Living with Therapy
Michael Helquist

Nothing from my experience of 10 years of working with AIDS prepared me for the shock, confusion, and depression that came with my diagnosis of Pneumocystis carinii pneumonia. It wasn’t for lack of familiarity that I felt so ill-equipped. I had lost a lover to AIDS in 1983—he was one of the first 100 people with AIDS in San Francisco. There have been far too many other losses since: best friends, colleagues, roommates. For many of them I had been a primary caregiver. I knew about the devastation HIV disease brings upon others. I didn't have a clue about the devastation it would bring upon me.

I had joined the “AIDS industry” in the early 1980s as a journalist, and eventually took on assignments as a columnist, consultant, and editor of five books. I had interviewed researchers, medical doctors, people with HIV disease and their families, lovers, and friends. For five years, I conceived international HIV prevention programs for use in developing countries and traveled extensively to help implement them. I was fully immersed in all facets of the epidemic. I had become an AIDS professional.

Yet AIDS, in the form of PCP, came at me like a hard, cold slap in the face that knocked me to the floor. The shock I might have expected, but I could not have anticipated the confusing and threatening mix of new emotions. Two-and-one-half years later, I continue to be jolted by the onset of new infections and disabilities. Now, however, I am less surprised about what I do not understand. I know that I have to work very hard to grasp what is happening to someone else with AIDS, ostensibly in the same predicament but, in reality, facing a condition different from mine. I recognize that my knowledge of the emotional and psychic effects of HIV infection is limited mostly to my own experience with the disease.

I believe that other AIDS professionals, including mental health practitioners, even those with many years of experience, may very well be in the same position. Just because we provide counseling to people with HIV disease, or lead group discussions, or write papers for publication, or generally “talk AIDS” does not mean we understand the experience. In the end, I have found that familiarity with AIDS is not enough. I fear that as providers immersed in the epidemic, we may develop an overblown sense of our knowledge, and that many of us have come to think we do understand more than we can.

Knowledge, Empathy, and Flexibility

Several months into therapy, I realized that I wanted to achieve a sense of being heard, of being understood in a way that is different, perhaps more profound, than a friend or lover might understand. As part of my own seeking, I came to identify what I consider some of the basic skills and knowledge that would facilitate this goal, that I would want and expect a therapist to possess.

Knowledge. The key medical facts about HIV disease are prerequisites. Familiarity with the primary treatments for HIV disease and its associated infections is essential, and this must be more than knowing about the primary antivirals and new protease inhibitors. I would want a therapist to know of the dozen or so prophylactic drugs prescribed for various infections, their possible side effects, alternatives to these drugs, and the general track record of their effectiveness. I do not believe that it is sufficient for practi-
Editorial: Surviving AIDS Jargon

Robert Marks, Editor

In the last two weeks before this issue went into production, Michael Helquist exercised an author’s prerogative to shift the topic of his lead article. Those of you who read the “Next Month” column will notice that instead of focusing on how the broad language of diagnosis—words like “asymptomatic,” “symptomatic,” and “AIDS”—can become a psychological straitjacket for people with HIV disease, he looks at a related issue: how a therapist’s generalizations about HIV disease can inhibit therapy.

These topics are quite similar. Each is about the assumptions that human beings make naturally when we interpret our perceptions through the filter of experience. While we are all liable for the false judgments that result from overgeneralizing, this filtering process is necessary and usually effective. But, for therapists whose aim is to remain “client-centered,” any assumption can sabotage the process.

Language remains an important incubator for these assumptions, particularly in the world of HIV disease. Politicized from the beginning, laced with myth and fear, AIDS has always been about finding the right words to describe concepts about which no one agrees. This remains true, since treatment has not yet cooled controversy by ushering in the routine of a “manageable, chronic condition.”

Awash in Terminology

The words we use have been coined by different constituencies—primarily scientists, politicians, and activists—with different goals. These terms have been recouped again and again in all the arenas in which these constituencies function—the laboratory, the legislature, and the streets—and publicized on television and in newspapers and newsletters, including this one. The result is that HIV disease (aka: HIV, HIV infection, HIV/AIDS, and AIDS) is awash in terminology, and as with any body of jargon, this specialized language can be as much an impediment to communication as a tool leading to precision.

