



UCSF AIDS Health Project Guide to Counseling

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Chapter 9 HIV Disease over the Long Haul: Hope, Uncertainty, Grief, and Survival

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—Since the beginning of the epidemic in the early 1980s, the history of HIV treatment has been marked by intermittent flurries of excitement based on rumors, anecdotal stories, clinical trials, and a deeply shared longing for hopeful news to sustain people's spirits. Over time, new treatments have been able to check the progress of the virus, to protect immune-compromised people against various opportunistic infections, and to strengthen the immune system itself. Increasingly, people with HIV are living longer and healthier lives than they would have a decade or even a few years ago.¹

In the course of the epidemic, however, many promising developments ended in disappointment or, at least, fell short of initial expectations. The roller coaster of HIV treatment, as pioneering HIV therapist Michael Shernoff has called it,² is long, steep, and unpredictable, and riding it remains a daily reality for those who are living with HIV as well as all those who care for them.

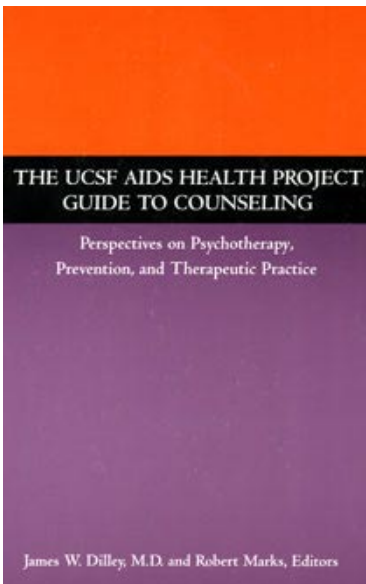
In the mid-1990s, with the advent of protease inhibitors and triple combination therapy, hopes and expectations rose to new heights. Among those who have had access to these powerful drugs, many have responded remarkably well, with viral loads plummeting to lower than detectable levels, immune system measurements rebounding, dramatic reductions in opportunistic infections and moderate to severe symptoms, and surges of new vitality. In the waning

days of 1997, this trend continues for some, although both clinical studies and anecdotal evidence reveal that many individuals are not able to remain at the plateaus they had reached. Many are managing difficult side effects, switching to new combinations, waiting for the newest drug to get approved, and continuing to live with hope and uncertainty. Though the roller coaster continues, there has been a paradigm shift, with the language and assumptions of hope firmly incorporated into the vocabulary of the epidemic.

For those who are doing well, living with HIV disease as a chronic manageable condition is not necessarily as simple as "The epidemic is over for me and I'm getting on with my life." First, although some have asserted otherwise, the epidemic is not over.³ To quote Shernoff again: "The epidemic is only over for those who have died."⁴ Second, even those who are doing well face a complex set of issues in going about the profound task of reconstructing the future. This challenge is the primary focus of this chapter, which addresses some of the psychosocial issues that accompany this process, primarily issues of hope, uncertainty, meaning, and survival.

Before beginning, however, it is important to express a caveat, already implied. Globally, the vast majority of the 29 million people currently living with HIV disease⁵ do not have access to any basic medical care, much less the expensive new medications that, for some, have transformed the epidemic. Many of these people do not have access to simple antibiotics, and some also lack resources for adequate nutrition, clean water, and other basic pre-conditions for maintaining good health.

In the United States, statistics that show declining death rates and drops in the incidence of opportunistic infections also reveal



significant disparities, with the new hope and the new treatments failing to benefit many women and people of color, particularly African Americans. While acknowledging improved treatment and prospects for survival, we must be mindful of these differences and remain committed to advocating for access to hope for everyone.

