



# Face to Face: A Guide to AIDS Counseling

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## The HIV-Positive Client

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The prospect of counseling clients who are HIV antibody positive understandably raises serious concerns for counselors. For some, misplaced fear of contagion from casual contact, a reluctance to talk about sexual matters, or concern about having to confront illness and potentially progressive disability in their clients are primary considerations. For others, deciding to work with this population involves, at least in part, a desire to confront directly one's own discomfort and anxiety about AIDS. For most, there is confusion stemming from the lack of clear professional guidelines or precedents about how to work with this client population.

Fears of inadequacy and of becoming overwhelmed or "burned out" are also common sources of hesitation. Anticipating

the client's high level of need and urgent wish for change can add to the anxiety of counselors who may already question their capacity to be helpful. In this chapter, common themes raised by those who are seropositive will be discussed, and practical suggestions for ways to intervene will be offered.

### Common Themes

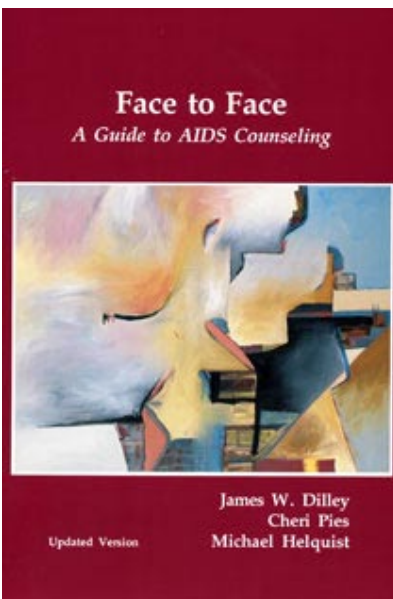
Clients who seek counseling after receiving an antibody positive test result often do so with acute subjective distress, including anxiety, depression, and feeling "out of control." They may also complain of a general

lack of feeling, or a sense of being "numb." More commonly, clients report some combination of these feelings and describe feeling emotionally overwhelmed on the one hand, and emotionally numbed on the other. In essence, they report their experience as that of being on an emotional "roller coaster." They speak freely of a sense of imminent doom and describe the terror of sickness and dying, of becoming physically disabled and unable to care for themselves, and of ending their lives by suicide. Clients often question whether they can continue with their day-to-day routines and responsibilities, including jobs and social relationships. Hopelessness is a prominent theme; and a fundamental question, often not stated explicitly, is whether to prepare to die or to continue directing one's focus toward living.

Uncertainty is another recurring theme for seropositive individuals and is seen in virtually all areas of their lives. Uncertainty about the future is prominent as individuals ask themselves about their ability to cope with the knowledge of their antibody status and wonder about the future state of their health. They are beset by a host of questions about how to handle this new information; they may question plans for the future, current life situations, and personal relationships. Additionally, there is often uncertainty about how to avoid infecting others, how best to take care of their own health, whether to continue in a job or relationship which is stressful or displeasing, and whether to disclose their antibody status and to whom. These many levels of uncertainty often leave seropositive clients feeling they have lost control of their lives, a source of anxiety in itself.

### Managing Stress

Seropositive individuals frequently experience a range of stressful physical and psy-



chological symptoms. Depression and anxiety are common and can result in sleep and appetite disturbances, fatigue, loss or a lessening of sexual desire and sexual impotence. Panic attacks, phobic reactions, impaired concentration, and ruminative thinking which involves a repeated and frequent focus on the hopelessness of the situation or about the unfairness of an “early death,” are also common and can complicate the client’s ability to cope. The stress experienced is often intensified by the perception that stress must be lowered to protect an immune system already compromised by HIV.

### Self-Esteem and Social Isolation

Lowered self-esteem and a sense of social isolation are frequent reactions of those who learn they are infected with HIV. The seropositive client’s self-esteem is challenged on several fronts. First, self-image as an essentially healthy being is challenged and may be temporarily or permanently lost. Seropositive individuals often describe feeling contaminated or dirty. These feelings parallel negative societal messages about HIV. Secondly, because most individuals became infected through sexual contact, many feel they have done something wrong or have been a “bad” person who has gotten what was “deserved.”

For the gay man who is seropositive, learning his antibody status may trigger internalized homophobia as he “blames” his being infected on his homosexuality. The gay man who has chosen to remain largely “in the closet” often struggles with his own homophobia when he contemplates disclosing his antibody status to others. Alternatively, the gay man who is comfortable being open about his sexual preference may be distressed at the prospect of his HIV disclosure as he remembers painful coming-out experiences from the past. Heterosexuals may feel they are now unable or unwilling to take the risk of parenting since they may infect their unborn child or their sexual partner or may not live to see their children grow to adulthood. This potential loss of the ability to have children can have profound effects on feelings of self-worth.

