HIV Treatment: Mental Health Aspects of Antiviral Therapy

Michael Shernoff MSW  Raymond A Smith PhD
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Today, increasing numbers of seropositive people are truly "living" with HIV disease. Though many are still dying, overall rates of illness and death have dramatically decreased, due largely to combination antiviral treatment. Yet, ironically, as news of combination treatment has hit the mainstream media, people with HIV – both those for whom treatments have succeeded and for whom they have failed – face a new set of psychological and social challenges. The fourth in the UCSF AIDS Health Project's Monograph Series, HIV Treatment: Mental Health Aspects of Antiviral Therapy is a primer for mental health providers working in this altered landscape. It describes the new treatment paradigm, the mental health issues it raises, and ways to help clients navigate this changing world.

The University of California San Francisco AIDS Health Project Monograph Series

Affiliated with the Langley Porter Psychiatric Institute of the University of California San Francisco's world-renowned medical school, the AIDS Health Project has been a leader in developing services and professional education to meet the mental health needs of people affected by HIV disease. Since 1984, AHP has been recognized for pioneering programs in HIV-related counseling and support, antibody testing and counseling, and HIV and substance abuse services. AHP publishes FOCUS: A Guide to AIDS Research and Counseling, one of the longest-running HIV newsletters, and publications including The UCSF AIDS Health Project Guide to Counseling. The Monograph Series, underwritten by the California Department of Mental Health, offers concise and practical information on HIV-related topics of particular concern to mental health providers.
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UCSF AIDS Health Project Monographs

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The UCSF AIDS Health Project Monograph Series, underwritten by the California Department of Mental Health, offers clear, concise, and practical information on HIV-related topics of particular concern to mental health providers. The first three books in the series are: AIDS and the Impact of Cognitive Impairment: A Treatment Guide for Mental Health Providers ($7.95); The Alcohol and Drug Wildcard: Substance Use and Psychiatric Problems in People with HIV ($9.95); and Working with AIDS Bereavement: A Comprehensive Approach for Mental Health Providers ($10.95).

UCSF AIDS Health Project Publications

THE UCSF AIDS HEALTH PROJECT publishes a range of other publications for mental health and health care providers. The AIDS Health Project published what has become a standard in HIV counseling primers, Face to Face: A Guide to AIDS Counseling ($16.95). In late 1998, AHP joined with Jossey-Bass Publishers, Inc. to publish a successor to this volume: The UCSF AIDS Health Project Guide to Counseling: Perspectives on Psychotherapy, Prevention, and Therapeutic Practice ($27.95; direct price).

In addition, AHP has published other books for mental health providers, including: Risk and Recovery: AIDS, HIV, and Alcohol ($16.95) and AIDS Law for Mental Health Professionals: A Guide to Judicious Practice ($39.95).

Finally, AHP publishes several newsletters, including FOCUS: A Guide to AIDS Research and Counseling, one of the longest-running HIV-related newsletters in the country. FOCUS, which has an international reputation, reviews the counseling aspects of HIV disease and is an indispensable reference for counselors, health care providers, and scholars ($36.00 for an individual subscription; $90.00 for an institutional subscription; international rates available). AHP also publishes the FOCUS Supplement on Antibody Test Counseling and HIV Counselor PERSPECTIVES, both of which are newsletters for antibody test counselors.

For more information or to order AHP publications, please write UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884; call 415-502-4930; fax 415-476-7996; or visit our web site: www.ucsf-ahp.org.
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Putting a monograph like this together requires the efforts of many people. The authors and the editors extend their appreciation to UCSF AIDS Health Project staff and volunteers who contributed to the process. (See the copyright page for a list of these individuals.) In addition, the editors and authors thank the following people who reviewed all or part of the manuscript and offered valuable feedback: Stephen Follansbee, MD, Robert B. Hays, PhD, Amanda Houston-Hamilton, DMH, and Avi Rose, LCSW. Finally, the authors offer these specific acknowledgments:

I wish to acknowledge the intelligent, insightful, and skillful suggestions, input and editing of Jim Ditley and Rob Marks.

Working on this book was the single most difficult writing project I have yet undertaken. Perhaps the reason for this was my own status as a long-term HIV-positive nonprogressor. This reality made the subject matter inextricable from either my own personal or professional life.
After the first draft was completed, and skillfully edited by Rob and Jim, I experienced a total "writer's block." As much as I discussed my inability to revise the manuscript in my own therapy, I was completely stymied in my efforts. For many months, I was unable to do a stitch of work on incorporating Jim and Rob's suggestions. Just when I thought I would have to admit defeat and back out of the project, my therapist, Ellen Siroka-Robinson, made the brilliant and logical suggestion that I try to find a co-author to help me complete the book. Fortunately, my friend and esteemed colleague Ray Smith courageously and graciously agreed to come on board as co-author.

This manuscript would never have been completed had not Ray provided the intelligence, energy, and good humor needed to rescue the project from its moribund state. For that, I am profoundly grateful to him. In addition to the above-mentioned qualities, Ray possesses an encyclopedic knowledge of HIV research and impeccable skills as a writer. I have never before experienced such a seamless and completely noncontentious relationship with any co-author, which made working with him a joy and loads of fun.

— Michael Shernoff, MSW
New York

I would like to thank Michael Shernoff for inviting me to join him in this project and for being such a wonderful and enthusiastic co-author and friend. I'd also like to acknowledge the hard work of Rob Marks and Jim Dilley of the UCSF AIDS Health Project in keeping the two of us focused on such a fast-moving target.

Finally, I would like to thank my colleagues for their consistent advice and support. This includes my former colleagues at the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University — in particular Joyce Hunter and Bob Remien — and my current co-workers at the National Alliance of State and Territorial AIDS Directors (NASTAD) in Washington.

— Raymond A. Smith, PhD
Washington, D.C.
Introduction

Combination therapy has allowed me to begin to believe that HIV disease doesn’t have to be in the way of my dreaming big dreams.
— Billy

For the first time since being diagnosed with AIDS, I am allowing myself to dare to hope that I just might live long enough to raise my daughter and see her grow into . . . a woman.
— Tanya

I’m real pissed off and terrified that no matter what new drug I take, it has not been effective in fighting whatever strain of virus I have. It’s real hard to feel like I am being completely left out of this latest miracle.
— Roberto

Today, near the end of the second decade of the AIDS epidemic in the United States and other developed countries, increasing numbers of people with HIV are truly living with the disease. Though
many are still dying from HIV-related illnesses, overall rates of illness and death in the developed world have dramatically decreased, largely due to the introduction of combination antiviral treatment (also known as combination therapy). So many seriously ill people with HIV disease have seen significant improvements that combination therapies are described as producing a “Lazarus Syndrome,” named for the biblical story about a man Jesus was said to have raised from the dead. Yet, ironically, as news of the success of combination treatment has hit the mainstream media, client after client has arrived in therapists’ offices with feelings that have ranged from anxiety to outright panic. Because they have begun to contemplate continued life after having prepared for death, some actually have asked: “What if I don’t die?”

Mental health professionals have played a critical role in helping their clients make sense of the everchanging terrain of the AIDS epidemic. Combination therapy has indeed altered the landscape of AIDS, but in ways that have not always been predictable or expected. In order to address these issues, therapists and counselors need to understand the concerns that have accompanied the arrival of combination treatment.

Two Challenges

The changes brought about by combination treatment have created unique challenges for therapists in two different areas. The first relates to the rapidly changing knowledge base; the second is about becoming familiar with the psychosocial issues raised by combination treatment.

In order to help their clients handle the new treatment landscape, mental health professionals need to understand some basic concepts related to medical treatment and treatment decision making. Topics include treatment adherence approaches, the side effects of the new antiviral combinations, and the various laboratory tests used to assess stage of illness. Mental health professionals potentially also have a role to play in helping clients make decisions about treatment: ensuring that clients are knowledgeable about the medications they are considering, assessing the limitations of the medications, and helping clients explore the implications of their decisions. Part of the decision-making process includes helping clients understand the range of their options and their readiness to undertake treatment, and
empowering them to make decisions. Providers must also appreciate the difficulties of making such decisions, including managing the differences of opinion that exist among medical experts.

In addition to having some conception of the medical context of HIV treatment, therapists must also be able to support clients in obtaining information from their medical providers and other sources and coach them in strategies to manage the doctor-patient relationship. It is not essential for non-medical mental health professionals to fully comprehend all of these complex issues; but it is useful for them to urge their clients to question their medical providers over time and in enough detail for clients to feel that they are partners in their medical treatment. For instance, a client may be afraid to be honest with his or her physician about not taking medications exactly as prescribed, for fear of being labeled a “bad patient.” In situations like this, the therapist can go a long way to prepare the client to be more authentic by first probing the client about the motivating factors for his or her reluctance and then doing some role-playing and assertiveness training. Therapists can also be enormously helpful in helping clients develop strategies for remaining adherent to difficult medication schedules, again by coaching clients to be honest about their own limitations when faced with the potential of adjusting their lifestyles in order to accommodate a medication suggested by a physician.

The second challenge – becoming familiar with the psychosocial issues raised by combination treatment – is at the crux of HIV-related psychotherapy. For example, clients who regain their health may feel overwhelmed by other problems in their lives such as addictions or unsatisfying relationships that may have been eclipsed by HIV disease. Some clients who regain a sex drive may face a broadening horizon of intimate relationships, an exhilarating prospect that may also bring complications, including the possibility of engaging in sexual behaviors that can either transmit the virus, or expose them to other sexually transmitted diseases (STDs) or drug resistant strains of HIV. Additionally, clients who regain their physical health may discontinue counseling or therapy prematurely before addressing major intrapsychic or interpersonal problems. Finally, clients who do not do well on combination treatment or who cannot tolerate these regimens may unfavorably compare themselves to others around them who have regained their health. Conversely, some who
do well report feeling guilty about friends who are not. Mental health professionals can be particularly useful in helping clients manage these feelings and complex issues.

