Counseling for HIV-Infected Adolescents
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Teenagers are not simply “older children” or “younger adults”: adolescence is a unique developmental phase that occurs as one proceeds from childhood to adulthood. More changes occur between the ages of 10 and 20 than during any other period, and these may include dramatic shifts in biological and cognitive functioning. Psychosocial development shows even greater diversity as adolescents develop their own identities, experimenting with an array of sexual, moral, vocational, and political paths. This diversity frames the experience of adolescents with HIV disease, which complicates this already challenging period.

For seropositive adolescents, HIV infection can be a terrifying and mysterious intrusion into life, and teenagers react to HIV infection in a variety of ways. As with HIV-infected adults, seropositive and at-risk adolescents form a diverse group, one for which a single, formulaic approach to treatment and care is sure to result in failure. Similarly, reactions to HIV disease depend upon each youth’s stage of illness, life history, social and familial support system, and levels of cognitive development, moral development, emotional maturity, and self-acceptance.

In response to these factors, therapists should pay special attention to two issues: level of understanding and rapport. First, while many adolescents, particularly older ones, are psychologically sophisticated, therapists should assume, until proven otherwise, that clients have not attained mature levels of abstract thought. Second, as with adult clients, rapport with counselors is crucial to therapeutic success. Achieving rapport is especially challenging since teens may see therapists as authority figures and feel that they have been forced into talking with them about something that they find terrifying and hateful.

This article examines four specific issues that require special emphasis when attending to the needs of adolescents: responding to the news of infection, disclosing infection status, coping with disease progression, and approaching death and dying.

Responding to Seroconversion
The only generality that can be made about adolescents is that each will, either overtly or covertly, have a strong reaction to the news that he or she is HIV-infected. Reactions may include anger, guilt, anxiety, depression, suicidal or homicidal ideation, numbness, or terror, and, in all likelihood, all of these will be present to one degree or another.

Adolescents may have difficulty confronting HIV disease for reasons similar to adults. Unlike most adults, however, many teens—particularly younger ones—have difficulty, in the absence of overt signs of infection, understanding and believing that they are HIV infected. This can be frustrating to clinicians in that it adds to the difficulty of motivating changes in risk-related behaviors and ensuring compliance to medical regimens and prudent care.

Adolescents who do not fully acknowledge the implications of being HIV infected may not simply be confused, oppositional, or in denial. Many teens have not yet achieved the cognitive maturity level whereby full acceptance and understanding is even possible. The ability to think in abstract terms occurs slowly and idiosyncratically during the adolescent years. Until the capacity for mature thought is achieved, youths frequently
perceive themselves to be immortal, are predominantly egocentric, and view the world in very concrete terms. Some adolescents may understand the implications of being HIV infected but may still be in denial about their health. While denial can be a useful defense that keeps intense anxiety out of awareness, it can also be destructive if it results in missed clinic appointments or inconsistent medication compliance, avoidance of others with HIV disease, or intermittent periods of acute anxiety. When these situations occur, it is important to gently re-orient youths to the realities of HIV disease, and to assist them in integrating seropositivity with other aspects of their sense of self.

During this period, adolescents may need the more active and concrete support of health care advocates in addition to the emotionally supportive care therapists normally provide to HIV-infected adults. Negotiating medical care is an especially monumental task for adolescents, for whom the health care system has not been designed. Hooking adolescents into appropriate medical care, helping them make appointments, assisting with applications for entitlements, and explaining medical jargon are important components of adolescent care. It is particularly important for practitioners used to working with populations of adults who have become sophisticated about HIV disease to remember that, despite the wealth of information available in some communities, most adolescents are likely to be at the beginning of the learning curve. What may be common knowledge or basic information to most adult clients may be new to HIV-infected youth, especially if they are disenfranchised from the mainstream due to homelessness, ethnicity, or sexual orientation.

