homeless people who are actively drinking and using or for a mix of active users and others trying to stop (see Chapter Six). Although they may not be labeled as such, elements of harm reduction are common in abstinence-oriented treatment. For example, trauma survivors may experience intolerable feelings when they stop using alcohol and drugs because they are flooded with emotions and memories. Securing an abstinence commitment from such clients may take time. In the interim, therapists may strive to help clients avoid situations that are most harmful—for instance, visiting certain neighborhoods that may trigger use, or driving while intoxicated.

Abstinence-oriented programs have been criticized for their failure to produce long-term continuous abstinence. Indeed, only 10 to 20 percent of those treated in such programs actually achieve relatively unbroken abstinence. But addiction treatment is complex. Even in abstinence-oriented programs, abstinence itself is only one criterion of success, and researchers and evaluators usually do not consider it the most important. The issue has become confounded because the drug and alcohol treatment programs themselves do consider abstinence to be the main indicator of their success—the result being that they fail to communicate to the public the considerable accomplishments they achieve that nonetheless fall short of abstinence.

In this light, it is useful to review the original federal outcome evaluation criteria for substance abuse treatment: reduction or elimination of alcohol and drug use, reduction in crime, increase in employment and self-support, improved family functioning, increased social support, and improved medical and psychosocial status. Measured by all these criteria, abstinence-based treatment, though imperfect, is remarkably effective. Finally, a recent public policy paper, comparing substance abuse to hypertension, diabetes, and asthma, found that treatment outcomes were remarkably similar among all these chronic disorders. That is, there were similar rates of compliance with treatment among the conditions, even in the face of similarly serious consequences for noncompliance. The data thus do not warrant the pessimistic attitude many hold toward abstinence-oriented treatment. Rather, it has been the failure to disseminate research findings that has resulted in the widespread view that abstinence-oriented treatment does not work.
Phases of Recovery

Once a client has committed to abstinence, even for a short time, the provider can begin to address other tasks of recovery. Although some elements unfold on their own or can be accomplished without professional help, there are many ways in which providers can accelerate and enhance the recovery process. What is most essential, regardless of the theoretical orientation, is that the provider understand the tasks of recovery. These tasks can be summarized as follows:

- Becoming motivated to change
- Discontinuing alcohol and drug use
- Achieving and consolidating abstinence
- Changing life patterns (for example, in terms of employment, recreation, and interpersonal relationships) to support recovery
- Addressing the individual and interpersonal issues that emerge

It should be emphasized that although many seasoned therapists have been trained to believe that addiction must be addressed primarily through work on the “underlying” problems, there is little if any evidence from systematic studies to support this view. On the other hand, most addiction specialists hold the view that abstinence is the foundation of therapeutic progress and that work on coexisting issues must take into account a client’s stage of recovery. At the far end of the continuum are some who maintain that no other issue should be tackled until abstinence is secure. This is impractical, especially in complex patients.

Many addiction specialists have adapted to the reality that for many clients, abstinence will never be achieved if care providers ignore coexisting problems such as low self-esteem or the desire to block out rather than experience painful feeling states. Regardless whether these coexisting problems are major psychiatric disorders or charged emotional issues, substance use is best viewed as an independent behavior or disorder requiring specific intervention, concurrent with or subsequent to working on other issues—a behavior that in fact quickly becomes functionally autonomous from these underlying problems and may be amenable to modification long before other issues can be resolved.
The goal is to achieve an appropriate balance in the provider's mind between the questions How can this client stop using? and Why is this client using? The task for providers is thus to pay attention to increased psychological insight in the service of abstinence-related behavior change—acknowledging that although insight and recognition often make change possible, they do not automatically produce it.

**Treating Triple Diagnosis: The Challenge of Providing Comprehensive Care**

The clinician treating clients with three disorders has a daunting task. He or she must prioritize treatment and integrate interventions to address all three disorders in a sequence that is appropriately timed. There is no simple formula for developing this plan. Factors that affect the client's safety must be tackled first. These may include acute medical problems, abusive relationships, alcohol and other drug use, psychotic symptoms, or housing problems. The clinician must ask, Where is the best place to start if the goal is to keep my client safe and set the stage to permit my other efforts to bear fruit?

After clinicians have addressed any immediate crisis, they can consider other factors relevant to stabilizing the client. It is desirable to reduce disturbing psychiatric symptoms when possible, and it is important to motivate the patient to look at his or her alcohol and drug use and begin to make changes in behavior. Clinicians must also identify acute medical problems and develop a plan to address them. Important strategies for stabilizing the client also include assembling the elements in a support system: defining constructive participation of family and friends, connecting the patient to available benefits and services, and putting together a long-term plan to maximize improvement.

In the maintenance phase of care, it is important to monitor activities that sustain the gains achieved. These include all aspects of self-care. For example, when patients who have responded well to twelve-step programs begin to reduce their participation without discussing how they made their decisions, it may signal an impending relapse. Becoming careless about sleep, nutrition, or exercise can also destabilize a client. A client with bipolar disorder, HIV,
and alcohol problems, for example, may be taught to recognize increasing sleeplessness as a warning sign that a manic episode is imminent. Warning signals are often best detected in mundane details the patient may not report unless specifically asked, so it is important that clinicians routinely review areas known to be sensitive indicators.

The greatest threat to effective treatment of triply diagnosed clients is the potential for fragmentation among the agencies, disciplines, and individual providers necessary for appropriate care. At one time or another, or simultaneously, the client may be involved with the social service, mental health, addiction treatment, and criminal justice systems. Each system has its own set of resources and expectations. As a result, implementing comprehensive treatment plans is time-consuming and frequently overwhelms clients with contradictory expectations and with the task of mastering the idiosyncratic demands of many systems. The potentially debilitating nature of HIV disease adds to this process the dimensions of fatigue and disability, making matters even more difficult.

Richard Ries discusses the strengths and limits of three models of care—sequential, parallel, and integrated—applied depending on the profile of a particular client. This conceptual framework, described in more detail in the sections that follow, provides a good foundation on which practitioners may construct an appropriate treatment plan for triply diagnosed clients.

**Sequential Treatment:**
**Responding to a Severe Problem in One Area**

In this model, clients are treated first by one system and then by another. For example, many clinicians believe that addiction treatment must precede other aspects of care and that clients must be abstinent in order for psychosocial interventions or psychiatric medication to be effective. At other times, psychiatric symptoms must become the focus, such as when a client makes a serious suicide attempt. In some cases, a client's alcohol or drug use so undermines the efficacy of other interventions that problems may need to be addressed concurrently in order to make progress. This undermining effect is the key issue in determining whether sequential treatment makes sense.
Sequential treatment may work well when a client has a severe problem in one area but only mild problems in other areas. For example, a schizophrenic client who uses drugs moderately and episodically may come to a psychiatric service because of a psychotic episode or seek medical services because of an exacerbation of HIV symptoms. If the alcohol and drug use is indeed not severe, addressing it can be postponed until the other crises are resolved. Although often an effective approach, rigid adherence to addressing problems sequentially may undermine substance abuse treatment efforts—for instance, leaving unexplored the client’s psychological resistance to addressing the alcohol and drug use because the other issues are seen as “more central.”

Another problem can arise when a client who has been stabilized on psychotropic medication enters an addiction treatment program that discourages the use of such medication. Although this situation is becoming less common as educational efforts change attitudes in the addiction treatment system, it nonetheless does occur in programs that remain isolated from recent staff training efforts.

Parallel Treatment: An Approach for Highly Functional Clients

Like sequential treatment, parallel treatment may work well when a client has a severe problem in one area and mild problems in others. In parallel treatment, clients are simultaneously involved in treatment undertaken by providers in different systems. In clients who are triply diagnosed, there is almost always an element of parallel treatment as the client receives medical care for his or her HIV disease at the same time he or she is receiving treatment for a mental health or substance abuse problem. Parallel treatment is usually initiated by the provider in the system in which the client first appears for help.

Notably, the application of parallel treatment often is dictated by the limitations of existing services in the community rather than by thoughtful decisions about optimal help. For example, a depressed client with HIV disease may first seek help from an individual therapist in the community, who then may identify an alcohol and drug problem. As the treatment unfolds, the client may take antidepressants, participate in psychotherapy, and attend
classes on coping with depression, at the same time as he or she goes to twelve-step meetings, a recovery support group, and alcohol and drug refusal classes. Problems arise if this array of treatment is provided by clinicians who do not communicate with each other. Many psychotherapists, for example, emphasize the importance of the one-on-one relationship and do not initiate coordinating activities. While focusing on empowering the client, the therapist may miss the bigger picture of his or her client's multiple problems and limited resources. Clients in this situation must be highly functional to navigate treatment options and potential philosophical conflicts.

Integrated Treatment: The Alternative for Multiple Dysfunction

Integrated treatment combines mental health and addiction care, involving clinicians who have been cross-trained in both fields and applying unified case management. In many cases, integrated treatment has the greatest chance of success; certainly for clients with severe dysfunction in more than one area of diagnosis, this approach makes sense. For these clients, bouncing between two or three systems usually results in conflicting messages with inadequate opportunities for their resolution, and diminishes the chance of compliance with any treatment plan.

Integrated treatment places the burden of consistency and continuity of treatment on staff, not clients. In a setting designed for simultaneous treatment of both disorders, flexibility promotes the most effective resolution of conflict.

Clients with HIV disease who also suffer from substance abuse and mental health disorders are the most challenging clients for providers and systems of care alike. They raise a host of complicated issues ranging from making a differential diagnosis to deciding on the goals of treatment.

Most recently, these clients have provoked a debate on the ethics of treating them with complex antiviral regimens. Some providers and policymakers have raised concerns about whether these clients can adhere to these regimens and about the consequences of nonadherence for individuals (resistance to the antiv-
viral drugs in the combination) and for their future sexual and needle-sharing partners (the potential for infection with a drug-resistant virus). There is a growing consensus, however, that these clients deserve to be treated and that it is the responsibility of providers to establish structures that help these clients adhere, rather than to deny treatment based on the assumption that they cannot adhere.  

There have also been recent successes in creating environments where mental health, substance abuse, and medical treatments have been gathered together. Refinement and evaluation of these existing models will, we hope, bring clarity about which are the most effective. The HIV service community has an opportunity and an obligation to promote these kinds of arrangements for the well-being of their clients.

Notes


17. Ries, Assessment and Treatment.


Part Four

Therapeutic Practice and Countertransference
Personal Challenges for Therapists

Therapists working in the midst of the epidemic have had to adjust to the myriad accommodations that AIDS work demands. HIV disease has required a flexibility of approach, therapeutic frame, attitude, role, and standards of care: from becoming fluent in virology and infectious disease treatment, to confronting ongoing disability and death, to applying appropriate self-disclosure, to responding to ever-challenging countertransference issues.

None of these concerns is new, and none may be in and of itself onerous. But of course, these issues are not "in and of themselves"; they are related, and together they can be overwhelming; over time, they can be exhausting. Seventeen years have taught that there is no obvious solution—only mitigation—to the effect of these demands. For many, the substantial rewards of working with HIV have balanced the burnout. But even though balancing may be as good a solution as can be expected, it may not be ideal.

As it becomes clearer that, despite treatment advances, HIV-related psychotherapy can become a lifelong career, therapists need to consider more consciously their approaches to therapeutic practice. No longer can they respond in extraordinary ways to what has become relentless.
This exploration must embrace a broad as well as a long view, taking into account all the accommodations an individual can conceive of over time, identifying those that seem achievable and sustainable, and then formulating ways of maintaining boundaries that protect—without calcifying—these commitments. Part Four, written by and for therapists practicing in the epidemic, provides a thoughtful discussion of these issues.
Therapists who work with clients with HIV disease face profound challenges to their clinical skills and sense of hope. A unique circumstance in our time, the HIV epidemic has challenged therapists to serve clients in new ways and to integrate experiences that are sometimes very disturbing and often very stressful. It is through meeting these challenges, however, that many therapists have undergone transformative experiences and developed vital relationships that in some instances have provided rewards beyond what any of us might have anticipated.

In the first decade of the disease, many therapists responded to a crisis of health and community by entering into HIV-related work. With the identification of the virus, the door opened to research and to hope. Into the second decade of the epidemic, many therapists came to feel, as one therapist put it, “like an emotional punching bag,” with so much devastation, illness, and death around them. What was once motivated by a compelling sense of duty and a desire to jump into the fray gradually became complicated by a desire to escape what had become overwhelming.

By the time of the 1996 International Conference on AIDS in Vancouver, a revolution in HIV antiviral treatment once more shifted the experience of therapists working in the epidemic.
Although not a cure, the emergence of new drug protocols has provided new hope and the promise of the chronic, manageable disease that providers and clients have been talking about for years. After years of vacillating between the depths of despair and the heights of unmitigated optimism, many in the United States and other developed countries are currently experiencing renewed health.

For others, however, the new drug combinations have been ineffective. Check-ins at the beginning of HIV support-group sessions bear out this range of experience, revealing vast differences in clinical response to treatment and, as a result, emotional outlook. For clients on disability for whom treatment has been unsuccessful, seminars sponsored by AIDS services organizations on such issues as "Should you return to work?" are painfully out of reach. One therapist reports having gone to more funerals in 1997 than in many years, demonstrating to him that the epidemic is far from over and that for some, the promise of a long life remains elusive.