Since the onset of the epidemic, therapists have experimented with new therapeutic approaches in order to meet client needs. The paradigm of what constitutes “good mental health treatment” for this client population has most often been an eclectic approach that actively addresses interpersonal, systemic, and intrapsychic issues and dynamics. There have been, and remain, times when a primary therapist may function as a case manager or counselor rather than as a safely distant and objective clinician. Even with the arrival of combination treatment, there remains a need for mental health professionals of all disciplines to understand when it is appropriate to add counseling or case management to the process of intrapsychic exploration that has been the hallmark of classic psychotherapy.

Overview of the Monograph

This monograph is intended to inform mental health providers about the range of issues raised by the improved treatment of HIV disease and to suggest approaches to managing some of the most common manifestations. Chapter One provides an overview of combination therapies, including the related biomedical, psychological, and HIV prevention issues. Chapter Two emphasizes the importance of the decision-making process and the role that mental health providers can play in this process. Chapters Three and Four discuss the implications of, respectively, treatment success and treatment failure. Several of the chapters include hypothetical case studies (a composite of actual cases using fictional names for both the client and therapist) that highlight some of the mental health issues raised in that chapter. In each chapter where these hypothetical case studies are included, more than one case is presented to demonstrate how a variety of clients and therapists have dealt with a specific issue. Providing a variety of cases also underscores the reality that the knowledge base for working with people on combination antiviral therapy is still in its infancy and that, similar to working with any other psychotherapy client, there is no single “right” way to work. The monograph closes with one appendix: a listing of on-line and print resources that can help both provider and client remain informed about the latest medical and psychosocial issues.
This monograph in no way does justice to the devastation of the AIDS epidemic in the developing world or even in parts of the industrialized world in which access to treatment is limited. “Bridging the gap” between richer and poorer parts of the world remains a major challenge. Particularly within developed countries, health care professionals have an ethical imperative to mobilize for the delivery of equitable access to clinical trials and care – including a full range of diagnostic tools and medications – for all people with HIV, whether or not they are covered by health insurance.
Combination Treatment:
An Overview

Combination therapy has not made my viral load undetectable, yet it has still been a godsend and I am not complaining, despite the side effects. The few KS lesions I used to have are now gone, and my CMV retinitis has not gotten any worse. Prior to beginning these drugs, I would also become confused at times, which my physician assumed was a neuropsychiatric complication of HIV. This symptom is also a thing of the past.
— Thomas

The introduction of antiviral medications used in combination is among the most important advances in the treatment of HIV disease. By using more than one drug at a time, combination therapy is able to “pin down” HIV from more than one angle so that even if one drug fails, another can continue to suppress viral replication. This chapter begins with an overview of the scientific advances that have made combination therapy possible. These scientific realities strongly influence many of
the psychosocial challenges related to HIV medical treatment, and, as such, it is essential to have at least a rudimentary understanding of them. This chapter proceeds to review advances in the monitoring of treatment progress, the current state of combination therapy, and the barriers to treatment success, including side effects and the difficulties of adhering to challenging drug regimens. It concludes with a brief review of the implications of the new treatments for HIV prevention.

A History of Scientific Advance

In the summer of 1981, the Morbidity and Mortality Weekly Report, published by the U.S. Centers for Disease Control and Prevention (CDC), included two reports about increases in previously rare infections among gay men in New York and California. “Physicians should be alert for Kaposi’s sarcoma, pneumonia, and other opportunistic infections associated with immunosuppression in homosexual men.” Thus began a process of medical discovery about Acquired Immunodeficiency Syndrome (AIDS) that continues to the present day.

Although medical progress has often seemed slow in coming, advances in knowledge about AIDS have in many ways actually been swift. Within a year of the CDC report, epidemiological evidence had made clear that the causative agent of AIDS was sexually transmitted, and that it had spread particularly within sexual networks of gay men. Within two years, advances in the then-nascent field of virology enabled researchers at the Pasteur Institute in Paris to isolate the “AIDS virus,” which eventually came to be known as the Human Immunodeficiency Virus, or HIV.

Further research gradually determined the precise means by which HIV invades the human body. Transmitted from person to person primarily through blood, semen, and vaginal secretions, HIVs principal targets are the very cells of the immune system (particularly CD4+ cells and macrophages) that are intended to clear foreign pathogens from the body. After entering a cell of the immune system, the virus begins a relentless process of replication, its sole activity, allowing it to constantly spread to new cells. In the process, the immune system can be devastated.

Whereas most viruses retain their genetic information on strands of DNA, retroviruses like HIV employ simpler RNA for this purpose. The outer coat of the virus consists of particular glycoproteins, which can form biochemical bonds with certain proteins that are
found on the surface of some cells, notably those in the immune system. Once bonding occurs, the HIV life cycle requires the insertion of its own genetic material into the host cell and ultimately the use of three important viral enzymes. The first, “reverse transcriptase,” converts RNA into DNA (a process called reverse transcription). The second, “integrase,” integrates the viral DNA into the human cell’s DNA. The third, “protease,” later cleaves off new copies of the viral proteins, allowing new virus particles to be assembled and enabling these new viruses to leave the cell. These three enzymes are essential to the process of viral replication, and most advances in HIV treatment inhibit the activity of one of these enzymes. (There are currently no commercially available integrase inhibitors, but these drugs are the subject of intense research.)

In 1986, the U.S. Food and Drug Administration (FDA) approved the first antiviral drug, zidovudine (ZDV; AZT), which prevents HIV replication by inhibiting the activity of the reverse transcriptase enzyme. ZDV is part of a class of drugs formally known as nucleoside reverse transcriptase inhibitors (also known as nucleoside analogs). After 1991, several other nucleoside analogs were added to the anti-HIV arsenal, as were a new class of anti-HIV drugs called the non-nucleoside reverse transcriptase inhibitors (also known as non-nucleoside analogs), which work in similar ways to the nucleoside analogs but which are more quickly activated once inside the bloodstream. In 1991, researchers also introduced a class of antiviral drugs known as protease inhibitors, which are distinctly different from the reverse transcriptase inhibitors: they do not seek to prevent infection of a host cell, but rather to prevent an already infected cell from producing more copies of HIV. Despite this proliferation of drug options, the standard antiviral therapy between 1986 and 1995 was primarily “monotherapy,” or treatment with a single drug. Such drugs appeared to be partly effective, although efficacy varied among individuals.

During this period, there were also significant advances in the understanding of how HIV functions in the body. In particular, while it was once believed that people went into a latency period of ten years or more after initial infection with HIV, it came to be understood that huge amounts of viral replication continued throughout the entire period of infection, even in the absence of any symptoms of illness. Thus, the onset of HIV-related symptoms is now known to be the result not of a sudden resurgence of a latent virus, but rather
of a slow “war of attrition” between HIV and the host immune system, the latter slowly being overwhelmed by the former.

The recognition of the persistence of viral replication – with billions of copies of HIV being produced and destroyed daily – also led to a better understanding of the process by which the virus may become less sensitive to specific antiviral medications. This process, known as drug resistance, most often occurs under the “selective pressure” exerted by a specific antiviral drug: during HIV replication, a random mutation causes a small genetic change in HIV’s RNA, making it less vulnerable to the effects of the drug. In other words, those viral particles susceptible to the drug will be inhibited by the drug, but others mutate, thereby escaping the effect of the drug. Mutated virus then multiply and form new strains that predominate. Drug resistance can seriously complicate treatment by rendering drugs less effective or even completely ineffective. Further, an organism that has developed resistance to one drug can also become resistant to other drugs in the same class (cross-resistance) or to a number of different drugs (multidrug resistance).

Monotherapy – even with protease inhibitors – often led to the development of drug resistance. However, the expansion of the number of distinct classes of antiviral medications made possible a shift from monotherapy to combination therapy, in which drugs from two or more antiviral classes are used simultaneously (see Table 1: Commercially Available HIV Antiviral Drugs for a listing of specific medications). This switch to combination therapy has had dramatic effects because “combination therapy suffocates mutated forms of HIV before they have a chance to flourish. For example, in a combination of ddI, d4T, and indinavir, a strain of HIV that is naturally resistant to ddI will be kept in check by d4T and indinavir, while a strain of HIV that is resistant to indinavir will be kept in check by d4T and ddI.”

When nucleoside analog drugs, non-nucleoside analog drugs, and protease inhibitors are used in concert, these drug combinations are referred to as “highly active antiretroviral therapy” or HAART.

Employing Combination Therapy

HAART has been prescribed by physicians in a variety of combinations, and, over time, convincing evidence has emerged that particular combinations consisting of one protease inhibitor and one or two other drugs can have dramatic effects. Among these results have
been: a reduction in the amount of virus in the blood; an increase in the number of CD4+ cells; improved health and well-being; and a decrease in opportunities for new mutations that might create drug-resistant strains of HIV. By the start of 1997, combination therapy had become the standard of care for HIV-infected people who had begun to exhibit signs of significant immunosuppression, and although there is no consensus about the best time to initiate therapy, formal panels of researchers and clinicians offer and continually update guidelines for treatment.\textsuperscript{10} The treatment decision must be based on balancing a variety of factors, including the length of time since initial infection, current CD4+ cell count and viral load, clinical prognosis, side effect profile, and an individual's psychological readiness and motivation to begin and adhere to treatment. (See Chapter 2: Making Decisions about Antiviral Treatment for more discussion of the treatment decision-making process and the debate about when to initiate treatment.)

Three years into its widespread use, combination antiviral therapy has demonstrated enormous potential, eliminating early fears that it would prove to be yet another dead end in the treatment of HIV infection. On the other hand, combination therapies have not yet achieved the most optimistic goals set by scientists, much less the often-hyped claims of the popular media. In particular, researchers have demonstrated that the goal of completely eradicating HIV from an infected individual may never be achieved, because HIV has the capacity to remain dormant in certain cells and to infect difficult-to-reach cells in the central nervous system and other parts of the body.\textsuperscript{11} Additionally, irregular use or missed doses of antiviral medications, even over the course of only one week, can lead to full or partial resistance, and cross-resistance is very common among the protease inhibitors.

