Whether To Take the Test: Counseling Guidelines

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As the availability and use of the AIDS antibody test become more widespread, many more individuals are evaluating the benefits and risks of learning their antibody status. Some of these individuals will seek counsel from mental health professionals to help them decide whether to take the test. Clients already involved in counseling may wish to discuss these issues as part of their ongoing work. In addition, clients whose physicians have recommended the test for medical reasons may want to discuss their concerns about the possible negative psychological and social effects of taking the test. We outline here guidelines to help mental health practitioners in their work with clients concerned about taking the test and coping with the results.

Background and History

In early 1983 researchers identified the virus (now named the Human Immunodeficiency Virus, HIV) believed to cause AIDS. Shortly thereafter, private companies developed a sophisticated laboratory test called ELISA (enzyme-linked immunosorbent assay) to detect antibodies to the virus. The primary purpose of the test was to screen blood and blood products for HIV contamination. The test in and of itself is not a test for AIDS and the test result does not reveal whether a person will develop AIDS.

Infection by the AIDS virus causes a response by the body’s immune system. Part of this response is the production of antibodies which recognize and attach to specific proteins on the virus, called antigens. Since the antibodies are tailor-made for particular antigens, tests can be designed to detect these specific antibodies. Tests for antibodies include the ELISA, the IFA (immunofluorescence assay), and the Western Blot. Each of these tests is based on the same principle, and each uses different methods to detect the same antibodies. Thus, the IFA or the Western Blot can be used as a way to support results obtained by the less-expensive ELISA.

The antibody tests are all very sensitive, which means that they detect almost all of the positive sera. They are also very specific, seldom indicating negative sera as positive. While testing procedures may vary, the required repeat testing of positive tests increases the accuracy of the test. False reactions do occur for reasons that are not completely understood. A false negative result may occur because an individual has not yet developed antibodies to the virus. Most people produce antibodies within 2 to 8 weeks after exposure; some, however, will take up to 6 months.

Conversely, a false positive reaction may occur if the antibodies have developed in response to other similar proteins in the blood. Also, antibodies may have developed in reaction to another part of the test system, such as the cells in which the virus is grown. This would be called a non-specific reaction.

For individuals with little risk, the probability that a positive result is a "false positive" is greater only because there seems little chance that such individuals would have been exposed to HIV. Especially in these cases, testing by another method or repeat testing in a few months should be encouraged. The recommended procedure for all positive results is to be tested by another method such as IFA or Western Blot. While false positive and false negative reactions may occur, accumulating evidence shows that the ELISA test is very accurate, especially for individuals at high risk.

Mental health professionals must examine their own bias about the test before they counsel persons about it. It is important to understand fully the limits of the test and to appreciate the real risks that the test presents to clients.

Concerned that people at high risk might donate blood to learn their antibody status, public health officials developed an alternative test site program providing either anonymity or at least strict confidentiality to participants. Over time other purposes of the test have emerged. These include diagnostic and epidemiological applications as well as use in family planning settings to help clients make informed choices about pregnancy, parenthood, and birth control. Many see the test as an important preventive education tool for use in helping people understand their risk of contracting and transmitting the AIDS virus.

Ever since the antibody tests were developed, confusion and conflict about individual civil rights and public health interests have prevailed. Several public health officials and medical investigators wanted to use the test to help track and control the spread of the disease and to study the effects of infection. Advocates for people at high risk for HIV infection emphasized that many of these individuals are already socially stigmatized and that further use of the test might foster discrimination against those with positive results. Others, such as employers and insurance companies, showed an interest in the test for their own purposes.

Fears of discrimination have a realistic basis. Individuals in high-risk groups, regardless of their medical status, have lost continued on page 2
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jobs, have been denied housing and insurance, and have suffered from disruptions in relationships with families, partners, and friends. Homophobia, racism, and dislike or fear of drug addicts have been exacerbated by the hysteria and panic that have accompanied the AIDS epidemic. It is no wonder then that individuals in high-risk groups have been distrustful and suspicious in regard to the use of the antibody test. Given these facts, mental health professionals who counsel clients about the antibody test should provide information about possible consequences of taking the test and ways of managing the test information to prevent later difficulties.