Reclaiming the Future

For the global minority who do have access to care and are doing well with combination therapy, there are many positive and hopeful developments to acknowledge and celebrate. Many of these people are feeling a renewed energy and strength they have not felt in years. Some are returning to work or to school or are seriously contemplating such life changes, making long-term plans they had expected never to make again. Some people are building new relationships with new life partners, while others are mustering the courage to leave relationships that have been unhealthy. Some are experiencing joy and pleasure in their resurgent sexuality. Some are feeling much more motivated to confront their addictions to alcohol, tobacco, and other drugs, as well as other forms of addictive behavior. Others are engaging in or increasing various kinds of physical and recreational activity. Overall, many people are reclaiming a future, a profoundly hopeful shift away from the despair and resignation many have understandably felt in the past.

There have always been seropositive people who lived with a tremendous amount of energy and spirit, believing that they would survive for a long time, or at least that they would make the most of whatever time they were going to have.⁶ For some of these people, the new surges of hope have not changed their lives dramatically. However, the breadth and intensity of these new hopes have had an effect on everyone affected by the epidemic, including those on the periphery whose ideas about and images of the epidemic are being re-shaped. In the industrialized world everyone's expectations have been heightened.

The Spectrum of Experience

Heightened expectations are, of course, experienced differently by different groups of people. For those doing well with the new medications, these expectations can spur them on to make, or at least consider, major

life changes. But for those who are having problems due to viral resistance or to troubling side effects, it is difficult to avoid succumbing to panic or despair. Feelings of failure and self-blame are common as people struggle to come to terms with not doing as well as others. It is not new for groups of seropositive people to experience wide disparities of success with treatment, often for no apparent reason. However, now the stakes of success or failure seem higher than ever, so the attendant feelings of inadequacy, shame, or despondency sometimes run deeper.

Especially in communities hardest hit by the epidemic, such as the gay and bisexual men's community, where many have been sustained by the camaraderie of shared adversity as well as shared hopes, these disparities of treatment success are difficult to manage. In general, the atmosphere has become more optimistic since the advent of combination therapy, although it has grown more cautiously so. In this context, it has been hard for some who are not doing well to speak up; as someone recently said at a public forum, "I don't want to spoil the party for everyone else." Among those who are doing well, some feel self-conscious or guilty about the failed hopes of friends. It remains a challenge for both individuals and communities affected by HIV disease to continue to make room for the whole range of emotions, from exhilaration to despair, that people experience. The solidarity that has sustained so many people through this epidemic is as important as ever, possibly more so. Special attention must be directed to ensuring the inclusion and sustenance of those who are not doing well, who may inadvertently be avoided or even abandoned by care providers and others who feel powerless to restore their health.

Disparities in treatment success are best faced directly. When people are able to speak openly about the awkwardness and pain regarding these differences, it is usually a relief to everyone involved, an opportunity to share the pain that may have become a taboo topic. This kind of openness is, of course, easier and more likely to be successful in the context of an ongoing support group or a retreat for seropositive people, where participants have the opportunity to develop a sense of caring and community. It is important to note that with current treatments, individuals may move back

and forth between “success” and “failure,” rendering categories fluid and requiring participants and facilitators to be inclusive of every experience.

Living with Uncertainty

The relative success of combination therapy has been exhilarating. But while exhilaration is hopeful and exciting, it can also leave people feeling dizzy and disoriented. For everyone affected by HIV disease, the underlying current of uncertainty still runs strong and deep. Questions abound regarding how long new treatments will remain effective, whether particular strains of the virus will become resistant, what short-term or long-term side effects might develop, whether the next wave of treatment alternatives will come along in time, and whether these new alternatives will be made available to all those who need them. Some people fear that they will make major life changes, get sick again, and then feel more vulnerable—physically, emotionally, and financially—than ever.

People living with HIV disease do not necessarily expect answers to these questions, but of course, they need to ask them. They do deserve full acknowledgment and empathy for the feelings behind the questions: fear, skepticism, anger, weariness. Those who provide care to seropositive clients may not always have sufficient time to address this spectrum of emotions. However, providers do carry the responsibility to at least acknowledge the unanswerable questions, to avoid fending them off out of discomfort, and to understand how frightening it might be to not have the answers.

