

## AIDS Antibody Testing: Evaluation and Counseling

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In early 1983 French researchers — and in 1984 American scientists — identified the virus 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 test was licensed by the Food and Drug Administration in March of 1985. The primary purpose of the test was to screen blood and blood products for contamination with the AIDS virus.

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. (*Ed. note: in San Francisco, the alternate test system offers complete anonymity.*)

In San Francisco the AIDS Health Project organized a program for disclosing AIDS antibody test results to participants. The major goals of the program are to ensure that test recipients understand the meaning and implications of their results, to help them cope with the results, and to help participants maintain or improve AIDS risk reduction behaviors.

During July and August of 1985, a questionnaire developed to address these issues was distributed to approximately 1000 participants at the two test sites. (All participants were offered the questionnaire; not everyone accepted it.) The questionnaire surveyed attitudes and experiences: expectations of test results, received test results, reasons for taking the test, evaluation of the disclosure session, changes in mood since taking the test, changes in risk reduction behavior, usefulness of referrals, and overall appraisal of the experience of taking the test. Test recipients received the questionnaire at the end of the disclosure session and were asked to return it by mail within three weeks. The whole procedure was voluntary and anonymous. This report is based on preliminary analysis of data from the survey.

The questionnaire was completed and returned by 298 test recipients. Most respondents were male (86%), white (82%), and between the ages of 30 and 39 years old (47%); of the total, 58% identified themselves as gay men.

The survey indicated important differences between clients' expectations and the actual results. While 49% of the clients expected a positive test result, only 20% actually received

one. Further analysis showed that 82% of seropositives, but only 59% of seronegatives, correctly anticipated their antibody status.

Clients reported various motivations for taking the test. The most common reasons given were concerns about the potential of infecting others (71%) and a general desire for information about their antibody status (61%). Twenty-nine percent of the respondents anticipated that knowing the result would assist them in changing unsafe sexual or health practices, and 19% wanted to learn about their antibody status in anticipation of possible future, required, non-anonymous screenings (such as those proposed by the military, insurance companies, or employers). "Positive" and "negative" respondents did not differ significantly in this category.

When clients were asked whom they planned to tell about the test result, their most common responses were current sexual partners (58%), non-sexual friends or families (53%), and future sexual partners (41%). As expected, seropositives indicated more reluctance to tell others their results; only 29% planned to tell future sexual partners, while 46% of seronegatives planned to do so. Also, 13% of seropositives anticipated disclosing their results to past sexual partners compared to 27% of seronegatives.

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The above percentages represent a variety of individual responses. For example, seronegatives mentioned the following reasons for why they would inform their sexual partners of their serostatus: (a) those in relationships wanted to know if their status was the same as that of their partners, (b) some said they would be more relaxed about possibly safe sexual activities, (c) if future partners are positive, the seronegatives said they would be more careful, and (d) some felt others would be more socially or emotionally open to them if it was known they were seronegative. It should be emphasized that all seronegatives were counseled to avoid high risk activities.

When clients were asked to evaluate the counseling in the disclosure session, 93% found it either "somewhat helpful" or "very helpful." Test recipients identified the following aspects of the counseling as most helpful: "talking with someone about my feelings and concerns" (50%) and "clarifying or increasing my understanding of the meaning of my test result" (57%).

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## AIDS Antibody Testing . . .

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As expected, there were marked differences in mood changes between clients receiving positive and negative test results. While 40% of the "positives" felt somewhat or much worse after they received their result, only 2% of the "negatives" felt the same way.

Perhaps the most important data relate to changes in risk reduction behaviors. When asked if the test affected risk reduction behaviors, 57% of the sample indicated they had improved these practices at least somewhat. An additional 35% said their behaviors had not changed since taking the test. (The question and answers did not reveal whether this percentage indicated that changes had already been made before the test was taken, but other surveys in the gay community have noted considerable changes away from high-risk activities.) The remaining 8% includes 1% of participants who said their activities had become "somewhat less healthy"; missing data accounted for 7%.

Finally, 92% of the respondents indicated that they would go through the whole procedure of taking the test again if they could reconsider their decision. Even 79% of those receiving positive results answered in the same manner, while 15% were not sure. Only 5% reported that they would not re-take the antibody test. Additionally, 94% of the test recipients felt it was at least "somewhat helpful" to know their test results.

