
XI: ADOLESCENTS¹

Donna Futterman, MD

Adolescence is a time of significant cognitive, emotional and physical development and is often characterized by exploration and experimentation. As adolescents explore intimacy, sexuality and develop autonomy, it is also a time of heightened vulnerability, including risk for HIV infection. This chapter focuses on young women as it reviews the epidemiology of HIV/AIDS in adolescents and provides guidelines for HIV counseling and testing, medical and psychosocial care and strategies for linking HIV-infected and at-risk youth to care.

I. EPIDEMIOLOGY

Adolescents are at high risk for HIV infection. Worldwide, one out of every two new cases of HIV — half of 5.8 million new infections during the past year — occurred in youth ages 15–24. In developing countries, women are becoming infected at significantly younger ages than men, with more young women in their teens and early twenties becoming infected than women in any other age groups. In the U.S., (CDC, 1999) more than half (53%) of adolescents newly infected with HIV are female, and 25% of all new infections, or some 10,000 new cases per year, are estimated to occur in youth ages 13 to 21. In addition, 19% of U.S. AIDS cases are reported in young adults in their 20s. Given a ten-year period, on average, from initial infection to clinical manifestations of AIDS, most of these young people were likely infected during their teens.

Compared with adults, female adolescents represent a much higher proportion of HIV/AIDS cases. In 1998, adolescent girls ages 13–19 years accounted for 51% of incident adolescent AIDS cases while female adults comprised 23% of incident adult AIDS cases. Between 1988 and 1993, estimated HIV prevalence increased 36% among young women aged 18 to 22, while dropping 27% among young men in the same age group. At highest risk are African-American youth, who comprised 58% of incident teen cases in 1997, while representing only 15% of the U.S. adolescent population.

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A. SEXUAL RISK

The majority of adolescent females (52%) with AIDS were infected through heterosexual intercourse. Moreover, an additional 15–20%, who are classified as having “no identified risk” because they were unable to identify their partners’ risk, are also assumed to have been infected through heterosexual encounters. This is consistent with widespread lack of awareness of their potential risk for HIV infection among sexually active adolescents and adult women. For example, of adolescents known to be HIV positive, 75% of young women are unable to identify their partners’ risk factors. (Futterman, 1993) A much smaller proportion of female youth (13% of 13–19 year olds and 27% of 20–24 year olds) were infected through injection drug use, compared with 44% of adult women with AIDS. Adolescents who were infected perinatally account for a small but growing number of adolescents with HIV/AIDS, and some are not diagnosed until adolescence.

Clinicians working with adolescents have noted additional risk factors for youth. A significant proportion of adolescents with HIV have experienced childhood sexual abuse; of adolescents screened at the Adolescent AIDS Program (AAP) at Montefiore Medical Center, 25–40% report having been sexually abused. (Futterman, 1993) Childhood sexual abuse has been associated with subsequent feelings of powerlessness in sexual situations and increased risk for unsafe sexual activity.

Moreover, 20% of sexually infected HIV+ youth seen in an Adolescent Program reported having a parent who is also HIV-infected. (Chabon, 1997) Further research is needed to assess parental influence on their children’s HIV status. Nevertheless, children of parents with HIV generally live in the same high prevalence neighborhoods as their parents and may also face increased risk as a sequela of parental illness, or substance abuse. Clinicians should ascertain a history of sexual abuse or forced sex as well as parental HIV history when taking a history with adolescents.

B. SEXUALLY TRANSMITTED DISEASES AND PREGNANCY

Sexually active teens are also at risk for pregnancy and other STDs. According to the 1997 Youth Risk Behavior Survey, nearly half of all U.S. female high school students are sexually active (including 62% of 12 graders), and 9% report having been pregnant. (CDC, 1998) Approximately one million teens become pregnant each year, 74–85% of them unintentionally. Both STDs and pregnancy are markers for unsafe sexual activity and, in addition, STDs (both ulcerative and inflammatory) increase susceptibility for HIV infection. Two-thirds of the 12 million cases of STDs reported in the U.S. each year occur in youth under age 25, and 1 out of 4 are reported in adolescents. Younger teens, particularly females, are least likely to be considered at risk or to be screened, particularly if they are asymptomatic, which is the case with the majority of STDs in women. For example, chlamydia is asymptomatic in three-fourths of infected women, while approximately half of gonorrhea infections in women

have no symptoms. This is especially salient since adolescent women have the highest age-specific incidence rates for both gonorrhea and chlamydia; 79% of reported cases of chlamydia occur in young women (46% in 15–19 year olds and 33% in 20–24 year olds).