Coming to terms with uncertainty as a basic existential fact of life is an ongoing challenge for all people. To do so while diagnosed with a life-threatening illness is especially challenging. Yet, it is crucial for people with HIV disease to address uncertainty if they are to cope with HIV infection over time. Denial may be an effective coping mechanism for a period, but as it wears down, the stressful nature of uncertainty requires a more mature and effective stance toward living in the face of a full range of possibilities.

A seropositive woman I knew for years—I’ll call her Sharon—was extremely hopeful about her prospects for long-term survival. She actively engaged in pursuing various treatment alternatives, was an extremely

well-informed and demanding consumer of health care services, and spoke publicly about her experiences, giving strength and hope to herself and to others in the process. For several years, Sharon felt angry and sabotaged by any hint that she might not live a long life. Over time, however, she was able to integrate the possibility of death without feeling threatened by it and as a result was able to make guardianship plans for her daughter. Sharon was able to make peace with the uncertainty of her own future without feeling compromised or as if she was giving up. The power of her positive thinking had a major impact on the quality of her life, and possibly on her physical health as well, and she was strengthened by being able to embrace her serostatus in a more grounded, less defensive manner.

Through the years, I have seen people like Sharon find relief and comfort in facing uncertainty head-on and learning to live with it. Especially in the early stages of coming to terms with a HIV diagnosis, it can be too overwhelming to confront the possibility of death. But beyond this initial period, it becomes important for someone who is relatively intact psychologically to confront the whole range of their possibilities. As Steven Schwartzberg writes in *A Crisis of Meaning: How Gay Men Are Making Sense of AIDS*, “coping effectively with HIV. . . involves allowing yourself to experience grievous loss along with bittersweet growth.”⁷ While Sharon tended toward the hopeful and discounted potential illness and death, some clients on the other end of the spectrum firmly expect only the worst of outcomes. This distortion may help some feel less vulnerable to feelings of disappointment and better prepared for health crises, but they run the risk of not noticing that life is unfolding in the meantime.

Control and Change

Uncertainty inevitably brings up the issue of “control,” which is an issue that tends to be surrounded by myth and illusion. Schwartzberg discusses the importance of distinguishing (within the environmental, health, and economic constraints) between what can be controlled—for example, current and future life decisions, health care choices, and personal goals—and what cannot be controlled—the past, other people’s behavior, and who your parents or siblings are. Further, he discusses the cultural mean-

ing of “control,” which some pursue unrealistically and others abandon out of a sense of despair or defeat.⁷ Clearly, issues of control tend to run deep into a person’s psyche. To the degree a person can learn to relate to control realistically and in a relaxed way, he or she can also develop an easier relationship with issues of uncertainty.

Related to the twin issues of uncertainty and control is the difficulty of adjusting to change. There are many people with HIV disease whose basic expectation was that over the years, they would gradually get sicker and die. They had planned the rest of their lives according to this scenario. Not that they were looking forward to these outcomes; but the process of reformulating the scenario in order to prepare for a future of new possibilities was a profound and difficult one.

In the process of assisting people who are facing the whole range of issues related to uncertainty, care providers need to be scrupulously honest about what they do and do not know. For some, this means dealing with their own discomfort about uncertainty, their desire for control, and their feelings of responsibility to “fix” things far beyond their control. When providers take these appropriate steps and do not pretend to have the answers to unanswerable questions, they need to be prepared to deal with their clients’ anger in reaction to uncertainty, trusting that ultimately, clients will be more reassured by honesty than by pretense. This is crucial: facing something difficult or disturbing does not mean that a person has to like it. It can be helpful for people to have the opportunity to rail at the cosmic unfairness of living in a world where so much remains unknown and uncontrollable. Ironically, in coming to terms with uncertainty and lack of control, people usually end up feeling more empowered.

