Perspective

HIV in Adolescents and Young Adults: Half of all New Infections in the United States

Half of new HIV infections in the United States are in individuals aged 13 to 24 years, accounting for 20,000 new infections annually, or 1 every hour. Two thirds of infected youth contract HIV sexually, and more than 60% of new infections are in young women. Approximately 75% of infected youth are in racial or ethnic minority groups. More than one third of HIV-infected young people have not been tested for HIV infection, and the majority of homosexual HIV-infected youth are unaware of their infection status. Increased efforts are needed in comprehensive sex education, including safer sex practices, bringing young people into health care networks, increasing health care provider awareness of risk, and extending counseling and testing to young people. This article summarizes a presentation by Donna Futterman, MD, at the 7th Annual Clinical Conference for Ryan White CARE Act Title I, II, III, and IV Grantees, held in August 2004 in Washington, DC.

In the United States, 50% of new HIV infections occur among 13- to 24-year-olds. This group accounts for 20,000 new infections annually, or on average, 1 every hour. Two thirds of these youth contract HIV sexually, and more than 60% of new infections are in young women. Approximately 75% of HIV-infected youth are in racial or ethnic minority groups. More than one third have not been tested for HIV infection. Approximately 80% of homosexual HIV-infected youth are unaware of their infection status (Centers for Disease Control and Prevention [CDC] 2004; Valleroy et al, *JAMA*, 2002).

In addition to the new infections in America's youth, a growing number of perinatally infected children are surviving into adolescence. In the early 1980s, it was thought that perinatally acquired HIV infection was a disease of infants and that children did not exhibit the same protracted course of disease without clinical symptoms that adults exhibited. However, it is now known that the course of HIV infection can be asymptomatic in children for many years. With the use of antiretroviral therapy, many perinatally infected children are now well into adolescence. Indeed, half of the HIV-infected children in some of the cohorts that formed the original pediatric programs are now adolescents. Clinically, these adolescents may be sicker, but present with many of the same issues regarding sexual relationships and drug treatment adherence as do others their age.

Dr Futterman is Director of the Adolescent AIDS Program and Professor of Clinical Pediatrics at Albert Einstein College of Medicine in Bronx, NY.

Youth Susceptibility to HIV

Factors affecting youth susceptibility to acquiring HIV infection include behavioral, biologic, and socioeconomic factors. One behavioral factor is that a large proportion of young people in the United States are sexually active. According to the CDC, half of US high school students (including those in grades 9 through 12) have had sex (CDC, *MMWR*, 2004). By the time they are in 12th grade, 70% of teens have had sex. Another behavioral factor is that relationships between young people are often marked by a gender power imbalance, wherein it is more difficult for young women to insist on condom use or other safer sex practices, particularly when they are involved with older men.

There are several biologic factors contributing to youth susceptibility to HIV. The immature cervix of a young woman is lined with single-layer columnar cells that increase vulnerability to infection compared with the multilayer squamous cell structure in the cervix of an older woman. Sexually transmitted diseases (STDs) in the young are also more likely to be asymptomatic—for example, inflammatory diseases, such as chlamydial infection, can often go undetected in young women—and both ulcerative and inflammatory STDs can facilitate HIV transmission. HIV is more efficiently transmitted from men to women. It is thought that the majority of cases of HIV transmission in women occur through the cervix, but the percentage that results from invasion of the vaginal wall remains unclear. With regard to female-to-male transmission, the urethral opening in the penis is the main site of acquisition, and this location obviously presents a much smaller vulnerable surface area than that found in women. The higher rate of transmission to uncircumcised men indicates that the lining of the foreskin may be comparable to the cervix in terms of vulnerability to infection.

Socioeconomic factors putting youth at risk include the fact that they are the least-insured segment of the population and are thus liable to receive less than adequate health care and support. In addition, much of the youth sex education is inadequate. From a public health standpoint alone, it is crucial that young people learn the methods of safer sex. Further, the lack of confidentiality in health care is a problem for younger people. Many rely on confidentiality in the health

care setting in order to access health care, and confidential care is an important component of adolescent medicine with regard to sensitive issues such as sexuality, pregnancy, and substance abuse. Confidentiality is not inviolable in situations in which individuals are endangering themselves or others, and every effort should be made to involve parents or other caretakers when necessary. However, confidentiality is a starting point for bringing young patients in to receive the care that they need.