Isolation is another significant issue for seropositive clients. Most seropositive people encounter social isolation to some degree as they experience or fear rejection from large segments of society, including friends, family, and co-workers. Urban areas

with large visible gay populations offer readily available opportunities for peer support to gay seropositive men, yet these services are often missing for heterosexuals. It is very common for women or heterosexual men who are seropositive to be entirely alone with the information. They are likely to know few if any heterosexuals with HIV. Smaller communities may offer no support services to either gay or heterosexual seropositives. Consequently, both groups typically feel a mixture of sadness and disappointment as well as anger at the lack of responsiveness of others in the community.

Gay men who live in high AIDS incidence areas often experience an additional source of isolation due to the loss of significant others in their lives who have died of AIDS. They mourn both the loss of companionship as well as the support of now-deceased friends. In areas with large gay populations, clients often describe their environment as a “war zone” because so many have died and because their community has been so hard hit by illness and death.

#### [2d subhead] Decision-Making Dilemmas

Seropositive individuals confront a host of decisions that need to be made, and frequently there is a feeling that these decisions need to be made immediately. For example, seropositives often question how deeply to immerse themselves in thinking and learning about HIV. Many worry that they will miss something important to their health if they don’t stay current about ongoing developments with treatments for HIV. On the other hand, many feel overwhelmed by trying to keep up with the ever-increasing volume of AIDS information and tend to avoid reading about HIV or attending informational meetings.

The progressively grim statistics concerning the course of HIV infection leaves many seropositives caught between their desire to know as much as possible about HIV and their fear of becoming immobilized by bad news. Those who are monitored closely by their physicians (See Appendix A: “Natural History of HIV Disease”) are frequently buffeted by changes in their laboratory values which are an ever-present reminder of the slow deterioration of their immune systems.

A related issue is whether to pursue medical treatments. This decision frequently touches on the issues of denial versus confrontation. Deciding to pursue treatment is tantamount to acknowledging directly that a

serious situation exists. Yet some seropositive individuals come to view the decision to pursue treatment as a means of regaining a sense of control and mastery in their situation. (See Editor's Notes, page 25.)

Another important decision often faced is whether to remain in a job or other life pursuit that is less than satisfying. The question is often related to the ambiguity about medical prognosis ("How much longer will I be healthy enough to remain active?"). Some clients worry that they may not live much longer and that they cannot afford to waste time unhappily. Or, they worry that remaining in a stressful situation will only hasten the progression of illness because of the suspected negative effects of stress. Others may feel trapped in their present work situation because of the real fear of the loss of health insurance were they to leave their job, or they fear being rejected for new jobs because of their antibody status.

### Disclosure

Most seropositive clients question whether to tell others about their status. At a time when they are already feeling emotionally fragile and isolated because of their antibody status, they fear further alienation from those who they imagine might reject or abandon them. Fears of discrimination at one's job as well as in other areas of life, including housing, health insurance and medical care, are reinforced by the abundance of anecdotes concerning mistreatment of seropositive individuals in the general community. The client may have already experienced adverse consequences from disclosing this information to others, thus heightening the level of ambivalence about further disclosure.

Concern about damaging one's interpersonal relationships is often a focus of discussion related to disclosure. Many worry that an early disclosure might drive a potential partner away before an opportunity for commitment to the relationship has had time to develop. On the other hand, delaying disclosure might be unfair to the other if in fact a commitment has already begun. Despite these misgivings, there is often a simultaneous sense of urgency to use whatever time is remaining in life to develop supportive and satisfying connections with others. Consequently, clients feel a heightened need to make the most of their time, leading them to re-examine their existing rela-

tionships and to consider withdrawing from those that do not seem fulfilling. For those already in a primary relationship, the antibody status and health of the partner can be an additional source of strain and potential isolation in the relationship.

### Counseling Interventions

There is a role for both individual and group counseling in the care of people who are seropositive. Some clients use the knowledge of their antibody status as an impetus to seek in-depth kinds of counseling or psychotherapy.

#### Individual Counseling

For the client who has recently tested positive and who is experiencing a flurry of disturbing and disorganizing emotions, some form of crisis intervention is frequently indicated. This means providing support and validation for feelings, mobilizing resources for coping, providing educational information, and helping the client solve pressing situational demands.