Facing the Past, Facing the Future

Recreating a sense of having a future is an awesome, complex task. Much of it is joyful, but much depends in part on what the future looked like before one’s life was transformed by HIV disease. No adult came to this experience as a blank slate; each already had his or her own history, circumstances, and character. For those fortunate enough to have had a sense of purpose and direction in life, to have felt generally good about themselves, to have had positive

and fulfilling relationships with family and friends, to have done meaningful work, and to have felt connected to a community, the opportunity to recreate a future will most likely be experienced as joyful and exciting.

However, for the growing numbers of seropositive people who felt chronically isolated, anxious, or depressed, struggled with major addictions, had limited job skills and opportunities or were doing work they did not like, or were barely able to make ends meet, recreating the future is likely to be a fearful and problematic process. For an increasing number of people with HIV disease, dealing with these long-standing problems as well as with current governmental policies regarding welfare, health care coverage, and immigration makes it difficult to feel hopeful about the future, no matter how promising new treatments may be. Care providers need to look far beyond the traditionally defined parameters of “HIV issues” in order to assist the full spectrum of clients.

Seropositive people have always needed practical assistance as well as emotional and psychological support. Earlier in the epidemic, practical assistance often focused on tasks related to serious illness and death, for example, arranging for wills and durable powers of attorney to protect the life partners of gay men, or organizing networks of family and friends to provide enough care to enable a person to die at home. These needs still exist, but there are many new tasks related to living for longer periods of time: arranging for long-term housing subsidies; supporting people through long-term substance abuse treatment and recovery; and increasingly, assisting people in the process of going back to work. This process is both psychological and practical: people need counseling to realistically assess their own skills and work and education history, to protect their own confidentiality and appropriately disclose HIV serostatus, and to face fears of failure. In addition, clients may need help understanding disability benefits, health insurance, and legal protections against workplace discrimination. As clients prepare to take such major steps, it is crucial that they be helped to take them successfully.

Facing the future is further complicated for some by having felt left behind by uninfected peers in the past. For a large number of seropositive people, HIV infection interrupted their lives during a stage of life when

they ordinarily would have been building the foundation for a seemingly secure future. When viewing seronegative friends who have settled down to careers, families, financial security, or retirement planning, it is difficult for them not to feel envious, even resentful. It is important to offer clients opportunities to express and face these feelings. It is important, as well, for them to mourn the lost opportunities of the past in order to move forward into a reconstructed future.

The History and Meaning of Survival

Even though the epidemic is not over, successful combination therapy has encouraged growing numbers of seropositive people to contemplate living a normal life span, to confront the prospect of survival and its implications. Some are thinking about post-traumatic stress, even as they acknowledge that we are not yet “post.” This epidemic will end at some point, and it is not too early to face the challenge of envisioning a future beyond AIDS and preparing people to live in it.

In speculating about the nature and future of HIV survival, one source of wisdom is reflected in the experience of others who have survived or witnessed ongoing life-threatening trauma. Throughout human history, people have experienced both natural and human-made disasters, with some managing to survive against great odds. In recent memory, one cannot help but think of the Holocaust—not as an opportunity to compare such starkly different phenomena, but to learn from the experiences of people who survived.

One lesson from the experiences of these survivors is that “back to the future” is not the same as “back to normal.” Life after a massive trauma is never the same. That is not at all to say that healing is impossible. It is to emphasize, however, the importance of acknowledging the reality and power of trauma as well as the task of rebuilding afterwards.

Another lesson is that it is difficult to reconstruct life when so many people from one’s past have not survived. Mourning such losses is a lifelong process that will be reactivated at all life stages, especially at times of separation or loss. The prospect of aging without one’s peers, for example, is a common issue for many people with HIV disease. In the experience of past survivors, it is possible to build new families and communities and there can arise a tremendously powerful

feeling of triumph in doing so. However, the loss of those with whom history was shared is permanent; honoring that history and those who did not survive is crucial.

