Counseling Mixed Antibody Status Couples

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With so many pressing AIDS issues vying for the attention of health care providers, the difficulties faced by gay male couples of mixed antibody status are often overlooked. Many providers find the controversial aspects of gay male relationships daunting enough without adding to this equation the complexities of the issues posed by the mixed antibody status couple. Yet the needs of these men are important to understand, even for practitioners who work primarily with single seropositive clients.

"Mixed antibody status" usually refers to a couple in which one partner is positive for HIV antibody and the other is negative. In addition, there are other situations that may be defined as mixed status. For instance, both partners may have HIV disease, one with mild to medium symptoms and the other with an AIDS diagnosis, or both partners may be HIV infected, but only one may be symptomatic. For these couples the very real presence of illness in the relationship becomes a primary focus in counseling.

For partners of mixed status where one is seropositive but asymptomatic and the other seronegative, psychological and emotional issues, rather than physical ones, are paramount. In addition, partners of different ethnic backgrounds often present special issues related to different cultural responses to illness, death, family relations, and personal feelings about dependence and independence. We have limited our attention here to only those aspects that are common to all variations of mixed antibody status couples, and have used as a model the couple comprised of one partner who is HIV antibody positive and one who is HIV antibody negative.

Gay Couples: Myths and Other Difficulties

One cannot begin to understand the issues of mixed antibody status couples without first acknowledging the context in which gay male relationships occur. This environment is replete with challenges to successful relationships, including; male and gay socialization patterns, societal and internalized homophobia, differing levels of personal development, and, often, difficulties with alcohol and drug use.

The mixed antibody status couple also faces the pervasive context of the epidemic itself: all the despair, sadness, anger, and frustration that come with living in what feels like a war zone. When HIV infection intrudes upon a relationship, the partners contend individually and together with waves of irrationality, guilt and dread. These feelings often become personalized; for example, the infected partner may blame himself, or be blamed by his seronegative partner, for bringing the disease into the relationship.

Finally, gay couples may face problems because of implicitly- or explicitly-held myths about love, sex, and relationships that permeate the modern gay subculture. These include the notions that love requires no work and comes easily, that love resolves all differences, that separation is a threat to the relationship, that gay relationships cannot last or that now, in these times, they should last. In addition, gay men sometimes subscribe to the belief that all gay men are the same, that each member of the couple plays only one role, and that relationships and sex require perpetual novelty.

Besides these commonly held myths, the mixed antibody status couple may face a new set of myths as well. These may include beliefs that seronegatives and seropositives cannot understand each other's needs, that HIV infection is the source of all problems in the relationship; that the relationship must shift to a crisis mode in which the partners' roles resemble movie stereotypes of the faithful, devoted, and sacrificial caregiver and the grateful, long-suffering, and brave victim; and that each partner must take unilateral steps to protect the other sexually and emotionally.

Communication Issues

Mixed antibody status couples should recognize the increased importance of communication, and should talk often and directly in order to confront the major changes HIV infection has wrought in their relationship. The task may be primarily one of renegotiation.

Sex is likely to be a painful area of renegotiation for mixed antibody status couples. The fear of transmission hovers over lovemaking, stifling spontaneity and creativity. Either partner may experience a diminished sexual drive as a result of HIV infection, the effects of ordinary aging, or the evolution of the sexual component of the relationship. Unfortunately, many couples avoid communicating about sex, leaving only silence, confusion, and frustrating nonverbal cues. There is an obvious need for discussion, for the couple to assess their previous sexual history, to agree on what feels safe and comfortable, and to be creative in their adaptation of safer sex practices. The maintenance of sexual intimacy, an issue for all gay couples, is especially important for the mixed antibody status couple.

Long-term and short-term planning is another key area for renegotiation. The potential life spans of seronegative and seropositive partners may be dramatically different. This affects decisions about housing, jobs, moves, trips, and schooling—any major change involving financial resources and time. The uncertainty of the course of HIV infection makes these decisions all the more complex. Either of the partners may grieve in anticipation of losing cherished dreams, for themselves or for the couple, that now seem unlikely to come true.