Identifying with the challenge, struggle, joy, despondency, and uncertainty of clients, therapists may progress through a delicate and parallel process as they struggle with the existential concerns and outcomes of this epidemic as it unfolds one client at a time. Therapists need to acknowledge and value the struggles and the resilience of individuals and communities while they continue to experience both the relentless quality of individual, interpersonal, and community destruction and the prospect of renewed health and rejuvenation.

This connection to the experience of the client is crucial to the empathic relationship therapy requires. The shadow side of this experience appears when the self-observing therapist loses sight of the separation between client and counselor, when lines that were parallel begin to cross. Whether evolution occurs in response to unattended grief and loss, survivor guilt, multiple loss, restimulation of past trauma, or a combination of these factors, the therapist may lose sight of appropriate boundaries and the distinctions between the client's and the therapist's experiences. The result is a blurring that can skew not only the therapist's experience but also the therapy itself.

In the second decade and for the foreseeable future, seasoned therapists working with HIV disease face challenges to clinical
boundaries and the therapeutic frame, to their sense of meaning, and to conceptions of time. This chapter explores these issues and suggests ways therapists can approach them and continue their work. By addressing such concerns, this chapter attempts to provide validation for experienced therapists, to stimulate introspection and discussion—overcoming isolation where it may exist—and to encourage therapists to reach out for consultation and support as they continue to respond to a shifting and persistent epidemic.

**Common Threads: A Review of the Literature**

Articles and books addressing the psychosocial aspects of HIV disease now appear more frequently than they did earlier in the epidemic, but most focus exclusively on intrapsychic and interpersonal issues for clients, not for therapists. When therapists’ experiences have been written about, several common themes have emerged, including responding to powerlessness, resolving anticipatory grief, maintaining clinical boundaries, and dealing with countertransference. The signal recommendation in the existing literature is for therapists to go beyond awareness of these issues, to avoid becoming inured to them as they arise, and to participate in ongoing case consultation.

Although therapists may be willing to comment on the rewards of HIV-related work, they often fail to discuss its profound personal toll. Therapists generally define rewards in terms of personal and spiritual maturity, which can be conceived of as encompassing the following gifts: working with someone facing illness or death and confronting the paradox this poses; helping individuals evolve from despair to reengagement; experiencing human resilience; and witnessing enormous courage and unanticipated revelation, which leads to the deepening of relationships with clients.

**Facing Powerlessness**

When therapists do acknowledge the shadow side of HIV-related therapy, it is expressed as feelings of helplessness and despair in response to the catastrophic nature of client needs. An HIV-infected client’s emotional life, which may become marked by increasing volatility, can also trigger an emotional response in therapists, and
this can exacerbate feelings of inadequacy, ineffectiveness, and hopelessness. Debilitating burnout results from the loss of professional distance, of appropriate levels of empathy, and of identification, and from the failure to see the bounds and limitations of therapy in light of a client’s life-threatening illness. Many therapists experience the hope-turned-fantasy that they can heal their clients or that the therapeutic relationship will contribute to physiological healing above and beyond its reasonable capacity to do so. But a client’s declining health and physical presentation challenge the fantasy, leading the therapist to feel powerless and inadequate. Although the new treatments are indeed resulting in increasing health for some, the difficulties of adhering to complex drug regimens and the uncertainty of treatment success and durability may amplify both hopes of revivification and sadness in response to treatment failure.

Facing a client’s mortality and anticipating the ravages of disease can lend a sense of urgency to therapy and may contribute to the therapist’s stress and pain. A client’s cognitive decline may affect the aspect of the therapeutic process by which clients gain insight and awareness. The therapist may fear being unskilled or ill equipped to work with a client who is cognitively impaired, a response that may reflect an objective assessment of clinical experience, a fear of dealing with this issue, or both. Further, fear may lead to the therapist’s denial of this aspect of a client’s reality, and, in an effort to avoid making the therapist uncomfortable, the client may deny failing cognitive abilities. In the face of real or anticipated decline in mental and physical functioning, therapist and client may also have different expectations of the goals of therapy. The therapist may want the client to resolve intrapsychic or family-of-origin conflicts, whereas the client may express a need to deal with day-to-day survival.

### Maintaining Therapeutic Objectivity

Clear expectations of therapy and the therapeutic relationship are paramount to successful care. Clarity is usually achieved by ensuring the stability of sessions, agreeing to concrete therapeutic goals, fostering a sense of support, and helping to define strategies for change. Although therapists are trained to balance emotional re-
straint and empathy, it is particularly challenging for them to maintain clear, albeit flexible, boundaries and therapeutic objectivity as the client’s physical and emotional needs take on greater urgency.\textsuperscript{16-20}

The loss of therapeutic objectivity may take forms ranging from overinvolvement to emotional distancing.\textsuperscript{21} In one case of overinvolvement, a therapist insisted, “Giving clients my home number and letting them know they can call me any time of day or night is my way of letting them know I care, I’m here for them; they can trust me.” The false equation of limitless availability and trustworthiness provided some secondary gain for the therapist. However, she also complained that she was always “bone tired” and that her life had “become HIV.” To the uninitiated, she appeared a model of commitment; to close colleagues, she was martyring herself, to her own and her clients’ detriment.

Emotional distancing may manifest as a flawed defense strategy that the therapist either brings to the work or calls on as a result of overinvolvement. “When one of my long-term clients called and said he couldn’t make his appointment, that he was ill, I was relieved,” observed one therapist. This therapist made no inquiry into his client’s health nor any effort to reschedule the client or invite rescheduling. He never saw the client again. It was much later that the therapist examined the process and saw how anomalous it was. Allowing the ill client to “terminate by phone”—to spare the therapist uncomfortable feelings about the client’s decline—was something he would never do with healthy clients. In both of these cases, failure to maintain therapeutic objectivity jeopardized the client’s sense of safety, compromised the integrity of the therapy, and upset the therapist’s emotional balance.

Confronting Countertransference Challenges

Diane Sadowy, a psychoanalyst describing her own conflicts treating a client with advanced HIV disease, speaks to this issue: “The transference that I had a magical cure and the countertransference that I was omnipotent initially defended me and [my client’s] position of helplessness. I found that acknowledging our helplessness opened up possibilities of contact and other choices she might make for herself.”\textsuperscript{22} Sadowy’s informed self-analysis enabled the therapy to progress with authenticity and integrity. Such struggles
with intense countertransference can be life-shaking. Facing one’s own mortality, life choices, helplessness, sexuality, and sexual problems, among other issues, provides enormous grist for the mill in the therapist’s own growth.23,24

To support clinicians in their efforts to acknowledge and address these countertransference challenges, and to make use of the wealth of emotional and existential issues triggered by HIV-related work, therapists across disciplines and theoretical orientations emphasize the importance of consultation and collegial support. For therapists working in the arena of HIV disease, there is a tension between the compelling need for such support and the resistance to it, a tension arising from a sense of scarcity of time and resources.

The root causes of this resistance may include a “mentality of poverty”—for example, the belief that resources are too few and time too limited to allow for process groups for therapists—or personal inflexibility; that is, therapists may fear that they will be overwhelmed and incapacitated if they stop to reflect on personal ramifications of the work. Whether discussed in terms of the impairment or narcissism of the therapist25 or in the language of codependency, resistance may lead some therapists to respond to the internal stresses of their work in isolation. These therapists assert that they have no need for support, that their needs do not compare to those of the people with whom they work and therefore do not need to be addressed. Coupled with a level of resentment or victimization, these therapists do not permit themselves to have needs. It is just such a psychological bind that underscores the necessity of including clinical consultation as a regular part of—not an optional adjunct to—the work of therapists in the field of HIV disease.

Acknowledging the Service Environment

The institutions in or with which therapists work have an important effect on therapists’ response to HIV-related treatment challenges. To understand fully the nature of provider stress and to develop appropriate responses, therapists must examine the context in which they provide services.26 In many cases, the phenomenon of burnout has been attributed more to these influences than to actual work with clients. Although some providers tend to resort to blaming the system in order to avoid looking at the difficult in-
terpersonal and social issues related to working with clients with HIV disease, nevertheless the politics and bureaucracy of AIDS have indeed “chewed up and spit out” many providers. Program administrators at clinics and other institutions would do well to examine the work ethic at their sites and how the sites operate, to reward healthy limit setting and boundaries, and to nurture and support staff in their day-to-day work.

The Therapeutic Frame

The traditional therapeutic frame provides clear boundaries that protect both client and therapist, but it may fail to respond to clients living with what can become debilitating illness. Therapists are trained to work with clients in a room with a door—a therapy room, sacrosanct, neutral, where confidentiality is ensured. The therapy session starts on the hour or half hour and ends in fifty minutes. Therapists take great care in retrieving clients from their waiting chairs, guiding them to the therapy room, and closing the door before beginning. Therapists and clients agree on fees, and therapists adjust fees periodically. Clients pay for missed sessions or late cancellations. If a client wants to terminate the therapy prematurely, that is, at a time the therapist assesses as too soon, therapists will encourage discussion and suggest an appropriate number of sessions to address termination issues.

Redefining the Traditional Frame

As therapists have gained experience working with clients facing multiple bouts of debilitating illness, decreased mobility, or cognitive dysfunction, they have raised questions regarding expanding the parameters of the traditional therapeutic frame to fit the erratic picture of advanced HIV disease. To what extent should therapists intervene with other health care providers to facilitate care for clients? In what circumstances should they decrease or eliminate client fees? Should they conduct therapy in clients’ homes or hospital rooms when clients are physically disabled? Committed to responding to the crisis of the epidemic, many therapists have made these adjustments without considering the long-term affects of extending themselves in these ways.
That therapists have begun to define personal limits reflects a maturity of involvement with clients with HIV disease. It is this honest reflection upon and permission to have personal limits that, in fact, supports both the authenticity and depth of the relationship.

The temporary or permanent failure of the therapeutic relationship to fit within the traditional frame may indicate the need for additional changes in order to further therapy. In fact, this process of change may actually facilitate the therapy: the adaptations themselves become grist for the therapeutic healing process. For example, advocacy—taking an active role on behalf of the client to initiate or enhance communications within the interdisciplinary care team—can serve therapy by modeling for the client ways of asserting his or her own needs and negotiating complicated and intimidating systems. One social worker put it this way: “Maybe it’s my training, or why I sought the training I did, but I’ve always viewed my role as . . . helping clients to access both internal and external resources.” Therapists without social work training, such as marriage and family therapists and psychologists, often find themselves facing these role-related conflicts, and by virtue of both their clinical training and their willingness to expand the frame of therapy, are equally successful in meeting the challenge.

Regardless of a therapist’s training, the task of advocating for a client can seem daunting and outside the realm of therapy. The frustrations and the time-consuming nature of advocacy can cause anger and resentment toward the client as well as toward “the system.” If the therapist begins unconsciously to blame the client for complicating factors such as insurance company bureaucracy, he or she may find ways, literally or figuratively, to let go of the therapy.

Whereas advocacy changes the content of the traditional therapeutic frame, home visits and free sessions alter its structure. The physical container for therapy is the therapy room. It is the place the therapist provides and, therefore, is an environment that he or she controls. The therapy room is perhaps one of the most fundamental aspects of therapy—on a par with the therapist’s role as an attentive, caring other—and even in the most protracted therapeutic relationships, it provides a foundation for safety and trust.

In deciding whether to offer home or hospital visits, the therapist must acknowledge the declining health of the client and recognize that in order to continue the relationship, the frame must
change to accommodate the client’s health. The alternative is to interrupt or end the relationship, which may reinforce a client’s feelings of abandonment and be detrimental to his or her sense of well-being. As we saw in the case in which a client’s hospitalization enabled the therapist to terminate the relationship without seeing the client, logistical circumstances may seem to provide the therapist an easy escape hatch: by maintaining traditional structures, the therapist can avoid further involvement and pain, and retreat from the client’s decline or dying process. This may be especially convenient if the therapist feels either closely connected to or alienated from the client.

By choosing to allow the therapeutic frame to change, the therapist can affirm the therapeutic relationship, address the client’s fears of abandonment, and acknowledge the client’s life force even in the face of his or her impending death. In accepting this course, the therapist must face being in a physical environment that, to some extent, is not in his or her control, that may make privacy or confidentiality difficult, and in which there may be interruptions to continuity and focus. Indeed, some of these conditions may already exist for therapists working in HIV outpatient settings; they require flexibility on the part of mental health providers and other staff to maximize privacy. Degree of flexibility and issues of privacy cannot always be anticipated, and therapists must evaluate on a case-by-case basis what will serve the integrity and content of therapy and what they feel they can and will do.

Likewise, therapists treating clients with HIV-related concerns must determine whether they are willing to participate in a relationship that requires responding to biological, psychological, social, and environmental factors in new ways. This legitimate and necessary question takes many therapists well beyond the boundaries of their previous professional training.

**Experiencing Multiple Loss**

Multiple loss has profound effects on therapists, particularly in areas with high incidences of HIV disease. Loss occurs when the therapist learns a client is HIV-infected, has an opportunistic infection, or is exhibiting symptoms such as memory loss or neuropathy that may affect the client’s mobility or sense of security.
Because the pattern of HIV disease commonly includes ups and downs, therapist and client may have more than one opportunity to discuss these changes and losses. In some cases, they have the opportunity for closure nearer the end of the client's life.

