Talking About AIDS with Young Children
Marcia Quackenbush, MS and Sylvia Villarreal, MD

Although some may question whether children under the age of ten are aware of the AIDS epidemic and have concerns about it, the spread of HIV has meant that even children must confront the fact that they know people with HIV infection. Health care workers, including mental health practitioners, should prepare themselves to address the questions of young children and their parents about AIDS and HIV infection. Others who work with young children and their families— including teachers, childcare workers, religious leaders and community leaders—should consider these issues as well.

Adults may hesitate to discuss AIDS with young children for a number of reasons. They may find related issues, such as sexuality, drug use, illness and death, to be complicated, difficult and embarrassing to explain. In addition, some adults may feel these topics are inappropriate for young people. Finally, most adults want to protect young children from information that may cause anxiety, alarm or distress.

Children are naturally curious about the world around them, and they have questions—often difficult ones—about the elements of that world. Children as young as four or five years of age hear about AIDS on television programs and advertisements, or they overhear adult conversations about AIDS. Older children sound out the word in newspaper headlines as they learn to read. Children hear stories about the disease from peers at school and create games about it, for example, “AIDS tag,” in which the person who is “it” tags others and “gives them AIDS.” Some children know people with AIDS. Some have uncles, parents or siblings who are seropositive. Some children are themselves at risk of infection.

In all these instances, children have questions about HIV disease. Health care workers can play an important role in ensuring that children receive appropriate AIDS information. Providers may work directly with young children, they may work with parents of young children, or they may be asked by educators to suggest policies and guidelines for educating young children. This article outlines what children need to know about AIDS and what questions they ask about it, and offers health care workers insights into the best ways to present this information.

What Young Children Need to Know

The U.S. Centers for Disease Control (CDC) recommends that AIDS be addressed as part of a comprehensive school health education program for very young children and not as an isolated topic. The CDC advises that such a program include the following themes: 1) AIDS is a disease that causes some adults to get very sick, but it does not commonly affect children; 2) AIDS is hard to get and you cannot get it just by being near or touching someone who has it; 3) scientists are working hard to find a way to stop people from getting AIDS and to cure those who have it.

While these guidelines are valuable, they define only the minimum of appropriate information for young children. Health and mental health professionals need not interpret the CDC as limiting AIDS information to these three points alone. Most children who have heard about AIDS will have questions that require additional information presented in a simple and age-appropriate manner. Clear and direct responses to such questions will help decrease the anxiety children may be feeling about HIV. Often, children whose questions are answered directly are reassured and forget about the issue entirely. Young children ask a range of questions about AIDS. Their questions may reflect their curiosity: “What is AIDS?” “How do people get it?” “What is sex?” “Why don’t doctors help people with AIDS get better?” “What is it like to die?” Or they may reflect their anxiety: “How do children get AIDS?” “If I am bad, will I get AIDS?” “Will my mom get AIDS?” “Can I get AIDS from getting a shot at the doctor’s?” “Will my dog get AIDS?” “Does AIDS hurt?” Other resources offer more in-depth explorations of these questions. If adults listen to such questions and respond accordingly by offering information when children are curious and reassurance when they are anxious, children will ask questions with comfort and confidence.

Parents and providers may wonder what are “age-appropriate” answers to such questions. To determine this, adults must consider the child’s age, maturity and past experience with the subject. In general, however, as long as answers are clear and straightforward, children will not be harmed by information about HIV transmission.

Children up to age three are unlikely to ask AIDS-specific questions at all. Their cognitive language skills are usually not developed enough to formulate them. From about four years on, however, such questions may arise. The younger or less sophisticated child should be given a straightforward but simple answer: “AIDS is a disease, a sickness, that some people get. I wonder what you have heard about it?” Questioning a child in this way offers an opportunity to assess a child’s knowledge and level of curiosity.

The older or more sophisticated child—one living in a high-incidence community or one who has discussed health or sexuality with parent or provider before—may benefit from more in-depth responses: “AIDS is a serious disease. Fortunately, it is continued on page 2
a hard disease for people to get, and by being careful, people can be sure they don't get it. Do you know how people get AIDS?"