Like Helquist, Jonathan Grimshaw, the author of the second article in this issue, is a person with HIV disease and a pioneer in AIDS communication, education, and care. Essentially asymptomatic since he found out he was HIV-infected in 1984, Grimshaw offers some surprising observations about the emotional reality of being a “non-progressor” and the conflict between this descriptor and his self-perception. While here the language of HIV disease inspires optimism, the history of the epidemic evokes only a sense of uncertainty, leaving someone like Grimshaw, who is essentially “well,” looking to the future with trepidation and at the present with confusion.

The bottom line is that while people with HIV disease have sometimes been the source of HIV-related language, more often they have become the unwitting object. Therapists, educators, and policy makers have an obligation to use this language precisely, to apply broad assumptions sparingly, and to look actively to people with HIV disease for lessons about their experience, an experience that changes more quickly than even our words.

tioners simply to refer clients to AIDS hotlines, health care providers, or treatment advocacy groups. Such referrals can be invaluable, but I think they should supplement the information therapists can give directly.

For example, I have been greatly aided when my therapist was able to explain some of the possible manifestations of different infections, especially when he could give me some perspective on the degree of discomfort or pain that might be involved. I have not looked to my therapist for medical advice; I have an excellent physician to turn to for that assistance. But my therapist has helped me manage my anxiety around certain medical procedures, and he has guided me in dealing with my fears about loss of vision, disfigurement, and dementia, for example.

Empathic Surrender. Time and schedule demands for therapists can be restrictive and unrelenting, possibly interfering with their ability to learn about the HIV experience. A convenient and likely source of HIV-related information, especially the more subtle manifestations and implications, can be the client. If I had CMV retinitis, I would welcome a therapist acknowledging, for example, that he or she could not fully comprehend the reality of losing one’s vision but was interested in knowing more about what I was experiencing. The therapist could follow this acknowledgment of limits and of being uninformed with questions to the client about the physical and psychological impact of vision loss.

I think practitioners may need to surrender themselves to particular experiences of their clients. In addition to listening, analyzing, and being support-
ive, therapists might be willing, in a sense, to enter the world of their clients. For instance, two years ago I was diagnosed with an uncommon HIV-related blood circulation problem that resulted in bone cell death in my hip joints. Walking became difficult and often required my using a cane. Although I could identify for my therapist some of my feelings about these circumstances, his extra effort to enter my world allowed both of us to confront and feel my panic, fear, shame, and despair over my disability. During this time, each of us expressed, through silence and conversation, the pain of so many losses and the courage it required to surmount the embarrassment and shame of an AIDS disability in public. This experience emphasized for me that my therapist was truly present with me. I felt that I could trust him even more to accompany me on the journey I face with AIDS.

**Flexibility.** I have felt profoundly humbled by the challenges of living with AIDS. I never imagined that I would have such difficulty expressing my feelings. Sometimes in therapy, I do not want to have to struggle to verbalize what I am experiencing on the deepest levels. I don’t want to be cognitive and rational and explanatory—a process that seems to glide over my feelings. In these instances, I do not want my therapist to exhort me to express myself simply. I want a therapist who understands the limits of language, who understands that there are no words to describe the profound nature of many feelings.

What I have found helpful is to define with my therapist ahead of time a way of conducting a session or part of a session in nonverbal ways, a period of time to explore my most profound feelings. For example, during one session, I acknowledged my belief in a Divine Spirit and talked with my therapist about my desire to find a way of more emphatically experiencing spirituality in my life. My therapist suggested that throughout my day I might invoke the Spirit and request help and guidance from it. We decided that I would also pursue this engagement with the Spirit in my next session.

I arrived the following week to find the lights dimmed, candles lit, and vases of flowers in my therapist’s office. I was quite moved by his willingness to alter the therapeutic environment and process. I sat this time on the couch closer to his chair. I asked that we hold hands to help me focus as we recognized the Divine Spirit among us. I asked the Spirit for help with specific personal struggles and for guidance in general. In the ensuing silence, I felt calm and grounded in my own reality.