Teenagers also tend to be less deliberate in what they do or say and are less likely to follow through on actions; their impulse control and frustration tolerance may not yet be developed to the point where they can behave in a manner that ultimately serves their best interests. It is vital that caregivers be ready to provide adolescents with a more mature perspective and necessary structure when the capacity to provide it for themselves is not operating. They can do this by helping adolescents to verbalize feelings and explore the consequences of planned actions. This approach will discourage acting out in potentially self-destructive ways—such as suicidal gestures, revenge towards others, or refusal to keep appointments or to take medications—behaviors that may function to camouflage feelings of fear, anger, and despair.
Finally, it is critical during this period to assist adolescents in disentangling reality from fantasy and to correct distortions stemming from internalized fears and judgments. For example, it can be difficult for teenagers to make the fine distinctions required to understand that the desire to engage in oral, anal, or vaginal intercourse did not lead to infection; the act of sexual intercourse without barrier protection did.

**Disclosing Infection**

The issue of when and to whom to disclose the fact that they are HIV-infected is one of the first major decisions adolescents must face. Many adolescents face greater pressure to disclose because they are more likely than adults to live with family, who assume an entitlement to this knowledge, and because they are less likely than adults to have learned the resourcefulness necessary to access help. In addition, disclosure to family may be potentially more difficult among adolescents because families are legally and socially able to exert greater control over minors. Like adults, many youths fear the loss of support from family, friends, and present and future sexual partners.

For some adolescents disclosure is two-fold. Those adolescents who became infected through male-to-male or female-to-female sexual activity effectively “come out” about homosexual experimentation or orientation at the same time they disclose HIV infection status. Some support systems can tolerate the reality of HIV disease, but cannot tolerate homosexuality. Sometimes these completely separate concepts become psychologically fused. In working with gay or lesbian adolescents, it is important to continually stress that being HIV-infected is not a function of sexual orientation. Heterosexual adolescents face similar issues of disclosure.

Telling a parent may be more difficult than telling a friend. The decision should be based on a thorough exploration of potential consequences. Are the parents likely to support or reject the adolescent?

Will they provide emotional and financial support? Are they capable of providing such support? Does the adolescent want to tell his or her parents, or does he or she feel compelled to do so? If a youth decides to tell a parent, it may be useful to role-play the conversation to help him or her prepare for parental reactions. It may also help the adolescent for the therapist to be with him or her during the disclosure, and to have follow-up meetings to help the family adjust to the news. Referral for family therapy is another good option.

It is worth mentioning that while the involvement of a supportive adult is ideal, informing parents may not always be in the best interests of adolescents and may even be dangerous. This is particularly relevant in cases of runaway or throwaway youth.

**Coping with Disease Progression**

Teenagers tend to think in a concrete manner, to believe that a fixed T-helper cell number implies a specific serious illness or impending death. The idea that T-helper cell counts are a barometer of immune system function is a difficult concept for adolescents to grasp. Therefore, T-helper cell counts should not be discussed in an isolated manner; such a discussion should always be in the context of current medical status and level of functioning. To help adolescents negotiate these issues, practitioners should focus on the concept of the spectrum of HIV-related illnesses, and not on fixed cutoffs for disease diagnosis and progression, explain the usefulness of T-helper cell counts as guidelines for medication and prophylaxis of opportunistic infections, and explicitly state that many people with low T-helper cell counts can continue to maintain active, healthy lives.

It is equally essential to provide a safe, non-judgmental forum for teenagers to voice fears and concerns if and when T-helper cell counts fall, particularly since they may be doing everything they can to stave off such a deterioration of health. In general, adolescents are less able to permanently integrate this information without intense fear, anxiety, and defensive-ness distorting their perceptions of reality, and they often require repetition of basic facts regarding their illness. In response, therapists should repeatedly explain concepts in different ways.

As adolescents develop symptoms, they may be jolted from the denial about the severity of their conditions. Therapists should fully explore with these patients the...
subjective meanings and implications of each symptom and should seek to validate these impressions while simultaneously correcting misconceptions. In particular, adolescents may need help in putting symptoms into perspective, to understand that not all infections are equally serious and not all are AIDS-defining.

If hospitalization is required, inpatient visits enable the continuity of the clinician's relationship with the client and minimize feelings of abandonment and loneliness. Clinicians should deal directly with topics such as adjusting to decreased levels of functioning or adhering to rigid schedules of medication. Above all, it is important for therapists to help clients integrate feelings of vulnerability to HIV disease with feelings of hope.