Therapists may also experience loss when treatment fails, when a client engages in unsafe practices after having engaged in safer behaviors, or when the hope for survival gives way to visions of terminal decline. Even though the therapist may understand that both successful treatment and behavior change are difficult to achieve and sustain, lapses or setbacks in progress can contribute to a therapist's sense of hopelessness, grief, or feelings that undesired or feared consequences are inevitable. The therapist may collude with the client and fail to address feelings about such losses, particularly deteriorating health, in order to avoid the pain of such a discussion.

The therapist's expectations about the course of a client's disease may determine the therapist's feelings when decline does occur: sudden death will engender a loss different from long-term, incremental decline. The course of HIV disease may at one turn seem individual and unpredictable, whereas at another resemble past events that apparently prepare the therapist for what is about to unfold. Perhaps there are visual cues that anyone working with people living with HIV disease learns to see as signposts along the way. Even if there are not, when the uncertainty is too much for the therapist, he or she may reach for a fixed picture—even if it portrays an unpleasant reality—in order to rest the anxious heart.

It is impossible to talk about HIV-related loss without acknowledging suicide and suicidal ideation. Therapists must be open to the needs of clients to discuss their thoughts or plans, while considering the ethical issues inherent in "self-deliverance." Professional obligations do not fully relieve the conscientious provider from the ambiguity of these discussions. This ambiguity stems from distinctions between "rational" and "reactive" suicides, the traditional connection between depression and suicide, and the taboo associated, for some, with the religious "sin" of suicide.

Therapists often feel responsible for client suicides, and the fact that this feeling is vocational does not mitigate a sense of guilt. Second-guessing about interventions the therapist might have made to prevent a suicide may dominate the therapist's thinking.
The therapist may also feel reluctant to discuss his or her feelings with colleagues for fear of judgment and of comparisons with how other therapists have dealt with similar circumstances. This devaluation may, in turn, complicate the therapist's grieving process and interfere with more fully experiencing loss.

For the therapist working in the epidemic over time, the different levels of loss and the compression of losses may seem to offer little opportunity to grieve. For some, the sense that there is no room to stop, to allow oneself to feel the loss, reflects the relentless quality of the epidemic: there is always someone else waiting in the wings with therapeutic needs that require attention. This understanding does not preclude the possibility that the therapist may unconsciously avoid experiencing feelings about anticipated or past losses.

Therapists who have reflected on the ramifications of unattended loss and grief in their own lives report experiencing typical signs of burnout at one or more points over the years: inattentiveness, negative attitudes, argumentativeness, preoccupation with peripheral issues, sleep or eating disturbance, relationship problems, and depression. (See Chapter Seventeen for a larger discussion of this issue.) These therapists may project unattended feelings about one client onto another client, or fail to attend to client fears and concerns in an unconscious effort to ward off unwanted feelings.

There are, however, lessons that therapists seasoned with HIV-related experience have learned. Chief among these is the observation that in some measure we are all walking around with broken, or at least repeatedly wounded, hearts. Multiple loss and grief are rarely resolved, and resolution of grief and complete acceptance of a loss may be unrealistic and undesirable goals. Grief and loss must be attended to, acknowledged, experienced, and tolerated, but neither resolved and overcome nor pushed aside. Therapists can, in fact, bear both their own losses and, in a different relationship to the losses, those of their clients, colleagues, and communities. Perhaps it is therapists, when they avoid Shouldering these emotions in isolation, who are by the nature of their training and attitude the most competent vessels for containing the emotions related to loss.

In this light, therapists may be better able than many other providers to tolerate and accept a lack of closure or a different
kind of closure when a relationship ends with loss. Although death or illness may mean that a client did not resolve particular issues in the course of therapy, this loss can be balanced by a sense that what the client did address was, in a larger way, enough. The therapist's ability to appreciate incremental change will decrease the risk of burnout. With this perspective, the therapist has a better chance of experiencing more authentic closure with a client.

**On the Matter of Time**

In the context of therapy, time is measured in prosaic ways: by the fifty-minute hour, as the span of time over which a clinical plan is mapped, or in terms of the client's late arrival or missed sessions. For people living in the epidemic, however, time takes on a surreal elasticity: perhaps terrifyingly compressed if one is newly diagnosed, interminably slowed if one is a survivor watching one after another friend succumb. In this setting, time becomes a central theme of therapy.

Time represents hope, and whether conscious or unconscious, hope can motivate people to engage with life, the future representing an image of a fertile place where dreams and plans can blossom. For the client with HIV disease, time is framed by uncertainty. Questions of time arise at every transition: When will I get sick? How long will it be before I am unable to function as an independent adult? How much time before I die? For those for whom antiviral treatment holds hope of improved immune system function and overall health, the questions take a different shape: Should I return to work? Do I have time to pursue an education or new line of work? How long will treatment work? Can I get on with my life now?

The recurrent anxiety that accompanies these questions becomes the backdrop for the therapeutic relationship. The therapist can productively reflect and process this anxiety in order to enhance the client's coping skills. Conversely, the therapist, spurred on by his or her own anxiety for the client and ultimately for himself or herself, runs the risk of pushing the client, subtly or overtly, into a race against time in order to resolve intrapsychic material that has been problematic for much of the client's life. The danger of such an approach is that the therapy may proceed at the
pace of the anxious therapist rather than at the psychological, cognitive, and emotional pace of the client. Such enmeshed boundaries will impair therapy and may lead to an increased sense of anxiety, helplessness, pain, and frustration for both the client and the therapist.

One therapist told a story of this enmeshment with a dying client: "I felt enormous grief, as if it were my own family that needed healing, when my client [became] disinterested in deepening the intimacy in his relationships with [his] mom and dad by telling them his true feelings." The therapist came to understand, as he witnessed this scenario so many times, that as people come to the very end of life, they may gradually let go of the people and things of this world in preparation for death.

Another therapist reported attending the memorial service of a group client. The client had only recently gotten together his résumé and was pursuing job interviews. Although the client had expressed hopes of getting on with his life, his work, and a new relationship, he had also expressed fears and doubts. "The treatments weren't working, that seemed true enough. But [the client] was pulled along by the current of optimism generated by the good response of other group members. I had felt the failure, the hopelessness, as did others in the group. But we all were pulling for him, almost like trying to will him onto the bandwagon. It just pulled out without him, and the helplessness we all felt was palpable."

Therapeutic goals must change with the changing needs and circumstances of any client. As a response to feeling emotionally overwhelmed—as if to stave off the feared decline of the client's health—therapist and client may collude in maintaining inappropriate goals that fail to reflect new circumstances and time constraints. It is the therapist, as well as others in a dying client's world, who must work at staying in sync with the client's measured journey. With the approach of death, time may be defined for the client by the form it takes around dying, a process that may become the primary focus. Others, including the therapist, may experience their own surrender to this new and fundamental human reality.

It is also important to acknowledge the changing expectations clients and therapists alike can develop in those instances in which clients’ health is rebounding and clients are revisiting
former goals regarding work, school, relationships, and family. In an epidemic in which many people have declined in health, lingered with long-term illness, and ultimately died, this shift can be disorienting. The shift calls for a redefinition, sometimes, of therapeutic goals and relationship.

This need for redefinition is most apparent in serodiscordant couples. As a partner supporting someone who is ill, facing illness and very possibly death, certain aspects of relationship sacrificed regain importance. One obvious issue is that of becoming a biological parent. When one has a sense that someday the partner will die, the noninfected individual may table hope of becoming a biological parent. However, because partners live without a current way to ensure that partners or offspring will not be infected, the noninfected partner faces the prospect of a life with someone with whom they may not wish to conceive.

**The AIDS Warrior Syndrome**

Like nurses on intensive care units, physicians on oncology wards, and soldiers engaged in trench warfare, psychotherapists working with HIV disease struggle to maintain balance and perspective. In the face of growing expectations, more and more therapists struggle to clarify a sense of personal and professional identity, purpose, and ability.

At its extreme, the “AIDS Warrior Syndrome” idealizes the role of the helper as ever willing and ever able to meet whatever client needs arise. It may be the product of overidentification, prolonged involvement, or an authentic empathic response. Some therapists will fail to acknowledge personal limits if to do so violates their sense of what the AIDS warrior should do. What distinguishes AIDS Warrior Syndrome from experiences of health care providers facing similar demands are those factors that distinguish HIV disease from other illnesses: the phenomenal increase in numbers of people affected, the fact that entire communities face devastation, and the social taboos and prejudices that lace the epidemic.

The almost heroic stature ascribed by society to people living with HIV disease is also ascribed to those who work with them. Although not all HIV providers are AIDS warriors in this sense, it is not uncommon to find those who cross that line. There is a ro-
mantic quality, an appearance of selflessness in some quarters, a bigger-than-life aspect to being one of these distinguished troops. Therapists are not immune to adopting this perspective, their training in self-observance and self-examination notwithstanding. The societal alienation that many of us face only adds to this response: some providers seek fulfillment from such compelling work because the richness of their lives is either absent or unrecognized, and the HIV community appears to be an ideal nest for emotional nurturing.

Over time, the AIDS warrior is unable to maintain perspective or boundaries and allows overidentification with the client or the HIV community to interfere with personal and professional wellness. When asked to identify what they were doing before AIDS work, these providers may struggle to recall. In day-to-day living, they may sacrifice serenity, personal relationships, and professional maturity to the cause.

**Meaning for the Therapist**

Is there any way to add balance to this sense of all or nothing, to get something out of AIDS work without sacrificing one's life to it? Many therapists look to their clients' struggles and triumphs for meaning and avoid unreasonable expectations for themselves. “Ninety percent of people with HIV disease who come into therapy, will die as they lived,” a Berkeley therapist said. “Perhaps 10 percent come into therapy spurred on by this race with time and can do some incredible work very quickly.” In some instances, a sense of limited time may quicken therapy, catapulting clients through difficult clinical issues in amazing ways. Many therapists say that such cases inspire and teach them and contribute to their professional and personal lives.

One of the more profound experiences therapists describe is witnessing the resilience of their clients. Inspired by a client's ability to grapple with painful clinical material—shame, mortality, parental rejection, internalized homophobia, failure to attain life goals, societal disdain, and disability—some therapists find the sustenance to continue the work. Although it is often the case that as a container for the material of the client, the therapist may experience feelings ranging from rage to hopelessness, these feelings
may be less dominant than the sense of humility and wonder that comes from the experience of bearing witness.

The therapist who surrenders to the external reality of the disease, remaining connected to experience no matter what piece of reality presents itself from session to session, is likely to manage most successfully. The process becomes one of maturation for many therapists as they develop the ability to shift with what is happening and to resist devaluing their own experience of the therapy. Rather than an exercise in futility, therapy becomes a pathway through which both client and therapist can accept pain and frustration as parts of the treatment. As a result, some therapists experience a deepening intimacy and a greater capacity for intimacy.

HIV-related therapy confronts many therapists with their own life choices, and some examine these choices. What is really important to me? Is there balance in my life? What issues remain unexamined in my life? This reflection often leads to a more conscious focus on living, on life-affirming choices, and on conflicts regarding mortality, loss, and grief. To facilitate this process and provide a framework for it, some therapists use spiritual, religious, political, or social filters, or resources that combine several of these perspectives. In understanding the work of therapy in light of these new experiences, some therapists are arriving at new therapeutic models that posit a more holistic view of human experience, for example, a biopsychosocial-spiritual model.27

Therapists must bring the ability to set limits and manage an HIV-affected caseload to the process of therapy. Some therapists choose to diversify their client base, seeing clients other than those with HIV-related issues, and in this way maintain balance in clinical practice and enhance their emotional well-being and a sense of control over their lives. Working with clients with HIV disease thus becomes a more conscious choice.

Perhaps the greatest personal rewards of this work are emotional growth and the spiritual journey, particularly for those therapists who remain open to the vulnerability clinical relationships evoke. With open hearts, therapists can use the experience of HIV-related therapy—combined with their own therapy and clinical consultation—as a means for personal healing.
For some, a healing occurs in a spiritual sense, as a resolution that takes them to a place more connected to the self yet also beyond the boundaries of body, roles, and projections. By accepting limitations, experiencing pain and release, obtaining collegial support, and seeking hope both through traditional sources (family, community, and spirituality) and in unacknowledged places (such as by working through the death of a client), therapists can transcend the difficulties of HIV-related work and, ultimately, discover truths about themselves.

Notes
1. The authors conducted more than twenty-five interviews with therapists working with clients living with HIV disease. All unattributed quotes from therapists are taken from these interviews as well as from discussions in consultation groups with other therapists.
4. Shernoff, “Eight Years.”
10. Tunnel, “Complications.”
12. See Note 1.
13. Shernoff, “Eight Years.”
14. Sadowy, “Is There a Role.”
15. Schaffner, “Psychotherapy with HIV-Infected Patients.”
16. Shernoff, “Eight Years.”
17. Sleek, “AIDS Therapy.”
18. Schaffner, “Psychotherapy with HIV-Infected Patients.”
21. McKusick, “The Impact of AIDS.”
Chapter Seventeen

Multiple Loss and the Grief of Therapists Working with HIV

Barbara E. Davis
David W. Cramer

Ned J., Richard K., Paul R., Kathy D., Vern H. . . . As Jan heard the names being read slowly over the microphone, above the hum of the people viewing the quilt, her heart began to beat more rapidly, her throat began to tighten, and she felt herself fight back an impulse to scream or run. When she had agreed to read the names of people she had known—mostly clients—who had died of AIDS, Jan had felt honored. But she had become preoccupied with making the list and wanting to leave no one out. It was very important to her that every person was named, was acknowledged for his or her life. She was surprised at the number of names—almost eighty. Could that be right? Now it was time to read those names aloud, and the feelings Jan had been suppressing for months were thundering to the surface.