During other sessions with my therapist, I found it helpful when he disclosed something of his own life that was relevant to the feelings I presented. For example, when I was talking about my fear of losing my mental abilities, my therapist mentioned that one of his close friends had experienced such a loss. We did not dwell on his friend’s fate, but the disclosure reduced my sense of isolation. I felt that he knew firsthand some of what I feared. Although some might fear that such a flexible and creative response would transform the therapeutic relationship into a “friendship,” I have found that my therapist’s actions have strengthened the therapeutic bond. As a client with advanced AIDS, my sense of separateness and isolation is always hovering nearby, and I cherish any demonstration of understanding and empathy with heartfelt gratitude.

**Treatment, Health, and Self-Esteem**

With the increasing availability of protease inhibitors, many people with HIV disease have watched their T-helper cell counts climb and their viral loads plummet. Taking these drugs may result in longer life spans. In fact, we may need to adjust our thinking about the average time that lapses before someone becomes ill and before the illness leads to death. But, despite the fact that I have experienced the benefits of the protease inhibitors, I feel that I am neither a non-progressor—my HIV infection is certainly progressing—nor a long-term survivor—what I experience does not resemble survival. I have come to think of my HIV status as one of “extension”: my life has been possibly extended as a result of my treatment. Practitioners can expect their clients with outcomes similar to mine to express wonder and joy as well as some confusion and even anger about having to re-think their lives and prospects once again. The future looks improved, but it

As a client with advanced AIDS, my sense of isolation is always present. I cherish any demonstration of understanding and empathy—even my therapist’s disclosure about his own losses—with heartfelt gratitude.
remains uncertain. “Extended” life has practical as well as psychological implications. In recent months I have watched my body weight drop 20 pounds, and I have noticed the loss of lean muscle mass. Both conditions affect my energy level, my self-esteem, and my overall quality of life. I have begun to reverse these conditions by doing rigorous resistance exercises and increasing my attention to my nutritional intake, including using appetite enhancers. I have also begun taking an oral steroid, oxandrolone, to increase my muscle tone and lean muscle mass. Therapists should consider regularly asking their HIV-infected clients about nutritional status, body weight, and exercise regimens. These factors are important not only to physical health but also to psychological well-being. In retrospect, I wish that I had received in therapy more inquiry and encouragement to exercise and to maintain my weight.

It would also be helpful for practitioners to inquire periodically about their clients’ compliance with medication regimens. Those of us with advanced AIDS must manage the logistics of taking several dozen pills and capsules a day, some with food, others on an empty stomach. Then there are the daily or weekly infusions and injections. Sooner or later people experience some degree of “pill fatigue” and become less vigilant about taking the correct dosages at the right intervals. Therapists may sometimes feel that their more articulate and knowledgeable clients do not need any assistance maintaining medical regimens. This is not necessarily the case. Regular “checking in” could be valuable both in a practical sense and in revealing a client’s feelings about taking care of him or herself.

Conclusion

During the course of the last fifteen years, mental health practitioners have provided invaluable assistance to thousands of people with AIDS. Working with AIDS may be professionally challenging and rewarding, but the generosity and compassion of the therapeutic spirit must get battered and worn down by these struggles with roller-coaster crises, dying, and death. I believe the best therapists are those who recognize their own limits of understanding, and who commit themselves to greater learning and experience to bridge such gaps with their clients. In seeking therapy, I would make a commitment to a practitioner who was willing to alter standard practice to deal effectively with my unique issues and needs. Finally, I would question any practitioner who does not feel humbled by the invasive power of this disease and who does not feel awed by the endurance and courage of those who live with it daily.

Clearinghouse: Stages of Infection


Kalichman SC, Sikkema KJ, Somlai A. Assessing persons with human immunodeficiency virus (HIV) infection using the Beck Depression Inventory: Disease processes and other potential con-

Author

Michael Helquist, Founding Editor of FOCUS, was one of the first journalists in the world to cover the AIDS epidemic, publishing some of the first interviews with people with AIDS and their lovers, friends, and family. Since then Mr. Helquist wrote for six years The Advocate column, “The Helquist Report,” co-edited two books for the UCSF AIDS Health Project—Working with AIDS and Face to Face: A Guide to AIDS Counseling—and was the program director of AIDSCOM, a federally funded and internationally focused HIV prevention project located in Washington, DC.
Life as an HIV “Non-Progressor”

Jonathan Grimshaw

True non-progressors—people who have had HIV for up to 15 years with no symptoms and with continually normal and stable T-helper cell counts—are extremely rare. The majority of non-progressors are, in fact, “slow-progressors”—people who have had HIV for 10 years or more and who are healthy but whose T-helper cell counts, although not falling below 500, have gradually declined. People with AIDS or a very low T-helper cell count who have survived for exceptionally long periods of time are usually described as “long-term survivors.”