None of this diminishes the overall impact of combination treatment. Since the mid-1990s, there has been a significant decline in death rates from AIDS in the United States.* Between 1996 and 1997, the number of AIDS deaths dropped 42 percent, and between

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* The term "AIDS" is of course used synonymously with HIV. An "AIDS case," however, used in the context of epidemiological studies technically refers to HIV infection plus the occurrence in an individual of one of a number of HIV-related opportunistic conditions or a CD4+ cell count of less than 200. The U.S. Centers for Disease Control and Prevention (CDC) determines the list of AIDS-defining conditions and uses AIDS diagnoses, which are reportable by law, for tracking the course of the HIV epidemic.
Table 1. Commercially Available HIV Antiviral Drugs


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<tr>
<th>Generic Name</th>
<th>Abbreviation</th>
<th>Brand Name</th>
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<tr>
<td><strong>Nucleoside Reverse Transcriptase Inhibitors</strong></td>
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<tr>
<td>zidovudine</td>
<td>ZDV or AZT</td>
<td>Retrovir</td>
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<tr>
<td>didanosine</td>
<td>ddl</td>
<td>Videx</td>
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<td>zalcitabine</td>
<td>ddC</td>
<td>Hivid</td>
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<td>stavudine</td>
<td>d4T</td>
<td>Zerit</td>
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<tr>
<td>lamivudine</td>
<td>3TC</td>
<td>Epivir</td>
</tr>
<tr>
<td>zidovudine + lamivudine</td>
<td>ZDV + 3TC</td>
<td>Combivir</td>
</tr>
<tr>
<td>abacavir sulfate</td>
<td>1592</td>
<td>Zagen</td>
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<tr>
<td>adefovir dipivoxil</td>
<td>PMEA</td>
<td>Preveon</td>
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<td><strong>Protease Inhibitors</strong></td>
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<td>saquinavir hard gel</td>
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<td>Invirase</td>
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<td>saquinavir</td>
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<td>Norvir</td>
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<td>indinavir</td>
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<td>amprenavir</td>
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<td>Agenerase</td>
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<td><strong>Non-Nucleoside Reverse Transcriptase Inhibitors</strong></td>
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<td>nevirapine</td>
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<td>delavirdine</td>
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1997 and 1998, it dropped 20 percent.\textsuperscript{12} In addition – in response to the efficacy of the new treatments in slowing disease progression – the number of cases of adults or adolescents who progressed to an AIDS diagnosis dropped by 18 percent between 1996 and 1997 and by 5 percent between 1997 and 1998.\textsuperscript{12}

The decline in AIDS-related deaths has been attributed to a variety of causes, including improved treatment of and prophylaxis against opportunistic infections, as well as a long-projected epidemiological drop-off as the huge first wave of people infected with HIV in the 1970s or early 1980s died in the early to mid-1990s. However, the introduction of combination therapies has also played a crucial role in this decline.
Indeed, combination therapies have brought many people back from the proverbial “brink of death,” restored many thousands to a semblance of their earlier health, and sharply reduced the incidence of new HIV-related opportunistic infections and cancers. It appears that this trend of declining deaths will continue, though because advances in treatment have been available only for a relatively short time, no one can say for certain what the long-term effects of these treatments will be. Antiviral success, even if it is temporary, may provide a window of opportunity for immune-boosting therapies and perhaps even a restoration to normal immunological functioning. On the other hand, continued use of these powerful and toxic medications creates complicating factors, notably damage to vital organs such as the liver, kidneys, and heart.

**Monitoring Treatment Progress**

Concurrent with the evolution of combination therapy has been the development of new assays that have improved the ability of physicians to track the effects of medications on the progression of HIV disease. These tests – the polymerase chain reaction (PCR) and branched DNA (bDNA) – quantify “viral load,” calculated as the amount of HIV RNA in a milliliter of blood. Previously, clinicians relied upon the CD4+ cell count as the principal “surrogate marker” for the efficacy of antiviral treatment. But CD4+ cell counts focus more on the extent to which HIV has damaged the immune system in the past than on the extent to which a particular drug combination is successfully battling HIV. Knowing both CD4+ cell count and viral load is necessary to form a better appreciation of likely future outcomes.\(^\text{13}\)

Viral load tests are used to monitor the success of treatment and to determine when a particular combination therapy is not working. Viral load can range as high as several million copies per milliliter of blood; in general, the higher the viral load, the more rapid the progression of illness. Successful treatment often leads to a viral load reading “below the level of detection” (formerly, and somewhat confusingly, known as “undetectable”), indicating that the concentration of HIV in the blood is too low to be detected using a particular assay. Depending upon the type of assay used, the level of detection may range from as high as 500 copies to less than 40 copies of viral RNA per milliliter of blood. While a viral load below the level of detection is an affirmation of good health, it does not mean that the blood is virus free or that viral load will remain low over time. Further, studies
have shown that people who have viral loads below the level of detection in the blood may have higher concentration of virus in semen or vaginal secretions. Both of these facts suggest that people with viral loads below the level of detection remain potentially infectious.

When HIV develops resistance to a particular drug or combination, the virus is said to “break through,” and viral load begins to rise. At this point, health care providers usually recommend a new regimen of antiviral drugs. Choosing the new combination is a complex matter because of issues of cross-resistance. Thus, while switching is possible, the number of times a change in regimen may be made is limited. Without viral load testing, health care providers would be without truly significant markers of medication success, and the efficacy of combination therapy would be severely hampered.

The Current State of Combination Treatment

Overall, for people living with HIV disease and the professionals working with them, the news about combination therapies that emerged in 1996 was heartening. But it was also confusing. Arising from presentations at the XI International Conference on AIDS in Vancouver, mainstream media reporting made it seem as if scientists had discovered a cure for AIDS.

For example, an article by Andrew Sullivan in the New York Times Magazine was called “When Plagues End: Notes on the Twilight of an Epidemic,” an overly optimistic title that reflected the tensions surrounding advances in treatment. While there seemed to be a reason to hope that HIV disease might become a chronic and manageable illness, proclaiming the “twilight of the epidemic” was misleading. Combination therapy is a complex and difficult course even under the most successful circumstances, and it requires strict adherence; non-adherence often results in a rebound in viral activity. (There is research currently underway into the use of “strategic treatment interruptions” or “structured intermittent treatment” to determine to what extent people can miss doses and still maintain treatment efficacy.)

Two studies published in the journal Science showed that HIV lurked in the immune system of patients on triple combination therapy, although it occupied very few cells. These studies found that while HIV obtained from study subjects may not have been resistant to antiviral drugs, the virus was still competent, that is, capable of causing widespread infection in the absence of effective drug therapy. These
findings support the idea that treatment needs to be lifelong. Steven Deeks, a researcher at the University of California San Francisco, characterized drug failure as occurring most often in patients who had become drug resistant as a result of previous treatment or who had not adhered to dosage schedules for current treatments. Deeks went on to explain that the Science studies "support the observation that in patients who have not taken antiviral drugs before and who take the combination as directed, 80 percent to 90 percent do well."\textsuperscript{17}

By early 1999, the euphoria – as well as sensationalism and excessive optimism – that followed the Vancouver conference had diminished. "For many people, protease inhibitors are now 'old news,'" said Alan Berkman, an HIV clinician in New York City. "At first, there were all these dramatic examples of people rising from their deathbeds, but that was already a while ago. In the intervening time, people have seen that these medications are not a 'miracle cure,' and that they can be difficult to take. A lot of the skepticism about the medical system has returned among many patients, although there is still a recognition that antiretrovirals can help people with HIV stay well longer."\textsuperscript{18}

The mood identified by Berkman was reflected in the first post-Vancouver international AIDS conference, held in Geneva, Switzerland in July 1998. While the Vancouver conference displayed the revolutionary potential of the new treatment paradigm, the Geneva conference focused on small, incremental steps necessary to refine this paradigm and the careful analysis of existing data on combination therapies. The Geneva conference covered a number of major themes, including viral activity and the mechanics of viral eradication, ways to strengthen and rebuild the immune system, drug resistance, new treatments, simpler drug regimens, strategies for using and adhering to antiviral drugs, longer-term side effects, and perinatal transmission. In almost every field, there was evidence both that combination therapy was effective over time and that the drugs did not work for everyone. In addition, it remained unclear how long the beneficial effect of treatment could be expected to last.

**Barriers to Successful Combination Therapy**

Health care providers and their patients have always been aware of the barriers to the successful implementation of combination treatment, but it is only since the late 1990s that these obstacles have garnered the attention they deserve. Chief among these are significant
side effects, which can become intolerable and result in the cessation of therapy; non-adherence, which can undermine treatment efficacy and can be caused by a whole range of factors; and financial barriers, which can impede access to health care and to medications.

Side Effects

Primary among the problems associated with combination therapy are side effects, which are unintended actions caused by a drug, called “adverse reactions” when they are negative.\(^1\) Each drug in the combination treatment arsenal comes with a number of side effects that can cause a significant amount of discomfort and prevent continued use. The range of possible side effects is broad and includes nausea, vomiting, diarrhea, skin rashes, headaches, fever, chills, and peripheral neuropathy (painful tingling of the hands and feet). Protease inhibitor use may also lead to lipodystrophy, or the redistribution of body fat from the extremities to the torso, as well as elevated levels of fat or cholesterol in the bloodstream, posing a risk for heart attacks and strokes. Side effects may not only cause discomfort, they may also affect the absorption of antiviral medications. For example, diarrhea or gastrointestinal problems can flush out medications before they are fully absorbed into the body.