Sexual Transmission Among Youth

Epidemiologic characteristics of HIV transmission in youth include a wide variation in the number of sexual partners among those infected. Half of the infected young women in the Adolescent AIDS Program at Children's Hospital at Montefiore in Bronx, New York, over the last 15 years reported having only 1 sexual partner. Thus, one of the commonly disseminated messages about reducing risk—reduce the number of partners—turns out to not be protective in some settings. In fact, it has been reported that being married is one of the leading risk factors for HIV acquisition in women in some areas in Africa. Thus, women can be at risk for HIV infection even if they have only 1 sexual partner. Overall, three quarters of HIV-infected young women were unaware that the partner from whom they acquired the infection was at risk.

Among young men, male-to-male sex remains the leading risk behavior. In this regard, it is important to recognize that sexual orientation does not necessarily equal sexual behavior. Many young men who ultimately will be heterosexual experiment sexually with other men; others may experiment with other men long before they self-identify as homosexual; and others confidently identify themselves as gay but have not yet had sex with another man. These distinctions are important for discussion and counseling, which should focus on behaviors as well as orientation.

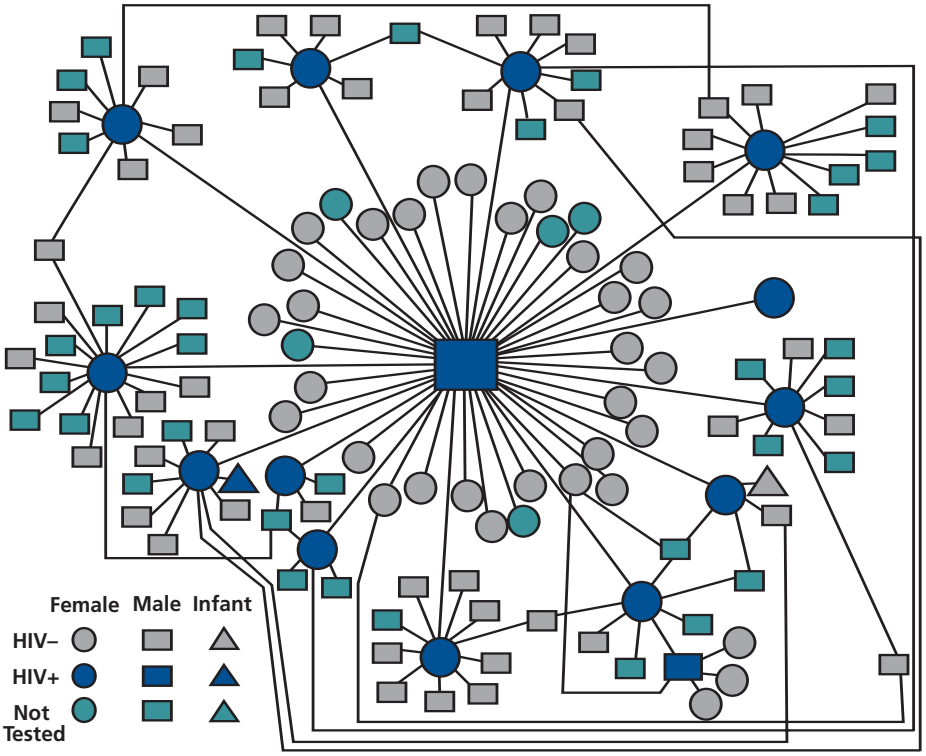

Figure **1.** HIV contact case investigation, Chautauqua County: December 1997. Sexual network showing HIV transmission in a town in New York. Lines connect sex partners. Courtesy of the New York Department of Public Health.

Figure 1 shows a sexual transmission network from a small town in upstate New York, where an outbreak of HIV infection was not expected. The blue square in the center represents a young man with HIV infection, and every circle to which the square is connected represents a woman with whom he had sex. The blue circles indicate those contacts who acquired HIV infection; the sexual contacts of those women and their HIV infection status are also shown. The young man at the center of this network was a drug dealer, who also offered the women gifts and clothing. Most of the women did not know that the man might be putting them at risk, and they may have been unaware that he was also having sex with many other women.