Health providers who work with parents of young children should ask their clients if they need guidance about how to provide information about AIDS to their children. For most children, AIDS is only one part of their complex world. Parents may follow the CDC guidelines mentioned above and provide AIDS education in the context of other information about health, sexuality and drug use.

Providers may suggest that parents establish an ongoing dialogue with their children about these sensitive issues. Most children enjoy thought-provoking discussions with adults who take them seriously. These discussions offer parents a remarkable opportunity to engage in regular talks with their children about moral values, self-concept and self-esteem, and to encourage openness and honesty within the family.

**Children with Special Circumstances**

Special circumstances may call for other kinds of interventions. Some children have friends or family members who are known to be at risk for AIDS or who have HIV infection. Other children are at risk for infection or are infected themselves. These children may raise questions about the progression of HIV disease, the pain it causes, the risk of contagion or the likelihood of death. Neither parents nor providers should be dishonest or evasive when answering children's questions. However, answers should be considered carefully to avoid unnecessarily burdening children. Children may feel concerned about events over which they have no control, but for which they may feel responsible. For example, a child might feel responsible for having caused his or her father's HIV infection.

Concepts of the past, present and future are difficult for young children, and the distinctions between long and short periods of time are not always clear to them. In general, children close to persons with HIV infection should be given messages of concern and hope, for example, "Yes, our friend Bob is very sick; we are hoping he will feel stronger soon." If young children specifically ask about the likelihood of a person's dying, they should be given honest answers. Parents might respond, "Many people with AIDS die, and Bob may die too; but we are still hoping that the doctors will be able to figure out how to help him get better."

Deciding when to discuss, with a young child, the coming death of a family member or close friend is difficult. Such a talk might take place when it is clear the illness is in its terminal stages and that death will occur within a few weeks or less. To initiate discussion with young children much earlier than this may confuse and trouble them unnecessarily.

For some children who have family or friends with HIV infection, adults may feel it is best to speak of the disease in general terms without making reference to HIV itself: "Mother is very ill," or, "Our friend Bob has an illness that could become very serious." However, few families avoid using the words "AIDS" or "ARC" when adult friends are visiting, when relatives call on the telephone, or when nurses or doctors make home visits. Children overhear these words and conversations and have some understanding of what they mean. Because of the special stigma associated with HIV infection, it is best for children to hear information about HIV stated without euphemism from a family member. Providers may encourage parents to speak to their children about the illness and may coach them on appropriate ways to discuss it. Family therapy sessions may be useful as well, especially when the ill person is particularly close to the child or children in question.

Children in foster care may have special concerns. In urban settings, these children often come from homes where one or both parents are known to have used intravenous and non-intravenous drugs. In some cases, the mother of a foster child may have been prosecuted for prostitution. These children may have confused notions about the relationship between drug use, sexual activity and HIV infections, but many young foster children are sophisticated enough to understand that some relationship does exist. Usually, these children already face tremendous turmoil and ambiguity in their lives; further concerns about their parents', or their own risk of HIV infection compound these difficult circumstances. Therefore, providers working within the foster care system must be alert to children's anxieties concerning AIDS. Foster parents should be educated about these possibilities as well, and helped to develop appropriate responses to children's questions or statements about AIDS.

Providers must also consider children who may be at risk for or be known to have HIV infection themselves. Each family and each child will handle this circumstance differently. A broad guideline is appropriate: prolonged anticipation of pain, disability or death is not helpful for young children. HIV-infected children who feel vigorous and healthy do not need extensive details about the possible progression of their illnesses; hopeful and positive messages are most helpful.

If there are obvious signs of physical decline, a child may want to discuss feelings and thoughts about the illness. Counselors and parents should respond to these feelings by offering support and honest answers. If the child does not raise these issues, parents and counselors themselves may encourage this interchange. Providers can help parents monitor their child's status and suggest appropriate times to raise specific points of information. Family therapy can offer support to both parents and children during this process.