There is a dizzying array of specific conditions associated with different medications. For instance, a low red blood cell count is associated with ZDV; when ZDV is combined with 3TC in the form of Combivir, it can also disrupt sleep and cause flu-like symptoms and dizziness. Researchers have associated ddC with ulcers in the mouth and with peripheral neuropathy, and ddI with potentially life-threatening pancreatitis. Indinavir is well-known for its tendency to promote the development of kidney stones, requiring those who use it to ingest large quantities of water daily. Several antiviral drugs, including indinavir, can also play havoc with blood sugar levels to the point that glucose monitoring is required. Others, such as nelfinavir and ritonavir, can diminish the efficacy of birth control pills; thus, women on these drugs may need to use a backup form of contraception. Some people with hemophilia have reported increased bleeding when taking some protease inhibitors.

Equally troubling are a wide variety of potentially serious drug interactions, which can limit the types of combinations available for any individual. For instance, providers avoid prescribing more than
one drug associated with peripheral neuropathy. Likewise, saquinivir is not safe to take with certain drugs used against tuberculosis and *Mycobacterium avium* complex. Some drugs in combination may diminish the effects of other drugs: for instance, nevirapine diminishes the effects of protease inhibitors at their normal doses. The list of contraindications is long and complex, including quite a number of routine antihistamines and psychotropic medications. The latter, of course, are of particular relevance for mental health providers.\(^{20-22}\)

While these symptoms can sometimes be treated, their impact on quality of life can be significant when they limit mobility or otherwise prevent people from going about their normal routines. Some side effects can be effectively treated with anti-diarrheal and anti-nausea medications. Nonetheless, many people may experience side effects as the primary effects of the medications, and in the short term, side effects may seem more serious than the symptoms of HIV infection. Although the existence of serious side effects can present a valid reason for physician and patient to alter the course of a medication regimen, altering a regimen without consulting a physician can lead to resistance to all the drugs in a combination regimen.

**Adherence**

Medication adherence is central to drug efficacy and to avoiding drug resistance.\(^*\) However, successfully taking medications as prescribed, even short-term antibiotic protocols for minor infections, has long been recognized as problematic for nearly all types of conditions and treatments.\(^{23}\) Adherence is generally most challenging when the regimen is complex, intrusive, and of long duration, the exact characteristics of anti-HIV therapies. Adherence is also difficult when the treatment is for chronic conditions, which are often asymptomatic. Again, this is the case for many people with HIV disease.

HIV combination treatments are among the most demanding, inflexible, and "unforgiving" of oral medications. Because of limited bioavailability (the ability of a drug to be absorbed by the body) and short half-lives (the period during which a drug remains effective), combination therapies must be taken at fixed intervals, usually

\(^*\) The traditional term for adherence is "compliance." While "compliance" connotes a hierarchical relationship between patient and health care provider, "adherence" suggests a collaborative effort between the two.
either every eight or twelve hours. Depending on the specific drug, this may be either with meals or on an empty stomach. Different antiviral drugs have different schedules that may conflict with each other, and the number of pills may rise to as many as 20 or more per day. Many people on combination therapy must also take additional medications, either as prophylactic treatments against opportunistic disease or in direct response to these diseases, and each of these other medications has its own scheduling requirements. In addition, HIV-infected people may already contend with weight loss or disrupted sleep patterns, making it more difficult to maintain a medical regimen that places further restrictions on eating and sleeping. Finally, some people may skip doses to avoid side effects.

Compared with the finality of an all-out cure, the prospect of long-term adherence to a complex regimen of combination therapy is disheartening and confusing. Nonetheless, the simple reality is that if a person cannot adhere to the strict dosing schedule and food requirements, the therapy is destined to fail.

A Day in the Life of a Pill-Taker

A couple of examples of typical “day in the life” scenarios of people taking combination therapy will better help clinicians understand the complexity and intrusiveness of these treatment regimens into people’s daily routines. The hypothetical examples that follow show that taking antiviral medications is not simply a matter of popping a few pills a few times a day. Rather, these drug regimens have a radiating effect that can profoundly influence eating, sleeping, and work schedules, as well as day-to-day interactions with other people. (It is important to note that in the case that follows, there is no clinical evidence supporting a twice-a-day combination of indinavir and saquinavir.)

Julio. After years of anti-HIV monotherapy and then a course of two nucleoside analog drugs, “Julio” began triple combination therapy in 1996. The combination included ritonavir (which had to be taken with food), d4T, and 3TC. Julio stopped taking d4T after it caused painful peripheral neuropathy in the balls of his feet. He also asked his doctor to take him off ritonavir because it was causing flatulence, nausea, diarrhea, a foul taste in his mouth, and numbness in his lips. He began taking a combination of indinavir, saquinavir, and 3TC.

Julio wakes up at 5:00 am to take three indinavir tablets and then dozes until 6:00 because he needs to wait an hour after taking the
indinavir before he can eat. With breakfast, he takes six saquinavir, one 3TC, and one valacyclovir (Valtrex; a prophylaxis against herpes zoster). Between noon and 2:00 pm, Julio has lunch; he cannot eat anything between 3:00 pm and 6:00 pm, because he must take his second dose of three indinavir tablets at 5:00 pm along with a second valacyclovir. Julio eats dinner sometime after 6:00 pm, and takes his second dose of six saquinavir, one 3TC, one aspirin, and two atorvastatin (Lipitor; to control his cholesterol levels).

Because Julio has always been an early riser, this schedule works for him with a minimum amount of discomfort or disruption. He considers himself lucky. The only time he feels stressed by his dosing schedule is when he travels, which he does frequently as a buyer for a woman's shoe manufacturer. He has purchased several electronic pill boxes with beepers to ensure he adheres to his medication schedule. Julio says with pride, “I've literally never missed one dose of my medication,” which probably accounts for a drop in his viral load from over a million to below the level of detection.

Anne. In contrast to Julio, “Anne” feels that her entire life revolves around her medication schedule. She sets an alarm to wake her at 4:00 am in order to take two indinavir on an empty stomach and not have it conflict with her dose of two ddI, which she also must take on an empty stomach but never with the indinavir. She takes the ddI at 9:00 am after having a 7:00 am breakfast. Since she has had a problem keeping weight on, Anne forces herself to eat lunch at noon whether she is hungry or not, because at 2:00 pm she has to take her second dose of two indinavir. At 3:00 pm, she forces herself to have another snack since at 6:00 pm, she has to take a second dose of ddI on an empty stomach. Anne has her dinner sometime after 7:00 pm and takes her final dose of indinavir when she goes to bed.

Anne also takes three ZDV and one acyclovir with meals, along with other medications to prevent against Pneumocystis carinii pneumonia, toxoplasmosis, and Mycobacterium avium complex. Anne is planning to talk to her doctor about switching from protease inhibitors to a once-a-day non-nucleoside analog drug in order to decrease her sense of being imprisoned by her medication schedule.

Studies of Adherence

To achieve a better understanding of protease inhibitor use among its clients, the Gay Men’s Health Crisis (GMHC) in New York
conducted three pilot studies, two of which sought to assess the extent of, reasons for, and predictors of non-adherence to combination therapy. Although this study included a small sample (only 37 people participated in the arm of the study that dealt with missed doses), the result contained important information.24

First, the studies demonstrated that missing medication doses was a common occurrence. Approximately three-quarters of the participants in the focus group segment of this study reported missing doses of antiviral drugs in the previous six months, and nearly one-third had missed a dose in the past week. Among those who missed a dose within the past six months, the following were the mostly widely reported reasons: being away from home without the medications; forgetting to take a dose; fatigue; conflict with eating; and running out of medication. It is interesting to note that in this small study, gay men also cited stress, anxiety, and depression as reasons for missing doses, suggesting that psychological factors join with practical ones to complicate adherence.

Two 1997 national surveys conducted by DuPont Pharmaceuticals confirm the findings of the much smaller GMHC study.25 The first survey collected data through telephone interviews with 665 seropositive individuals on antiviral treatment. The second survey targeted 100 physicians who treat patients with HIV. Nearly all the participants in the DuPont study reported that they had been well-educated about the importance of adherence by their physicians. The majority said that their health care providers explained the meaning of viral resistance and the consequences of not taking the antiviral drugs according to schedule. Additionally, many had received educational materials about the importance of adherence. Most respondents said they understood the consequences of non-adherence and agreed that adherence is important and would prolong their life.

Despite high levels of awareness and understanding, 26 percent of the subjects said they had missed doses the prior day, and 43 percent admitted to missing doses in the prior week. Further, 54 percent said they knew other people who were non-adherent. Respondents were more likely to miss a dose of all their medications or take an entire dose at the wrong time than they were to miss a specific pill, take a pill at the wrong time, or not follow the food requirements of their regimen. Factors that most often led to missed doses included: side effects, the requirement to take three or more doses a day, the necessity to take
medications on an empty stomach, and difficulty taking pills (for example, because of difficulty with swallowing). Of the physicians, 89 percent reported that certain characteristics exacerbated non-adherence. For example, 61 percent cited injection drug use as a complicating factor. Other factors included: lack of education (19 percent), demanding jobs (17 percent), poverty (16 percent), mental incompetence (15 percent), substance abuse other than injection drug use (15 percent), and homelessness (15 percent).

The GMHC study found that the following factors improved a person's ability to adhere: belief in the effectiveness of treatment, evidence that the regimen was working, success in minimizing side effects, and support from family and friends. Another key factor was the level of trust in the health provider. Although all the study participants had discussed combination treatment with their doctors, almost a quarter felt that their doctors did not clearly explain drug interactions, and almost one-fifth felt that their doctors had not clearly explained side effects or the consequences of non-adherence.