Several factors may be related to HIV progression, including “lifestyle” factors such as good nutrition and avoidance of recreational drugs, psychological factors such as positive mental attitude and effective coping, and biological factors such as having a weak strain of HIV or a robust immune system. Recently, researchers have discovered that non-progressors have unusually low levels of the virus, apparently because they mount a particularly vigorous cell-mediated immune response.

While most of the literature on the psychology of non-progression approaches the subject from a biomedical perspective, it is equally important to examine the psychological impact of non-progression on the individual. In my experience, while non-progression is in most ways a victory, it takes a toll on mental health that is, for the moment, largely unrecognized.

Progression

I found out I was HIV-infected in September 1984. Like many people confronted by their own mortality, I learned that I could accept death if, when it came, I was satisfied that I had used my life well. In my case, this meant striving for an AIDS-educated society.

I wasn’t sure what I could do to affect my own prognosis, but I needed to feel that I was in some sense, if not immunologically, fighting HIV. AIDS activism offered a way of externalizing HIV and attacking it in a context where effort and success were tangible and enduring. It was a kind of race. I had to stay alive long enough to meet my expectations of myself in this arena. Several years ago, I won the race. I reached the point of knowing that I had used my life well.

Then, about three years ago my T-helper cell count began a steady decline from 1,000 towards 500. I seemed to be more susceptible to infections and had an bout of shingles. This seemed a sure indication of disease progression. I retired from full-time paid employment and spent most of my savings on making my home as comfortable as possible. I found myself socializing less and learning to be content with “simple pleasures.” I could see myself behaving in a way that I thought of as characteristic of elderly people.

At that time I envisioned a graph showing my T-helper cell count falling steadily past 500 down to zero. In fact, to my shock, the fall stopped at just above 500 and over the past nine months, the count has fluctuated between 550 and 700.

I can almost convince myself that my good health is due to my own actions and psychological response to HIV disease. For the first few years, AIDS activism provided a clear purpose for living. But after achieving the goals I had set myself, my purpose for living became less clear. Work

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See also references cited in articles in this issue.
became exhausting rather than invigorating, and exhaustion could have contributed to the decline in T-helper cells. The subsequent rise came not long after I retired from work and recovered my strength. My doctor, on the other hand, is convinced that I have a weak strain of HIV.

Uncertainty

I don’t know what to believe. The terms non- or slow-progressor suggest a more or less continuous, predictable state. But, ironically, the psychological experience may be one of constant insecurity. Although there is sometimes an overwhelming need to find a reason for non-progression, there is an equal need not to pin belief to an uncertain cause. Every explanation offered for non-progression is a hypothesis, and I am afraid that belief may betray me. One of the most difficult problems faced by anyone with asymptomatic HIV disease is coping with uncertainty as a fundamental condition of life. Non-progression, although it can offer some compensation, extends and deepens this challenge.

In retrospect, my conviction that I was progressing was probably not rational. I know that T-helper cell counts are not necessarily, in and of themselves, reliable indicators. Inventing a certainty to believe in, even the certainty of progression, may have been an involuntary coping mechanism.

When my T-helper cell count improved I was overjoyed, but angry with myself. HIV had fooled me, or I had fooled myself, into retiring from work. I had taken a step down from my involvement in life and could not step back up again, even though I was well enough to do so.

I’m caught up again in the movement to fight HIV, but largely on a voluntary and unpaid basis. The effort fuels my self-esteem, but my motivation is weaker. Sometimes I find myself agreeing to do work, more from a fear of losing touch or being forgotten than from a need to change society.

Isolation

Recently, I’ve also become more aware of emotional isolation. I haven’t been in a relationship for several years and the longer I go without one, the more daunting the prospect of trying to establish one. I am afraid to reveal the fact that I am HIV-infected because a potential partner might reject me or, as has sometimes happened, would want to spend the whole night talking earnestly about HIV. If I don’t reveal my HIV status at first, and a relationship develops, I risk rejection when eventually it becomes impossible to conceal something so central to one’s life. Sex, however safe, has become associated with anxiety for me.