Approaching Death and Dying

Perhaps the most agonizing area of adjustment for clients and counselors alike involves confronting the possibility of death. Adolescents, many of whom lack the capacity for abstract thought, have fixed ideas about death, and this lack of flexibility may raise anxiety. As with adults, teenagers may respond to this anxiety with subtle verbal and nonverbal cues. Therapists should be particularly aware of cues such as tearfulness, anger, silence, or anxious fidgeting, which may indicate discomfort.

Discussions of death should be preceded by a thorough exploration of any preconceived notions about dying. From that base, providers can gently and compassionately help adolescents prepare for death.

Avoiding euphemistic terms such as “passing away” communicates comfort in discussing death directly. Asking adolescents if they have thought about death, plans and preferences for burial or cremation, and what death might “feel like” are ways of exploring this topic. So too are questions about what adolescents think they will be missing and what will remain “unfinished business” in their lives. Some adolescents may be more at ease writing about or making pictures of their feelings. Discussions about living wills and health care proxies may help more mature adolescents organize their thoughts, confront difficult issues directly, and consider their wishes.

Ironically, this conversation is frequently a relief for adolescents. It may be a topic they have thought about, but have been afraid to verbalize for fear of upsetting family, loved ones, and friends. In keeping silent, teenagers, sensing the discomfort of others, may have actually been taking care of parents and health care providers.

Conclusion

In the best of circumstances, one of the most challenging developmental milestones of adolescence is to master and integrate the inner experience of self with external reality. Teenagers begin to feel in control of their own destinies, and come to believe, rightly or wrongly, that random circumstances do not have undue influence upon the direction and continuity of their lives. HIV disease interferes with this process.

Adolescents must therefore be encouraged to identify areas in which they continue to be powerful and effective. This may be the key challenge to therapists treating adolescents with HIV disease as the situation changes over time from seroconversion to potential death.

References


I am an 18-year-old Latino who is gay, and I'm HIV positive.
I came out when I was 16 years old, but I'd had sex with other men since I was 15. Before I took the antibody test, I didn't talk about AIDS or safe sex. I was afraid if I brought it up I'd be rejected by a sex partner. In the end, no one talked about it a lot. None of my teachers talked about it either; there was no real AIDS education in the classroom.

Testing
The first time I tested I was 16 years old: my results came back negative. I hadn't been infected, so I figured that my sexual activities were okay and I didn't change. I decided to test again, one year later, because two of my friends were testing at the same time. I planned my second test around my vacation, in the spring. I chose a family planning health clinic three cities away from suburbia and my home. I didn't want to run into anyone I knew. I was afraid that I might be positive. But I couldn't believe it when I was.

I cried for a while and shouted, "Fuck! I can't have my own kids." After I calmed down, my counselor directed me to services for HIV-infected youth: a nurse practitioner, a support group, and a case manager. I really didn't want to use the services provided in my county so I went to the neighboring one; I wanted to keep this anonymous from everyone I knew, especially my parents.

Support from Friends
I feel kind of a release when I tell my friends that I am HIV positive. Many know that I am gay but only a few know about the HIV. I'm afraid if I tell more, they'll reject me. Those I do tell are very supportive and caring and want to know if I'm taking care of myself.

Surprisingly, my strongest support for being gay and having HIV has come from the place I never thought it would: high school. High school failed me: the teachers never taught me about AIDS, and because of that I have HIV. My best support, however, has come from two teachers. I speak with them at least once a week.

The support group for HIV positive youth is okay for meeting people who are going through my experience. I'd prefer talking to people I've known for a while because we're friends already, but it's risky because I don't know how they'll react. Luckily, they've all been supportive.

None of my friends has rejected me or acted differently towards me. My homosexuality and HIV status haven't really changed these relationships. Most of the people who offer me support are straight women ranging in age from 17 to 52.

I don't have many gay friends, and...
those that I have don't know I'm infected. I'm closed off from people because I'm afraid they'll reject me for having HIV. You'd think after living through the experience of growing up gay, gay people would realize how hard it is to have HIV disease; but they don't and they run away from you if you have HIV. All my other gay or lesbian friendships have been formed through my support group for youth with HIV or my group for young gays and lesbians.