This is an area in which counselors and therapists can coach clients, helping them to develop questions to ask their doctors before deciding whether or not to begin combination therapy. In addition, mental health professionals working with clients wrestling with complicated treatment regimens may need to depart from traditional psychotherapy and engage in problem solving in order to help clients discover methods that will support adherence. The respondents in the DuPont study often suggested that adherence could be enhanced by a pill box with an alarm and fewer pills per dose. Physicians invariably responded that the biggest boost to adherence would be antiviral drugs with once-a-day dosing and fewer side effects.

**Improving Adherence**

San Francisco AIDS Foundation Treatment Support Supervisor Tim Teeter works with homeless clients, but many of his suggestions about improving adherence might apply to any client. He notes that "The factors that complicate medication adherence among homeless people are similar in most respects to the factors facing other people ... but these challenges are often complicated by concurrent substance abuse and mental illness, and require different approaches in a population that has neither the financial nor social resources of more stable clients."

Teeter states that supportive case management, which assists clients in
stabilizing their lives and addressing basic needs, is a prerequisite for helping homeless clients establish regular medical care. Once these prerequisites are achieved, initiating substance abuse and mental health treatment works well as part of helping the client obtain medical care.

The case manager can play a vital role in encouraging the homeless client to have regular health care visits. Teeter also suggests that case managers talk with homeless clients regarding their beliefs about HIV and what having HIV means to them. Finally, he says that when conducting basic HIV education, it is important to use language and explanations that match the client's level of understanding. Homeless clients, in particular, may appreciate the efforts of providers to present treatment information in a brief and easy to understand format.

Offering concrete incentives can encourage homeless clients to return for continued education and counseling sessions. These incentives may take the form of lunches, at which clients can discuss treatment issues, or showers. Providing snacks and nutritional supplements that clients can take with them will increase the likelihood that they will return for follow-up visits. Helping homeless clients devise strategies for medication storage is especially important. Teeter notes that providing clients with medication sets that allow them to prepare a week's supply of medications is one solution. He also suggests that prior to beginning medication, homeless clients fill a medication set with a week's supply of different colored candy and attempt to take them on a regular basis in order to determine the likelihood of their being able to follow the medication schedule. Since most debilitating side effects are worse in the first two weeks of treatment, Teeter encourages case managers to focus on this period of time, trying to stabilize a client's housing situation, addressing nutritional needs, reducing stress, and providing ongoing support and counseling.

Australian physician Cassy Workman asserts that adherence can be improved if a member of the health care team intervenes at three critical points in the process: before treatment is initiated, immediately after treatment has begun, and at regular points during the therapy.27 She suggests that counselors or medical providers ensure that clients understand three things: why they need to begin treatment; that they are able to take the medications as prescribed; and what strategies can ensure that they will take the medications as prescribed.
Counselors can assist medical providers by asking clients about their experiences taking medications. Workman notes that when clients are asked if they have missed any doses, they typically answer with one-dimensional responses like “once” or “a couple of times.” She urges counselors to ask instead, “In what situations have you found it difficult to take your medication in the past week?” This kind of question gives both the counselor and client specific information. Often clients have begun to figure out how to remedy these situations by themselves. Once a client has clarity about his or her experience, he or she can then take this information back to the prescribing physician in order to work out either a new medication regimen or a better variation on the current one.

According to University of California San Francisco physician Michelle Roland, complex treatment decisions “must be driven by personal preference, common sense, rapidly accumulating data, changes in community prescribing patterns, and perhaps most important, a comfort with uncertainty.”28 It can be helpful for counselors to initiate conversations about these topics while a client is still contemplating taking the new treatments. Roland adds, “Clinicians and patients can maximize adherence by identifying cues to help remind patients to take medications, anticipating changes in daily patterns, and reviewing medications in the clinic prior to starting them.”

Financial Barriers

The extremely high cost of the new HIV medications is another significant barrier for initiating treatment.29-31 The average annual cost of HIV antiviral therapy is about $15,000, and this does not include any of the other drugs that people with HIV routinely take.29 According to the CDC, 750,000 Americans are infected with HIV and fewer than one in five has private health insurance. Roughly half are insured by Medicaid or other government programs, and 29 percent have no insurance at all.30

In response to this challenge, the U.S. government created the AIDS Drug Assistance Program (ADAP), the federal-state partnership that provides HIV antiviral and other drugs to the poor. To qualify for ADAP, individuals must meet income qualifications. In California, for example, a person qualifies when his or her annual income is less than $32,200; in New York, a person qualifies when his or her annual income is less than $44,000. This figure varies from state to state.
Enrollment in ADAP has ballooned with the arrival of combination therapy. The rosters in some states have climbed as much as 2,000 percent, and as word of the benefits of the new regimens spread, clinics have become jammed with people anxious to try the new drugs.

According to the National ADAP Monitoring Project's Annual Report, ADAP is theoretically available in all 50 states, the District of Columbia, and Puerto Rico. State ADAPs served 53,765 clients in the month of June 1998, a 22 percent national increase over the month of July 1997. ADAP expenditures for antiviral drugs increased by 54 percent between July 1997 and June 1998, to $30.1 million. (It is notable that during the same period, expenditures for drugs for treating HIV-related opportunistic infections decreased by 31 percent to $3.8 million.)

The ADAP programs in 26 states have gone bankrupt. In October 1997, for instance, there were more than 600 people in Florida on the ADAP waiting list to receive subsidized antiviral medications. As patients with HIV live longer, there is almost no turnover in the ADAP programs. "In many parts of the country, precious slots are full, and state officials, short of cash, are faced with a wrenching problem: whether to cover all the drugs for some patients or some drugs for all." In addition, access to drugs for the uninsured varies from state to state and even from county to county, contributing to what one expert called "Greyhound Therapy," the tendency of some people to move to where the medications are available. This creates another dilemma for people with HIV: by choosing to move in order to obtain medication, they remove themselves from the realm of supportive professionals, family members, and medical and psychosocial services that provide care, contribute to their well-being, and improve adherence.

While the financial barriers to implementing HIV treatment are directly related to the cost of medications and the availability of insurance or ADAP funding, limits on mental health care may affect the availability of support to clients. In particular, mental health providers and their clients may have to contend with managed care limitations on long-term psychotherapy and with the involvement of managed care plans in monitoring therapeutic progress and approaches. Since the goal of managed care is to reduce health care costs, the focus in terms of mental health service has been the reduction of symptoms through brief treatment and psychopharma-
cologic interventions. While managed care may lead to the effective coordination of care and improved outcomes, it risks an inappropriate application of the medical model, which seeks adequate functioning rather than psychological growth.33

**Implications of New Treatment for HIV Prevention**

HIV-related research has traditionally been split into two relatively separate spheres: treatment of those already living with the virus, and prevention for those who are not. In practice, these spheres have at times overlapped, for example, in interventions designed to help seropositive people avoid infecting others. Advances in treatment, however, have in some ways fused the two spheres. Indeed, some have gone so far as to use the phrase “treatment is prevention” to reflect such new realities as the possibility of post-exposure prophylaxis for the uninfected, as well as the hope that the use of combination treatments to suppress viral load may also have the effect of making people with HIV less infectious.

**Post-Exposure Prophylaxis**

Post-exposure prophylaxis (PEP), also called post-exposure prevention, has the most important implications of HIV treatment advances for HIV prevention.34 According to a PEP research project at the University of California San Francisco, “There may be a window of opportunity in the first few hours or days after exposure in which these highly active drugs may prevent HIV infection.”35

According to David Ostrow, Director of the Awareness Intervention for Men Project at Howard Brown Health Center in Chicago, however, “There are too many differences between occupational and sexual exposure to recommend this treatment on the basis of the CDC studies. The time between exposure and treatment tends to be different. The dose of HIV delivered is different. And how it is delivered to the body is different. We just don’t have enough evidence.”36 In addition, health care workers almost always know whether the patient they are treating has HIV, but others often do not know the HIV status of their sexual and drug use partners. Finally, health care workers can usually gain access to antiviral drugs much more quickly than people exposed through sex or needle sharing. Limited research indicates that if PEP works at all, it is most effective when administered within twelve to thirty-six hours of exposure.37
Despite the uncertainty associated with PEP, a number of doctors around the country are using it, and as of February 1997, there are six PEP centers nationwide. According to Margaret Chesney, Co-Director of the UCSF Center for AIDS Prevention Studies, which is involved with one of the nation's largest PEP clinics at San Francisco General Hospital: "In addition to the therapy, people should be given hours and hours of counseling to help them think about their experience in having gotten exposed, what it means, and how they can keep from repeating it." The popular press has billed PEP as a "morning-after pill," similar to the one that prevents pregnancy by inducing menstruation. This has caused many HIV prevention professionals to fear that the overly-simplified publicity surrounding PEP will increase the incidence of unprotected sex. Mario Solis-Marich, former head of the National Task Force on AIDS Prevention believes that PEP "undermines the work we have been doing for prevention," adding that there are "serious ethical concerns involved in the consideration of PEP as a legitimate recommendation for people exposed to HIV through sex."

**Increased Sexual Risk Taking**

One of the most troubling potential outcomes of all the "good news" offered by combination treatment — and the possibility of post-exposure prophylaxis — is that HIV infection may come to be seen as less of a "big deal," and people may cool their commitment to safer sex. One specific concern is that HIV-infected people whose viral load is below the level of detection may erroneously believe that they are no longer able to transmit the virus. Another is that there may be a perception that a "cure" is either already available or at least right around the corner, or that through the use of PEP, any "slip" can just be "medicated away."

These issues pertain both to infected and uninfected people. Indeed, prevention among those who are already infected has assumed a new level of importance, given that many seropositive people are experiencing better health and renewed interest in sex. Increased sexual activity among people with HIV may lead to the potential not only for new infections but also for reinfection with different (and possibly drug resistant) strains of HIV and co-infection with other sexually transmitted diseases.

Two studies — one at the University of California San Francisco
AIDS Health Project\textsuperscript{40} and the other at Columbia University\textsuperscript{41} – outline some of the concerns about the ways in which perceptions about combination treatment might be increasing risks for infection. For example, the UCSF study found that 26 percent of respondents were less concerned than they had previously been about HIV risk in light of treatment advances; 13 percent were more willing to take risks; and 15 percent conceded that they had already done so.