Psychotherapists who work with HIV-infected clients are familiar with the emotional impact of the ceremonial reading of names at a presentation of the Names Project Quilt. Many of us carry our own quilts in our appointment books, and feel sadness, grief, and loss simply by glancing back through calendars from years past. Name after name, week after week, even year after year awakens remembrances of sessions with clients who shared their will to live and their struggles to cope with a devastating illness. Each memory raises emotions about how these therapeutic relationships affected
and changed us and about the parts of our own grieving yet to be experienced.

Therapists who work with people with HIV disease customarily do not have the time to come to terms with the loss of one client before experiencing anxiety about the HIV status of the others. This experience of multiple loss is in the nature of working on the front lines of the epidemic; it defines the greatest challenge for therapists facing HIV-related bereavement and is among the complications of practicing psychotherapy with seropositive clients. Without proper care and attention, cumulative grief may quickly lead to burnout, frustration, and a reduced capacity to empathize with the suffering and struggles of our clients. This chapter looks at HIV-related grief from the therapist’s perspective and focuses on the challenges of multiple loss to the therapist’s ability to continue providing care. It also offers approaches for handling grief and minimizing the impact of multiple loss on care.

**Jan**

After seven years of working with HIV-infected clients, Jan has gained thirty pounds and has increasingly isolated herself. She still works with seropositive clients but tends to back off from taking new clients with HIV-related issues. She focuses instead on supervising other therapists working with HIV disease. Colleagues commend her for “doing this work,” but they don’t seem to want to hear what it is like. Her friends in the gay community refer to her as “the Death Lady”; in response, she tries to keep a superficially “up” attitude when around them.

**Jake**

This work has given Jake, a colleague of Jan’s, an appreciation for “life in the moment” and a sense that he is privileged to share something very important with people with HIV disease. Because of the expertise he has developed by doing AIDS work since 1984, he is well respected in the community as an openly gay therapist. Losing friends and clients, however, has caused Jake to become numb; he is almost nonchalant when someone dies. He too has gained weight and is reticent to connect to new people—particularly clients with HIV. As a therapist in a close-knit community, the challenge of maintaining boundaries adds to his sense of isolation. This was highlighted when a client told Jake that Jake’s own therapist was HIV-positive; because of the confi-
dental nature of the interchange, Jake was unable to share this information and his feelings in the therapy group he attended, the very support he had set up for himself.

Robert

Robert experiences some of the same feelings that Jake does. After nine years of running a support group for people with HIV, Robert manages to find some comfort by viewing the deaths of clients as an end to their suffering, by maintaining a spiritual perspective on death, and by remembering positive experiences with these clients. As does Jake, Robert goes "numb" when a client dies, but he has found that later something will trigger a cathartic release for him.

Therapists working with people with HIV disease over the last few years have witnessed more pain and death than they could possibly have anticipated. The loss of clients has been compounded for many by the loss of friends, lovers, partners, colleagues, and even their own therapists or supervisors. The epidemic has gone on so long that to rest battle-weary psyches, many have stepped back to teach or supervise other therapists or have gone on to totally different work. Theirs is a "complicated grief" as they labor under conditions where a natural grieving and healing process is influenced by powerful factors including stigmatization, multiple and successive losses, and the anticipation of one's own death. Especially at a time when more people are doing well and fewer clients may be dying, therapists who have weathered multiple losses may finally experience the grief they may have had to put aside over the years.

Theoretical Perspectives on Grief and Loss

Elisabeth Kübler-Ross, William Worden, and Therese Rando each have proposed theories relating to the grieving process. Kübler-Ross's stage model, a standard in the field, helps to delineate the emotional aspects that make up the grieving process. Her crucial contribution was to emphasize the importance of moving through the process of emotional work that comprises her five stages: denial, isolation, anger, bargaining, depression, and acceptance. Grieving involves resolving the emotional challenges encountered at each stage, although not necessarily in a linear order.
Worden defines four tasks that are necessary for a healthy outcome to the grieving process: accepting the reality of the loss; identifying and expressing feelings, particularly the pain of the loss; making an adequate adjustment to living without the deceased; and withdrawing emotional attachment from the deceased and reinvesting oneself through new or enriched activities and attachments.

Rando focuses on three possible reactions to grief: avoidance, an attempt to block or buffer the pain; confrontation, an attempt to deal with the cascade of emotions—anger, guilt, despair, loneliness, and shame—brought on by the loss; and reestablishment, an attempt to become reinvested in living and more future-oriented.

These theorists hold in common the idea that grieving is a healing process and that any impediment to the completion of this process can harm the individual. Each also attempts to delineate the necessary elements of a healthy grieving process. For just this reason, many have criticized stage models as being too restrictive, suggesting that the wide variety of individualistic grieving patterns cannot be encapsulated into definitive, stepped, time-limited models. For example, Steven Schwartzberg argues that grief work may never be complete, never be finally resolved, particularly in cases where it is difficult to make sense out of a loss.

Robert Woodfield and Linda Viney propose a framework for bereavement that is based on a personal-construct psychology model. This framework does not assume a series of stages but is based instead on the psychological construct that people use to make sense of events and to anticipate the future. When a traumatic event, such as death, occurs, these constructs must change in order to accommodate the loss. New constructs may be either healthy and adaptive, or maladaptive. When our constructs fail to help us make sense of certain events, we may feel increased anxiety, depression, and anger. Multiple loss and cumulative grief can interfere with the process of accommodating to new constructs before facing yet another occurrence of loss. All of these theories suggest that HIV-related grief, particularly because of multiple loss, is unique, complicated, and often unresolved.

Whichever theory one ascribes to, grief is always an emotional reaction to a significant loss. As humans, we grow, develop, and thrive through our attachments to others. Grief is an emotional response to a broken attachment. We grieve most deeply for those
attachments that are most fundamental to our own sense of well-being and self-esteem. The more meaningful the attachment is to, for example, a lover, a pet, health, or ability, the more painful its loss will feel. Resolution, if any, depends in part on how well we are able to reattach emotionally and psychologically to other people, pets, and aspects of our lives.

**Characteristics of Multiple Loss**

Multiple loss is not a new issue for therapists working with cancer patients or in the hospice field.\textsuperscript{10-16} Sheila Namir and Scott Sherman review the literature, noting the “intense reactions and painful feelings elicited by working with people who are dying.” They suggest that such reactions result from the “need for therapists to confront their own separations and losses, fears of illness, death and dying, and unconscious fantasies related to rescuing others from death.”\textsuperscript{17} HIV-specific studies describe several characteristics that make HIV-related grief and multiple loss particularly difficult for providers on the front lines of the epidemic. One study describes the effects of multiple loss on grief resolution.\textsuperscript{18} Respondents, while exhibiting symptoms of the various stages of grieving, “jumped from one stage to another without establishing a pattern toward meaningful acceptance of one loss before experiencing another.” For those living in a world that has been strongly affected by AIDS, grief and loss can become common, almost daily experiences. Grieving then may no longer be a process through which one is working toward resolution as much as a way of life that offers little respite.

With the loss of multiple clients, the grieving process for the therapist can also become complicated and ongoing. Martha Gabriel has written about bereavement among therapists who must constantly explore the fears and hopes of seropositive clients.\textsuperscript{19} When loss and grief are constant, therapists are likely to have difficulty processing all the feelings, thoughts, transferences, and countertransference reactions that arise. Not only do therapists have to process their own losses, but because of the interpersonal nature of psychotherapy, many therapists also have to help contain and process the grieving of their clients, who themselves have experienced multiple losses.
Other commentators have described the traumatic stress indicators that multiple loss often produces in people. These responses include guilt, a questioning of spiritual beliefs, increased stress on holidays and anniversary dates, demoralization, and sleep disturbance. Therapists are not immune to these responses and are likely to carry them both into and out of the therapy office. This can greatly affect their ability to maintain a therapeutic stance as they attempt to assist clients in survival and life enhancement. Several studies have found a strong correlation between the experience of multiple loss and the existence of posttraumatic stress symptomatology in gay men grieving HIV-related deaths. These studies have also positively correlated adverse psychological reactions (such as demoralization) and suicidal ideation with the number of losses to AIDS.

Finally, HIV disease progression and its uncertainty may evoke an anticipation of grief among therapists. With each cough, sneeze, or new physical ailment, clients and therapists may experience "shadow grief"—a vague sense of anxiety and dread that points to an impending loss, whether real or fantasized. Sometimes the loss of a client’s abilities, such as sight, mobility, or sexual desire or functioning also engender grief in the therapist.

Grief for therapists may be further complicated if they are stigmatized as a result of their treating people with HIV disease. In such cases, they may lose the support of peers and other people on whom they count for emotional sustenance. In general, society as a whole continues to treat people with HIV disease as modern-day lepers, and their pain and suffering, as well as the grief experienced by their survivors, are often shrouded in feelings of fear, shame, guilt, and even hatred. These feelings often extend to those who care for people with HIV disease, and if they become known as "AIDS experts," therapists may find themselves losing referrals or even friends at a time when they most need outside support to grieve. (Such was the experience of Jan, the therapist who became identified as "the Death Lady.")

Drawing from both the literature and anecdotal reports, several factors emerge that complicate grief and loss for therapists:

- Many therapists tend by nature to be comfortable only in caretaking roles and have difficulty actively seeking support for themselves.
• Because they must maintain professional boundaries, therapists may not be able to participate fully in the grieving process with the friends and family of deceased clients, even though the therapeutic relationship may have been emotionally intimate.
• Because of the ongoing grief issues, it is more difficult for therapists to maintain boundaries. They may be more prone to acting out or discharging in inappropriate ways, for example, becoming lax about confidentiality, socializing with clients, or drinking too much.
• If blocked in their grief, therapists may avoid their own pain and may be unable to be present for the pain of their clients.

HIV disease itself adds to these difficult circumstances in the following ways:

• Because of the stigma connected with HIV disease, it is harder for therapists in some areas to find support in the psychotherapy community or in the general community.
• It is common for therapists to experience a sense of failure when clients are dying, particularly when—as with people with HIV disease—the clients are likely to be young.
• The nature of HIV-related multiple loss makes it difficult or impossible for therapists to complete the process necessary to resolve grief.
• Traditional boundaries may feel inappropriately constraining in the face of life-threatening illness, and this may become a source of conflict as therapists struggle to be available to clients in whatever way is needed, for example, by making hospital or home visits. Bertram Schaffner suggests that when confronting HIV-related issues, “the psychotherapist must be able to act in several different roles and to switch skillfully between them.”
• Therapists often deal with HIV-related illness and deaths in their personal lives, watching their friends, partners, and sometimes themselves succumb.

The Impact of Loss on Therapy and the Therapist

Therapists by the nature of their work are caregivers. But their ability to support and nurture their clients is directly tied to their own emotional well-being. If therapists do not acknowledge and resolve
their own feelings of loss and grief, the therapeutic relationship is likely to suffer. Therapists working with seropositive clients may have a multitude of countertransference feelings to manage, including helplessness, survivor guilt, and fear of mortality, all of which are further complicated by the death of a client. Denial and countertransference arising from the unresolved grief may sabotage therapy, leading, for example, to the therapist’s avoidance or incomplete processing of a client’s current or past experiences of loss or of a client’s feelings regarding deterioration and death. In addition, therapists who are not aware of their grieving are likely to avoid topics that are tangentially attached to loss, such as a client’s diminishing physical prowess and health or the writing of wills and powers of attorney.

Therapists in denial of their own grieving process also risk misperceiving client issues as a reflection of unconscious or fantasy material, and this may result in the therapist’s paying inadequate attention to the reality of a client’s condition. For example, a client’s cancellation may truly be more about the client’s physical ability than about his or her unconscious anxiety about therapy material; conversely, not everything in the client’s life is about their competing physical problems.

Failure to acknowledge, feel, and process grief will also affect therapeutic choices made about which issues to explore in sessions and how deeply and intimately the material will be processed. Anger about AIDS may be unintentionally displaced onto HIV-infected clients. Michael Shernoff has written about his personal experiences as a therapist struggling to handle the wide range of emotions and conflicts brought on by providing psychotherapy to clients with HIV disease. Among these responses are anger, exhaustion, resentment, fear of mortality and disfigurement, a feeling of lack of closure from abrupt termination of therapy, and feelings of hopelessness and helplessness.

Shernoff discusses a specific incident: while dealing with progression of his own HIV disease and the hospitalization of his best friend and business partner, he broke connection with a long-time client who was dramatically deteriorating and nearing death. When, during a hospital visit, the client tried to discuss suicidal feelings, Shernoff “was annoyed with him and glibly replied, ‘I can understand why you would feel that way,’ and left.” He used super-
vision to confront his countertransference issues and was able to go back to the client and explore the client’s suicidal feelings in a more appropriate way. Shernoff explains that he was angry and sad that his client had AIDS. “I often felt relieved when he did not want to discuss his deterioration or dying because this provided me with a much desired reprieve from facing my own feelings about his illness and ultimate death. As his illness progressed, my anger at him increased. . . . By saying that I could understand his feeling the way he did, I implicitly suggested that he kill himself, thereby ending our work together and relieving me of facing my conflicting feelings.”