I haven't told my family that I am HIV-infected. My mother and two of my brothers know I am gay, and telling my mother truly helped me become in tune with my gayness. She has been very nurturing and my coming out has made us closer. My father is from Guatemala, and he would reject me if he found out I was a “joto.” That is one of the reasons I am so happy I will hopefully die of AIDS and not some other disaster. I want my family to learn something from all the hardships I have endured, hardships through which they never helped me. At a time when they are the people I need most, they have chosen to keep their own hate and prejudices alive instead of helping one of their own.

It makes me angry that if our society didn't make homosexuality such an awful thing, maybe I wouldn't have denied to myself that I was gay. Maybe I wouldn't have thought all the sex I began having at 15 was something that never really happened. Maybe I wouldn't have thought you had to be a gay man from San Francisco to get AIDS. All in all, I somehow overcame all the obstacles growing up in suburbia and going to school with so many closed-minded, ignorant people, and now I can actually be my own self.

How it Feels

Most of the time I wonder what did I ever do to deserve such a harsh life? And I begin to think of all the people my age who would never be able to deal with such a problem.

The thing that really got me was when my best friend—who was 21 and just graduated from college—died of AIDS in May. I am still devastated. I truly don't know how I've dealt with all the cards some “dealer” dealt me, but I learned through my friend that in any situation no matter how many obstacles seem to be ahead of you, you should always try to make yourself better and make the most of any situation. My friend found out he was infected and had PCP in the space of a few weeks. His life was turned upside-down, but he still managed to maintain a 4.0 grade point average at Berkeley and graduate from college in three years.

I definitely think that being a teenager with this disease is different from being an adult. Does anyone really think that at 17 I would have attained every skill that I needed to do better in life? Well, I sure hadn't. And because I had to learn fast, I lost out on my teenage years, which should have been fun. I wasn't prepared to figure out how to set goals, how to decide what to accomplish in my life.

The Future

One of the main things that I feel is important in my life is being able to put a face to this disease. I belong to a speakers bureau, and I speak to various providers and agencies that work with at-risk youth. It is a release that is indescribable, and at the same time exhausting. Being able to share my own experiences with people has made me quite an open person, even though I haven't told many friends and family that I'm HIV-infected.

I just passed my one-year milestone of learning I was HIV-infected. I didn't think much about it at the time; I was just happy that I had lived for one more year. That's one stereotype that I wish more people would forget, that once you test positive, you die the next day.

In June, I graduated from high school, and I am going to go to junior college in the fall. I plan on transferring to UC Berkeley or Stanford to focus on becoming a psychologist or public health worker. I hope to do something to improve the way American society thinks. HIV hasn't made me change my future plans; it has just made me focus more on what I want to attain in the future.
Characteristics of HIV-Infected Adolescents

Substance use, multiple sex partners, survival sex, and sexually transmitted diseases (STDs) were characteristic of both HIV-infected and uninfected adolescents in a New York City study. Only higher rates of anal intercourse and histories of sexual abuse among HIV-infected males statistically distinguished the two groups.

Researchers interviewed 93 adolescents who were seen by the Adolescent AIDS Program from 1988 to 1991. Subjects were predominantly African American and Hispanic. Of the 50 who were HIV-infected, nearly half had measurable immune dysfunction and were eligible for treatment with zidovudine (ZDV; AZT). Of the seropositives, 66 percent were male; of the seronegatives, 53 percent were male.

Almost half (22 subjects) of the HIV-infected adolescents reported using crack cocaine and of these, most had engaged in survival sex—sex for money or drugs—to secure the drug. Eighty-two percent of the HIV-infected males reported having sex with other males; however, many did not identify as gay. Most of the HIV-infected females identified heterosexual intercourse as their only potential exposure but were not knowledgeable about the specific risk behaviors of their partners.

Of the HIV-infected adolescents, 76 percent of female and 51 percent of male youths had had multiple STDs, some acquiring a new STD after HIV diagnosis. Consistent condom use among these subjects was rare. Their number of lifetime sexual partners varied widely: 21 percent of males and 35 percent of females reporting fewer than 10 lifetime partners, while almost half of females reported more than 50 partners, and almost half of males reported 10 to 50 partners.

Only 12 percent of female and 30 percent of male adolescents informed sexual partners that they were HIV-infected.

Communicating with Parents
Leland NL, Barth RP. Characteristics of adolescents who have attempted to avoid HIV and who have communicated with parents about sex. Journal of Adolescent Research. 1993; 8(1): 58-76. (University of Minnesota and University of California, Berkeley.)