Disagreements about finances may threaten the harmony of the mixed antibody status couple. This is especially true if medical expenses begin to soar. Health concerns and decisions about daily life regimens can also determine how the couple spends time together: when and how much they sleep, what they eat, or whether they use drugs and alcohol. HIV infection may seem to invade every niche of the relationship. While decisions governing daily life may more often be made in light of the needs of the infected partner, both partners may feel frustration and anger if they do not discuss and resolve these issues together.

Assessing a couple's relationship, as it was before and after one partner was infected, will help shift "responsibility" for complications in the relationship from the infected partner alone to both partners.

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Partners in mixed antibody status couples may find they need additional time apart from each other. This may be healthy, but only if it results from a conscious choice and not from a secret or unilateral decision on the part of one of the partners. The choice to seek support individually, from friends or family, is healthy and may be crucial. It can offer each partner relief from emotional burdens, and a different quality of support. Likewise, a conscious decision to separate and enjoy interests and activities with others may also strengthen the bonds of the relationship. For example, infected partners who fatigue easily might encourage their seronegative partners to continue enjoying late-night dancing with other friends.

A different kind of separation may occur if the family, friends, or even ex-lovers of the infected person re-enter his life and claim more time to be with him. The seronegative partner will need to be direct and honest about his own needs for attention, and the couple will have to make necessary shifts in social time and private time together to accommodate each other as well as these new people.

Disclosure—who informs others about the HIV infection, and who can and should know—is also a sensitive area for negotiation. It is crucial for partners to discuss this issue if they are to feel safe in their overall social environment of friends, family, employers, landlords, and others, and if the partners are to retain their trust of each other.

Finally, partners will have to communicate about their grief over the threatened future of their relationship and, perhaps, for loved ones who have died. The HIV-positive partner, in particular, may not want to focus much or often on grief. The seronegative partner, on the other hand, may need to grieve and may feel frustrated or afraid to burden his infected partner. Sometimes these positions are reversed, and the negative partner expresses hope while the positive partner allows himself to grieve and to experience despair. Both may fear that expressing grief will define and affirm potentially frightening prospects. In all these cases, appropriate support systems and individual counseling may be necessary, but open and direct communication can help couples avoid second-guessing, mutual frustration, and feelings of rejection.

Interventions

The general interventions described here offer the mental health practitioner suggestions for helping partners to understand and nourish their relationship, and to communicate more directly. These interventions can be employed either with the partners individually or together as a couple. In order to effectively apply these interventions, mental health practitioners should be aggressive about asking questions of both partners.

The first task in counseling may be an honest assessment of the health of a couple’s relationship both before and after HIV infection. This assessment may help define the appropriate social support and therapeutic work. It will also facilitate the shifting of all “responsibility” for complications in the relationship from the infected partner, and will identify for each partner the appropriate individual or couples counseling necessary, counseling needs that may have predated the relationship itself. Couples who look at their relationship styles, for example, how their personalities mesh, the implicit and explicit roles and rules of the relationship, and the patterns of sharing and separation, may more easily identify their choices and, as a result, become more closely bonded.

Once the issues for each partner and for the couple are defined, the mental health practitioner can develop a counseling plan. First, the practitioner should encourage the partners to employ active renegotiation, as described above, to help them cope with their new circumstances. Mixed antibody status couples, as all couples facing HIV infection, need to reassess their relationships in the presence of a life-threatening disability.

The therapist can help couples who think they need to be faultless in their responses to their mixed antibody status by helping them define norms: reminding them of the difficulties and myths they have faced, the new issues raised by the epidemic and their different antibody statuses, and their need to both challenge and nurture one another. Setting their current struggle within this context can highlight strengths in the relationship as well as target weaknesses that need improvement.