C. HEIGHTENED VULNERABILITY FOR INFECTION

Adolescents are at risk for HIV and STDs as a result of the interplay between behavioral, biological and socioeconomic factors. (IOM, 1997)

BEHAVIORAL RISK

During adolescence, sexual activity is often initiated, risk taking and experimentation are normative, and many sexually active adolescents fail to take appropriate prevention precautions, despite basic knowledge of HIV transmission and prevention. During their last sexual encounter, nearly half of 9–12 grade girls did not use condoms, while one 1 in 7 (14%) reported having more than 3 sexual partners. Many teens follow a pattern of sexual “serial monogamy” and may not consider themselves as having multiple partners. Nearly 1 in 5 (19%) reported using alcohol and drugs which can impair judgment and increase potential for high risk behaviors. Most high school seniors have used alcohol, and 1 out of 3 students report having five or more drinks at least once during the past 30 days. More than 25% smoke marijuana, 16% report using inhalants and nearly 1 in 50 have injected illegal drugs. (CDC, 1998)

Specific populations of teens are at especially high risk, including adolescents who are lesbian, bisexual and transgender, homeless or runaway, injection drug users, mentally ill and youth who have been sexually or physically abused, incarcerated or in foster care. These youth experience increased vulnerability and multiple health and social problems as a result of abuse and neglect and lack of services and care. Lesbian and bisexual youth may view themselves at lower risk but those who are sexually active with gay male peers are at risk for infection due to higher HIV prevalence among gay males.

BIOLOGICAL RISK

Several biological factors also contribute to heightened risk in adolescent females. During puberty, the cervix undergoes physical maturation that makes the cellular lining less susceptible to infection as the single-layer columnar epithelium of the cervix is replaced with thicker multilayered squamous cells. Until this occurs, the cervix is much more vulnerable to STDs, particularly chlamydia and gonococcus, which have an affinity for columnar cells and have also been shown to facilitate STD transmission. At the same time, male to female transmission of STDs is much more efficient than female-to-male transmission given the larger surface area of the lower female genital tract and mechanics of sexual intercourse, which can result in mucosal trauma to women. In addition, STDs in women are more likely to remain asymptomatic and thus, unrecognized and untreated, for a longer period of time.

SOCIOECONOMIC RISK

Adolescents are the most uninsured and underinsured group in the United States and are the least likely to receive office-based medical care or to use primary care services. Twenty-five percent of youth ages 15–29 have no health insurance and approximately 1 in 5 suffers from at least one serious health problem. Poverty, poor access to care and lack of education and prevention skills further increase vulnerability to HIV. Additional barriers include mistrust of the health care system, fear of inappropriate disclosure and providers' lack of understanding of adolescent rights to confidentiality and care without parental consent for sensitive health issues.

Moreover, many adolescents use emergency and walk-in facilities for acute care needs. As a result, they lack a primary care provider who can ensure ongoing care and address prevention and health promotion needs. Because adolescence is a time when help-seeking behaviors and attitudes about health and self-care are formed, the experiences adolescents have with health care providers are especially important. They form the basis for future provider-client interaction, communication patterns and relationships.

II. HIV CARE FOR ADOLESCENTS

Cornerstones of adolescent care include consent policies, confidentiality, accessibility, outreach and linkage to care and prevention. Even though youth prefer health care settings that are geared to their needs, most teens will not receive care in adolescent programs. Although most facilities are unable to offer the ideal “one stop shopping” for teens, quality care can be provided by identifying a staff member and/or provider team who wants to work with adolescents and by adapting adult and family programs to meet an adolescent's needs. This can be done by accommodating walk-ins since youth do not often plan ahead, addressing payment barriers and providing flexible appointments that will not conflict with school or work.