The Columbia study found that 23 percent of the 62 mixed antibody status couples reported engaging in unprotected anal sex in the previous six months. About half of the participants agreed with the statement, “Reducing viral load also reduces the risk of HIV transmission.” About one-third agreed with the statement, “New treatments will soon be able to reverse HIV infection and eliminate the virus from the body.” And one-seventh agreed with the statement, “New treatments have made me more willing to take risks in my sexual behavior with my partner.” In each case, seronegative men who agreed with these statements were statistically more likely to have unprotected anal intercourse with their seropositive partners.\textsuperscript{41}

Further, some of the specific beliefs endorsed by many couples are not necessarily supported by the latest scientific findings. According to Robert Remien, principal investigator of the Columbia study, “We know that when HIV is lowered in the bloodstream, it is also lowered in semen – but the correspondence is not one-to-one. That means it’s still possible for a person with undetectable viral load to transmit the virus – particularly if the person already has another genital-tract infection, which can increase the infectivity of semen. In addition, we also know that even virus which is dormant can be transmitted and can reanimate in the new host.”\textsuperscript{42}

In one case from the Columbia study, the partners in a mixed-status male couple reported that after years of always using condoms during anal intercourse, they had an episode of unprotected sex shortly after the seropositive partner learned that his viral load had sunk below the level of detection. Even though the partners understood that “undetectability” did not equate with non-infectivity, this result was enough for them to believe that unprotected anal intercourse was now within the realm of the other types of sexual risks with which they had already decided they were comfortable. Although the partners characterized the experience as an isolated case, and their explanation may indeed have been a post-hoc rationalization,
the fact remains that the concept of viral load being "undetectable" can have a powerful influence on people who are tired of the constant vigilance demanded by safer sex.42

It is important to note that some studies have not found that information about the treatment success leads to increased risk-taking.43,44 However, most researchers agree that, at least for a portion of people, widely publicized treatment success can lead to responses such as the ones found in the UCSF and Columbia studies.45-47

These realities have direct implications for counseling both infected and uninfected people. When working with infected people who are sexually active, it is important that the therapist inquire about an individual's beliefs regarding how having their own or a sexual partner's viral loads be below the level of detectability might affect specific sexual practices. In order to encourage people who may be taking increased sexual risks to keep discussing this issue in therapy, it is crucial for the therapist to remain nonjudgmental even when a client may be putting him or herself, or his or her sexual partners, at risk for infection or reinfection. One way of accomplishing this is to empathize with how difficult it is to sustain a commitment to safer sex while exploring all of the thoughts, feelings, and motivations contributing to a person's behavior in this regard. Some clients benefit from counseling that integrates a psychoeducational approach that provides them with the specific facts about reinfection, multi-drug resistant strains, and infectivity, in addition to an exploration of feelings.

**Conclusion**

The long and eventful history of HIV treatment joins with the significant barriers to combination therapy to qualify the hope that has accompanied the miraculous treatment success of the past few years. This is the backdrop for the HIV treatment decision-making process discussed in the next chapter and for the range of psychosocial issues covered throughout this monograph.
Making Decisions about Antiviral Treatment

For the ten years prior to triple combination therapy, I had been living waiting to die. With triple combination therapy I had to do a 360-degree turn-around at a moment's notice. Boy was that a mind fuck!

– John

The proliferation of new medical options for people with HIV comes as a welcome respite. Compared with the earlier days of the epidemic, HIV infection and even clinical AIDS are no longer immediate "death sentences." Yet the very expansion of options has made treatment decision making more difficult. For many clients, the sense of urgency about treatment decision making and timing creates a potent anxiety. Complicating this is the reality that while standard therapies have been published, many physicians, especially those who are not HIV specialists, are unsure about or unfamiliar with them and fail to adequately manage patients with HIV.
Clients are faced with the need to make a number of decisions about treatment: whether or not to begin combination therapy; when to do so; whether or not to change treatments in response to an increase in viral load or intolerable side effects; and, in some cases, whether or not to stop combination therapy. Therapists can provide valuable assistance to clients in making these kinds of decisions. This chapter discusses some of the most important of these issues in detail and suggests ways of working with clients who are facing these decisions.

**Risks and Benefits of Combination Therapy**

At first glance it might seem ridiculous for an HIV-infected person to even consider not initiating combination therapy and its life-extending potential. Yet, this decision is not a straightforward one, and to make it, an individual confronts many questions. This is true especially for HIV-positive people who are “treatment naive” (that is, those who have never taken an antiviral drug), for whom there is considerable uncertainty about when is the best time to begin therapy. The U.S. Department of Health and Human Services (DHHS) guidelines reflect this ambiguity in their summary of the potential benefits and risks of early treatment in asymptomatic patients.48

Potential benefits include:
- Control of viral replication and mutation, and reduction of viral burden;
- Prevention of progressive immunodeficiency and potential maintenance or reconstitution of a normal immune system;
- Delayed progression to AIDS and prolongation of life;
- Decreased risk of resistant virus;
- Decreased risk of drug toxicity.

Potential risks include:
- Reduction in quality of life from adverse drug effects and inconvenience of current maximally suppressive regimens;
- Earlier development of drug resistance;
- Limits of future antiviral choices due to development of resistance;
- Unknown long-term toxicity of antiviral drugs;
- Unknown duration of effectiveness of current antiviral therapies.
One matter about which almost all the experts are certain is that no one should begin monotherapy, that is, treatment with a single antiviral drug. To prevent resistance and increase efficacy, drugs must be taken in combination. Combinations often include drugs from at least two of the currently existing different classes of antiviral drugs, although there are some regimens that include three drugs from the same class.

"Uncertainty" is the word that best describes one of the major dynamics confronting people choosing whether and when to begin combination therapy. One school of thought is highlighted in a 1995 article by David Ho, Director of the Aaron Diamond AIDS Research Center in New York, who declared that it is "Time to Hit HIV, Early and Hard." The "hit early and hard" perspective acknowledges the growing body of evidence that the untreated virus does damage even in asymptomatic people with HIV. It encourages initiating combination therapy as soon as people know they are HIV-positive. The evidence that early intervention with antiviral drugs is effective is so compelling that many major AIDS service organizations have now issued policy statements urging all people at risk for exposure to HIV to get tested so that they can begin treatment as early as possible in the course of their disease.

Despite the enthusiasm for hitting early and hard, however, this approach is not universally endorsed, especially as hopes of viral eradication have proven to be unfounded. One of the most notable voices of caution has been pioneering virologist Jay Levy of the University of California San Francisco. Citing concerns about the need to take antiviral medication indefinitely, on a strict schedule, and with the potential for serious side effects and drug interactions, Levy asks, "With these concerns, are we then choosing the right direction by giving these drugs to all infected individuals who have evidence of virus in their blood? Would we not serve infected people better by reserving certain therapies and administering them at a time when their use is clearly required?" Levy also discusses the importance of preserving the immune system's capacity to fight the virus. He notes that individuals who have discontinued combination therapy often undergo a dramatic increase in viral load, suggesting "that the immune system has either been compromised by the drugs or 'put to rest' by the therapy. Without exposure to a sufficient amount of viral antigens, the ability to recognize replicating HIV is lost. Thus the host, off treatment, cannot respond effectively to a re-establishment of productive virus infection."
Following Levy's line of thought, some people with HIV—including many who are highly educated about treatment—are postponing treatment for as long as possible. Indeed, several organizations around the country conduct support groups for HIV-infected people who choose not to begin any form of antiviral therapy. Mark Niedzolkowski, a member of such a group in New York, told The New York Times that the group is important because “It’s really hard to maintain your resolve when you’re all by yourself and everyone is saying you’re crazy. There’s no one to talk to.” Despite a CD4+ cell count of 168, a viral load of 177,000, and symptoms of immune suppression, Niedzolkowski remains resolute: “My life doesn’t need to be saved yet. I feel there’s an awful lot of hype out there about saving people’s lives with these drugs. Many people are dealing with really severe side effects with these drugs. We’re trying to push it to the limit in terms of saving these drugs for later.”

Adding to this sense of uncertainty is a movement to discredit the assertion that HIV is the cause of AIDS. Not only does this movement leave some people without a clear sense that HIV is the appropriate target of treatment, they also specifically blame antiviral medications for the immune breakdown that characterizes AIDS. In many ways, the view that HIV does not cause AIDS is a holdover from the early years of the epidemic, when the workings of retroviruses were not well understood. For instance, early critics of the so-called “HIV-AIDS hypothesis” questioned how HIV could have a latent period of ten years or more before its effects manifest as clinical illness.

The challenge posed by this question actually may have helped to accelerate the discovery that HIV is not latent between infection and illness, but rather wages a constant “war of attrition” with the immune system. While not denying that large numbers of people have died as a result of immunodeficiency, dissidents who do not believe HIV is the cause of AIDS ascribe these deaths to causes such as repeated infections with sexually transmitted diseases, multiple drug use, environmental pathogens, and in Africa, undiagnosed tuberculosis and malaria, and endemic malnutrition. In their view, antiviral medications simply accelerate the process of immune destruction.

One barrier to the use of combination therapy is the guideline stated in the current DHHS recommendations, that once started, antiviral drugs need to be taken for the rest of an individual’s life. For people who become infected in their twenties or thirties, the
spector of sustaining a demanding drug regimen for decades is understandably daunting. In addition, most people with HIV already coordinate an extensive regimen of drugs for other conditions. “I was an attorney before I went out on medical disability,” explained Bob, a psychotherapy client. “Managing my medical care and prescriptions, and monitoring when and how each needs to be taken has become my full time job. I’ve put it all on my computer. There is simply no other way I could keep track of it all.” Even the most sophisticated consumer of medical care, who has the capacity to organize his or her own life, can find managing the required scheduling of anti-HIV drugs to be a daunting task. For parents of children with HIV, many of whom are single HIV-positive mothers, making certain that they and their children adhere to the rigorous medication schedules is often nearly impossible.