Clinicians can also help a couple recognize separation as a valuable event that flows from and nourishes a committed bond. By combining conscious time for coming together with chosen periods of separation, and by presenting both occasions as opportunities for cooperation and not combat, mental health practitioners can suggest a new way of relating for couples accustomed to either exclusively distancing or merging. Encouraging the couple to plan structured separation times can relieve pressure, and having the couple schedule regular “relationship meetings,” or dates, can ensure more open and ongoing communication. In addition, periodic vacations and “healthy” denial, a conscious retreat by either or both partners from HIV-related issues, are effective safety valves.

Training in how to conduct arguments fairly, including recognizing signals of recurring patterns and taking time-out periods, can offer effective interventions for mixed antibody status couples. Recommending individuals and couples for short-term crisis counseling for positive mental health reasons can be the most important referral for these couples.

Although we have emphasized interventions aimed at helping couples stay together, there may be times when it is more appropriate to facilitate a breakup. For example, a partner who has decided to breakup prior to discovering his lover is seropositive may need help proceeding with this course and handling the guilt he may feel. On the other hand, a healthy relationship may be threatened by a partner who wants to leave only because his lover is seropositive. No matter what course is ultimately taken, it is important for counselors to slow the process and facilitate communication between the partners.

Conclusion

Tens of thousands of individuals will find themselves in mixed antibody status relationships as antibody testing becomes more available and pertinent for monitoring the course of HIV infection. This article offers tools that mental health practitioners may use to help mixed antibody status couples deal with emotional and psychological difficulties, clarify their values, and recognize choices they can make to create lives of intimacy and satisfaction.

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Psychosocial Issues for Seronegative Gay Men in San Francisco

Rachel Schochet, MFCC

The San Francisco Department of Public Health estimates that approximately 50 percent of the gay and bisexual men in San Francisco are infected with HIV. In response, the city has developed an extensive network of services for these individuals. As it endures the trauma of losing as many as half of its members, the city’s gay male community is undergoing profound changes and struggling with the issues that face the long-term survivors of an epidemic.

There is a predictable skepticism in response to the idea that survivors of the AIDS epidemic face issues similar to those of survivors of wars and natural disasters. Unlike the survivors of the Holocaust, survivors of the epidemic experience a life-threatening situation that has taken the lives of many friends, neighbors and loved ones. Initially, survivors of any disaster are happy to be alive; however, their responses may eventually stretch far beyond relief to guilt, anxiety and depression. Mental health practitioners treating people with AIDS, their partners and friends must confront these complex psychosocial responses.

This article explores the issues for survivors in the gay male community in San Francisco, a group whose experience with the epidemic has been particularly severe. It has been noted that in this population, the role of community affiliation is a strong predictor for determining the impact survival might have on an individual’s mental health. For some, the epidemic has obliterated their social networks, making these men more vulnerable to associated psychological problems. Others, whose personal connections are not as rooted in the gay community, have managed to remain aloof from the worst psychological effects.

While this article focuses on issues for seronegatives, some of these concerns will be relevant to asymptomatic seropositives due to the long latency period of HIV. In addition, these issues may be relevant to other communities, for example, gay men living outside the San Francisco Bay Area, people with hemophilia, intravenous drug users, and people living in areas hardest hit by AIDS in Africa and the Caribbean.

### Traumatic Stress and Community Disasters

Mental health professionals who worked with survivors of the Holocaust, Hiroshima bombing, Vietnam war, and other community disasters found that many survivors had lingering, sometimes severe emotional problems, collectively referred to as “survivor syndrome.” Psychiatrist Robert Lifton characterized some of the aspects of survivor syndrome as intrusive images of the disaster, psychic numbing, struggles to find meaning, and survivor guilt, which occurs when an individual feels that his survival was purchased at the cost of another life.