Most HIV transmission does not occur as in this example, featuring 1 "supertransmitter" with a large number of sexual partners. However, there is reason to suspect the existence of numerous transmission networks that are similar (although smaller) to this in inner cities and elsewhere. For example, the presentation at one clinic of numerous HIV-seropositive young women from the same ZIP code may indicate that sexual networks are involved. Years ago, many clinicians would hesitate to think about partner notification when seeing a new patient, because it seemed in some way contrary to the patient's best interest. This type of thinking must be eschewed for the sake of preventing new cases, and the tried–and-true public health techniques of identifying cases and contacts should be adopted when appropriate. A recent report from North Carolina of a group of young African-American men acquiring HIV infection through college sexual networks emphasizes the need for vigilance in this regard (CDC, *MMWR*, 2004)

With regard to men who have sex with men, the landmark study conducted by the CDC from 1994 to 1998 showed that of a random sampling of 3449 males aged 15 to 22 years who

reported having sex with men, 7% were HIV seropositive. (Valleroy et al, *JAMA*, 2002) This HIV seroprevalence rate is higher than that in Haiti, for example, which has been declared a focus country for the President's Emergency Plan for AIDS Relief. Among African American men in the CDC sample, the seroprevalence rate was 14%, higher than the estimated seroprevalence in Kenya. Among 15- to 19-year-old men in the CDC study, 6% were HIV seropositive. Among all infected individuals in this study, 82% were unaware of their infection status. Of those infected, 87% reported having anal sex with a man and 31% reported unprotected receptive anal sex. The fact that 61% reported having sex with a woman emphasizes that both opposite-sex and same-sex sexual experimentation is common among youth who ultimately identify themselves as homosexual. Homosexual youth today live with psychosocial pressure that adds to the pressures posed by adolescence per se. Societal prejudice against homosexuality, coupled with challenges in accessing comprehensive sex education and prevention information, discourages the development of the self-love and self-motivation that can form the basis of safer-sex practices.

Dr Futterman and colleagues at the Adolescent AIDS Program have identified history of sexual abuse and having a parent with HIV infection as risk factors for infection in young people. There is a high frequency of history of sexual abuse among young people of both sexes infected with HIV. At the Adolescent AIDS Program, rates of sexual abuse range from 25% to 40%. Safer-sex behavior depends on some degree of self-motivation and self-love, and unless young people (or adults) have worked through the consequences of sexual abuse, it is difficult for them to successfully maintain safer-sex practices in later life.

In a study conducted at the Adolescent AIDS Program, 20% of HIV-infected young people who were infected sexually knew that at least 1 parent had HIV infection. Identification of this risk group emphasizes that vulnerable youth are vulnerable to acquiring HIV infection. Young people growing up with a parent who is sick, who uses drugs, or who is otherwise "absent" are vulnerable because they lack a supportive and involved parent. In addition, geography is destiny in the sense that adolescents growing up in a neighborhood with high rates of HIV infection are generally more vulnerable because their sexual involvement with partners from their neighborhood puts them at greater risk than would the same behaviors in a location with low HIV infection rates. There is no doubt that there is a heightened vulnerability among young people growing up in neighborhoods that are poor and without resources and that have high rates of substance abuse.

After identifying the rate of HIV-infected young people in the abovementioned study who were aware of their parents' HIV-seropositive status, the interviewers found that less than half of patients in the adult HIV clinic who had teenage children had told their children of their HIV status. Thus, the 20% figure cited for the proportion of young patients knowing that a parent was infected very likely reflects a low estimate of the number of HIV-infected youth with at least 1 HIV-infected patient.

Challenges in Adolescent HIV and Other STD Care

Risk Awareness and Retention in Care

A primary challenge in care for at-risk youth is increasing risk awareness among health care practitioners. Every STD program should provide or have a link to HIV counseling and testing services. Unfortunately, many do not, which results in missed opportunities for diagnosis (Burstein et al, *Pediatrics*, 2003). If linkage to health care can be accomplished, the challenges are to retain the patients in care, including guiding the transition of patients from pediatric to adolescent programs and from adolescent to adult programs, and to provide support regarding drug treatment adherence. Success in these areas frequently involves collaboration with schools and community-based organizations and health programs.

Treatment and Treatment Adherence

The course of HIV disease in adolescents is similar to that in adults, largely because most adolescents are infected after the immune system has matured. Adolescents appear to have more resilient immune systems, and thus constitute an ideal target for early antiretroviral intervention (Rudy et al, *J Adolesc Health*, 2001). Treatment is based on adult treatment guidelines, depending on the Tanner stage of the individual, (Working Group on Antiretroviral Therapy and Medical Management of HIV-infected children. http://aidsinfo.nih.gov/, 2005). In the Adolescent AIDS Program, the preferred approach to antiretroviral treatment is to provide the best regimen with the highest chance of adherence, an approach termed "Keep It Simple and Safe," or "KISS." The manner of coping with disease and treatment varies by stage of development; in general, maturity enhances adherence. One cognitive barrier to adherence in young people is concrete, rather than abstract, thinking: Although concrete thought, which encourages following rules, can actually aid adherence, for the most part it is difficult for younger patients to imagine the virus multiplying in their bodies, to attach meaning to the numbers used in assessing and monitoring disease, and to feel the need to keep taking medication while they do not feel sick, especially if the medication makes them feel unwell. Other cognitive barriers include decreased future orientation and a limited understanding of medicines. In addition, many young people do not disclose their HIV serostatus to their family and are therefore deprived of potential support that may improve adherence (Schietinger et al, 2005).