The counselor can begin by normalizing the emotional "roller coaster" that is so commonly experienced. As many of these clients have had little if any opportunity to discuss their situation with anyone in depth, the experience of feeling heard, understood, and accepted by an empathic counselor who actively listens can be a significant starting point. Learning that many others have experienced similarly severe reactions to testing positive can also help reduce their sense of isolation.

The counselor should be sensitive to the possibility of suicidal ideation, though actual hospitalization of suicidal seropositive clients has been a rare occurrence in our experience. A useful initial response to such thinking is to normalize it by pointing out its commonness among seropositive individuals. When present, suicidal ideation should be monitored carefully and can be expected to subside as the client begins to adjust to the information and the sense of immediate crisis is alleviated.

Helping the client mobilize resources for coping can include identifying internal strengths and abilities as well as external supports, such as friends, family and social services in the community. Identifying effective coping strategies in past situations of high stress or crisis is also useful. Teaching coping strategies ranging from

controlled breathing, visualization, or taking a walk in the park, to problem-solving approaches such as “taking things one step at a time,” ensuring frequent rest periods or “mini vacations,” and remembering other successes in coping with past adversity have all been used effectively.

Friends and family supports of the HIV-infected individual are often underutilized. This is sometimes due to the fear of a negative reaction or to the fear of overburdening them. The counselor can assist the client in realistically considering which friends or family members would be the most likely to respond in an accepting and supportive way. Referral to support services in the community, such as emotional support groups and AIDS informational centers, contributes further to the sense of having a range of resources from which to draw.

Finally, reminding clients who have recently tested seropositive that the emotional turmoil of the initial adjustment period is time limited can be extremely useful. It is critical that the counselor provide an opportunity for clients to recognize, express, and eventually accept the full range of feelings that are sparked by facing a life-threatening illness. When negative thinking predominates, however, and clients become trapped in a downward spiral of hopelessness, cognitive techniques can help to replace some of the dysfunctional thought patterns with more constructive ways of thinking. For example, the client who repeatedly thinks “I’m going to die, so I may as well give up,” or “I am unacceptable now that I am seropositive,” or “I’m failing if I don’t keep a positive outlook all the time,” can be helped to examine the dysfunctional nature of these thoughts and to recognize the potential for changing them. Efforts at altering dysfunctional thinking can contribute to a growing sense of being able to manage life’s problems.

Role playing can provide a forum for the counselor to model effective communication and for clients to practice disclosing information about their antibody status in a supportive setting. Often the client’s difficulty in disclosing antibody status to friends or family reflects problems with self-esteem associated with being seropositive. In such cases, it may be important to first address negative feelings before encouraging disclosure to others.

It is not uncommon for the counselor

to encounter a client who is continuing to engage in potentially self-destructive behaviors such as drug or alcohol abuse, unsafe sexual activity, or poor daily health habits involving diet, sleep patterns, and so on. If these behaviors do not change during the course of counseling, firm but gentle confrontation of the behaviors is indicated. Sometimes providing information about the potential harm of such behaviors to an already vulnerable immune system can help motivate the client who is poorly informed. For others, being pushed to seriously examine such behaviors requires confronting the potential seriousness of the situation in a way which may have been avoided out of fear. Such fears need to be explored with careful timing and in an atmosphere of respect. In other cases, unhealthy patterns such as those involving diet, sleep, or substance use may reflect an underlying depression or crippling anxiety which inhibits the client from making important changes. In such instances, a referral to a psychiatrist for evaluation for medication should be made.

Throughout the work, it is important that the counselor convey a sense of hope and encouragement while at the same time allowing space for experiencing emotional pain and loss. The re-examination of basic values and priorities in life that many seropositive clients undergo can be framed by the counselor as an opportunity to enrich the quality of life. Giving examples of others in similar circumstances who have managed to survive and make progress over time can be inspiring. Supporting the client’s right to engage in “healthy” denial—i.e., regularly taking breaks from dealing with emotionally painful realities—is also key. Finally, the value of using humor in a compassionate way cannot be overemphasized.

The crisis which most clients experience following an antibody-positive test result can be a source not only of emotional turmoil, but also of motivation for making significant positive changes. The confrontation with potential mortality brought on by the test result leads many individuals to a commitment to work through troubling personal issues which they previously lacked ability or motivation to address effectively. For such clients, a decision to enter longer-term psychotherapy may be an important step towards turning the crisis into a profoundly life-enhancing transition.