A. CONFIDENTIALITY AND LEGAL ISSUES

All states have laws that allow minors to consent to treatment without parental consent for specific health services including emergency care, STDs or reproductive health and substance abuse treatment services. In many, but not all states, this includes the right to consent for HIV counseling and testing. However, not all providers are aware of these rights or understand their significance for adolescents and these rights vary by state and the medical service provided. Most importantly, lack of confidentiality may cause adolescents to avoid or delay needed care. Even though parental consent may not be needed to provide an HIV test or HIV-related care, providers should carefully assess an adolescent's cognitive capacity to understand the implications of having HIV disease and should encourage them to involve a supportive adult in their care.

B. COUNSELING AND TESTING

Although most youth do not think they are at risk for HIV infection, they prefer providers to initiate discussion concerning HIV prevention and risk assessment. All adolescents should receive HIV prevention education, and sexually active adolescents should routinely receive HIV counseling and be offered HIV testing with informed consent. This enables providers to identify positive youth and provide ongoing medical care and support services, while relieving anxiety and reinforcing preventive behaviors for youth who are HIV negative. For adolescents who are not sexually active, counseling provides an opportunity to talk about sexual readiness, delaying intercourse and low risk ways to explore intimacy.

New testing options such as those that test for antibodies in oral fluids or urine are helpful with youth who are afraid of needles and allow providers to offer testing in a variety of settings including mobile vans, school-based clinics and drug treatment programs. Same-day testing may also be useful by eliminating the need for a return visit for results, but will require careful planning for the delivery of HIV-positive results. Meeting adolescent needs for flexibility, accessibility and low or no fee HIV testing is important in overcoming primary barriers to accessing care and can serve as an entry point to care. Like other underserved populations, adolescents are generally diagnosed with HIV/AIDS late in the course of illness, relatively few receive care for HIV disease and most do not know they are infected. Thus, ensuring access to HIV counseling and testing is essential in enabling adolescents to receive ongoing treatment and care.

Although counseling and testing for adults has generally been based on one initial pre-test counseling session with providers, a “one-shot” approach to counseling is not effective with all at-risk youth. Two short counseling sessions prior to testing, using personalized risk reduction plans, can increase condom use and prevent new HIV and other STD infections. Pre- and post-test counseling provide an opportunity to promote preventive health behaviors and to assess substance use and family planning needs, while providing basic information on HIV, obtaining consent and conducting a comprehensive risk assessment. (Table 11-1, on the following page) More extensive guidelines are also available for adolescent HIV counseling and testing in all health settings. (Chabon, 1998) Because adolescents may have misconceptions about aspects of HIV transmission and prevention, providers should assess their capacity to understand basic concepts of HIV disease and viral transmission. Effective HIV counseling for adolescents should be culturally sensitive and tailored to an adolescent’s developmental needs. In addition, providers should take special precautions to ensure confidentiality in institutional settings such as foster care, residential treatment or detention.

Knowledge of appropriate condom use and widespread availability of condoms are especially important in promoting risk reduction behaviors among youth. All facilities that provide health care for adolescents should make condoms available and providers should demonstrate condom use with

TABLE 11-1: TEEN AIDER (ASSESS, INQUIRE, DISCUSS, EDUCATE, READINESS) INTERVIEW FOR HIV COUNSELING, TESTING AND RISK REDUCTION

ASSESS AND INQUIRE
<p>Create a confidential atmosphere</p> <ul style="list-style-type: none"> ■ Assure youth about confidentiality of visit and ability to consent for testing per local laws ■ Assure youth that testing is their choice ■ Acknowledge that it can be embarrassing to discuss sexual behaviors ■ Help youth to identify supportive adult who is aware that youth is being tested
<p>HIV/AIDS Knowledge</p> <ul style="list-style-type: none"> ■ Allow adolescent to verbalize understanding of HIV, clarify misconceptions and fill in gaps in knowledge ■ Assess feelings about testing and previous HIV testing experiences ■ Inquire if youth knows anyone with HIV/AIDS (e.g., sexual partner, family member)
<p>Sexual Risk Assessment</p> <ul style="list-style-type: none"> ■ Assess sexual behaviors without making assumptions about sexual orientation, not all youth are heterosexual and not all youth who have engaged in same sex behavior self-identify as lesbian or gay ■ Assess number of partners, age differential and partner's known risks ■ Assess frequency of substance use in the context of sexual behavior ■ Assess consistency of condom use and obstacles to use such as unassertiveness, desire to become pregnant, fear of violence and religiosity ■ Assess for history of sexual abuse or rape
<p>Substance Use and Other Risk Assessment</p> <ul style="list-style-type: none"> ■ Assess level of drug and alcohol use and reasons and context in which use occurs ■ Review risk of impaired judgement that may result leading to unsafe sex ■ Assess potential need for drug treatment ■ Assess violence and substance use in home and community
<i>Table continues . . .</i>