I am also isolated as a non- and slow-progressor, a minority within the minority of HIV-infected people. I am afraid to disclose my status for fear of arousing envy or even resentment.

It is difficult to admit these problems, even to myself, because, in the eyes of others, I am lucky to be healthy. Acknowledging my angst seems not only ungrateful, but disrespectful to those who have not been so lucky. There are support groups for non-progressors. I have thought of joining one, but for the moment, it would seem too much like a concession to HIV, and I have perhaps become too accustomed to keeping my anxieties and emotions to myself.

Conclusion

Despite these problems, I would describe my mental health as good. If non-progression involves repeatedly and fundamentally redefining what life means for oneself, it is a price worth paying for health. Just as one can learn how to maintain a physical equilibrium by “listening” to one’s body, one can learn how to maintain a mental equilibrium. In my experience, one of the surest ways to upset the equilibrium is to speculate too much on the future or to search too closely for a prognosis. If and when I become a progressor, I will still feel a kind of triumph. But for me, and I suspect many others, prolonged good health has not been achieved without pain.

Corrections


In addition, the citation for the first Recent Report in the April 1996 issue—under the heading “Tailoring Safer Sex for Adolescents”—omitted the journal name: Journal of Personality and Social Psychology. We apologize for any inconvenience these errors may have caused.
Recent Reports

Mental Health Correlates to Progression
Krikorian R, Kay J, Liang WM. Emotional distress, coping, and adjustment in human immunodeficiency virus infection and acquired immune deficiency syndrome. The Journal of Nervous and Mental Disease. 1995; 183(5): 293-298. (University of Cincinnati.)

Increased concern with deteriorating physical symptoms and cognitive performance marks the symptomatic phases of HIV disease, according to a small study of patients who were free from acute illness. People with symptomatic disease also experience enhanced psychological distress associated with disturbances in occupational and domestic functioning, altered sexual activity, and disrupted social activities.

The study comprised 57 HIV-positive patients of the AIDS Treatment Center at the University of Cincinnati Medical Center in various stages of disease. Sixteen had CDC-defined AIDS, 22 had early symptomatic HIV illness without an AIDS-defining condition, and 19 were asymptomatic.

Control subjects included 17 uninfected people from the community. All subjects were middle-aged, well-educated, gay men. Subjects were assessed for emotional distress, coping mechanisms, and adjustment to illness.

Emotional distress was uniformly high among all subjects, but greatest for people with symptomatic HIV disease and AIDS. Among all subjects, mean levels of coping activity were one-and-one-half to two times the normative levels that had been established in previous studies for married people: this suggests that the risk of infection and advanced illness may stimulate a similar increase in coping regardless of serostatus or disease stage. The ability to plan or cope through problem-solving, however, decreased for people with symptomatic illness.

Demographics and Progression to AIDS

HIV disease progression and survival are not related to race, sex, drug use, or income if and when patients with HIV infection receive consistent medical care, according to a large study of patients at a Baltimore clinic. Employment at the time of enrollment, initiation of antiviral therapy after enrollment, and the use of prophylaxis against Pneumocystis carinii pneumonia (PCP) were associated with increased survival time.

Researchers studied 958 HIV-infected men (70 percent) and 414 HIV-infected women (30 percent) between the ages of 17 and 72 (the median was 34 years). Seventy-seven percent were Black, 21 percent were White, and 2 percent were other races. Risk factors for HIV infection included homosexual contact (27 percent), injection drug use (29 percent), injection drug use and sexual contact with an HIV-infected partner (25 percent), and heterosexual contact (14 percent).

After a median follow-up time of 1.6 years, 31 percent of the patients had died. Of the 740 patients (54 percent of the total sample) without an AIDS diagnosis at entry, 134 (18 percent) developed AIDS during follow-up. Variables significantly associated with mortality included older age, diagnosis of AIDS at enrollment, and prior use of zidovudine (ZDV) or other antiviral therapy at enrollment. Patients with T-helper cell counts below 200 and with a history of ZDV use had a median survival of 600 days, while those with a T-helper cell count below 200 who initiated ZDV after enrollment lived a median of 820 days, presumably because those who had taken ZDV before the study had already reaped the survival benefits of treatment. Only two percent did not use ZDV at all.

