AIDS.

As for the substance of messages, it’s important to promote prevention that works: abstinence, condom use, and communication. Another vital component is to make sure that young people understand the links between sex, STDs, and HIV. “Finally, and this is very important, is to get teens and adolescents to understand that prevention isn’t simply about abstinence or condom use and hoping for the best,” Dr. Futterman concluded, “it’s also about getting counseling and getting tested.”

For more information about youth and HIV, as well as the social marketing materials discussed in this article, visit: www.adolescents.org or www.gettingbusy.org.



References

- Department of Health and Human Services and the Henry J. Kaiser Family Foundation. *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*. February 4, 2002. Access at: http://www.aidsinfo.nih.gov/guidelines/adult/html_adult_02-04-02.html (February 19, 2003).
- Futterman D, Chabon B, Hoffman ND. *HIV and AIDS in adolescents*. *Ped Clin North Amer* 47(1):171-88, 2000.
- Institute of Medicine. *The hidden epidemic: Confronting sexually transmitted diseases*. Washington, DC, National Academy of Press, 1997.
- Valleroy LA, MacKellar DA, Karon JM, et al. *HIV prevalence and associated risks in young men who have sex with men*. *JAMA* 284(2):198-204, 2000.