**Working Directly with Children**

With most child clients, providers can use the same principles and guidelines concerning AIDS information that they would use with other sensitive issues, such as sexuality, health and death. When there is an open and comfortable relationship between child and provider, questions of this nature usually arise naturally in the course of treatment. When this happens, providers can offer answers in an age-appropriate, straightforward manner.

For children with the special concerns discussed earlier, providers may need to take a more active role in eliciting concerns about AIDS and in providing appropriate responses. In addition, providers working with children individually should consider special family sessions in these circumstances.

**Conclusion**

Children want and deserve accurate and age-appropriate information about AIDS. They look to their parents and teachers to offer them guidance in dealing with an issue about which they probably have become familiar and may be afraid.

Teaching young children about AIDS may seem less essential than the other tasks that face those dealing with the epidemic, particularly since such education has aroused controversy. In fact, professionals working with AIDS can have a significant impact on the epidemic by reassuring children and helping them define what is reasonable and what is unreasonable about their fears of HIV infection, and by ensuring that as children get older they understand the ways to avoid HIV infection.

Marcia Quackenbush, MS is the Director of Training at the UCSF AIDS Health Project. Sylvia F. Villarreal, MD is Assistant Clinical Professor of Pediatrics at the University of California San Francisco and the Director of the Kempe High Risk Clinic and Early Childhood Services. They are the co-authors of *Does AIDS Hurt? Educating Young Children about AIDS.*

**REFERENCES**


Counseling High-Risk Youth

Ken Dunnigan, MD, MPH

Widespread experimentation with sexual and drug-using activity is common among adolescents and places them at extreme risk of acquiring and transmitting HIV. For this reason, adolescents comprise a growing population of people infected with the virus and present a considerable challenge to counselors attempting to facilitate changes in high-risk behaviors. Among those adolescents at greatest risk are: homeless youth and runaways; youth involved in the drug culture; adolescents who are out of school; sexually and physically abused youth; adolescents involved in prostitution; incarcerated youth; and youth who are members of sexual minorities.

The goal of HIV prevention counseling for adolescents, as for other populations, is to decrease unsafe sexual activity, needle sharing, and the use of substances that often lead to these behaviors. The counseling model presented here is based on the notion that behavioral change is the product of a counselor-client relationship that emphasizes personal empowerment rather than social control. The presentation of HIV information, no matter how compelling, is presumed to be an adjunct to this process and not a goal in and of itself.

The process of counseling high-risk adolescents involves at least three steps: assessing the cognitive development of the client and the factors that promote risky behaviors, understanding the factors that may encourage changes in risky behaviors, and defining the counselor's own feelings about the issues involved.

Assessment of Risk Factors

Cognitive development, a universal developmental process in adolescents, represents the maturation of the ability to reason. During early to mid-adolescence most youths change the way they reason from a concrete perspective, characterized by expedient decisions with immediate outcomes and immediate gratification, to a more abstract perspective. The abstract perspective is defined by the ability to conceive future possibilities, to contemplate an array of options, to predict the consequences of actions, and to see oneself through the eyes of others.

Determining a client's stage of cognitive development is the first step in establishing communication. It is unreasonable and ineffective to approach a concrete thinker using abstract reasoning. Note that the rate of cognitive development varies from person to person but may be slower in individuals, such as homeless youth, whose survival depends upon immediate actions.

Counselors also must develop an understanding of the factors that perpetuate high-risk behaviors. Adolescents universally believe in their own invulnerability and immunity. For some adolescents, risky behavior may serve to establish autonomy from parents and other authority figures, and may be essential in gaining the acceptance of a peer group that is increasingly important to the adolescent's self-esteem.

For some youth, high-risk behavior may reap rewards of money and fame—powerful reinforcers, particularly if rewards are not available elsewhere. Youth may ignore or repress the negative emotional consequences of risky behaviors in order to obtain these immediate rewards. In doing so, they make it more acceptable for themselves to continue these behaviors. A person may avoid certain behaviors when thinking rationally but embrace them when under the influence of drugs or alcohol. Finally, interventions may be rejected if they focus only on high-risk behaviors and not on how these behaviors are related to an adolescent's other needs, for instance food and shelter.