Helping Clients Make Decisions

One way to begin the life-changing conversation with clients facing complex treatment decisions is to suggest that they make lists of what is most important to them and how the decisions they face will affect various aspects of their lives. For instance, if spontaneous socializing around meals is something the client cherishes, then he or she may decide not to begin taking indinavir, which requires precise scheduling of both medication and meals. If a client is very athletic or travels a lot for business, he or she may decide not to begin taking medication that will likely cause diarrhea. At the same time, therapists should engage with clients to evaluate how well they cope with ambiguity and uncertainty and determine how clients feel about the fact that there is usually no “one right answer” when it comes to treatment options.

A survey in Treatment Issues, a newsletter published by GMHC, quotes several physicians about their approaches to helping clients make treatment decisions. “Factors that go into making treatment decisions are so varied that it is truly difficult to format the complex thinking into words,” Charles Carpenter of Brown University Hospital explained. “For those who do not want to initiate aggressive triple combination therapy including a protease inhibitor, I generally recommend that no therapy at all, with monitoring of plasma viral loads quarterly, is generally preferable to beginning dual nucleoside therapy. In such instances, I try to work out with each patient a virtually agreed upon measurement (for example, when the plasma
viral load exceeds 40,000) which will eventually trigger initiation of triple therapy." Cal Cohen of Community Research Initiative (CRI)/New England explained, “The primary issue is a person’s interest/enthusiasm to take medications. If the patient is ambivalent, I’d rather wait a bit and have them try taking vitamins to see how it feels to take pills regularly."

Michael Aldermen, a physician from Cleveland, Ohio said, “I am not eager to begin therapy unless the patient is committed for the long haul and prepared to make adherence to the regimen a major priority.” Michael Para, a physician from Columbus, Ohio stressed, “I don’t decide, the patient does. I may recommend it but will go along with almost all patient wishes if they are informed and understand the risks/benefits.” Rona Vail of Gouverneur Hospital in Manhattan said, “I believe that ability to adhere to treatment is the strongest decision point for beginning treatment. I would rather have the patients hold off on therapy than to take it and not be committed to it.”

To help clients evaluate issues related to beginning and maintaining treatment, mental health providers should be prepared to:

- Explain to clients that there now exists a new approach to treatment that may help prolong their lives;
- Help clients evaluate if they feel that they want to begin this new treatment;
- Communicate to clients the difficulties of taking these drugs, including the possibility of severe side effects and of lifelong treatment (although it is important to note that research is pursuing alternatives to the scenario of perpetual treatment);
- Discuss with clients the challenge of adherence;

It is important to note that, by and large, society does not encourage anyone to advocate for him or herself in medical settings. But, it is easier to encourage a middle-class and well-educated client to be a sophisticated and demanding consumer of health care. When a client is poor and less educated, he or she is likely to have had little experience advocating with doctors, nurses, and health care institutions and agencies. It is, therefore, necessary to support and coach some clients on how to become empowered, self-advocating consumers of medical care without necessarily becoming adversarial. Hospital social workers play an especially vital role in communicating patient decisions about combination therapy to medical colleagues, seeking to do so in such a
way that medical staff will not view these patients as non-compliant or self-destructive. It is important that patients who cannot or choose not to employ combination therapy are seen as having made a treatment decision that is correct to them at the present time. Finally, if clients, after beginning combination therapy, decide to discontinue treatment, it is important for providers to help them redefine the experience, to ensure that clients see it as a self-empowering decision about health care rather than as a failure or the result of pathology.

**Medical Decision Making: A Framework**

Baruch Fischhoff and Julie Downs, researchers at Carnegie-Mellon University, have developed a multipart strategy to assist people faced with the task of making important medical decisions. The first step is for the client to identify his or her options. Traditionally, clients have relied on their health care professionals to research and present treatment and care options. But the AIDS self-empowerment movement has encouraged people living with HIV to become well-informed and sophisticated consumers of health care in order to enter into a healing partnership with their health care professionals. Especially in the area of combination therapy, where there is no common standard of care, a client’s understanding of the consequences of each potential decision is crucial. Once the options have been identified, the provider must work with the client to ensure that he or she understands the ramifications of each option. It is useful for clients to write down all their questions before seeing their physicians.

The second step in the decision-making process is to address the uncertainties inherent in facing a large field of choices. “Once clients understand their options, they can focus on how likely it is that the consequences will come to pass.” Fischhoff and Downs urge clinicians to avoid vague terms such as “rarely,” “uncommon,” or “likely,” because clients are very good at remembering and interpreting actual numerical data about potential outcomes, efficacy, and side effects. This is especially useful for people pondering whether to begin an existing treatment protocol or to wait for the results of a clinical trial that may give them clearer information in the near future.

It is often helpful for the client wrestling with these decisions to hear from a member of his or her treatment team that indeed “treatment dilemmas often pose irreconcilable trade-offs.” For example, in evaluating a regimen that includes indinavir, it is important to
acknowledge that there will be difficulties in juggling medication schedules and meal times to allow for a three-hour window (two hours prior to taking the drug and one hour after taking it) during which the client cannot eat. Additionally, since several antiviral drugs cause diarrhea, it is useful for providers to acknowledge the potential discomfort, and the inconvenience of either needing to stay close to a bathroom, taking other medications to control the diarrhea, or suffering the potential indignity of soiling oneself. It is important for the provider to help the client come to a realistic assessment of the difficulties likely to be encountered in order to achieve a viral load below the level of detection and to elicit all of the client’s feelings about what he or she will have to put up with to try and achieve this goal.

This leads to the third part of the decision-making process: developing an understanding of as many of the consequences as possible before actually choosing a particular course of action. It is important for the client to consider trade-offs, for instance, in determining if he or she wants to take a drug that has the potential to extend life while leaving him or her with chronic fatigue, nausea, diarrhea, and disrupted sleep. In order for the decision making to be as informed as possible, the potential consequences need to be as specific as possible. Individuals facing choices about beginning treatment should speak with or read accounts by other people who have already been on the drug or regimen to learn about real-life reactions. Clients often feel burdened by the societal construct that the extension of life – at any cost – is the only or best option. Providers can help clients who question this belief by offering support for alternate views, including those that center on personal values about the kind and quality of life a client desires and feels able to manage. This attention helps clients to assert control over their lives, thus turning the burden of decision making into a life-affirming challenge.

**Culture and Countertransference**

While counseling clients with HIV disease may require providers to be directive at times, helping clients make treatment decisions is a quintessentially client-centered process. But it is also one particularly prone to the effects of a provider’s own perspective about health care and medical approaches to HIV disease. Two areas in which such perspectives may undermine the counseling process are the lack of cultural competence and the presence of unacknowledged countertransference.
The Effect of Culture on Treatment Decisions

Attitudes toward health and health care are very much influenced by a person's culture. Health may be perceived as related to everything from spiritual balance to fate to a divine response to sin. Health care may be affected by issues of economic access and racial or ethnic marginalization. It may also be associated with cultural attitudes toward governmental institutions or quasi-governmental institutions. For example, many people of color in the United States—reflecting experiences ranging from the Tuskegee Institute syphilis experiments and forced sterilizations to diminished access and quality of care available to poor people—historically have a high level of distrust of what is perceived as the White-dominated, Euro-centric health-care system, at variance with their cultural values regarding health, illness, and help seeking. Understandably, the legacy of these experiences continues to exert a powerful influence on many marginalized populations, instilling in them an unwillingness to trust the existing medical system; in the context of HIV, this may lead to disbelief in theories about causes and treatments and the motives of health care providers and health care systems.

For some cultural groups, language may be a barrier, particularly in the context of communicating about complex topics such as treatment. But culture implies a whole set of ways of living that go beyond language to either support or undermine the process of making and implementing treatment decisions. For example, Columbia University researcher Alex Carballo-Dieguez notes that while the main problem for Latinos dealing with HIV treatment is access to medical care, other culturally influenced behaviors may affect treatment: “Many of the medications have regimens which require a very structured lifestyle, but many Latinos have a different relationship to time, such as having their meals at hours that may differ day by day.”

The variety of cultural influences is staggering, and seeking to understand them may lead counselors, however well-informed, to construct stereotypes that will interfere with the individuality of each client. As San Francisco therapist and researcher Amanda Houston-Hamilton states:

*Counselors establish cross-cultural credentials with clients not by showing off bits of knowledge about the traditional behaviors or beliefs of a group, but by regularly demonstrating an openness to learning about the
forces that affect clients. . . . To this end, it may be useful for providers to consider every client interaction to be cross-cultural and to wonder out loud and without interpretation when they encounter behaviors that seem inappropriate or incomprehensible. . . . It is essential to go through an explicit process of uncovering expectations and determining with the client the parameters of an appropriate exchange.58

While counselors may learn about culture from colleagues, consultants, friends, and acquaintances, clients are the greatest teachers about themselves and their cultural perspectives. Counselors helping clients make treatment decisions must remember this and use client-centered counseling skills to uncover the meaning of health and treatment as a way of helping clients clarify their own values.

Countertransference and Bias

This approach is also crucial when dealing with the countertransference that inevitably arises as counselors watch clients make decisions about treatment. In practice, countertransferential biases are similar to cultural ones. Both involve the overlay of the counselor’s perspective on the client’s, both may interfere with the counselor’s ability to help the client make decisions that are consistent with the client’s values, and both are remedied by a strong commitment to a client-centered approach.