anatomical models. Adolescents have difficulty using condoms during intercourse for several reasons, including: 1) lack of knowledge about effective use; 2) lack of communication and social skills; 3) lack of availability of condoms at the time of sexual activity; and 4) impulsive behavior exacerbated by drug or alcohol use. Gender and power imbalances in relationships make condom use especially difficult for adolescent women whose partners are older and who are just beginning to develop communication and negotiation skills. Helping youth identify their personal values may increase self-esteem and help them resist pressures to engage in sexual risk behaviors. (Table 11-2)

C. PREVENTION

Promoting risk reduction among adolescents is especially challenging since developmental characteristics encourage concrete, short term thinking and experimentation and increased reliance on peers. Thus, successful primary and secondary programs for adolescents are those that provide interventions to

TABLE 11-1: TEEN AIDER (ASSESS, INQUIRE, DISCUSS, EDUCATE, READINESS) INTERVIEW FOR HIV COUNSELING, TESTING AND RISK REDUCTION (continued)**DISCUSS AND EDUCATE**

- Discuss sexual activities that don't involve exchange of body fluids (outercourse)
- Demonstrate proper male condom, female condom and dental dam use on anatomical model and provide opportunity for practice
- Rehearse effective ways to communicate risk reduction with sexual partner (s)
- Discuss harm reduction strategies for youth using drugs
- Develop a personalized risk reduction plan
- Discuss postponing sex for youth who are not sexually active
- Determine referral needs (e.g., Medical, Psychosocial, School /Vocational, Substance Abuse, Reproductive Health, Legal, Housing, Psychiatric)

READINESS FOR HIV TESTING AND REFERRAL

- Adolescent should be informed about both anonymous and confidential testing
- Provide education about Partner Notification programs and other options for disclosure to partners
- Assess understanding of meaning of a positive and negative test result
- Assess understanding of benefits of early intervention
- Determine with youth if testing should occur at this time and obtain informed consent
- Strategies for coping (how to relieve stress and anxiety during the testing process)
- Arrange follow-up appointment and method for confidentially contacting youth, if needed

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TABLE 11-2: FACTORS ASSOCIATED WITH CONDOM USE

<i>ENCOURAGES USE</i>	<i>DISCOURAGES USE</i>
<ul style="list-style-type: none"> ■ Knowledge about condoms ■ Belief in effectiveness ■ Discussion with health care provider ■ Self-esteem/self-efficacy ■ Communication/negotiation skills ■ Availability/accessibility 	<ul style="list-style-type: none"> ■ Drug/alcohol use ■ Relationship power imbalances ■ Peer pressure may discourage use ■ Lack of effective sex education ■ Lack of media/cultural support of condom use

increase self-esteem and self efficacy, build social skills and provide basic information geared to the adolescent's developmental level, using a peer support model. For high risk youth, the AIDS Risk Reduction Model (Catania, 1990) has been widely used to foster primary and secondary prevention, based on the premise that behavior must first be acknowledged as risky before youth will initiate change.

School-based programs that provide comprehensive health education in conjunction with school health clinics offer optimal opportunities to reinforce

positive health behaviors and ensure routine screening for a range of health and mental health concerns. But they are especially important in reducing risk and identifying sexually active youth who are at risk for STDs and pregnancy. A comprehensive review of school-based programs designed to reduce risky behavior in teens found that adolescents who received AIDS education were less likely to engage in sexual activity and more likely to practice safer sex than peers who lacked AIDS education in school. (Kirby, 1998) In particular, successful programs include skills building, reinforcement of values and norms to prevent unprotected sex that are based on age and experience levels, and discussion of social influence and pressure. School clinics also offer an important venue for access to condoms and appropriate instruction on condom use. Although not widely available, school clinics provide an important site for HIV counseling and testing for in-school youth, given new rapid testing options. Ultimately, successful prevention must also involve society and the media – until youth see condom use and safer sex discussions incorporated into sex scenes in music videos and movies, they will not believe that this is a social norm.