Identifying HIV-Infected Youth

Health care providers provide a key role in identifying HIV-infected young people. They occupy a unique position at the intersection of case finding and care, and the respect that they typically garner from young people and parents can facilitate their activities in this regard. Although the CDC, the American Academy of Pediatrics, and other bodies recommend routine testing or offering of HIV testing to young people, testing is still not standard practice in many health care settings.

The Adolescent AIDS Program has designed an HIV testing program that is intended to facilitate the adoption of HIV-related assessment into routine practice in high-HIV-prevalence areas. The initial step in the development of the program was to determine the degree to which HIV testing was not linked to other STD care. Providers were interviewed and data obtained from 9 community health centers in Bronx, New York. The majority of providers performed HIV testing in 10% or less of their clients; they performed Chlamydia testing in 20% to 50% (Figure 2). Based on the contention that every person receiving a Chlamydia test should also be tested for HIV, interviews were then conducted with providers and key staff to identify barriers to offering HIV testing. These barriers included the feeling of a lack of skills, time constraints, lack of appropriate staff training, and the belief that their patients were not at risk for HIV infection.

In response to provider and patient needs, a simple, rapid protocol was designed for HIV counseling and testing for use in high-prevalence areas, called Assess, Consent, Test, Support (ACTS). The program is concise and comprehensive; its components include a laminated pocket guide, a manual for instruction and reference (including keyed discussion of talking points listed on the pocket guide), and a tool kit containing screening and consent forms and patient materials. The program includes meeting with key staff to discuss challenges and solutions and an academic detailing session to train providers to use the program. The front of the laminated pocket guide is reproduced in Table 1. New York State has among the strictest counseling and testing regulations, and the ACTS system allows them to be met in 5 minutes. The time-constraint barrier was minimized by removing preven-

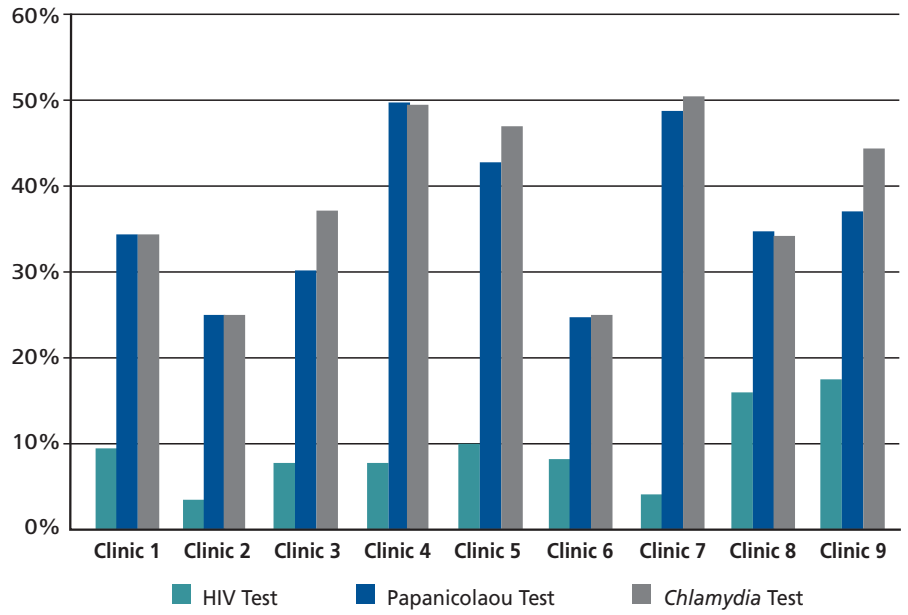

Figure **2.** Frequency of HIV, Papanicolaou, and *chlamydia* testing in 9 clinics in Bronx, New York. Date are from Futterman D and Meissner P (personal communication)