In order to survive trauma, particularly the effects of massive cumulative grief, survivors defend against becoming psychically overwhelmed by learning how to numb themselves. This “psychic numbing” is one of the five themes enumerated by Robert Lifton as an outgrowth of his work with survivors of massive death experiences; the others are “death imprint,” survivor guilt, “suspicion of counterfeit nurturance”—that is, a mistrust of the depth of understanding or even the motives of those who offer comfort—and the struggle for meaning.⁸ Numbing can become habitual, and it can be very difficult for a survivor to feel psychologically prepared to reopen him or herself to the whole spectrum of human emotions. Survivors may fear that in allowing themselves to experience any feeling, they may get flooded by horrific images and emotions, and intrusive thoughts are common among those who have survived trauma. Sometimes the most compassionate and intelligent approach to treating trauma is to help a client contain rather than express these emotions, with the hope that over time, the client can build enough psychic strength to dip into the well of horror and grief. Not all wounds heal, and not all should be reopened. People learn to live with scars, and some are able to do so with great wisdom and grace.

Studies of Holocaust survivors teach us that those who resisted and stood up for themselves and for others, even very privately and quietly, often did better afterwards. To a remarkable degree, many people who have lived with HIV disease have done so with the aid of their own great altruism and powerful activism. The experience of helping others and feeling connected to the larger world reduces isolation and expands feelings of mastery and empowerment both in the present and the future. Survivors also teach us that it helps to stay connected to the community of others who have gone through the traumatic experience, although people sometimes feel compelled to dissociate from these connections in order to build new lives.

Finally, survivors teach us about the importance of memory. While some survivors need to contain their emotions about

and images of the trauma, many others need to recount their stories to people who will listen with honor and respect. Though the HIV epidemic has been documented in many ways and with much creativity, there are potential oral and video history projects, for example, that could have great value and meaning in the years to come. The community of people affected by HIV has been well-served by the NAMES Project Memorial Quilt, but we need additional communal rituals of remembrance, affirmation, and renewal.

As a powerful image of the kind of ritual we require, Schwartzberg movingly describes the “onion cellar,” a fictitious nightclub in Gunter Grass’s post-war novel, *The Tin Drum*:⁹

The Onion Cellar is an unusual place. It serves no food or drink, offers no conventional entertainment. Instead, well-heeled patrons sit at crude tables, where they are given cutting boards, paring knives, and onions. They wait obediently until the club owner instructs them to cut and peel the onions. They start timidly. But then they cut and peel with abandon. And they begin to cry. Their crying soon turns to wailing, a communal grief mirrored in a skein of individual tears. The patrons turn to their friends and to strangers, weeping and comforting each other. They confess their sins, their hurts, their guilt. They use the onions to gain access to the pain they carry but cannot otherwise express. They come to the Onion Cellar to share this pain publicly, because the experience is less fulfilling if one cuts onion at home and cries alone. Some patrons come only once, others repeatedly, until exhausted of their tears. And somehow, in the process, they feel healed.

This is what we face with the AIDS epidemic right now. We need onion cellars. As a community, as shared witnesses and bearers of so much loss, we must find ways to express the pain, the grief, the despair that feels increasingly out of our scope—and to do so safely, emotionally, repeatedly. And we must do so communally, so that others may be there to support and witness, so that we may each serve as comforter and mourner.⁷

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Survivors of any trauma never form a homogenous group, and this is certainly true about people living in the shadow of HIV. To say that they are uniformly resilient or heroic would be untrue, although many have shown both characteristics to a remarkable degree. It would also be untrue to romanticize AIDS as a transformative experience, without acknowledging the depth of the losses so many have suffered.

We will continue to suffer losses. Some people will demonstrate dazzling resilience, and some will not. The degree to which we will as individuals and as a society be transformed by this epidemic remains to be seen. The hope, courage, humor, resourcefulness, and determination that have sustained so many to this point will be crucial for the rest of our lives. Therapists will be challenged to persevere over a completely unpredictable and long haul, summoning the full depth and breadth of their skill and their humanity in the process of helping seropositive clients face the past, live in the present, and reinvent the future. May we all have the strength to continue until the epidemic really is over. ■

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