Preparation for Counseling

To prepare for counseling, mental health professionals should first become familiar with the test, what it means and does not mean, its level of accuracy, and the potential benefits and risks of knowing one's antibody status. It is helpful to have ready access to community resources that can provide updated information relative to the test. Government-sponsored test sites have been established in several communities to offer information about the test and to provide anonymous testing free of charge. Clients can receive basic information at these sites and then return to their primary mental health counselors to review the information and weigh the personal benefits and risks prior to making a final decision.

Mental health professionals must examine their own bias toward the AIDS antibody test before they counsel clients about it. Counselors should understand fully the limits of the test and the real risks that the test can present. Clients must understand that the test alone will not indicate if they have AIDS or ARC, and that it will not predict who will develop these diseases.

In some cases antibody testing has resulted in a positive psychological and behavioral adaptation to the threat of AIDS. For those who prove to be antibody negative, knowledge of their test results usually reduces unneeded anxiety, although some recipients may face problems with "survivor guilt" and extra stress about remaining negative. Many individuals who receive a positive test result have been motivated to take their health more seriously and to improve their health behaviors. Since research has shown that most people with AIDS antibodies have active virus in their bodies, a positive result strongly implies that an individual is able to pass the virus to another. Knowledge of a positive status has motivated many individuals to be more judicious in following safer sex guidelines and in no longer sharing I.V. needles. However, for many individuals troubling psychological reactions to test results frequently accompany the news of seropositivity. These responses range from mild to moderate anxiety to full-blown anxiety and depressive disorders. Although adequate pre-counseling can lessen the likelihood of these reactions, it is no guarantee that these will not happen.

Outline of Benefits and Risks

The benefits of antibody testing include:

1. to protect the blood supply by testing individuals who are considering donating blood;
2. to ensure that organ donations are safe from HIV contamination;
3. to help support a medical diagnosis in individuals who exhibit unexplained symptoms that their doctors think might be related to a HIV infection;
4. to help women at high risk decide whether to become pregnant or give birth;
5. to help women with a history of risk behavior decide whether to breastfeed an infant or have an infant innoculated with vaccine produced from live virus;
6. to reduce anxiety in individuals who are at low risk for HIV infection yet who have extremely high anxiety about it;
7. to motivate individuals who continue to practice high-risk behavior and who feel that a positive test result may help them reduce these behaviors;
8. to help researchers design experimental treatment protocols and to help potential subjects determine whether or not to participate in the drug trials;
9. to help scientists determine the extent of HIV infection in the population at large, and, by following sero-positive individuals, to understand the natural history of HIV infection.

The risks of antibody testing include:

1. severe psychological reactions, including anxiety, nightmares, sleep disturbance, depression, and suicidal behavior;
2. disrupted interpersonal relations, including potential for rape reactions and their extreme manifestations, such as homicidal behavior;
3. social ostracism and self-imposed social withdrawal;
4. relationship problems (blaming partners, sexual dysfunction, disrupted ability to make plans as a couple);
5. stigmatization and discrimination if a positive antibody status is made known to others outside of guarantees of confidentiality;
6. problems with employment or insurance;
7. preoccupations with bodily symptoms; and
8. a false sense of security and denial if the test proves negative (for example, believing one is immune to infection and thus continuing with risk behavior).

The Counseling Process

The process for helping clients decide whether to take the antibody test should be based on three important elements: (1) accurate information about the test, (2) a systematic decision-making process, and (3) an action plan that will maximize benefits and minimize risk.