D. LINKING YOUTH TO CARE

Linking at risk youth to care is essential in meeting their needs for risk reduction education and appropriate ongoing HIV medical and psychosocial care. Most HIV-infected youth do not know they are infected, and many providers are not aware of available community service agencies that can help address their multiple mental health and social service needs. Community outreach is a primary component in ensuring access to care for youth with HIV disease. Peer-based outreach services are frequently employed, as adolescents are more likely to listen to their peers. Unlike adult women who have more opportunities to obtain HIV testing and to access care related to their reproductive health needs, adolescents who are not pregnant require proactive outreach efforts to promote HIV testing and engage them in care. This includes city-wide campaigns to encourage testing and to make it more widely available, with direct linkages to adolescent health care facilities. One such initiative — a social marketing campaign spanning the continuum from HIV prevention through testing to care — was developed by the Adolescent AIDS Program at Montefiore Medical Center in New York City in 1996. “HIV. Live with it. Get Tested” was designed with marketing experts, health providers and most importantly youth themselves, to combine media advertisements such as posters, radio and TV ads with community outreach in settings where at-risk youth access information and are likely to congregate. Using teen language for sexual activity (e.g., “Knockin’ Boots” or “Hittin’ the Skins”) to promote testing and care services through a coalition of adolescent HIV programs and community based youth agencies, the initiative is intended to help adolescents link having sex with HIV risk and the importance of HIV testing. Now in its third year, the initiative focuses annual activity around a “Get Tested! Week” launched with a youth-led Town Hall meeting and peer outreach. The campaign’s success has also resulted in a national initiative that during 1999 took

place in 5 additional cities — Baltimore, Los Angeles, Miami, Philadelphia and Washington, D.C. — within the NIH- and HRSA sponsored Adolescent Medicine HIV/AIDS Research Network (AMHARN) Network. In each city, new coalitions were successfully built, increased numbers of youth were tested, and HIV-positive youth were identified and linked to care. (Futterman, 2000)

E. HIV CLINICAL AND PSYCHOSOCIAL CARE

Although the natural history of HIV infection in adolescence is still being defined, the course of disease appears to follow that of adults. A national prospective study with sites in 13 cities — AMHARN — has been funded by the National Institutes of Health and the Health Resources and Services Administration to identify the course of disease in adolescents, including its spectrum, manifestations, effects of puberty, and developmental and psychosocial interactions. (Rogers, 1998) Initial findings suggest that adolescents may have greater potential for immune reconstitution than adults as a result of residual thymic function, which underscores the need for aggressive outreach efforts and access to early effective treatment and has also identified a high prevalence of sexually transmitted disease in this population.

PHYSICAL EXAM, LABORATORY TESTS AND IMMUNIZATIONS

Physical examinations for adolescents should follow guidelines for adults, however, providers should use Tanner staging of puberty (characterizing breasts, genitalia and pubic hair) to interpret blood values and prescribe medications. (Schneider, 1998) Because sexually active adolescents are at very high risk for STDs, providers should routinely screen with cervical cytology, and for chlamydia, gonorrhea, syphilis, and hepatitis B and C, as well as follow Tuberculosis screening guidelines for adults with HIV infection. Pregnancy testing should be performed when indicated by history or exam findings, but should always be considered with missed menses, abnormal bleeding or development of pelvic pain. Adolescents require more immunizations than adults. (Table 11-3) Since immunizations may briefly boost viral load, they should be

TABLE 11-3: IMMUNIZATIONS FOR ADOLESCENTS
■ Measles, Mumps and Rubella (MMR) booster
■ Diphtheria-Tetanus toxoid (dT) booster
■ Hepatitis B Vaccine (3 in series)
■ Hepatitis A Vaccine (2 in series) (not routine; recommended for males who have sex with males)
■ Influenza (yearly)
■ Pneumococcal vaccine
■ HIB (optional)
■ Varicella zoster vaccine for contacts (not currently approved for HIV+ persons)
<i>Source:</i> Reprinted with permission from: Hoffman ND, Futterman D, Myerson A. Treatment Issues for HIV+ Adolescents. <i>AIDS Clinical Care</i> . Massachusetts Medical Society. Vol. 11:3, 17-24, March 1999.

scheduled on the same day or after viral load measurements. At present, CD4 counts and viral load measurements are interpreted as for adults and used to guide treatment.