Pathological survivor syndrome reactions may lead to clinical symptoms such as chronic anxiety and depression, sleep disorders, psychosomatic conditions, impaired concentration, inability to experience pleasure, and self-destructive behaviors such as drug and alcohol abuse. Studies describe the major defense against death anxiety and survivor guilt as psychic numbing, a diminished ability to feel in response to powerful underlying emotions, including shame over helplessness, guilt over real or imagined contribution to the disaster, and rage.

### Responses to Seronegative Status

The large majority who are uninfected by HIV respond to this news in life-affirming ways, with relief and joy. These men still feel grief and concern, but are able to resolve their feelings without serious impairment. Some may derive a renewed emphasis on life planning, focusing on long-term versus short-term goals, for instance, saving versus spending money. Others may become more involved in community efforts to combat the epidemic, such as volunteering time, donating money, or responding with other humanitarian efforts.

Relief and joy, however, may be tainted by survivor guilt. In addition to the effects of traumatic stress that Lifton describes above, many gay men wonder, “Why not me? Why was I spared?” As greater numbers of individuals seek antibody testing, the prevalence of survivor guilt can be expected to increase.

Individuals who test negative may manifest a range of sexual problems from celibacy, induced by AIDS-phobia, to increased high-risk activity in response to the illusion of immunity. Dating and sexual behaviors may be altered by concern over serological status of potential partners, fear of contagion, and fear of intimacy. Many seronegatives withdraw socially and sexually in an effort to avoid even more pain and loss.

In extreme cases, some men find it difficult to disclose a seronegative antibody status because they fear friends who are positive will reject them. In order to gain social acceptance, some men may lie about their serostatus in an effort to join with seropositive friends and avoid their potential rejection. This may be particularly true in communities where social and political activities focus on AIDS, and where people with AIDS may be the greatest folk heroes and receive the most attention.

### Treatment Considerations

The changing impact of AIDS on society complicates the task of determining the incidence of survivor syndrome among seronegatives. This task requires practitioners to perform an overall assessment of the patient, including coping style, level of community affiliation, and degree of bereavement. In an attempt to gain mastery over his survivor experience, the client faces painful feelings such as shame, guilt, helplessness, fear and grief; mourns the passage of his pre-epidemic life; and struggles to find meaning in his present circumstances. Working through these feelings often results in renewed vitality and attention to future planning.

Social support is important to help combat isolation. Practitioners may encourage their patients to attend support groups for seronegatives. These groups already exist in several major U.S. cities; therapists should consider forming such groups as the need arises. In addition, constructive adaptations for survivors include volunteering for community services and becoming political active in terms of improved health care and policies.

Long after HIV infection is considered a manageable chronic condition, those who have survived the decimation of their communities will continue to confront complex psychosocial issues. Health professionals must be prepared to acknowledge the situation faced by seronegative people, particularly gay men, whose good physical health may conceal serious emotional concerns.

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References:


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Recent Reports


A study of 4,954 gay and bisexual men found that the presence of perceived HIV-related symptoms—such as swollen glands, weight loss and fever—and not the presence of HIV antibodies were associated with self-reported psychological distress. The study also found that greater distress was correlated to the absence of someone with whom subjects could discuss problems and a subject’s perception that he had lymphadenopathy.

Beginning in April 1984, 4,954 gay and bisexual men without AIDS enrolled in a study that required semiannual physical examinations, HIV antibody testing, self-reporting of possible HIV infection symptoms, and response to the Center for Epidemiological Studies Depression (CES-D) Scale. Using the scale, subjects report the number of symptoms of psychological distress, such as depression and enervation, they have experienced in the previous week. Subjects did not know their antibody status when they responded.

The study found, consistent with the literature, that greater age and education were associated with less psychological distress. Since the presence of HIV antibodies was not independently associated with high CES-D Scale scores, however, the study implies that there is no relationship between psychological distress and the physiological presence of HIV.