Although the availability of information about the antibody test varies from one location to another, basic information and the location of the nearest test site should be available at any Public Health Department office. Some clinicians feel that clients should take responsibility for locating and obtaining information; others feel more comfortable providing information directly. In any case, clinicians should emphasize the importance of not proceeding with the test without proper background knowledge.

Clinicians should take responsibility for providing a structure for facilitating the decision-making process. This may be a process that has been used already with ongoing clients or one which is geared specifically for the immediate purpose. One process that has been used successfully is based on a "benefit-risk analysis." The client is asked to list the potential benefits that might be involved with taking the test. Subsequently, the client lists the potential risks. For the benefits list, the counselor encourages the client to consider each item and determine whether the benefit can be received by some means (other than the antibody test) that does not have concomitant risk. For example, if an individual is taking the test to lower the risk of contracting the disease through sexual contact, understanding that the same guidelines hold true for those who test positive as those who test negative may obviate the need to take the test.

If a greater overall benefit has been established to proceed with the test, a careful review of risks must be undertaken. In some cases perceived risks are in fact groundless, such as the fear that someone could obtain an individual's name from an anonymous test site. (A participant’s anonymity is protected at these test sites; the individual's name is never recorded). Other risks can be reduced somewhat by careful planning; for example, discussions by couples prior to testing about how they will cope with the test results.

After a careful examination of the benefits and risks, the final choice — an educated decision — is the client's own to make.
An Action Plan

If a client chooses to take the test, additional attention should focus on how to minimize risks once the results are known. Clients may begin to process their feelings and thoughts by imagining their reactions to receiving a positive result and developing strategies to cope with these reactions. This process may take several sessions before the client is psychologically prepared to take the test. Even this preparation is no guarantee that unexpected reactions may not overwhelm the client.

Clients can be encouraged to arrange for additional emotional support during the testing process, including the period of waiting for the results. A counseling session should be scheduled shortly after clients receive the test results so they have the opportunity to discuss their reactions. Additional resources may be needed in order to assist adaptation to the test results. Clients should also think beforehand about disclosure of information about being tested, and they should consider how to protect their civil liberties. For example, when possible, clients should be encouraged to use anonymous testing sites. In some cases negative psychological reactions have emerged some time after receiving a positive test result. Clients should be assured of continued availability of assistance if this should occur.

Follow-up counseling may also be required to help clients incorporate test results into a plan of action that will produce the anticipated benefit. For example, the person who feels that it is necessary to take the test in order to be shocked into compliance with risk guidelines may need to continue seeing a counselor to accomplish this goal realistically. Shock value is only effective in the short-term, and long-term strategies are essential with AIDS risk prevention. Such a counseling plan may be established prior to taking the test.

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Diagnosis/Treatment/Prevention

Heterosexuals and AIDS: Report from Atlanta

Michael Helquist

"AIDS has always been transmitted heterosexually; only our denial has kept this fact from us," asserted James Curran, MD of the U.S. Centers for Disease Control (CDC) during a recent presentation. The steady increase in media coverage of the threat of AIDS to heterosexuals has begun to challenge that denial. In February a major conference in Atlanta took that interest one step further and focused on the prevalence and prevention of AIDS in children, adolescents, and heterosexual adults.

Apparent among the nearly 800 conference participants was a consensus about how our understanding of the AIDS epidemic and our efforts to control it should be framed. Researchers and health officials appear to have adopted the notion that we should move away from the epidemiology of AIDS to an epidemiology of the HIV infection. Robert Redfield, MD of Walter Reed Medical Center advised his colleagues at the conference that "to focus on the number of AIDS cases today is to be five years out of date; the cases we record today tell us where HIV infection was five years ago."

General agreement has also developed about the need to emphasize high-risk behaviors rather than high-risk groups. Redfield suggested that the only realistic risk group is that one comprised of humans with potential sexual, parenteral, or perinatal exposure to HIV. Even with this broader understanding of HIV transmission, the CDC monitors the spread of AIDS by looking at rates of increase among different population groups. Curran of the CDC explained that these rates have shifted during the period from 1985 to 1986. Among gay men there has been a 50% increase in the number of cases. That number corresponds with an 82% increase among bisexual men, a 63% rise for heterosexual men, and a 77% increase among women.

