Making the Grade

Quality examination and care of adolescents with HIV

September 1, 1998 By Donna Futterman

The following guide was prepared for POZ by Donna Futterman, MD, director of the Adolescent AIDS Program (the nation's largest) at Montefiore Medical Center in New York City.

Adolescents represent a growing proportion of those newly infected with HIV. Recent studies have shown that a quarter of people with HIV in the United States were infected before age 22, and one to two teenagers become positive each hour. (In this group, people of color are twice their proportion of the overall population.) Yet adolescent HIV providers report that few of these youth are receiving care since most remain untested and thus unaware of their diagnosis. Adolescents' reactions to learning of HIV infection vary, depending on their stage of illness, developmental level, emotional maturity and life history. Caregivers can best help the newly diagnosed teenager by correcting misconceptions, alleviating guilt and providing emotional support. Establishing a rapport with the teenager is key and can be promoted by addressing issues of confidentiality and when and if to disclose to parents, partners and friends.

Medical care alone is inadequate for most youths with HIV. It is important to formulate with the client a coordinated plan including medical treatment, psychosocial care and support, nutrition, recreation, work and school life and financial support. At Montefiore, our "one-stop shopping" setup (multidisciplinary staff plus specialist-consultants to maximize services) is very helpful for adolescents, who find negotiating the medical/social service system difficult and intimidating. Where such an approach is not possible, the primary-care provider should carefully coordinate the client's medical treatment with other care programs.

Adolescents (even without HIV) are not well-served by the current U.S. health care system: Many teens have to rely on hospital emergency rooms for care, and nearly half of adolescent visits with doctors last less than 10 minutes. For youth with HIV, research on the ways their disease patterns and treatment responses differ from adults has only begun recently; the NIH-funded AMHARN study is enrolling in 13 cities. Hopefully, more care providers will incorporate adolescent-specific HIV prevention, screening and direct medical care for HIV positive youth into their practices.

PROCEDURE: MEDICAL HISTORY

HOW TO DO IT: Include questions about possible seroconversion illness (a flulikesyndrome),

fatigue, fever, night sweats, sinusitis, lymph node enlargements, skin lesions or rashes, weight loss or failure to gain during the pubertal growth spurt, and past or present illnesses, including sexually transmitted diseases (STDs), recurrent pneumonia and tuberculosis. Ask females about vaginal candidiasis, menstrual and pregnancy history. If the teen might have been infected perinatally, include history of parents' drug use, HIV-related risk behavior orknown HIV infection.

PROCEDURE: PSYCHOSOCIAL HISTORY

HOW TO DO IT: Explore the teen's ability to cope with HIV, their level of disclosurein the context of their current living situation, work and schoolcircumstances and psychological status (history of past or present depression, anxiety, suicidal thoughts or attempts, hospitalizations or treatments). Ask sexual questions carefully andclearly, using common terms and distinguishing sexual behaviors from orientation—ask about the gender and number of sexual partners, ratherthan "Are you gay?" Ask about certain safer sex practices andreproductive desires and plans. A complete drug history should dealwith the full range of licit and illicit substances (including alcohol) and needle-sharing.

PROCEDURE: MEDICAL EVALUATION

HOW TO DO IT: Besides standard physical exam, determine Tanner stage of sexual maturity, perform a rectal inspection and exam, do a pelvic exam on females who have had intercourse or are over 18 and a genital exam on all males. Perform standard exams of neurological function, mental status and abstract thinking; determine patient's level of cognitive understanding to facilitate treatment planning. Have lab tests done for immune function and viral load measures, complete blood count,chemistry as well as standard urinalysis, TB tests and STD screens. Refer annually for nutritional assessment and counseling. Pregnancy test if needed.

PROCEDURE: IMMUNIZATIONS

HOW TO DO IT: Pneumococcal vaccine, annual influenza shots (if condition allows), age-appropriate DT (diptheria and tetanus), MMR (measles, mumps andrubella), HIB (hemophilus influenza B) immunization and hepatitis Bvaccine for those without immunity.

PROCEDURE: MONITORING

HOW TO DO IT: Use Public Health Service guidelines to assess immune function, viral load and degree of symptomology, but recognize that while the course ofinfection in behaviorally infected adolescents is generally similar to that in adults, unique immunological features may be present, and the course in perinatally infected youths is unknown. Because adolescents need more support than adults, schedule more frequent appointments, quarterly being the minimum. Staff should phone patients to remind themof appointments, and for referrals, give clear directions, travel fare or even send a staff person with them on the first appointment.

PROCEDURE: TREATMENT

HOW TO DO IT: Use dose-adjusted protocols for medications. Adolescents in Tanner Stages I and II should receive pediatric dose schedules; in Stages IV and V, adult dose schedules, regardless of age; and inStage III, adult dose schedules with more careful monitoring. Recognize the unique developmental challenges of treatment adherence inadolescents. Consider using the EARS protocol: Engage: Ensure that teen is engaged with provider and understands their own health issues by building a therapeutic alliance between provider and adolescent; Assess: Perform medical assessment of treatment needs and, with teen, determine interest/readiness for medications; Regimen: Select simplest regimen (twice-a-day schedules work best); determine with teen which regimen will fit best with their lifestyle; Support: provide ongoing support, recognizing that adherence is difficult to sustain.

PROCEDURE: PSYCHOSOCIAL CARE

HOW TO DO IT: All youth with HIV need support: Encourage client to attend group sessions for support and coping ideas. Help client enroll in entitlement programs and social services, including substance abuse treatment and psychotherapy. Runaway and homeless youth may need basic food and shelter. Provide education about the importance of safer sex and, if relevant, clean needle use.

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