Table **1.** ACTS—A Rapid System for HIV Counseling and Testing

Assess for HIV Testing

- Note it is now standard practice to discuss HIV with all patients
  - Explain benefits of testing for patient's health and prevention
  - Describe HIV transmission: sex/needles/perinatal
- Review risk screen or explain that HIV testing is advisable if:
  - You have ever had sex (esp. if condoms are not always used)
  - You have ever used injection drugs (especially if sharing needles)
- If yes, recommend testing and assess testing readiness

Consent

- Review DOH consent form: meaning of positive and negative results, confidential vs anonymous testing, names reporting, partner notification and domestic violence screening
- Obtain consent

Test

- Describe/provide HIV test (blood, oral, urine, or rapid)
- Make a plan to deliver results or have patient wait for rapid results

Support During Testing and Afterward

- HIV-seronegative
  - HIV testing by itself is not prevention: provide prevention strategies and referrals
  - Clarify if need to retest in 3 months (window period)
- HIV-seropositive
  - Provide support and link to care and prevention
  - Review HIV reporting, partner notification and domestic/partner violence issues

Adapted from the pocket guide for the Assess, Consent, Test, Support (ACTS) project of the Adolescent AIDS Program at Montefiore Medical Center (See www.adolescentaids.org).

tion and risk assessment from the pretest counseling and testing program. This is a controversial strategy. If an individual site has time to fit risk assessment and prevention counseling into its counseling and testing program, it should do so; however, the time constraint posed by offering all of these components should not stand in the way of the primary objective of pretest counseling and testing.

Barriers to HIV Prevention

A barrier to HIV prevention among adolescents is how they think about the need for prevention. "I don't think I have anything to worry about. I assume they are negative. If they were positive, they wouldn't put you at risk. You can tell a lot by appearance" is a typical thought among adolescents in regard to the HIV serostatus of a sexual partner. This way of thinking is often supported by society and current American culture. Sex is commonly portrayed in the entertainment media, but it is rarely accompanied by the depiction of safer-sex practices. There is almost no social marketing regarding HIV and its prevention. In addition, physicians in many areas are still unaware of the risk to young people and are resistant to offering testing.

Still, some progress has been made. As shown in Figure 3, the proportion of sexually active high-school students reporting condom use during their most recent sexual intercourse increased from 46% in 1991 to 63% in 2003. Reality-based prevention programs that go beyond "abstinence only" are needed to maintain and improve the gains that have been made. Safer-sex practice needs to be discussed as a continuum, starting with issues of communication regarding readiness for sex and decision-making for oneself and with one's partner. The possibility of abstinence should be discussed, along with ways to be sexually active without exchanging body fluids (ie, outercourse). Condom use needs to be discussed realistically, acknowledging

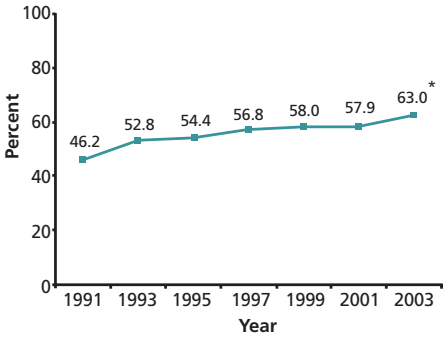

Figure **3.** Proportion of currently sexually active high-school students reporting condom use at most recent sexual intercourse. *Significant linear increase, *P*<.05. Adapted from the Centers for Disease Control and Prevention, National Youth Risk Behavior Surveys, 1991-2003

that although it is not easy and certainly not always convenient, it is nonetheless necessary. Issues arising for youth with older sexual partners need to be addressed. Information on the links among sex, STDs, and HIV and the link between prevention and testing needs to be delivered to young people in ways that they can easily access and understand. The Adolescent AIDS Program has attempted to convey these messages through the intermittently published magazine "The Deal," which talks to kids about sexuality in language they use and understand and does so in the context of other lifestyle issues. (See www.adolescentaids.org.) Other public health initiatives have included social marketing campaigns using radio, outdoor media, and handouts to reach young people.

Conclusion

Currently there is a sense of complacency about the HIV/AIDS epidemic in the United States, but the epidemic is not over. It is now, officially, the worst epidemic in human history. Here in the United States, more than half of the 40,000 new infections each year are among the youth population, and most of the young people who are infected do not know it and are not in treatment. Safer sexual practice is the key to preventing HIV infection and protecting America's youth.

Presented in August 2004. First draft prepared from transcripts by Matthew Stenger. Reviewed and updated by Dr Futterman in August 2005.

Dr Futterman has served as a scientific advisor to OraSure Technologies.

Suggested Reading

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