Unresolved grief can not only cause disruption in the client-therapist relationship but also foster frustration and burnout. Therapists in this situation may avoid processing and containing their clients’ fears and anxieties and instead work unconsciously to ease their own pain. They may function as if their clients were constantly in crisis and provide more concrete practical and directive therapy in order to avoid deepening explorations of death and the afterlife. This tendency of therapists to numb their pain may lead to a collusion between therapist and client that keeps the relationship on a superficial level. In addition, “empathy fatigue” is likely to impair the therapist’s ability to relate with compassion.

Awareness of grief and loss can also provide opportunities in therapy. The capacity to love and maintain intimacy with clients is directly connected to the capacity to grieve and feel despair for them. Avoiding one response will reduce the experience of the other. Facing fear and the pain of loss can profoundly enhance the ability to stay connected, both to the therapist’s own emotions as well as to the client’s, and this connection can enhance the therapist’s self-esteem and sense of competence. Confronting the experience of death also provides an opportunity for change as one searches for meaning in the loss and attempts to adapt to tragedy.

Inevitably, providing psychotherapy to the seriously ill and dying places the therapist directly in the position of experiencing the multiple loss of important attachments. And, as therapists, each of us often has a strong desire to help ourselves and others heal and grow. There are events in this world, however, that produce senseless tragedies—terrorist acts, wars, famine, AIDS. The “growth” a person experiences in relation to these events is real and powerful but often forced, and most of us would chose to have our loved
ones back, foregoing this opportunity to grow by coming to terms with loss.

These tragedies do remind us that there is much in life and, especially, death that we cannot control. Attempting to control the uncontrollable leads most likely to burnout and frustration. Although it may be important to advocate, raise money, push for better treatment, and take other actions to confront the epidemic, to some extent providers have to find ways to feel helpless in the face of the reality that all the attachments we make in the course of life will eventually be broken. Everything that is turned on is at some point turned off. Perhaps struggling to accept the inevitability of this fact will enable us to experience more fully the attachments we have today.

Coping Strategies

It is vitally important to develop methods of coping with the ongoing experience of illness and death for both the emotional survival of the therapist and the client-therapist relationship. Most therapists are in this field because of a desire to help others, but at some point along the way they have, in fact, realized personal growth; it is likely that therapists drawn to HIV-related therapy even have a desire, perhaps at an unconscious level, for the growth that is required to provide appropriate care. Such growth arises out of the vigilant exploration of countertransference issues, an openness to the therapist’s process in relationship to clients’ struggles, and the direct relationship with clients. It also often occurs in the development and improvement of the therapist’s own coping skills. “It is in what we do to be more available to our clients that we can find our own healing.”

Coping in Professional Practice

Coping approaches can be divided into two categories, reflecting the overlap between the professional and personal lives of therapists. Strategies that relate directly to professional practice include having professional help in place, finding personal meaning in the work, being aware of personal and professional limits, and acknowledging grief.
Have Professional Help in Place

It is important that no therapist dealing with multiple loss tries to handle this alone. All the strategies in this section encourage the use of ongoing professional supervision and personal therapy.

Find Personal Meaning in the Work

What makes this work worthwhile? Working with people dealing with HIV disease helps many therapists to be more focused in the present, leads them to a fuller appreciation of life, and provides them with opportunities to explore issues relating to death. Therapists who work with clients with life-threatening illness often value the experience because it enhances their own awareness of the immediacy and preciousness of life and its fullness. Multiple loss forces many therapists to create a framework by which they can explore spiritual and existential questions regarding pain, suffering, and death. This framework might enable them to find meaning in the very thing that threatens their significance. Ernest Becker wrote, “What man really fears is not so much extinction, but extinction with insignificance. Man wants to know that his life has somehow counted, if not for himself, then at least in a larger scheme of things, that it has left a trace, a trace that has meaning.”

To reduce internal stressors, Richard Riordan and Sandra Saltzer recommend assuming responsibility for choosing to work with the dying and reviewing honestly the reasons for the choice. “Do the reasons include unresolved personal issues? Are the expectations of accomplishment realistic? For example, the desire to restore an individual’s physical integrity may be unrealistic, but the goal of controlling pain and facilitating a better quality of life until death occurs may be realistic. To accomplish this, a personal philosophy of involvement must be developed which fosters empathic care while maintaining individuality.”

Sheila Namir emphasizes the personal meaning in her reply to the question “Which is really harder—to die or to witness death?”. “I can’t answer that, having experienced only the latter. But I can say that to witness is to participate, and to be forever changed by it.”

Be Aware of Personal and Professional Limits

Because of the life-and-death issues involved in this work it is easy for therapists to overextend themselves by, for example, offering
to conduct sessions in the hospital, waiving fees, and attending funerals. But setting limits—perhaps by restricting the number of HIV-infected clients or defining a minimum sliding-scale fee—can raise concerns on the part of therapists that they are being selfish or not caring enough. For others, the illusion that they can do it all may be a way of defending against grief and powerlessness. It is necessary for each therapist to assess whether he or she falls into one of these categories. Being clear about limits can help therapists be more present with clients, extend their ability to do the work over time, and model for clients skills in taking care of themselves.

**Acknowledge Grief**

The memories of clients who have died will remain valuable after the therapist fully experiences the grief arising from their deaths. For many, acknowledging grief begins by honoring the deceased client. For some it helps to attend the client’s funeral; for others, a more personal ceremony provides meaning, closure, and an opportunity to grieve. One therapist ceremonially burns clippings of her clients’ obituaries and records their names in a book. Another releases a helium balloon with the deceased person’s name attached. Other strategies include making AIDS quilt squares, inscribing the names of clients and friends who have died in a special book, or making charitable donations in memory of the client.

Many therapists report that the grieving process is easier when they are able to say good-bye to the client in person. Being able to tell the client that he or she has been important to the therapist, and in what way, brings closure to the relationship and eases the therapist’s moving on. “It is important for people who work with AIDS to understand that experiencing grief and loss is not a failure of the therapeutic relationship, nor is it crossing over a professional boundary; rather it is a reflection of having had a genuine and real relationship with the person who is entering the final stages of his or her life.”

Telling stories about clients—even writing them down—can be an important part of processing loss. This can be done in a support group or in individual therapy. One counseling center for HIV-infected people offered a day-long retreat for staff members to tell stories and share in a ceremonial good-bye to clients. The desire to repeat stories about a person or people who have died as
a way to process loss and to hold on to memories is an important, natural part of the grieving process. The need to repeat the story of a traumatic loss is exemplified by Chekhov’s story “The Cabman.” An old man driving a horse-drawn cab tries to tell each fare that his son has died. Although each of the passengers reacts differently, they all indicate disinterest. The story ends at the end of his work day when he unhitches his horse and says, “You know, my son died today.”

Therapists facilitating group therapy may acknowledge grief when a member dies, and a group ceremony may enhance this experience. The therapist plays an important role in helping the group deal with the loss, and by openly grieving, the therapist provides important modeling for group members. Be aware, however, that this sharing must be done in a way that does not lead members to take care of the therapist. One therapist brought in a consultant to colead the group after his cofacilitator had died. This enabled the therapist and the group to grieve together without losing track of client needs.

Coping in Personal Life

Strategies that relate directly to personal life include frequently examining feelings and beliefs about death, having some life away from HIV disease and outside of therapy, avoiding isolation, being aware of personal needs, being vigilant about “checking in” with yourself, finding ways to express and discharge feelings on a regular basis, and nurturing the physical self.

Frequently Examine Feelings and Beliefs About Death

The willingness to acknowledge their own mortality enables therapists to be more emotionally available to deal with issues of death raised by clients, whether or not they are terminally ill. This willingness also increases the ability to face each death more openly and will help in the resolution of each client’s passing.

Death-related counseling may be especially difficult for therapists who have elevated levels of personal death anxiety, because clients’ struggles with loss or death may trigger the counselors’ fears of their own mortality. One study found that beginning counselors responded to situations involving death with greater
anxiety than they did to other situations, leading the researchers to conclude that an “exploration of one’s own personal readiness to face death may be a prerequisite to helping the client struggling with life-and-death issues.”

Have Some Life Away from HIV Disease and Outside of Therapy
For many therapists working with HIV disease, it is difficult to escape the epidemic when the entire community seems to be dealing with the disease. AIDS may permeate every part of life: reading, thinking, dreaming. It is a challenge to avoid filling leisure time with political activities, fundraisers, and other HIV-related events. Don’t do it; it is crucial to find social, physical, and other activities that relieve the sense that HIV disease is all there is.

When dealing with pain and loss of such enormous proportions, some people are not able to accept that they have done enough. A poignant example of this was seen toward the end of the film Schindler’s List when Oscar Schindler, allowing himself to soften to the meaning of what he had done to save so many people, becomes overwhelmed by the sense that he had not done enough. Doing more may be a way to avoid feelings of helplessness and powerlessness in the face of devastation. Setting limits may mean that one has to admit a lack of control and to learn to experience and tolerate this feeling.

Likewise, if being a therapist is the primary focus of your life, it is too easy to fall into the trap of allowing or expecting clients to meet your intimacy needs. Dealing with life-and-death issues can be seductive to therapists who are more comfortable with the one-sided intimacy of therapy, in particular those who “need to be needed” and who thrive on intensity. The therapeutic relationship can take on an idealized magical quality, and therapists may use it as a reason to be less involved in the more mundane realities of relationships that have a greater potential for equal give and take. Such therapists must establish lives outside of therapy that include nurturing and supportive relationships. Reaching out to others and maintaining friendships may, however, require a great effort.

Avoid Isolation
Therapists, like clients, may isolate themselves for a variety of reasons, including HIV-related stigma and the difficulty of acknowledging the need for support. They may succumb to “the fallacy of
uniqueness," which refers to the belief that one is alone and unusual in experiencing distressing feelings and thoughts. Therapists may also isolate themselves because they judge feelings of attachment and caring for their clients as unprofessional, and they feel uncomfortable openly sharing their grief for the loss of the client. "These feelings of attachment, care, and concern must be acknowledged and validated."

It is vital for therapists to face the issues that encourage their isolation and to learn to reach out for support. A number of authors stress the importance of support groups for health care providers dealing with multiple loss. In addition to providing a forum for mutual support and sharing, such groups can open the way for members to acknowledge grief. Ultimately, it is the therapist's responsibility to create a support system by joining such support groups and seeking individual therapy or professional supervision. Support and consultation from others doing similar work permit therapists to share personal experiences and facilitate their identifying countertransference reactions.

Be Aware of Personal Needs

It is important for a therapist to clearly understand personal needs and to be sufficiently aware of them to be able to contain the impulses that unmet needs might provoke. In the context of the disequilibrium that results from the loss of one client after another, clarity about these needs—for example, the need for emotional and social support and for expressing grief—increases in importance. Without this clarity, therapists are more likely to put clients in situations in which they are indirectly meeting the needs of their therapists, which may inhibit clients from fully "being themselves."

To protect against this loss of professional boundaries, ensure that you are either meeting these needs or that your awareness of them protects your clients. For example, as members of the therapy group for people with HIV disease began to die, one therapist turned to members of the group for support and developed friendships that blurred boundaries and roles. In the process, the therapist lost track of group dynamics, the needs of some group members, and the awareness that group interactions were becoming more superficial. The therapist might have prevented this situation had she acknowledged her own bereavement, recognized her need for support, and acknowledged that however close she felt to her
clients, she had to maintain her support system outside these therapeutic relationships.

**Be Vigilant About “Checking In” with Yourself**
By “checking in,” therapists can stay in touch with their own needs and limits and ensure that they are not operating out of avoidance. Checking in can involve only a few minutes each day spent noticing breathing, feelings, and personal interactions. It is important to recognize the traumatic proportions of this epidemic and to be aware of the emotional impact on therapists who are supporting and sharing feelings of clients as these clients deteriorate and die. Supervision can also be a way of checking in. It is the responsibility of the therapist to seek out professional feedback when sensing he or she is “off” in dealing with a client or when suspecting that he or she may be operating in response to countertransference.

**Find Ways to Express and Discharge Feelings on a Regular Basis**
It is particularly important for therapists dealing with grief to focus on releasing strong feelings that may be difficult to express. This can be accomplished in individual therapy or among close friends. Some prefer to discharge strong feelings—cry or scream—alone, but having support may give the therapist the chance to receive comfort and the caring of another in the face of the deep pain. Having others around can provide a container that enhances a sense of safety and facilitates the letting go of the usual controls on self-expression. One therapist reported a very satisfying experience of discharging: she went to a scary movie with friends after the funeral of a long-time client. She was able to scream almost nonstop for two hours—joined by the entire audience.

**Nurture the Physical Self**
Emotional stress takes a toll on the body. Pay attention to needs for exercise, recreation, leisure, good nutrition, rest, and sleep. The effects of the other coping strategies will be greatly limited if therapists overlook this strategy.

There are no easy answers to questions about how to cope with multiple loss, an experience of such magnitude and with such an
impact on our emotional, physical, intellectual, and spiritual well-being. One hopes that therapists, having experienced and integrated the darker side of life, will emerge empowered and with an enhanced capacity for hope, joy, intimacy, celebration, humor, affirmation of life, and compassion.

Dictionaries define compassion as "a feeling for another's suffering or misery coupled with an urgent desire to aid or to spare." It is derived from the Latin words pati and cum, together meaning "to suffer with," the ability to be with another in his or her pain. One can only be with another as much as one can be with one's self. After the death of his wife, C. S. Lewis wrote, "Why love, if losing hurts so much? I have no answers anymore, only the life I've lived. Twice in that life I've been given the choice, as a boy, and as a man. The boy chose safety. The man chooses suffering. The pain, now, is part of the happiness, then. That's the deal."  