Although the current statistics clearly show the rise in overall numbers of AIDS cases among heterosexuals, researchers have yet to agree on the efficiency of the bidirectional transmission (from men to women and from women to men) of the virus. One recent study conducted at Walter Reed Medical Center showed that 44% of spouses of infected husbands became infected themselves as a result of unprotected sexual activity. While several researchers at the Atlanta conference asserted that HIV can be efficiently transmitted bidirectionally, other scientists regard male to female transmission as the more efficient route. One researcher noted that with many sexually transmitted diseases (STDs) there is a greater efficiency from men to women even though in every society STD prevalence is always greater in men.

Constance Wofsy, MD of San Francisco General Hospital suggested that the discussion of HIV transmission often reveals a bias that places major responsibility on women to control the spread of the AIDS virus. She cited the emphasis placed on prostitutes as supposed "reservoirs of infection," the expectation that women will adopt condom use in their sexual activities, and women's role in perinatal transmission. James Oleske, MD of the New Jersey College of Medicine in Newark called for men to share the responsibility of halting the spread of HIV. "Men are the major propagators of this disease," he said. Wofsy added that society must come to terms with its attitudes about prostitution. She posed the question, "Can we alter the existence of prostitution or can we make it safe?"

Pediatric AIDS

Oleske, who has worked with infants and children with AIDS for several years, estimated that by 1991 there will be 10,000 to 20,000 children with AIDS in the United States. In Newark alone Oleske and his staff are caring for 100 children now; by 1991 he expects that number to increase to 600. Oleske added, "Most pediatric cases are symptomatic, and the latency period is relatively brief for infants."

Other differences between manifestations of AIDS in children and in adults are the less common appearances of Kaposi's sarcoma (KS), B-cell lymphoma, and Hepatitis B in children. Oleske also reported that children frequently have severe lung involvement, that they may have normal T-cell ratios, and that neurological disease is secondary to primary HIV infection. Curran of the CDC announced during the conference that that agency is currently devising a classification system for pediatric symptoms.

Gwendolyn Scott, MD from the University of Miami noted that there appears to be a 30 to 50% chance that the fetus of an HIV-infected mother will also be infected. Sheldon Landesman, MD of the Downstate Medical Center in New York City said he believes there is no method at this time to determine readily the status of an infant whose mother is seropositive. "You will not be able to tell until the baby develops disease," he said. Landesman added that a foster care mother cannot be told whether a baby from an infected mother is itself infected since that baby is carrying the mother's antibodies. Scott of Miami mentioned that her studies showed that mothers do not follow predictable patterns: sometimes an infected mother will give birth to a well infant following the births of two infected infants.

Several researchers indicated that pediatric AIDS cases can be seen as the index of infection in the family, and they emphasized the importance of surveying the risk factors of the infant's mother and also those for the other family members.

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Prevention Among Adolescents

Richard Keeling, MD, chair of the AIDS Task Force for the American College Health Association, suggested that when planning AIDS education for adolescents, "We need to know who we are talking to and we must recognize that dealing with the problems of AIDS will involve not just education but also social justice."

Keeling advised his colleagues to consider three guidelines for their education efforts: (1) that adults cannot change the behavior of adolescents; only the adolescents themselves can change their behavior; (2) that community-based AIDS organizations, many comprised of gay men, have already dealt effectively with many questions about AIDS education and have much to teach those more recently involved in AIDS prevention; and (3) that while there is nothing wrong with choosing abstinence, there is nothing wrong with healthy sex.