HIV TREATMENT

Information from clinical trials is limited since few adolescents have participated in existing clinical trials. Although adolescent trials are under development, HIV and opportunistic infection treatment and prophylaxis recommendations for post-pubertal adolescents currently follow clinical guidelines for adults. Because pubertal changes may affect pharmacokinetics, dosage is based on Tanner staging, rather than age. For example, pediatric dosing should be used for adolescents who have entered/are in early puberty (Tanner stage I/II), while dosing for adolescents in mid-puberty (Tanner III/IV) should be based on whether or not they have completed the growth spurt. Adolescents who have completed puberty, (Tanner V) should receive adult dosages.

Treatment adherence, which is challenging for adults, can be especially challenging for adolescents who struggle with a range of developmental tasks that require them to balance dependence with increasing autonomy. As with any successful work with adolescents, the first step in promoting adherence is establishing a solid therapeutic alliance. Providers must develop a systematic approach that facilitates adherence by addressing four areas of interaction, including building trust, assessing and facilitating readiness, helping teens initiate and practice the new treatment regimen and providing ongoing support for adherence. (Table 11-4) This approach addresses barriers to maintaining a complex medication schedule for adolescents, such as lack of privacy in school, home or residential settings, the need to develop a reminder system, and the incongruity of having a serious illness while exhibiting few visible indicators of disease. For example, the most common reasons for missing medication by youth in a Los Angeles adolescent HIV/AIDS program include: forgetfulness, side effects, the inconvenience of having to take so many pills, and the fact that taking the medication is a continual reminder of being HIV infected. (Belzer, 1998)

AMHARN has designed a multi-level adherence initiative: Project TREAT (Treatment Regimens Enhancing Adherence in Teens) to address medication adherence in adolescents. A monograph describing the model has been developed for providers and is available from HRSA. (Schietinger, 1999) Based on Prochaska and DiClemente's Transtheoretical Model of Change, Project TREAT acknowledges the uniqueness of each adolescent's readiness for treatment. The model has developed specific interventions and materials (video and audio tapes and booklets) for each stage of readiness to facilitate successful adherence. (The Stages of Change are: Precontemplation, Contemplation, Preparation, Action, Maintenance and Relapse.) Practice regimens with vitamins help youth rehearse their medication regimen, while enabling them to problem-solve potential barriers without risking under-dosing. Medications

TABLE 11-4: ADHERENCE: USING YOUR EARS

ENGAGE
<ul style="list-style-type: none"> ■ Establish therapeutic alliance and build trust; goal is active participation by adolescent in all aspects of treatment ■ Address immediate needs (health, housing, insurance, family, and partners) ■ Educate about HIV infection: transmission, disease course and benefits of medications
ASSESS
<ul style="list-style-type: none"> ■ Stage HIV infection ■ Assess mental health and cognitive abilities ■ Assess physical ability to take medicines ■ Assess support systems and disclosure issues: family and friends ■ Assess readiness to begin medications
READINESS
<ul style="list-style-type: none"> ■ Decide with adolescent on regimen that integrates clinical needs with lifestyle — show different pills/combinations ■ Solidify support systems: family and/or treatment buddy ■ Practice chosen regimen with surrogate vitamins; distribute medications into a weekly medication planner, program one-day pill timer with the adolescent ■ Address adherence barriers discovered in practice run
SUPPORT
<ul style="list-style-type: none"> ■ Provide ongoing support with frequent clinic visits and phone contact ■ Acknowledge and address side effects ■ Develop strategies to ensure tolerability and regularity ■ Facilitate interactions with other youth taking medications
<p><i>Source:</i> Reprinted with permission from: Hoffman ND, Futterman D, Myerson A. Treatment Issues for HIV+ Adolescents. <i>AIDS Clinical Care</i>. Vol. 11:3, 17-24, March 1999.</p>

must be integrated into the adolescent's daily routine. Ideally, adolescents should be prescribed a daily or twice-daily medication regimen. Many providers also initiate treatment without using protease inhibitors (PI); these are incorporated into later regimens after the adolescent has demonstrated effective adherence, to avoid risking potential cross-resistance to PIs.