A large study of California high school students found that communication with parents about sex was a primary factor in delaying the initiation of sexual intercourse among adolescents and encouraging the use of contraception among sexually experienced youth. Students who discussed issues such as pregnancy, birth control, and sexually transmitted disease (STD) prevention were more likely to avoid HIV exposure.

More than 1,000 students responded to a questionnaire about sexual knowledge and behavior. The survey was developed as part of an adolescent pregnancy prevention curriculum and was administered before the program began. The sample was evenly split between male and female respondents. The average age of respondents was 15.4 years. Sixty percent were White; 21 percent were Hispanic.

Adolescents who had discussed sex with their parents (77 percent of the sample) were less likely to be sexually experienced than other adolescents and were more likely to have attempted to avoid AIDS by using condoms and decreasing the number of their sexual partners.

Of sexually experienced adolescents (43 percent of the sample), those who attempted to avoid AIDS were significantly more knowledgeable about STDs and more likely to use condoms than those who did not. Those who took precautions to prevent exposure were also more likely to have communicated with their parents. About 50 percent of all students reported changing behavior, although only one-fifth believed they were at risk of exposure.

Earlier studies have shown that behavior interventions to delay sexual activity and promote safer sex are most effective for students who do not initiate sexual intercourse during high school and for students who initiate sexual activity before they finish high school but after being educated about risky sexual behaviors. This study suggests that one-on-one communication—either with parents or other trusted adults—may delay sexual activity and increase HIV-related knowledge among adolescents.
Psychosocial Problems and Risk Behavior


High school students with multiple psychosocial problems are at increased risk for contracting HIV, according to a survey of tenth grade students residing in or near an AIDS epicenter. A substantial proportion of these students had engaged in high-risk behaviors.

Researchers surveyed 1,091 students from high schools in New York City and a nearby suburb about HIV-related behaviors. Subsamples provided further data on psychosocial stressors and supports, and other problem behaviors. Urban respondents were from poorer families, while suburban respondents were from middle-class families. The mean age of respondents was 15 years; 35 percent of the urban sample was male, and 52 percent of the suburban sample was male. While racial data collection was forbidden by local boards of education, most of those attending urban schools were African American and Hispanic, and those attending the suburban schools were primarily White.

Of the total sample, 3 percent engaged in very high-risk behaviors, and 25 percent engaged in higher-risk behaviors. Although injection drug use was low (less than 1 percent), the rate of unsafe sex practices were high. Among the students who were sexually active, more than two-thirds inconsistently used or did not use condoms, one-third had had two or more sex partners, and 5 percent had been sexual with higher risk partners. Seventy-nine percent reported using substances, such as alcohol, cigarettes, or marijuana.

Involvement in high-risk behaviors was significantly correlated with adverse life circumstances, such as familial disruption, parental discord, economic hardship, and crime. Other factors affecting risk-taking included minimal parental support and high self-esteem, which researchers note has been found to predispose boys to earlier sexual activity.

Risk in Adolescence and Young Adulthood


Neither HIV-related knowledge or counseling, experience with an HIV-infected individual, nor awareness of risk status had a measurable impact on risk levels among a group of inner-city youth, according to a large multi-site urban study of changes in risk from adolescence to young adulthood. This was true even though psychological development might have predicted greater caution and risk reduction.

Researchers interviewed 602 young adults in 1984-1985, 1985-1986, and 1989-1990 who were health clinic users from cities with high rates of homicide, suicide, drug use, and teen pregnancy. Divided into high-risk, moderate-risk and low-risk groups, 76 percent were female, 70 percent were African American, and 73 percent were from working-class families. The average age at the beginning of the study was 16.

Over time, risk levels decreased slightly; by young adulthood, the percentage of those involved in moderate- or high-risk behaviors had dropped from 46 percent to 35 percent. Although knowledge levels were high, knowledge was not linked to changes in risk behavior. Other factors that had no impact included knowing someone with HIV infection or someone who had died of AIDS. In fact, those in this category were more likely to increase their risk behaviors. The authors suggest that this result demonstrates the greater influence of peer behavior versus the outcomes of peer behavior in determining individual behavior.
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