Notes
7. Ibid.
10. Rando, Grief, Dying and Death.


22. Ibid.

23. Martin, “Psychological Consequences.”


27. Ibid, pp. 230, 231.


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32. Ibid., p. 274.
35. Kirchberg and Neimeyer, "Reactions of Beginning Counselors."
37. Feldman, "Bereavement Care."
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39. Riordan and Saltzer, "Burnout Prevention."
43. Namir and Sherman, "Coping with Countertransference." Reprinted with permission. No further reproduction authorized without written permission of the American Counseling Association.
Chapter Eighteen

Making Difficult Decisions

Eric Glassgold
James W. Dilley

The practice of psychotherapy is a complex and uncertain undertaking. Both therapist and client approach therapy unsure of the outcome and often even unclear about the factors that have led the client to seek professional help. Sometimes a general sense that “something is wrong” is the motivator—a broad feeling of discontent or a wish to be “happier.” At other times, the client comes for very specific reasons: he or she has had a history of mood problems or relationship difficulties, is struggling to cope with a loss, or has recently been diagnosed with a life-threatening illness.

Therapists working with people with HIV will be faced with clients from all along this spectrum. There will, of course, also be clients whose stated reason for seeking therapy fades into the background as the truly salient issues come to the fore—a situation well known to any experienced therapist and not uncommon in HIV-related psychotherapy. Although it may be the “stress of living with HIV” that draws a client into therapy, it often turns out that the client actually copes very well with his or her illness and that it is, rather, coping with life that is the problem.

For some people, an HIV diagnosis is without question a call to action: a spur to view their lives in a new way; a wake-up call that their drug or alcohol use has been “way out of line”; an opportunity to question their choice of work, or their primary relationship—or lack of one. Some will clearly feel the press of time and want to understand the long-standing problems that have pursued
them throughout their lives; some will want to explore the possibility of change.

For the therapist, the process of working with HIV disease is fascinating and rewarding: helping clients to face the initial task of coping with a life-threatening and stigmatized condition and then to examine their lives in the harsh light that HIV casts can be as exhilarating as it is challenging. This process also poses difficult questions for therapists, conundrums that are specific to working with seropositive clients, which often involve balancing legal and ethical concerns with clinical ones. Consider the following dilemmas:

- Working with a seropositive client who is having unsafe sex without informing his partner of his infection
- Managing a client who has become increasingly forgetful and slowed from HIV-associated cognitive impairment yet refuses to stop driving
- Counseling a client who refuses to take his doctor’s advice about treatment because he or she “doesn’t believe” in medication
- Responding to a physically failing client who wishes to end his or her life

It is precisely these kinds of difficult situations that make working with HIV compelling and at the same time daunting, even frightening. Where does the therapist’s responsibility to the client end and his or her responsibility to the community begin? How can a therapist proceed beyond immobilization when a complex set of legal, ethical, and clinical questions converge and compete with each other? A therapist may find it easy to attend empathically to the underlying emotions when a client says, “There is no way I’m going through what I’ve seen my friends go through—I’m not going to have people I don’t know putting me in diapers.” But he or she may feel wholly unprepared to respond when the client asks the therapist to assist in his wish to end his life.

Such clinical demands are an integral part of the landscape of providing psychotherapy to people with HIV, and the advent of improved treatment will not eliminate these challenges. In fact, it may well raise new ones. This chapter examines two such therapeutic dilemmas and reviews the elements of clinical decision making that therapists may apply when facing extreme circumstances.
The Duty to Warn: The Case of David

David, a twenty-nine-year-old seropositive White gay man, was referred for psychotherapy by his physician, who had prescribed antianxiety medication to help David deal with debilitating anxiety. His psychotherapist, John Kramer, Ph.D., although not gay himself, has treated many gay and lesbian clients, including people with HIV disease.

When David came for his initial appointment, he presented as sad, angry, and mildly agitated. An actor and performance artist, David complained bitterly about not being selected for a role he felt he should have gotten. He stated that although he knew his HIV status had nothing to do with his not getting the job, he couldn’t help but feel that “somehow it was related.” David was ambitious, felt he deserved “to make it,” and believed that he needed to work as much as he could, because eventually he would be seen by the “right people” who would “jump-start his career.”

History

David was an only child. His parents were both professionals who had given him “everything but their time” while he was growing up. They wanted him to follow in their footsteps, but he never really liked school, so he just “coasted through,” obtaining part-time work as an actor before he graduated from high school. His father died suddenly when David was in his last year of high school, leaving him feeling “surprisingly unaffected” and financially secure. After graduation, David moved to San Francisco, where he has lived alone since that time. He “came out” as a gay man shortly after the move. David has had a number of relationships, though none that felt deeply intimate to him, and he said he always found it easy to “find someone in the bars to go home with” whenever he wanted sex. He said he had no problems with drug or alcohol use.

David learned he was seropositive eight years ago, and despite some initial emotional upheaval and early physical problems, he has done well. He had taken zidovudine (ZDV/AZT) and didanosine (ddI) for the past five years without any problem. Recently, David’s viral load skyrocketed, and his physician suggested it was time to begin a new antiviral regimen that included a protease inhibitor. David understood that any treatments he started now might be the ones he would be on for the rest of his life and that he would have to take them religiously to avoid viral resistance. He knew that the new treatment regimens were complicated and that if he declined treatment, he was likely to become ill more quickly. All of this prompted his anxiety.
Combination Therapy

Kramer agreed to see David weekly for several sessions to help him think through his decision regarding starting combination treatment. Eventually, David announced that he was glad he “had finally done it,” going on to say that he had finally started a combination of four medications: ddI, stavudine (d4T), saquinavir, and ritonavir. David was clearly relieved, even elated.

David went on to say that he had met someone the previous weekend, someone he thought was going to be “important in my life,” an older actor, Chris, who seemed to know many important theater people in the area. The two men had met at a weekend-long seminar on the future of innovative theater. David added that he was attracted to Chris and that they had gone out for dinner the previous week. During the meal, Chris raised the issue of AIDS and told David he was HIV-negative. David had worried he would scare Chris away if he disclosed his serostatus, so he changed the subject and said nothing.

David explained to Kramer that one reason he decided to take the plunge with the new medications was to get his viral load down as low as possible so that he could have sex without fear of infecting Chris. His doctor had told him that many people who undertook combination therapy had an “undetectable viral load” within a couple weeks, and, because the chance of infecting someone else was so small anyway, David reasoned that an undetectable viral load would make it close to impossible. He also said, “Besides, I only need him to make a few introductions for me,” implying that he would be with Chris for only a short time and that his chance of infecting him would be small.

A Therapist’s Fury and Uncertainty

While listening to this story, Kramer found himself becoming furious with David for putting someone else at risk. He also felt angry because he thought David might be putting Kramer into a situation where the therapist might have a duty to “warn” Chris.

Kramer saw David’s disregard for the safety of his partner as an outgrowth of David’s long-standing narcissism: David had learned early on from his busy, self-absorbed parents that he must “learn to take care of myself” and that “people are bound to disappoint you.” The result was that David consistently used people to further his own wishes or satisfy his own needs.

Kramer commented to David that David’s proposed actions might put Chris at risk of infection. David replied that Chris was a gay man who “knew the ropes”; if Chris wanted unsafe sex with David, Chris was responsible for
making that decision and for whatever might happen as a result. Furthermore, David said, Chris had not insisted that David clarify his HIV status, so maybe Chris did not really want to know. David concluded by saying, “Anyway, none of this really matters because by the time I see Chris again, my viral load will be ‘zip’ and Chris will be safe.”

Kramer was unsure about what to do next. He was afraid that if he insisted that David had a responsibility to disclose his serostatus to Chris, David would experience Kramer as behaving like his parents, putting his values ahead of David’s without understanding David’s needs. Disappointed, David would almost certainly leave therapy. On the other hand, Kramer felt that if he did nothing and David infected Chris, the therapist would feel responsible and would never be able to forgive himself. Kramer felt trapped between his professional obligations to David and his wish to protect others from infection. He also had to contend with his own anger about David’s willingness to use Chris to further his career and to risk Chris’s life in the process.

**Ethical Responsibilities Versus Professional Obligations**

What options exist for Kramer and David at this point in the therapy? Where is the line between Kramer’s wish to continue to work with David and his concern about David’s putting another person at risk of HIV infection?

One legal question arises immediately: Is this a Tarasoff “duty to warn” situation? Could Kramer be held liable in the future for not having “warned” Chris that David was seropositive? The answer is “probably not.” (“Probably” is in quotation marks because the law is, by its nature, arguable and evolving.) Three points are central to this question. First, the discussion about unsafe sex at this point is hypothetical and uncertain. In order to warn, there must be an imminent and specific danger to an identifiable or reasonably identifiable individual (or individuals). The danger is not imminent or specific: David is talking about something that “might” happen. He is not stating that he is “going” to have unsafe sex with Chris, only that if Chris wants unsafe sex, David will not be the one to say no. To “warn” Chris in this situation, Kramer would violate David’s legal right to confidentiality about his serostatus and the professional standard that protects the therapist-client relationship.

Second, in this case, at least at this point, Chris is not a clearly identifiable person. Therapists do not have a duty to warn when the party to be warned is nonspecific or is a general class of individuals (for example, “all gay men” with whom David might have unsafe sex).
Third, does Kramer have an ethical obligation to tell David about the possibility that David could be found criminally liable if Chris were to become infected from having sex with David? In many states, an individual with a sexually transmitted disease—including HIV disease and sometimes specifically HIV disease—has a duty to tell a sexual partner that he or she has a sexually transmitted disease before engaging in activities that might transmit the disease. If David was unaware of this situation, he could be getting himself into legal as well as ethical difficulties. People with HIV in several states have been found guilty of criminal acts when they have infected others without telling these partners about the risk of infection. Finally, from a liability perspective, Kramer might also have a legal obligation to inform David that he could potentially be held criminally liable if Chris were to become infected, and as already noted, he almost certainly has an ethical obligation to do so.

Although Kramer understands all of this, he still feels unsure about what to do. He appreciates that even though he is probably not at risk legally, he still feels bad about the situation and worries that he is, in a sense, becoming an accomplice to a crime. Kramer also believes David when he says that if he and Chris were to have unsafe sex, it would be consensual. In this scenario, Chris does have a responsibility to protect himself. As a sexually active gay man, Chris is surely aware of AIDS and the risks associated with unprotected sex.

The Therapeutic Process

As a skilled psychotherapist, Kramer also believes that the therapeutic process can help resolve this situation—despite its complexities. Kramer reasons that David’s plan to take protease inhibitors as a way of reducing his viral load is evidence that David does not really want to infect Chris and that David’s biggest concern is that Chris will abandon him if he is honest about his HIV status. Kramer decides to take this tack with David and explore this possibility.

He also considers, reluctantly, what he would do if he were not eventually able to engage David successfully around this issue. He decides that because of their differences in opinion about this issue, he would simply no longer be able to work with David and would have to refer him to another therapist for ongoing care. By doing so, Kramer believes he would fulfill his obligation to himself by confronting the issue directly and doing all he could to work with David to resolve it; he would fulfill his legal and ethical obligation to his client by referring David to another therapist, thereby ensuring that David would not be abandoned.
In therapeutic terms, Kramer hypothesizes that David’s placing his own wishes above Chris’s safety was a reenactment of the times that David’s parents had placed their needs above David’s. He also wonders if David might well be bringing this situation into therapy as a way to test his therapist. Would Kramer confront him and help him reconsider his behavior, or would the counselor, like David’s parents, be “too busy” to hear this veiled request for help? Having gone through this thought process, Kramer feels clearer about engaging David in further discussions about David’s potential behavior, focusing on David’s concerns about his career, his using of Chris, his fears of being abandoned by Chris, and what appears to be some sense of responsibility and a real desire to protect Chris.

Finally, the only way to ensure that clients and therapists understand the “rules” of therapy is for therapists to outline them at the beginning of working together. When this is done, the therapist can be more confident about interpreting a client’s behavior. For example, had Kramer explained to David the therapist’s responsibility to inform identifiable third parties of a client’s physical threat, David may not have told Kramer about his plans for having unsafe sex with Chris. Alternately, knowing that David understands that Kramer would have to act under these circumstances enables Kramer to better interpret David’s raising the issue, for example, as a way of asking Kramer to intervene. Another example of this dynamic is in the context of suicidal intent: if clients know that therapists are required to hospitalize people against their will if they express active suicidal intent, clients may choose not to relate these feelings to the therapist. If the client should raise these feelings, the therapist may more clearly interpret this disclosure as a request for help.

Some might argue that the adverse result of this approach is that clients will put limits on the information they might share in therapy. Although this may be true, the degree to which clients express themselves is always up to them. If both therapist and client have clearly articulated the rules and the expected outcomes of these rules, both will be in a much better position to understand the meaning of the client’s disclosures. The result is that clients may be more willing to share because they will better comprehend the breadth of confidentiality protections by recognizing their limits.