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## Group Counseling

Groups for seropositive individuals can be a tremendous help in reducing social isolation, bolstering coping resources and capacities, and providing support for making positive changes. The average client feels a sense of relief when hearing others describe similar experiences and emotional reactions to a seropositive test result. Many benefit from involvement in such a group concurrently with individual counseling, whereas others prefer only one or the other.

In some communities, there may be a variety of types of groups from which to choose, including short-term topic-focused groups, drop-in support groups, longer-term closed-membership support groups, and psychotherapy groups. Short-term topic-focused groups, often lasting six to ten weeks, tend to have the dual objective of offering interpersonal support as well as information relevant to coping with HIV and protecting oneself and others. Drop-in support groups generally offer the individual an opportunity for group support and educational information without having to make an ongoing commitment to attend. Such groups are particularly helpful to those with limited experience in therapeutic groups and who want to “test the water” before considering a longer-term support group. More traditional psychotherapy groups for individuals who are seropositive can offer an opportunity for greater depth of exploration of personal and interpersonal concerns than is possible in short-term groups. Choosing among these types of groups is usually handled best in a process which actively involves the client.

## Countertransference Issues

A common feeling among counselors of seropositive clients is frustration over the tremendous ambiguity that must be faced in the work—ambiguity about HIV disease itself and about the appropriate therapeutic approaches to take. This ambiguity parallels that which the client is facing, and it can sometimes increase the empathy felt for the client. For the counselor who has particular difficulty accepting ambiguity, the risk of inhibiting the client’s freedom to recognize and experience the uncertainty of the situation must be carefully watched. Often clients resist the painful awareness of this uncertainty by looking for clear-cut, instant answers. The counselor may, in

turn, feel pulled to respond to this pressure by offering “quick fix” solutions. Related to this is the pressure many counselors feel to become experts on HIV as a way to be better prepared to provide answers whenever the client expresses confusion. This can lead to spending considerable time and energy attempting to stay current about research and treatment issues. The overwhelming amount of information available places such a counselor at risk of becoming seriously overextended, and the counselor must be willing to accept his or her own limitations, including the limits of one’s expertise. Often a critical element of being informed about HIV involves knowing which people or organizations to refer clients to for further information. Counselors who are in so-called “high-risk groups” themselves face special countertransference issues. The gay counselor, for instance, is likely to have been directly affected in his personal life by the epidemic, thereby increasing the likelihood of a strong identification with the client’s situation. This can both enhance and detract from the counseling relationship. It can serve to increase the capacity for empathy and the degree to which the counselor is perceived by the client as a potentially understanding helping figure. It can also lead to the counselor’s becoming overinvested in the work, and eventually unable to continue the work because of emotional strain. The antibody status of the counselor introduces another level of complexity. It is not uncommon for the seronegative counselor, whether gay or straight, to experience feelings of “survivor guilt.” These feelings may be fueled by the client’s anger and resentment at those who do not share the burden of being HIV infected. The antibody status of the counselor has implications in terms of perceived capacity for empathy and level of personal investment which are similar to those described above in the discussion about counselors’ personal risk. An additional issue the counselor must consider is whether, and under which circumstances, to disclose his antibody status to clients who ask. Finally, it is important that counselors be aware of the personal meanings attached to HIV as a result of their own past experiences, so as to decrease the likelihood of imposing these meanings on clients. For example, counselors who have friends recently deceased or ill with HIV disease may attribute more significance to a cli-

ent's recent seropositive test result than the client is prepared to hear. It is also important that counselors carefully examine their own attitudes and assumptions regarding such issues as homosexuality, IV drug use, and death and dying, so as to minimize the chances of colluding unconsciously with any self-ridicule their clients may feel in terms of these issues.

### Summary

Seropositive clients must cope with a range of painful emotions which typically accompany an antibody-positive test result, including fear, grief, anger, and sadness. They must also deal with decision-making in a number of important areas of their lives in which there is a great deal of uncertainty. This includes uncertainty about medical prognosis, health care options, how best

to spend one's time and plan for the future, and how to share the news of being seropositive with others. Furthermore, social ostracism and the strain often imposed by the antibody-positive test result on important interpersonal relationships may contribute to a plummeting self-esteem.

Counselors who choose to work with this client population face a demanding set of challenges. They must struggle with a high degree of ambiguity and with the difficulty of identifying clear guidelines for how to address the client's needs and how to measure progress. The counselor's own attitudes and anxieties about AIDS and HIV must also be channeled in a healthy direction. Ultimately the counselor, along with the client, has an opportunity to develop an enhanced sense of purpose and meaning within a situation of crisis proportions. ■