Promoting Behavior Change

The chances of changing a youth's behavior from high-risk to low-risk will improve if the adolescent perceives the change as rational and relevant, and if low-risk behaviors have peer support, appeal to an adolescent's emotions, and appear to confer some immediate advantage. For these reasons, counselors must be willing to negotiate behavioral goals. It may be easier to institute a lower-risk behavior, for example, condom use, if the counselor accepts the reality of a high-risk lifestyle, such as prostitution.

The way in which the adolescent perceives the counselor and the change is also important. Change is more likely to occur if adolescents believe they are taking the initiative rather than acquiescing to counselor pressure or social control, and if the adolescents perceive the counselor as knowledgeable, non-judgmental, trustworthy and "cool." Counselors should become familiar with the ways adolescents live and visit youth in their own environments, including the streets.

Counselors should be flexible and offer adolescents a range of counseling opportunities, including group sessions. For some youth, the involvement of friends and peers enhances the counseling experience. For others, the participation of people with HIV infection may evoke an emotional response that may be the most powerful stimulant for reducing risk.

When working with adolescents, counselors should be aware of their own values and prejudices regarding clients and their behaviors, particularly in terms of sexual orientation. Adolescents are adept at exposing the vulnerability and insincerity of adults, and counselors should never risk dishonesty. It is important for counselors to be comfortable when talking about sexual and drug-related issues and knowledgeable when discussing HIV infection and risk behaviors. Counselors must know and use appropriate language and should consider using humor to help establish credibility and bonds with adolescents.

Finally, a counselor's modeling of behavior—by disclosing sexual orientation, a history of chemical dependency or HIV status—can be a powerful learning tool and can help establish rapport.

Success in counseling depends upon the abilities of counselors to identify the feelings that arise for them during counseling sessions, and to establish and maintain boundaries and trust. Common feelings that may arise include: adopting a parental view of adolescent clients, becoming sexually attracted to clients, feeling discomfort with members of certain ethnic or sexual minorities, being judgmental about a client's way of life, for example drug dealing or prostitution, and feeling frustrated or angry about an adolescent's resistance to change. Adolescents at highest risk of HIV infection are likely to challenge their counselors' abilities to build trust without getting ensnared in these clients' lives. Counselors faced with emotional issues that are difficult to resolve should discuss these feelings with colleagues and not with clients. If the issues remain unresolved, the counselor should refer clients to co-workers.

Conclusion

When working with high-risk adolescents, counselors should continually reappraise their expectations of what constitutes a successful outcome. For adolescents at highest risk, success may be a small change: the development of rapport between provider and client or the beginnings of personal empowerment and trust. If counselors retain expectations that are too high or unrealistic, clinical services may be seen as ineffective and adolescents may be perceived as resistant to change. Providers need to find a balance between the ideal and what can actually be accomplished in the context of a client's environment and way of life.

Ken Dunnigan, MD, MPH is the Medical Director at the Larkin Street Youth Center and the District Health Officer at Health Center Number One in San Francisco.
BRIEFS

In Review

STATS: Students Teaching AIDS to Students. Grant Haven and Jeffrey Stolz. American Medical Students Association (AMSA) to health and AIDS education. It outlines a program for medical students to teach adolescents about HIV infection. Medical students are in an especially good position to conduct this kind of education: adolescents may perceive them as having the positive authority of doctors. At the same time, teenagers may see them as being more accessible than their older colleagues.

The manual includes a curriculum guide, pre- and post-tests, educational games and exercises, a slide presentation designed for parents and school board members, and an outline for creating a speakers bureau. The eight games and exercises provide a creative mechanism not only for reinforcing the educational material but also for exploring the social issues surrounding HIV infection. STATS information is designed to be presented over two one-hour class periods.

The authors have incorporated in the program a flexibility that allows the curriculum to be age-appropriate and sensitive to community standards, and that encourages users to create a program that works for them. Although STATS is intended for use by medical students, the program could be adapted for others who educate youth, including teens involved in peer education. The program has been implemented in over 40 schools so far.