Responding to Suicide: The Case of Steve

Steve was a thirty-six-year-old seropositive man of racially mixed descent—Native American and African American. He identified as bisexual and in recent years had been romantically involved only with gay men. He started therapy
with Joan Callen, L.C.S.W., to talk about his HIV status and romantic relationships. Callen had practiced psychotherapy for nineteen years. She had two children, one adopted; her husband died of cancer about two years earlier, and she herself had been in therapy recently, initially to deal with sadness and depression related to her husband's death.

Steve was frustrated by the pattern of his romantic relationships: he usually broke off these involvements after nine to twelve months, often fearing that he could not take care of himself or get taken care of in the relationship. At such times, he would very pragmatically seek other sources of fulfillment—intellectual, cultural, sexual. He seemed so able to cope that even as the relationship dissolved, it was a source of some pride that he could take care of himself so well.

Steve talked frequently and in no uncertain terms about his “selfishness,” a word he used to refer to this capacity to know when to say no to someone else's needs and when to focus on his own. Steve's mother relied on him—as the oldest of four children—to handle his younger siblings, disregarding her eldest son's own needs. As a result, Steve learned to escape from the house to meet those needs. As Callen and Steve worked together and explored his problems with romantic attachments, Callen began to suspect that Steve's calm, self-sufficient style might be guarding him from pain. Evidence of this submerged pain would surface from time to time, often in asides and in comments Steve would make about the success of his friends' relationships. When asked to explore these issues, Steve would most often divert the question. Eventually, Steve admitted that this way of coping, though comforting, sometimes left him feeling helpless and depressed.

Callen knew from the start that she liked Steve tremendously, but she was not initially aware how much she admired his coping skills, his self-assertion, and his insistence on maintaining an active sexual life while living with HIV. As time passed, Callen grew to understand that this admiration—even envy—contributed to an idealization of Steve's abilities, a positive countertransference that obscured from Callen Steve's fear that she would not be there if he needed her. When he learned that Callen had taken a leave after the death of her husband, Steve took this news to mean that he could not get the care he needed from her and that instead he must be careful about his therapist's feelings, a dynamic that recalled his family relationships.

**Antiviral Treatment**

Two years into therapy, Steve became symptomatic, and during the subsequent eight months, his illness progressed quickly. Steve had begun triple
combination therapy: zidovudine (ZDV, AZT), didanosine (ddI), and indinavir (Crixivan), a protease inhibitor that caused chronic nausea and fatigue. As time went on, Steve became resistant to the effects of his regimen, his viral load shot through the roof, and he began to get sick: he lost weight, eventually developed pneumonia, and was hospitalized several times. For a few months, Steve regularly attended therapy, but this took a tremendous effort. He stopped his antivirals, feeling they had clearly outrun their efficacy.

During his last visit to the hospital, Steve’s primary care physician started him on an antidepressant, and he became more awake, active, and tolerant of frustration.

Callen and Steve agreed to bend the therapeutic frame, allowing for missed sessions and for hospital and home visits. Except during Steve’s hospitalizations and Callen’s vacations, they had met two times a week for three and a half years. When Steve left the hospital, he resumed regularly scheduled therapy again. But, strangely, when he did, Callen began to notice in herself a sense of fatigue that was particularly intense just prior to the beginning of Steve’s session. On a few occasions, she even dozed—with great pleasure—for a few minutes at a time. She also found herself daydreaming, sometimes wishing she could delay Steve’s session for just a few minutes more.

Callen came to recognize her feelings of fatigue before sessions with Steve as an important clue into Steve’s unconscious life. She realized that Steve’s recent sessions had been substantially different: he was less present and involved. She further realized that what was happening in the therapy was a repetition of an old pattern: as he had as a child, Steve absented himself from—that is, ended—romantic relationships rather than risk the pain of feeling a loss of affection. The forays into various intellectual, cultural, or sexual pursuits seemed to obscure his fears that yet another relationship would fail to attend to his needs. And Callen noted that Steve’s withdrawal, though subtle, had resulted in her feelings of boredom and exhaustion in anticipation of his sessions.

Callen pointed out to Steve the parallels between his emotional distancing, her fatigue, and his problems in moving his romantic relationships toward a lasting intimacy. During these discussions, Steve had the opportunity to observe these parallels and experience Callen as being able to handle his deepest fears of abandonment without tuning out, falling asleep, or dismissing these fears. Despite her feelings of uncertainty and even pain, Callen believed that this disclosure about her feelings was appropriate and important and that it deepened the focus on her client.
Dependency and Escape

It was after the fourth or fifth session before which Callen felt so exhausted that Steve raised the issue of assisted dying—almost as an aside. He told her that a close friend had researched the issue and that his friend’s physician had prescribed barbiturates for self-deliverance. Steve joked that the physician had been extremely clear that his friend must not use more than a certain dose, lest it prove lethal, and that if he were to overdose, the only real risk would be if something incidentally happened to suffocate him.

Steve continued to joke, first about his friend’s plan to use Glad brand freezer bags to self-deliver, then about Steve’s own black humor in joking about an issue as serious as dying. Noting his own seeming nonchalance, Steve described the oddity of the discussion he had had with his friend. In particular, Steve wondered that his tone was “so casual, as if he were talking about making a plan for a weekend getaway.” Callen made a mental note that Steve was bringing up the idea of a pleasurable trip, an escape, something she saw as akin to her pre-session escape into sleep.

Steve had spoken frequently of being able to cope with adversity. But he had a harder time considering or assessing his feelings about depending on others for help. In the past, he had minimized his feelings both about being taken care of and about not having anyone to attend to his needs. When Steve casually joked about self-deliverance, Callen returned to the issue of dependency, asking him if envisioning a “getaway” relieved his discomfort about being dependent on other people. She also wondered if he felt that he could depend on her.

In later sessions, Steve and Callen talked about the possibility that Steve managed painful, conflicted feelings by taking short and pleasure-filled “escapes” instead of taking deeper journeys to explore what might be troubling him. Could he talk about death only as a brief vacation? Callen asked Steve if he felt he could demand more from her. Or was he careful not to demand too much? At this point, Steve mentioned his hesitation about talking about these issues, considering her husband’s death. (Callen had taken a month off at the time her husband died.) Steve expressed his fear that Callen would not welcome him back for further treatment if he honestly expressed his need to talk about dying, let alone his wish to make plans for his own death.

Self-Deliverance and Letting Go

Callen continued to work regularly and consistently with Steve, who had rebounded physically, for the subsequent six months. Steve began to date
another man, who was also seropositive, although he was clear that their relationship was "nothing serious." As she and Steve began to talk about coming to the end of their work together, Steve also began to complain of ongoing fatigue and shortness of breath as well as having worsening night sweats and nausea. He was diagnosed with KS of the lungs, and he continued to become more and more ill; he had trouble eating, sleeping, and breathing, and found it difficult to concentrate and stay awake during sessions at his home.

Callen felt an intense sadness and helplessness. She had always related to Steve by talking. Now he could hardly speak, and his silences appeared to be full of suffering. She felt unsure about how to come to terms with Steve's physical deterioration. Although Steve's home care staff deferentially dropped what they were doing when she visited, it seemed to Callen that she was the only person in the room who did not have a job to do.

Perhaps most frustrating to Callen was that Steve had done so much work to free up his life, and now he was losing it all. Callen began to learn how to sit with her frustrations and spend time just visiting the client she knew so well. Nonetheless, she found herself full of anger and sadness, and preoccupied with rushes of memory of her work with Steve.

About a month into Steve's decline, Callen received a note from Steve's boyfriend inviting her to a farewell gathering in Steve's honor. Although no mention was made of Steve's planning to end his life, she intuited that the invitation was an indirect way to announce his self-deliverance. She wanted to attend Steve's gathering, as she had always found that memorials enabled her to deal with and mark the death of a client—but she also felt conflicted: this was not an ordinary memorial.

Among her other feelings, Callen wondered if she would be held responsible if Steve's death were considered a suicide. But all the evidence suggested that Steve was neither depressed nor mentally incompetent. Steve had seen a psychiatrist periodically and had responded well to antidepressants, and neither Callen nor the psychiatrist currently saw him as depressed. Despite his physical deterioration, he appeared lucid and capable of making his own decisions. Steve's psychiatrist confirmed Callen's impressions.

Steve and Callen had never actually talked about the possibility of his choosing to end his own life; indeed, he had only mentioned it once, when talking about his friend. Steve had commented then that he would consider doing the same thing if and when he got really sick. Back then, more than two years ago, "getting really sick" had appeared very distant, almost hypothetical.
The Right to Die

Many therapists speak of the conflicts they experience when working with end-stage clients who actively contemplate ending their lives. Concerns range from fears about potential legal repercussions should a clinically depressed client commit suicide, to conflicts with spiritual, religious, and ethical beliefs. They also complain about a “shroud of silence” that leads supervisors and colleagues to avoid discussing the issue, leaving therapists on the front lines without support or peer consultation to help guide their actions. In a survey of volunteer therapists at the UCSF AIDS Health Project, 72 percent of the sixty-four licensed mental health professionals who participated in the project’s Volunteer Therapist Program stated that they confronted this issue in their work.⁵

The professional organizations that certify and license mental health professionals have actively participated in public debate over what has been variously called suicide, self-deliverance, and the right to die. In 1994, the National Association of Social Workers approved standards that allowed social workers to attend but not participate in assisted suicides and active voluntary euthanasia.⁶ Other professional organizations, such as the National Association of Marriage and Family Counselors and the American Psychological Association, have not yet taken a position on the issue but have encouraged discussion within the framework of their organizations’ conferences, publications, and journals. The codes of ethics of all professional associations emphasize that it is a professional’s duty “to comply with the law” as well as “to confront ethical issues in research and clinical practice” and “to avoid doing harm where it is foreseeable and unavoidable.”⁷

These standards are hardly black and white. For example, the American Psychiatric Association (APA) code of medical ethics
notes that a psychiatrist "shall respect the law and also recognize a responsibility to seek changes in those [parts of the law] which are contrary to the best interest of the patient." The code goes on to admit that a clinician might act in ways that are at once ethical and illegal. Nonetheless, in a separate position paper on physician-assisted suicide, the APA Ethics Committee explicitly states that it is "unethical" for a physician to advance death for any reason, under any circumstance. In 1991, Timothy Quill, a New York physician who knowingly prescribed sufficient medication for his terminally ill patient (whom he had treated for many years) to use to end her life, published a discussion in which he described the position of a physician who acts outside the letter of the law but in an ethical and competent fashion. Quill's patient had repeatedly requested assistance in dying, and a psychological assessment by an outside consultant found no signs of clinical depression. A court heard a case against Quill and took no action against him, and he received no other form of punishment.

Perceptions of Suicide
Concurrent with the rise of professional medical authority, political and social constraints of the nineteenth and early twentieth centuries led to the "medicalizing" of suicide in order to maintain state control over individuals and to ensure social order. Psychiatrists had the authority to manage and control suicide by sequestering mentally ill patients in psychiatric hospitals. Until recently, the psychiatric literature has classified suicidal ideas or behavior almost exclusively as manifestations of mental illness. However, past research in the psychiatric literature made use of unreliable methodologies to establish this connection. Biases in the research included the reconstruction of clients' motives from psychiatric autopsies: studies relied on the selective examination of clients who had long-standing histories of psychiatric illness or whose death certificates bore "suicide" as the cause of death. Such methods effectively excluded patients whose deaths seemed unremarkable—as is likely for those who were assisted in self-deliverance by compassionate physicians.

Recent research on psychiatric assessment suggests that in terminally ill populations with problems that mimic symptoms of de-
pression, major depression is overdiagnosed and minor depression is underdiagnosed. The reason may be that diagnostic criteria are too roughly hewn to differentiate affective, cognitive, and vegetative symptoms of depression from nonpsychiatric symptoms of physical illness and grief. Consequently, clinicians may dismiss a person's expressed wishes to end his or her life as being the result of a treatable depression.

Surveys of gay men with advanced HIV disease suggest that it is far from a small minority who might wish to actively end their lives. For example, in an Australian sample of 105 White, well-educated gay men, 94 percent said that an individual with a life-threatening illness should have the option of euthanasia. In the Netherlands, voluntary, active euthanasia and physician-assisted suicide are legal and account for 2.1 percent of all deaths. Research suggests that under these circumstances, the decision to end life takes place when there is a very high likelihood of death occurring in the immediate future, usually within less than one month.

The effort to attribute the desire for self-deliverance to depression is perhaps the result of anxieties about letting death run its course. One therapist, a former hospice worker, described the struggle with control that many of her patients experienced as they began hospice-level care. Hospice care involves more intensive pain control and attendance from nurses and thereby takes away much autonomy from patients. Dealing with a newfound dependency on hospice staff is often a major challenge and transition, although not necessarily a negative one. In the eyes of this therapist, hospice care offered the chance to let go gradually, as one was increasingly "held" by hospice workers through the process. For many, this gradual release of control was a "natural" stage in the process of dying, constituting, in developmental terms, almost the reverse of the child's movement toward separation and individuation.

The Laws of Self-Deliverance

In spite of change in professional codes of ethics and a broadening view of what constitutes suicide, therapists should realize that any involvement with a client's death may result in criminal or professional disciplinary proceedings or in malpractice suits. According
to current standards of care, a clinician has a duty to prevent suicide, and any breach of that duty constitutes malpractice. Even if the death occurs after a clinician’s treatment has terminated, the family or friends of a client who self-delivers may later charge abandonment if they believe the death was avoidable.