Having worked mostly with college-age youth, Keeling concluded that what may work better than simple AIDS information campaigns is a comprehensive, multi-faceted education effort that emphasizes the development of self-esteem, self-respect, and accountability. "We will be more successful marketing AIDS education in the context of qualities important to the developing adolescent: winning, achieving, competing, succeeding, and fitting in," Keeling explained. "This kind of approach will allow for messages of choice, morality, and safety — rather than instruction, moralism, and warning."

The three-day conference was sponsored by the International Interdisciplinary AIDS Foundation, based in Atlanta.

Michael Helquist is the editor of FOCUS.

BRIEFS

Recent Reports

Women At Risk: Effect of HIV Antibody Testing and Notification. A San Francisco study has found that HIV Antibody Testing can be particularly problematic for women. As a result of structured, open-ended interviews with 37 women at risk for HIV exposure, researchers Jane Zones and Diane Beeson identified five specific areas of difficulty: (1) social isolation — women confront the risk of AIDS in a context of less social and personal support; (2) absence of formal support — difficulty in obtaining adequate medical care and social services, especially outside urban areas; (3) the stress of media reports — news related to AIDS is perceived as increasingly grim and is a constant source of stress; (4) safer safer — antibody testing itself does not ensure safer sexual practices among women who are positive or in relationships with seropositive men; and (5) worry about children — children are the focus of tremendous anxiety with particular worry centered on reproductive risk, infection of their children, leaving children motherless, having them taken away, and exposing them to social stigma. This study was supported by UC San Francisco, the San Francisco Department of Public Health, and California State University at Hayward; current data was presented at the Bay Area Researchers’ Conference on Women, Children, and AIDS, sponsored by the San Francisco AIDS Foundation.

AIDS Awareness and Risk Behavior: Discrepancy Among Heterosexual I.V. Drug Users. Members of the Sacramento, California AIDS-I.V. Drug Abuse Task Force found that local I.V. drug users (IVDU) were aware of HIV transmission via shared needles and unprotected sexual intercourse, but significant numbers did not translate that knowledge into behavior change. By means of two questionnaires and personal interviews, the researchers determined the knowledge and risk behaviors of 150 IVDUs attending local IV drug abuse programs. Some of the findings from the study included the following: 93% believed that HIV was present in some IVDUs in Sacramento; 93% believed they would eventually acquire HIV and AIDS through needle-sharing; 95% said they wanted to avoid acquiring HIV; 91% believed HIV could be spread heterosexually; and 64% believed that condoms could prevent the transmission of HIV. However, a review of the IVDU’s behavior revealed that 77% of the time they shared their needle (rig) with someone else either before or after they shot up. Although 87% of the time, IVDUs said they cleaned their rigs between users, 87% of the time the cleaning only involved water. Of the 150 IVDUs 67% shared a rig 1-10 times in the last month, 13% approximately 30 times, and 7% approximately 50 times.

Reasons given for rig-sharing included general sociability, the criminal offense status of possessing a rig, and the cost of the equipment. The respondents said cleaning of their rigs between uses was complicated by perceived lack of disinfectant in immediate environment, compulsion to inject as quickly as possible, and a belief that the person with whom they were sharing wasn’t infected with HIV.

Next Month

The higher profile in the scientific race against AIDS is given to experimental drugs and the development of a vaccine. At the same time, however, other scientists study the interrelationships among the immune system, the nervous system, and psychological stress for clues about vulnerability to the AIDS virus and the body’s means to combat HIV infection. Current studies looking at how AIDS relates to a mind—body connection are part of a larger and established field of inquiry called psychoneuroimmunology.

In the May issue of FOCUS, George F. Solomon, MD, a pioneer in the field of psychoneuroimmunology, will consider questions relevant to HIV infection. These include whether an "immunosuppression-prone" personality can predispose one to HIV infection, whether stress can trigger HIV infection from a latent to an active state, and whether psychosocial factors are related to progression of disease. Solomon is a professor of psychiatry in residence at UCLA and an adjunct professor of psychiatry at UC San Francisco, where he has been a member of the Biopsychosocial AIDS Project since 1983.