Recent Reports

Update on Experimental Treatments. Two articles in the Annals of Internal Medicine (February 1, 1988) offer new data on dextran sulfate and dideoxycytidine, experimental treatments that interfere with HIV replication.

In a preliminary study of efficacy, researchers from the University of California, San Francisco and from Ueno Chemicals Industry in Osaka, Japan found no evidence that oral dextran sulfate, which is not easily absorbed by the body, is effective in human subjects. They state that further study is merited since there were no significant side effects at the doses used and the drug, which blocks the binding of HIV viral particles to target cells, has been an effective viral inhibitor in laboratory experiments.

In the study, dextran sulfate was administered three times a day over eight weeks in total daily doses of 900 to 5400 mg. Thirty-four patients were enrolled in the study, most of whom were gay men with persistent generalized lymphadenopathy. Dideoxycytidine (DDC), a drug closely related to AZT both chemically and in anti-viral action, lowers p24 antigen levels significantly at high doses (.06 mg/kg of body weight and .03 mg/kg), according to researchers from Stanford University, University of California, San Diego, University of Miami, and Harvard University. At these doses, however, DDC has negative side effects, including peripheral neuropathy. At .01 mg/kg, peripheral neuropathy was less severe, and at .005 mg/kg, it was only occasionally present. At these lower doses, p24 antigen suppression was less consistent, although it was more likely to occur in subjects with ARC versus AIDS.

The researchers studied 61 patients with AIDS or advanced ARC. They conclude that lower doses of DDC deserve further study, and suggest the possibility of alternating the use of DDC and AZT to give patients respite from the side effects of each of these toxic drugs.

Manifestation of AIDS among Children. Children are affected differently by HIV infection than are adults, according to National Cancer Institute researchers who discuss current problems and therapeutic considerations in treating infected children (The American Journal of Medicine, Suppl. 2A, August 29, 1988).

Of the 1,000 children with documented cases of AIDS, about 80 percent were born to a parent with HIV infection or one who was at risk of being infected, about 13 percent were infected through blood transfusion, and about 5 percent through treatment for hemophilia. Before September 1, 1987, many cases of pediatric AIDS were undiagnosed because CDC criteria defining such cases were too restrictive. Children with AIDS develop most often chronic viral infections and pneumocystis carinii pneumonia. Recurrent bacterial infections, such as meningitis, sepsis and pneumonia, are more common among children than adults. Neurologic complications, caused most often by HIV infection and which can cause dementia, are common among infants.

Diagnosing HIV infection in children younger than 15 months, particularly those younger than six months, is difficult because infants retain much of their mothers' immunological characteristics. In addition, opportunistic infections that may indicate HIV infection occur later in children than in adults. Children with opportunistic infections in their first year seldom live beyond the second year of life. Few congenitally infected children remain asymptomatic for longer than three years. CDC figures indicate mortality among children with AIDS to be more than 61 percent. Preliminary reports of AZT use show it to be as effective among children as among adults (including neurologic improvement).

Next Month

Discussions of the effects of HIV infection on people with hemophilia are usually limited to recitations of epidemiologic data showing that hemophiliacs are among those people most likely to be infected. In the March issue of FOCUS, Margaret V. Ragni, MD, Assistant Professor of Medicine at the University of Pittsburgh and the Director of the Hemophilia Center of Western Pennsylvania, offers an overview of the medical and psychosocial aspects of hemophilia and HIV infection. She discusses hemophilia and its management, the manifestations of HIV infection among people with hemophilia, the risk of transmission of HIV from people with hemophilia to their spouses, and the study of HIV infection in the hemophiliac population.

Debra DeMaio, ACSW, a clinical social worker at the Hemophilia Center of Rhode Island at Rhode Island Hospital in Providence, explores the HIV counseling issues that arise for children, adolescents and adults with hemophilia, and the psychosocial and behavioral responses of people with hemophilia to HIV infection.