Finally, seronegative subjects were as likely as seropositive subjects to endorse items such as “difficulty concentrating,” “everything an effort,” and “talked less,” cognitive symptoms that could be interpreted as secondary to central nervous system HIV infection. The researchers conclude from their data that, since these symptoms were reported by seronegatives as well as seropositives, this attribution does not automatically follow.


A prospective study of 161 seronegative gay men found a strong association between the lack of an immune response to dinitrochlorobenzene (DNCB) and 23 later HIV-1 seroconversions, providing some evidence that prior immune dysfunction predisposes to HIV-1 infection among gay men.

Between November 1982 and February 1984, the Vancouver Lymphadenopathy-AIDS Study recruited 700 gay male subjects, who were examined semiannually until October 1986, and annually thereafter. During each visit, subjects received a complete physical and an HIV-1 antibody test. At the time of the first two visits, a subsample of subjects was scheduled for skin testing for cutaneous anergy (lack of immune response to an antigen placed in contact with the skin). Among the antigens tested were: DNCB, a substance used in tests of cellular immune function, tuberculin, Candida albicans and Trichophyton mentagrophytes. Subjects were seronegative at the time of skin testing.

There was no association between anergy to Trichophyton or to tuberculin and later seroconversion. There was a trend toward greater rates of seroconversion among seronegative Canadian, although this association was not statistically significant. There was a significant correlation between DNCB anergy and later seroconversion: 9 out of 33 anergic subjects seroconverted (27.3 percent); 12 out of 116 reactive subjects seroconverted (10.3 percent). DNCB anergic and reactive subjects were similar in terms of age and behavior, including numbers of sex partners and frequency of receptive anal intercourse. (Editor's note: The researchers did not ask subjects whether they used condoms during intercourse. In 1985, however, when they did ask, frequency of condom use was low. From this, the researchers postulate that condom use among gay men was rare prior to 1985.)

While the researchers consider several explanations for their data, they conclude that host susceptibility should be seen as a determinant of infection following exposure to HIV, at least in terms of sexual transmission among gay men. While these findings may offer some explanation of why some individuals, for instance seronegative partners in mixed antibody status couples, remain uninfected after repeated exposure to HIV, the researchers warn there is currently no data to support the conclusion that the absence of host susceptibility implies absolute resistance to HIV.

Social Support and AIDS. Northwestern University (AIDS & Public Policy Journal, 1989, Volume 4, Number 1).

A review of the literature on the role of social support in an individual’s adoption to HIV infection explores a range of issues including: the process of adjusting to threatening events, searching for meaning in the events, restoring self-esteem, and gaining a sense of control over life events. It also discusses respite care for caregivers, and problems in providing support.

The review offers some insights into the supportive relationship between people with HIV infection and their partners. The trauma of HIV infection deeply affects relationships with spouses and lovers, “where the commingling of identities becomes part of a couple’s relational definition.” Since partners become a crucial source of support, especially when support is lost through unemployment or stigma, they must be offered special attention.

One study cited in the review found a positive correlation between self-esteem and spouse/lover support, and a negative correlation between self-esteem and professional support, which it suggested was related to stigma associated with formal therapy.

Next Month

The Fifth International Conference on AIDS was held in Montreal, June 4 through 9. Twelve thousand participants gathered to exchange information on scientific and social aspects of HIV infection. In September, FOCUS offers a multidisciplinary perspective of the conference findings, paying particular attention to issues of importance to mental health practitioners and educators.

Six participants present their views of the conference. AIDS Health Project Director James Dilley, MD reports on psychosocial and neurologic issues. Robert Gore, MD, Assistant Clinical Professor of Medicine at the University of California San Francisco, reports on clinical issues. Virologist Judith Wilber, PhD reports on basic science. San Francisco AIDS Foundation Assistant Director for Education Chuck Frutchey reports on education issues. Jerome Davis, JD, an attorney with the Civil Rights Division of the U.S. Department of Labor reports on legal issues. Michael Helquist, founding editor of FOCUS and Program Officer for AIDSCOM, reports on international issues.

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