### Discussion

The interpretation of the results presented in this article is limited by several methodological problems. Specifically, the respondents were self-selected both by their participation in the program as well as their decision to complete and return the questionnaire. Also, the data is based on clients' self-report. Finally, since most questionnaires were returned within three weeks, we do not know how long the reported behavioral changes will last. The anonymous nature of the testing process makes long-term follow-up impossible.

With these shortcomings in mind, these data nevertheless suggest that the AIDS antibody test may be a powerful tool in preventing the wider spread of AIDS. In general, the most important results are: (1) nearly half the respondents considered the counseling to be helpful in "clarifying and improving" understanding and adoption of critical AIDS risk reduction guidelines; (2) clients are motivated to take the test to discover their antibody status, and to ensure that they do not infect others; (3) clients plan to inform a sizeable number of past, present, and future sexual partners about their antibody status; and (4) the vast majority of test recipients felt it was helpful to know their test results and did not regret having participated in the testing experience.

Taking the test has a powerful impact on the emotional state of a person, with the expected outcome of great relief and mood improvement for those receiving negative results and heightened anxiety and depression for those with positive results. It should be noted, however, that irrespective of mood change, both groups seemed motivated to continue safe sex practices and risk reduction behaviors. Negatives wish to remain so; positives want to stay as healthy as possible and not infect others.

In summary, we conclude that an alternative test site program such as that offered by the San Francisco Department of Public Health — providing free, voluntary, and anonymous testing with effective pre-test education, sensitive and responsible counseling, and effective referral to appropriate follow-up services — may play an important role in AIDS prevention.

There remains, however, a need for more carefully controlled studies in order to confirm the outcomes of this survey. In addition, different populations should be studied, especially women at risk, needle-sharing I.V. drug users, minorities, hemophiliacs, and sexually active heterosexuals, to determine the relationship between knowledge of antibody status and risk reduction behavior in these groups.

## Diagnosis/Treatment Disclosing AIDS Antibody Test Results

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This protocol describes the principles and procedures of disclosing AIDS antibody test results. If the goals described in this protocol are met, the test may help to prevent the wider spread of AIDS and may fulfill the needs of individual test participants.

### I. Pre-Test Education

Individuals who express an interest in taking the AIDS antibody test can benefit from a pre-test educational program. This program can help individuals determine if the test might be useful to them, and it can help insure that each person has enough information to make an *informed decision* about whether or not to take the test.

Every client who considers taking the test enters the program with a set of two important variables. The first is the level of information about AIDS and the antibody test. The second variable is the client's motivation for taking the test. In order to assess the client's level of information and motivation, the clinician needs skills in individual and group health education with particular knowledge about AIDS and the meaning of the test. Additionally, experience in facilitating the process of non-directive decision-making is important.

The client needs to understand (a) the uses of the test, (b) the meaning of positive and negative test results, (c) how the AIDS virus acts on the immune system, (d) the concepts and means of AIDS risk reduction, (e) the accuracy of the test, (f) the two to six month time period for possible seroconversion after exposure to the AIDS virus, (g) how stress has been handled in the past, and (h) the voluntary and anonymous nature of the test program.

After the basic information about AIDS and the antibody test is presented, clients should have the opportunity to ask any remaining questions. The answers will help clients decide whether or not to proceed to the next step and have their blood drawn. Whether or not a person decides to take the test, the pre-test education can help clients understand critical AIDS risk-reduction behaviors.

Before blood is drawn, clients should be informed of the remaining steps in the test procedure, such as the return appointment. Some clients experience the waiting period between blood-drawing and disclosure of the result as the most stressful part of the test. Therefore, providing written information about coping and appropriate resources (such as, hotline services and counseling) is necessary.

### II. Discussion Session

The return appointment for receiving test results is an opportunity to reinforce the messages communicated in the pre-test education. It is important to provide consistent information at both appointments.

The process of disclosing test results is critical for several reasons. If the session is handled sensitively, it will help clients cope with the immediate psychological reactions to learning the result. The clients, however, are receiving information that can have a profound impact on their entire lives. Clients may experience disruptions in personal relationships, depression and anxiety, impotence, alienation, sleeping disorders, and other troubling feelings as a consequence of taking the test.

The disclosure session provides the clinician with an opportunity to develop a health plan with test recipients. Clients can

benefit from developing a plan to cope with the test result and manage the test information. Knowledge of follow-up services will help clients carry out this plan. To be effective, a counselor should receive special training to best serve the clients during these sessions. Such training should include role-playing of disclosure sessions, techniques of rapid assessment, crisis intervention, and effective resource linking. Ideally, a counselor should have a background in working with special populations, especially gay and bisexual men, I.V. drug users, women, and minorities.