PSYCHOSOCIAL ISSUES

The Adolescent AIDS Program has identified five key issues that adolescents with HIV/AIDS must address in coping with their changing health status. These include: 1) receiving an HIV diagnosis; 2) disclosing an HIV status to parents, partners and others; 3) coping with HIV disease; 4) becoming symptomatic; and 5) preparing for death. (Kunins, 1993)

1. **Receiving an HIV Diagnosis:** Providers should instill a sense of hope and encouragement when giving adolescents an HIV diagnosis. Asymptomatic youth must learn to balance healthy denial and preoccupation with HIV infection. Concrete thinking makes it difficult for some youth to integrate the concept of disease latency and

asymptomatic infection. Support is essential in helping youth integrate this life changing information. Individual and peer group interventions with psychologists and social workers can help facilitate adjustment. Psychotropic medication may be needed to manage pre-existing psychiatric problems and for anxiety and depression that may accompany the diagnosis.

2. **Disclosure of HIV Status:** After learning their diagnosis, adolescents must decide who to inform and when to disclose their HIV status. Telling their parents is difficult for many adolescents who fear losing their love and support. Fear of rejection and loss of confidentiality is also a concern in disclosing to sexual partners. Providers should offer to help with disclosure and offer guidance in determining when it is safe and appropriate for the youth to disclose her HIV status. Role playing and working through scenarios ahead of time can help the adolescent manage potential fears and concerns.
3. **Coping with HIV:** Adolescents also need guidance in learning how to interpret changes in their viral load and CD4 counts. Since fluctuation in results may cause some youth to panic, providers can help by explaining that variation is common and significant changes will not prevent them from leading satisfying and productive lives.
4. **Becoming Symptomatic:** The appearance of HIV-related symptoms can be especially disturbing for adolescents who may have only superficially acknowledged their HIV status. For some youth, becoming symptomatic may encourage them to fight HIV and may enhance treatment adherence and self-care. Others, however, may feel overwhelmed and may lose their motivation to live. When symptoms occur, providers should explore their meaning, correct misconceptions about their significance and ensure that adequate services and support are available.
5. **Preparing for Death:** Many adolescents have limited experience with death and have naive perceptions about what to expect. Introducing the topic by talking about living wills and health care proxies before HIV becomes too advanced is a practical way to help youth begin to deal with issues related to death. When clinically appropriate, providers can help adolescents explore their feelings about dying by discussing options for dying in the hospital or at home, talking about funeral or memorial services, and exploring child custody or permanency planning with adolescent parents.

MENTAL ILLNESS AND SUBSTANCE USE

Mental illness and substance abuse are important co-morbidities for HIV-positive adolescents. Accurate screening and diagnosis are essential in helping adolescents cope with their disease and successfully maintain their treatment regimen. Case studies of adolescents and young adults with HIV indicate a

high prevalence of depression, bipolar disorder and anxiety, often pre-dating their HIV diagnosis. Similarly, many adolescents with HIV report alcohol and drug abuse. Of adolescents in the REACH study, 14% percent of females and more than 25% of males report weekly use of alcohol during the past three months. During the same period, 7% of females and 20% of males reported using hard drugs. (Rogers, 1998) In addition, as already noted, a high proportion of HIV+ male and female youth report childhood sexual abuse. (See Chapter I on Epidemiology and Natural History) which has many psychological and behavioral sequelae, including depression, post traumatic stress disorder, substance abuse, suicidality and risk for HIV infection.

III. SUMMARY

The high risk of adolescent females for HIV infection makes the development of realistic prevention programs a vital necessity. This includes wider availability of prevention skills building and the routine offering of HIV counseling and testing to sexually active teens in all programs that provide adolescent care. While most youth will not receive services in adolescent programs, services can be readily adapted to provide a “youth-centered” approach, by such basic accommodations as offering flexible hours and low or no payment for services and care as well as providers who are knowledgeable about adolescents. Relevant clinical trials should be made available to adolescents, and there should be wide dissemination of information to health care providers about providing adolescent-related HIV care, such as use of Tanner staging for assessing test results and determining appropriate dosage. Youth at high risk for HIV should be identified and engaged in primary care as soon as possible and outreach programs are an important component for programs that seek to link HIV-positive youth to care. Adolescents with HIV need intensive individual and group support to maintain health and reduce transmission to others. Health care providers in all settings that serve adolescents need to assist in making services visible, flexible, affordable, confidential, culturally appropriate and available for all adolescents.

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