There was no correlation between mortality and demographic variables such as race, sex, income level, and history of injection drug use. These results contrast with previous studies that found survival was significantly shorter among women, Blacks, and injection drug users. The researchers theorize that differences in survival time is, in fact, a result of variances in adequacy of medical care.

Progressors and Non-progressors
Haynes BF, Pantaleo G, Fauci AS. Toward an understanding of the correlates of protective immunity to HIV infection. Science. 1996; 271(5247): 324-328. (Duke University; and National Institute of Allergy and Infectious Diseases.)

People with HIV infection can be categorized as "typical progressors," "rapid progressors," or "non-progressors," according to a sophisticated analysis of the research on the spectrum of HIV disease. While there is still controversy.
regarding the explanation for the differences among these three groups, it appears that these variations relate to the virus itself and the genetic background of the person infected, as well as the immunologic response to infection.

The majority of HIV-infected people are typical progressors and are projected to develop CDC-defined AIDS approximately 10 years after initial infection. After the initial phase of infection—characterized by high virus production—HIV replicates slowly during the “latent” phase, controlled by both HIV-specific T-killer cells and antibodies. Initially homogeneous, the virus mutates into variants that antibodies eventually fail to neutralize. The body responds to increased virus production with increased immune system activation. Progression to AIDS is associated with this generalized immune activation, which leads to production of more inflammatory proteins—for example, neopterin and beta2 microglobulin—and to tissue damage.

About 10 percent of HIV-infected people are rapid progressors and advance to AIDS within the first two to three years of infection. Generally, rapid progressors have a high viral load that usually does not fall dramatically to the levels seen with typical progressors. Many rapid progressors are infected with quickly replicating virulent HIV strains, and in response, T-helper cell levels rapidly decline. Levels of inflammatory substances remain high during the course of infection.

Non-progressors are asymptomatic more than 10 years after infection and have stable and fairly normal T-helper cell counts. They have low viral loads and often are found to have less pathogenic HIV variants. High levels of HIV-specific T-killer cells and neutralizing antibodies are present initially and do not fall over time. Low blood concentrations of serum and cell-associated immune activation proteins also characterize non-progressors.

Predicting Long-Term Survival


An analysis of Multicenter AIDS Cohort Study (MACS) data demonstrates that long-term survival and non-progression of HIV disease can be predicted based upon an evaluation of T-helper cell levels over time.

Drawing from the original cohort of 1,809 gay and bisexual men, researchers isolated a case group of 56 men who experienced no decline in T-helper cell level over a period of 14 visits (or seven years): the median T-helper cell count at entry was 725. They also identified two groups matched by race and age: the first consisted of 56 men with a moderate decline of T-helper cells (median T-helper cell count was 605); the second included 56 men with a rapid decline of T-helper cells (median T-helper cell count was 638). The majority of the men were White and in their early 30s. None had taken zidovudine.

After 19 visits (or an additional two and one-half years), the men who had previously experienced no decline in T-helper cells demonstrated a healthier profile in terms of onset of clinical AIDS, survival, and other immunologic variables. At follow-up, only 4 percent of the non-decliners had developed clinical AIDS and none had died (median T-helper cell count at follow-up was 643), while 88 percent of the rapid decliners had developed clinical AIDS and 84 percent had died (median T-helper cell count was 51), and 29 percent of the moderate decliners had developed clinical AIDS and 20 percent had died (median T-helper cell count was 285).

**Next Month**

Despite our best efforts, it seems unavoidable to think of HIV in terms of risk groups; and despite the CDC’s acknowledgement of a risk group that includes gay men who use injection drugs, none of these categories truly recognizes the extent to which gay men, drug use, and HIV disease intersect. In the June issue of *FOCUS,* two researchers discuss the implications of this situation for HIV prevention.

David G. Ostrow, MD, from the Medical College of Wisconsin, discusses the epidemiology of substance use in the gay and bisexual community, the relationship between substance use and risky behavior, and guidelines for clinical interventions. Michael Gorman, PhD, MSW from the University of Washington, highlights the epidemic of methamphetamine use that has hit the gay community and how this has affected HIV transmission and prevention.
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