In order to help clients feel comfortable in the disclosure session, counselors need to establish rapport very quickly. Basic attending behaviors such as establishing eye-contact, empathic listening and responding, and "being with the person" will facilitate this process.

It is important to be aware of the psychosocial variables, especially the client's expectations of a positive or negative result, their perceived risk, and the degree of anxiety and ability to cope with stressful events. Clinicians should also determine the extent of the clients' social support systems.

### III. Revelation of the Test Result

The actual revelation of the test result has proved to be most effective when presented in a straight-forward manner with direct eye contact and without undue expression of concern. Once the test result is delivered, the counselor should resist the temptation to fill the silence. By watching verbal and non-verbal cues, the counselor can determine the client's reaction and judge when the client is ready to discuss the result.

Clients will respond in various ways to the test result. Some may be shocked and unable to speak; others will express different, often strong emotions like anger, sadness, fear, joy or relief. The affective response to the test result is a primary indicator for directing the rest of the session. The counselor should use active listening and reflective statements to convey understanding and help the client move on to integrate the given information.

Helping clients integrate the result involves insuring that they (a) understand what the result means cognitively, including the medical knowledge as well as the impact on their lives; (b) assimilate the emotional impact of the test result; (c) develop a behavioral health plan to reduce or eliminate the possibility of becoming infected or infecting others and to reduce the chances of developing AIDS or ARC; and (d) develop a strategy for coping with the interpersonal implications of the test result.

Experience has shown that some clients will either distort, ruminate excessively, or exaggerate the implications of a positive test result. Often clients will have a difficult adjustment period that lasts about a month. Counselors may wish to let a person know about this response and thereby normalize the possible emotional reactions and decrease the level of stress experienced by the client.

Clients should be allowed to express feelings freely to better assimilate the emotional impact of a test result. For some individuals, receiving a test result has such an emotional impact that the counselor may need to focus on providing emotional support for most of the session. The goal of this intervention is to enable the client to leave the session at least relatively intact.

Developing a behavioral health plan to maintain or adopt health-enhancing and risk reduction behaviors is one of the main goals of the disclosure session. Besides safe sex practices, other possible co-factors should be considered. These include alcohol and drug abuse, stress, other viral infections, and poor nutrition. Formulating a health plan involves setting behavioral goals and selecting strategies to accomplish these goals, strategies that must be both meaningful and attainable.

It is also essential to have a plan for managing the test information. This plan should include different strategies depending on the person who may be informed of the client's antibody status. For example, telling physicians, insurance companies, or employers should be handled differently from sharing the information with past or present sexual partners, friends, or family members. Telling significant others can be powerful and

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threatening to the relationship and needs to be dealt with sensitively. At times, discussing the details of telling a particular person or even role-playing of the potentially problematic situation may be useful.

### IV. Summary and Referral

When ending the disclosure session, the counselor should try to review the most salient points discussed during the interview. This summary can help the client to remember the most important aspects and provide an opportunity to ask remaining questions. At the completion of the interview, it is essential to provide appropriate resources regarding further information, medical and social services, maintenance of the health plan, and emotional support. Written information describing various resources can also be distributed.

Follow-up sessions can be useful to review information from the disclosure session and to prepare for the future. Receiving test results is just the first step in a long process. Since seropositives are thought to be infectious for life, further help is needed to establish and maintain necessary changes, especially for those who experience stressful reactions after receiving the result. While feelings of prolonged depression, feelings of isolation and stigmatization, impotence, panic, or anxiety disorders have occurred for some individuals, most clients make a satisfactory adjustment to their situation. Providing a support group has shown to be extremely helpful for some test recipients.

It is unknown which seropositive test recipients will go on to develop AIDS or ARC. Medical follow-up should be established for continuity of care.

Futhermore, we believe that while legitimate disagreements can exist about the use of the test in various situations, it is important for health care providers to consider the larger implications of testing on the lives of those receiving results. Appropriate counseling should accompany the reporting of the result as outlined above. Such a framework can facilitate the individual's adaptation to the personal meaning of the test; it can also advance the public good by reducing the spread of the disease. Testing without educational support serves neither of these functions.

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These two articles are abstracts of the protocols and evaluation developed by the AIDS Health Project. To obtain the complete presentation of data, contact the Project office at 333 Valencia St., 4th Floor, San Francisco, CA 94103.