What can therapists do to respect their clients wishes, maintain ethical standards of care, and prevent legal action? Most protective actions are consistent with good clinical care and require careful documentation of the treatment plan and progress. It is important to establish a client’s competence to make informed decisions, his or her wishes to end life, and the absence of clinically significant depressive episodes. Other, more labor-intensive steps may be necessary, especially when a client’s clinical presentation defies easy categorization—for example, when a fully competent, terminally ill patient also exhibits depressive symptoms.

New laws in New York and Oregon, and those in the Netherlands and parts of Australia, where assisted suicide is now or soon to become legal, offer clinicians some guidelines. For example, in all of these cases, a clinician who hears about or witnesses a client’s request to die with assistance must document the following: first, that the client is terminally ill or has a “hopeless,” progressive, and incurable condition causing unrelenting suffering; second, that he or she experiences intractable symptoms despite optimal supportive care; third, that the client has a documentable physical cause for his or her suffering; fourth, that his or her request is voluntary, informed, and repeated; and fifth, that the clinician involved has a long-term relationship with the client.10,20

Considering that most therapists do not prescribe medications of any kind, such guidelines—drafted with physician assistance in mind—might be too stringent. They do offer some useful models for the psychiatrist who wants to assist, however. In such cases, it would be wise to seek outside consultation with another psychiatrist or another mental health professional and to evaluate a client’s competence to give informed consent. Documentation should include evidence of a client’s seeking medical consultation regarding appropriate treatment of pain and other forms of non-lethal, palliative care, including hospice care; of the client’s physician having considered all available treatment options; of the reasons for declining alternative treatments such as medication or
hospitalization; and of repeated mental status exams that are free of significant depressive ideation. Adjusting to HIV disease is complex not only because it is, as is often said, a stigmatized, life-threatening, and confusing illness but also because it potentially raises or amplifies a host of dilemmas for clients. For both client and therapist, such dilemmas may be new and without precedence. And for therapists, many of these challenges bump up against fundamental principles of law, ethics, and philosophies of life. As with most of life’s greatest riddles, there are no easy answers to these conundrums and sometimes no answers at all.

This situation is frustrating and sometimes frightening. Therapists may find some guidelines in the law and in professional codes of ethics, in their own moral and philosophical perspectives, and in their hearts. But despite these uncertainties, the epidemic has shown that therapy can be effective for many and even transcendent for some. It is this knowledge that must guide our actions and nurture our efforts to deal with issues of life and death.

Notes


18. Personal communication with S. Holland, May 10, 1996.


Epilogue
The Psychotherapist and HIV Disease
James W. Dilley

Over the course of the AIDS epidemic, psychotherapists have become recognized as important members of the multidisciplinary team created to care for people living with the disease. They have done their work with great enthusiasm, care, and compassion. Yet, similar to other aspects of the epidemic, the role of the psychotherapist has evolved over time, and, as we have come to expect, change is once again upon us. Recent advances in the medical treatment of HIV disease have been remarkably effective, and although the “cure” is still elusive, current treatment success has significantly changed the landscape of psychosocial care.

The Role of the Psychotherapist

In the early days of the epidemic, psychotherapists were confronted primarily with clients who were acutely ill, young, gay men who were frightened and confused by the specter of an unknown and virulent illness. These young men—often estranged from their families and living alone as they adjusted to life in the “Big City” after migrating from homophobic small towns—found themselves having to confront life-and-death situations with whatever emotional support they could muster. Many found solace in the consulting rooms of therapists as it became clear that HIV would, at least early on, be fought as much with psychosocial support and therapy as with medication.

Together, therapists and their clients sought to understand the implications of a “damaged immune system” and the development
of exotic illnesses such as Kaposi's sarcoma lesions or *Pneumocystis carinii* pneumonia. Therapists, along with their clients, had to become versed in medical jargon and concepts that were well beyond the scope of their training. They also had to deal with the confusion related to HIV transmission—at times even fearing that their clients might in some mysterious way spread HIV or some other strange “opportunistic disease” to both the therapist and other clients. As did others in the epicenters of the epidemic, therapists had to manage their own fears in order to help their clients adjust.

**Empathic Containment**

Before 1985, when the HIV antibody test was licensed, the survival of people with AIDS was measured in months. The role of the therapist was to function largely as an “empathic container.” He or she created a “holding environment” in which clients could share their pain and openly discuss their fears. There was usually little time for much else. Therapists offered a safe haven: a port in a storm populated by doctors, social workers, friends, and sometimes families, all well-meaning and important people, but all with an agenda that they imposed, consciously or unconsciously, on the person with HIV. There were papers to be filled out, decisions to be made, medications to take, and appointments to be kept. Through it all, there was a palpable sense of fear, anxiety, and uncertainty, and a desire to make sense of a catastrophic and unexpected event.

Exercising personal restraint and remaining client-centered, the therapist became a willing partner, providing an opportunity for the client to “think out loud,” to sort out his or her feelings about a whirlwind of events. The therapist was there to “be” with the client and accept his or her anger, fear, and despair: a human acknowledgment that there are events in life that can only be experienced and understood but cannot be “fixed” or changed. The therapist didn’t “give advice” or try to solve clients’ problems, but rather sought to assure clients that they were not alone and to help clients find a way to understand what had befallen them. By the late 1980s, having witnessed the devastation and confusion of the epidemic, many therapists took on a more activist role in their
clients’ care. This activism manifested itself, in some cases, as therapists taking on a role similar to that of case managers: advocating on behalf of their clients with physicians, social service systems, and substance abuse or other service providers.

Therapists also spent a good deal of time helping their clients cope with grief and mourning. Because HIV disease—particularly among gay men and injection drug users—is a disease of communities, it was not uncommon for both seropositive and seronegative community members to have lost many friends, family members, and partners to the disease. For seropositive individuals who cared for lovers and friends as they died, the inevitable and heartbreaking question was, Who will be there for me? For seronegative people, the question, no less grave, was, How can I go on with so many of the people who were important to me now dead? In the early days of HIV, therapists were also confronted with clients whose first knowledge of their infection was a serious disease, and managing the psychological trauma of an acute illness became a common task. Soon thereafter, as it became clear that HIV disease can cause progressive neurological damage, therapists had to be concerned about whether their clients would develop such problems and how these clients would manage if they did.

With the introduction of the HIV antibody test, therapists began to see a new class of individual in their offices: the person “living with HIV.” These were people who appeared to be well but who carried with them a miniature time bomb set in some mysterious way to go off at some unknowable time. The therapist frequently played the role of supporter, always holding in the back of his or her mind the questions, How will you live today, given that tomorrow is so uncertain? What can we accomplish together now that will help you live more fully each day? How much time do we have, and what therapeutic goals are achievable within this period?

The reality of living with “the virus” yet feeling well, combined with an uncertain future, became and continues today to be a major psychological theme. Over the years, therapists have had to manage enthusiasm about potential “breakthroughs” in treatment—always heralded with insufficient data as people clamored for hope and information—followed by a predictable “crash” as evidence showed that the breakthrough was not all we had hoped it would be. Yet, in the late 1980s, zidovudine (ZDV, AZT) and other antiviral
drugs plus advances in treating and preventing opportunistic infections were effective in extending life, and client and therapist alike found that as acute illness faded somewhat, other life issues came into focus. During this period, therapists worked to maintain realistic attitudes toward HIV infection, encouraging clients to seek and maintain medical treatment and to reinvest in life.

A New Era in AIDS Care

Today, advances in treatment have led to steadily declining death rates in the United States and other industrialized nations. In San Francisco, the number of people actually living with AIDS increased 50 percent between 1991 and 1996. Although the experience of narrowly escaping death is by no means universal, it is a frequent event; and although it is unclear how long effective treatment might last, the data suggest that many people continue to do well two and three years after beginning combination treatment.

Despite these dramatic improvements, therapists face an old challenge: helping clients manage the psychological impact of being “pulled from the lion’s jaws” all the while knowing that the lion is ready to pounce again. And for the therapist, statistical probabilities do not describe the situation of the client sitting across the room. Uncertainty remains.

The New Pharmacopoeia

At the 1996 International Conference on AIDS, held in Vancouver, researchers presented some of the first public data on the effectiveness of highly active antiretroviral treatment (HAART) or what has become known as combination therapy. Combination therapy usually includes three to five drugs, often two nucleoside analog reverse transcriptase inhibitors, plus either a protease inhibitor or a non-nucleoside analog reverse transcriptase inhibitor (NNRTI). Among the current nucleoside analogs are ZDV, didanosine (ddI), zalcitabine (ddC), stavudine (d4T), and lamivudine (3TC). Current protease inhibitors include ritonavir, indinavir, saquinavir, and nelfinavir. Current NNRTIs are nevirapine and delavirdine. There are more medications in the pipeline, and if you are reading this book a year after its publication, you are prob-
ably familiar with whole new families of antiviral drugs. The fruits of many years of labor have ripened, and researchers, clinicians, and people with HIV alike acknowledge that a new era in AIDS care is upon us.

After initial successes with combination treatment, the lay press and even researchers talked about the “eradication” of infection. If combination therapy could reduce viral load (a measure of the amount of virus present in the blood) to very low levels, and if this extended life, maybe it would be possible to eradicate HIV infection if treatment “hit hard and hit early.” In those moments, it was easy to imagine the evolution of AIDS into a chronic, manageable illness.

Several recently published long-term studies, however, have now shown that despite the suppression of viral replication for up to ninety-six weeks, virus that was taken from patients with viral loads that were beneath detectable levels and allowed to grow in the laboratory are fully capable of replicating. This is partly the result of viral particles resting in “reservoir sites” (for example, the brain and lymph nodes) that are relatively protected from the effects of antiviral drugs circulating in the blood, and partly the result of the apparent capacity of the virus to remain latent. It is important to note that the good news about these recent studies is that the HIV found in these reservoir sites had not developed resistance to the individual medications used in the combination therapy. This suggests that if treatment is initially successful, continued therapy should keep active HIV in check.

The bottom line is that the antiviral combinations currently available have been shown to be powerful and effective over time. But there is no evidence that they can eliminate HIV infection, so treatment must continue, presumably for life.

**Treatment Adherence**

To further complicate treatment, it has become clear that strict adherence to antiviral combinations is crucial to their success. The blood level of antiviral drugs that is needed to stop replication is fairly high, and if it is not maintained through regular dosing, the virus can multiply. In addition, if doses are skipped or missed for whatever reason, the virus not only will begin to multiply again but
also can develop resistance to the drugs in the combination. Once resistance develops, the drugs in the combination become ineffective, and HIV infection can reestablish itself and lead to progressive destruction of the immune system.

To make matters worse, most HIV strains that become resistant to one type of protease inhibitor become “cross-resistant” to other protease inhibitors; resistance to one drug in this medication family often confers resistance to others in the family, thereby greatly reducing the number of other drug combinations that may work.\textsuperscript{9,10,11} The effect of resistance is already apparent in the field: small studies have found that as many as 50 percent of patients see their viral loads rebound as early as six months after beginning treatment.\textsuperscript{12}

One of the biggest reasons for the failure of antiviral drugs is the difficulty of sticking regularly to complex treatment regimens. Combination therapy is difficult: it usually requires multiple pills, and each drug has its own time schedule with its own requirements (for example, some are taken with meals, others on an empty stomach) and its own side effects, some of which may be so intolerable for a given individual as to make treatment with that drug impossible.

Making Decisions About Treatment

The risk of resistance has led many clinicians to believe that people with HIV have very few chances to decide what treatment plan to undertake. This approach is different from the approach mental health providers might take with psychiatric disorders—depression, for example. A client might decide to start an antidepressant with the intention of stopping if side effects are too uncomfortable or if the drug is felt to be ineffective. But presenting an antiviral drug to HIV gives the virus a chance to “figure out” how to become resistant to it, the result being that, for many, the decision to start treatment is actually a decision to continue treatment.

In the context of all this information, it is crucial for therapists to appreciate the difficulty and the momentous nature of HIV treatment decisions.\textsuperscript{13,14} The media have made it seem that antiviral treatment is the obvious choice, but there is a daunting number of physiological and psychological factors that affect a person’s decision making regarding HIV treatment.
In a sense, these changes in the landscape of HIV care mean that therapists will reembrace the role they had taken earlier in the epidemic: that of creating a "holding environment" and offering clients an opportunity to "work through" their feelings. In the early days, this process was focused on adjusting to an early death. Now, for people for whom antiviral treatment is working, it is focused on adjusting to living with difficult treatment regimens; for those for whom treatments are not working, it is focused on the possibility of more effective treatments in the future and on managing disappointment and disintegrating health.

As people with HIV disease live and maintain physical health for longer periods, they will spend more time worrying about living, as opposed to dying. Providing support and helping clients find meaning in catastrophe will continue to be part of the psychotherapist's task, but therapists will also be asked, more and more, to help clients sustain. That is, therapists will help clients sustain themselves by refocusing on life and life problems and sustain treatment by maintaining a schedule of doctor's appointments and taking a handful of pills several times a day.

For more than fifteen years, psychotherapists have played a central role in AIDS treatment, performing their work with commitment and sensitivity. As members of the multidisciplinary team that has grown out of the need to provide comprehensive treatment for people living with HIV, they have earned the respect and gratitude of clients and coworkers alike. In an epidemic that encompasses so much of life, the therapist's role will always be to help clients and clinicians make sense of their life experiences. The hope of the moment is that although the past may remain on some level inexplicable, the future holds the promise of clarity, survival, and rejuvenation. Psychotherapists will continue to play an important role in this future.

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