## BRIEFS IN REVIEW

"Our Immune System: The Wars Within," Peter Jaret. *National Geographic*, Vol. 169, No. 6, June 1986. San Francisco medical writer Peter Jaret has once again tackled the complex field of immunology to write a clear and concise account of how the human immune system functions. Last year Harcourt Brace Jovanovich published *In Self Defense*, an in-depth look at recent advances in immunology, co-authored by Jaret and Steven Mizel, MD. Soon thereafter *National Geographic* recruited Jaret to condense and update his presentation of immunology for its readers.

The highly-regarded magazine complemented the author's accessible and personable style with a stunning set of photographs and graphics. The combination provides most viewers with a first-time-ever look at the body's defenses as they attempt to block foreign invaders. Familiar names for immune system components — such as, macrophages, helper T-cells, suppressor T-cells — acquire a new visual dimension for observers who now almost daily confront accounts of scientific probes into the immune response. This lengthy article places AIDS within a context of the overall study of the immune system. It provides a good, basic reference for the general public, health care professionals, and health educators. The article concludes with an acknowledgement of the potential immune-enhancing power of hope and determination, as embodied in photos of San Francisco's AIDS/ARC vigil.

Individual copies of *National Geographic* can be obtained by sending \$1.90 per copy desired to the National Geographic Society, 17th and M Streets, NW, Washington, D.C. 20036.

## RECENT REPORTS

**The Effects of Long-Term Seropositivity.** As the extent of HIV infection, and thus antibody seropositivity, becomes more apparent, researchers and the general public are anxious to know the effects of this exposure. Epidemiologists now estimate that from one to two million Americans have been exposed to and infected with the AIDS virus; studies have shown that from 4% to 20% of seropositive people followed for 2 to 5 years developed AIDS. Researchers in Denmark recently published in the *Annals of Internal Medicine* (April 1986) the results of their longitudinal study of a cohort of 250 previously healthy gay men. By December of 1981, 9% of the cohort had antibodies to AIDS; by September of 1984, 26% were seropositive. Only 2 of 22 initially healthy men who were seropositive in 1981 had developed AIDS as of June 1, 1985. None of the men who later seroconverted has been diagnosed as having AIDS. Although AIDS was infrequent among members of the cohort, the Danish researchers found that HIV infection had pronounced consequences on both the immune status and the clinical health of the seropositive subjects. The researchers also found that the ratio of T-helper to suppressor cells was a sensitive and reliable indicator of immunologic and clinical changes; they noted "a highly significant, steady time-related decline in the T-lymphocyte helper-to-suppressor ratio." The decline in the ratio was progressive but noticeable even in those men who had been recently infected.

Lymphadenopathy was significantly correlated among subjects who had been seropositive for both short-term and long-term periods. On the other hand, constitutional symptoms such as oral thrush, diarrhea, herpes zoster, unexplained fever, and weight loss were correlated only with long-term seropositivity (more than 29 months). There was also a significant and steady increase in medicine consumption related to the length of seropositivity, a further indication of a time-related increase in health problems, according to the researchers.

**Acute Encephalopathy Coincident with Seroconversion for Anti-HIV.** Infection with the AIDS virus is usually asymptomatic, long-term, and silent; in a small proportion of infected people, however, illness may become apparent as profound immunosuppression (AIDS). Previous studies have established that the viral infection in some people may result not in damage to the immune system but rather to the neurological system. Scientists have estimated that up to 50% of AIDS patients may have loss of cerebral function secondary to AIDS virus replication in the brain. Although the majority of people with AIDS developed symptoms after an incubation period of years, studies have shown that a lesser percentage of infected people will become ill at the time of actual infection with the virus.

A report in *The Lancet* (November 30, 1985) by a team of researchers in London describes three such cases of patients who presented with an acute and reversible encephalopathy, similar to the early phase of herpes encephalitis. The disease was preceded by a mild pyrexial illness (fever) during which character changes became manifest. In two of the patients, the brain dysfunction was associated with seroconversion for antibodies to the AIDS virus. The researchers estimated that seroconversion occurred during hospital admission for the patients. In addition, one of the patients clearly manifested disease sooner than current views relating HIV infection to CNS disease would have anticipated. The British report is important also because it establishes that infection with the virus may result in acute as well as in chronic disease.

The researchers conclude that although acute HIV encephalopathy is uncommon, "it seems prudent to consider it as a possibility in patients at risk of AIDS who present with an acute disturbance of cerebral function, personality changes, or frank encephalopathy."

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