In the context of HIV treatment decisions, countertransference may manifest in a variety of ways. For instance, if a counselor is a strong believer in nontraditional healing methods, this can be a useful resource to bring to the client’s process, but it can also be a potential liability if the counselor is unable to explore and support the client’s decisions to employ more conventional medical approaches to HIV. Alternately, if a clinician is a strong believer in the appropriateness of early medical intervention, he or she may communicate disapproval to a client who chooses to wait before starting on medication. For all counselors working in the epidemic, the issue of antiviral treatment may raise feelings about illness, physical and mental deterioration, and their own mortality. For counselors who may for some reason identify strongly with the epidemic, the challenge may be even greater: if the counselor is a parent, a gay man, or a person living with HIV, for instance, countertransferential conflicts may be especially problematic. For this reason, regular, ongoing supervision is an essential component of working with clients facing HIV.
Two hypothetical case studies (a composite of actual cases using fictional names for both the client and therapist) offer some insights into dealing with the range of personal feelings and biases that may enter into the therapeutic dyad and undermine therapy. Focused, in particular, on treatment decision making, they suggest the importance of dealing with these feelings in the context of any HIV-related treatment issue.

**Gladys and Sarah: Caring Too Much**

“Gladys Staley, PhD” is a 40-year-old seropositive, second-generation White American of Irish-Scottish descent and a psychologist who works in the AIDS program of a major New York City hospital. She has been on combination therapy since 1996, has experienced relatively minor side effects, and has achieved a viral load below the level of detection.

“Sarah,” a young, professional, African American woman initially consulted Staley about her fears of taking an HIV antibody test. After Sarah received a seropositive test result, she began ongoing therapy with Staley, which was available to her as a client of the hospital’s AIDS clinic. Staley also used these sessions to introduce Sarah to the idea of examining her role as caretaker within her family and her feelings about being in this role.

In the weeks following Sarah’s HIV diagnosis, Staley took a psychoeducational approach, eliciting Sarah’s feelings and concerns about having tested HIV-positive and exploring ways in which Sarah might disclose this information to her family. As Sarah had predicted, her mother and sisters were frightened by her news. Sarah and her family saw Staley for six sessions of family therapy, during which the therapist educated family members about HIV, validated their feelings and reactions, and helped them attain a realistic assessment of Sarah’s health status. Staley also referred Sarah’s mother to a group for mothers whose adult children were living with HIV.

As the family crisis resolved, Staley provided Sarah with a variety of articles and HIV-related internet site addresses about treatment options. Although Sarah felt fine physically, her blood work indicated that she had a low CD4+ count and an extremely high viral load. During an early supervision session, Staley said, “I felt that this indicated that Sarah was an ideal candidate for antiviral treatment and shared this opinion with her – without pushing her in any direction.”
Sarah decided, at least temporarily, not to start any treatment – despite a recommendation from her doctor – Staley acknowledged that she began to feel frustrated with Sarah. “When I explored her reasons for not beginning antiviral treatment at this time, she explained that since she was not yet ill, she did not want to use up any treatment options. I explained that there were reasons to consider early treatment, especially with such a high viral load, but Sarah told me that she had never completely trusted traditional western medicine, and she felt that there were too many uncertainties about the drugs, their side effects, and long-term impact for her to be willing to begin taking them.”

When Staley pushed Sarah to explore her reluctance to initiate treatment, Sarah said that she did not want to face the side effects of medications because she had just begun a demanding new job. Sarah said she was afraid that treatment would impair her vitality, energy, and independence. She also explained that her schedule was unpredictable, and that she was not confident of her ability to take the drugs on a precisely timed schedule. As Staley explored various options with Sarah, Sarah’s frustration only grew. Finally Sarah said, “Even if I could handle the drugs, what proof do I have that it’s not another Tuskegee?”* I’ve heard of plenty of people who have failed on the drugs, plenty who just got sicker – even if they got better for a little while!” Staley responded cautiously, “I can understand that you might be concerned about side effects, and I think we should talk more about this, because there are many people who successfully balance demanding jobs and antiviral treatment. Perhaps we should also talk a little about why you think this might be a conspiracy, when these efforts are really focused on getting you to feel well.”

Sarah continued cautiously, “Well, you might not understand, but I just can’t get the history of Tuskegee out of my mind. Lots of my friends talk about it, and it is only one example of a time that the government has lied to Black folk. Stranger things have happened.”

* Between 1932 and 1972, government-funded researchers openly conducted the Tuskegee Syphilis Study in Alabama, during which 400 low-income African American men were told that they were being treated for syphilis, when in fact, researchers were observing the long-term effects of untreated syphilis to the end point, that is, death: at least 28 and perhaps more than 100 participants died. Others suffered mental illness and permanent disability, including palsy and paralysis, and were unable to work. All risked transmitting the disease to wives, lovers, and children.
Surprised, Staley said, “Well, I’m sure we can help you put these fears behind you. After all, as an educated woman, you don’t have to take on other people’s paranoia. Then we can tackle your real concerns about fitting treatment into your life.” Staley spent the next five minutes reminding Sarah about the evidence for the efficacy of antiviral treatment. Staley then went on to suggest that she and Sarah bring in some of these treatment articles to review together.

Staley recalled, “Although I believe that I behaved clinically appropriately and kept exploring her reasons for not wanting to start treatment, in hindsight it is clear that my judgments about her decision were having a negative impact on our relationship. But I was blind to this effect. I believed Sarah needed information to make an educated decision. When she chose to behave in a way that I did not feel was in her best interest, I began to treat her as a disappointed parent might treat her child.”

Staley continued, “And I really missed the boat on the Tuskegee reference. I know about the experiments – and how horrible the real Tuskegee incident was – but I just could not see how an educated – a brilliant – woman could buy into these AIDS conspiracy theories. I grew up with parents who blamed everything on the English, and who tried to fill me with superstitions, but they were simple country folk. As a child, I knew they were just scared and ignorant. I got an education so that I could be more in control of my life than that. I thought Sarah was the same.”

Much to Sarah’s credit, she discussed with Staley the change in Staley’s attitude. “Up to that point, I had not been aware that my feelings were contaminating the therapy,” Staley reflected. “I did not feel it was appropriate to share with Sarah that I had struggled with this exact issue only a few months earlier. Yet I could not move beyond the feeling that I wanted to shake her and scream that she was playing with her life. When she raised Tuskegee, I felt she was really grasping at straws, and it took me right back to arguments with my parents.” Eventually, Sarah requested a transfer to another therapist. As Staley explored Sarah’s reasons for wanting to change therapists, she realized that Sarah was, after all, behaving appropriately and in an informed way that reflected Sarah’s experience and perceptions – ones that were different from Staley’s. Further, Staley became aware of the irony of the situation: her unwillingness to acknowledge their differences had made it impossible for therapist and client to establish an alliance.
During their final sessions, Staley told Sarah that she respected her decision and saw it as an example of Sarah’s skill at taking care of herself. Staley also urged her to continue to be as “take charge” with all members of her health-care team as she had been with Staley. Their last session was warm, and both women became teary upon saying good-bye.

As a result of Sarah’s termination, Staley sought private, outside supervision, during which Staley more clearly recognized Sarah’s decision as a good one. “I only wanted to help this woman who I really liked and identified with. Clearly one problem I had was that I overly identified with her and wanted to protect her.” Staley’s supervisor, “Rosalind Wells, PhD,” explored Staley’s feelings of being powerless to do anything to influence the course of HIV progression in her life other than to be aggressive in traditional medical ways. Staley also identified that Sarah had triggered strong maternal instincts in her and forced her to begin to confront her decision not to have children. Finally, Wells discussed Staley’s response to Sarah’s concern about the experimental nature of antiviral drugs and the history of exploitation of African Americans. Staley realized that her own cultural shame and bias coupled with her overwhelming desire to protect Sarah had led Staley to dismiss what was clearly an emotionally significant concern. Further, Staley had implied that Sarah should do what African Americans had done through much of their history in the United States: accept the dismissal of their concerns by White people who “knew better.”

Over the course of the supervision, Staley confronted several options, including discontinuing HIV-related work and considering ways to be alert in the future to emotionally charged situations with clients. Staley chose to continue to work with people with HIV disease and to resume her own individual psychotherapy. The encounter with Sarah also opened Staley to the possibility that her parents’ stories, which she had considered oppressive and limiting, had also helped them cope with hard choices. She resolved to rethink her self-imposed distance from her own culture. This case illustrates how unrecognized cultural biases and countertransference can impede the clinical work of an otherwise astute and self-examining clinician.

**Stephan and Leonard: Choosing to Let Go**

“Stephan Peretz, LCSW” is a 50-year-old, gay, White, seropositive social worker in private practice. He is on triple combination
therapy but his viral load has never dropped below detectable levels. Nonetheless, his health is excellent and he has never had any HIV-related symptoms. In 1994, just before protease inhibitors became widely available, his partner of many years died of AIDS. “Leonard,” a 54-year-old, seropositive, gay White man was referred to Peretz for psychotherapy by his doctor, because Leonard was depressed and was not adjusting well to the death of his lover, “Hank.” Hank had died a few months earlier after failing to benefit from combination therapy. The physician saw Leonard’s refusal to begin combination therapy as symptomatic of his depression, and referred Leonard to Peretz specifically because Peretz was open about being HIV-infected and was, like Leonard, a gay widower.

Leonard presented with very flat affect and multiple symptoms, diagnosable as either a complex depression or complicated grief. Leonard had been with his partner for more than 30 years, and his partner was the last person in his extended friendship group to die. To make matters worse, Leonard’s cat died suddenly three days after his partner’s death. When Peretz asked Leonard why he refused to begin combination therapy, Leonard said he no longer felt that he had any reason to live. As Peretz probed the extent of Leonard’s depression, Leonard explained that he would never actively hurt himself, but he felt that by refusing to take any antiviral or prophylactic medication, he was acting in a way to hasten his own death; Leonard said he was fine with this approach.

In response, Peretz said that he had felt similarly in the weeks following the death of his own lover. But when Leonard asked him if at that point there were any people he loved, Peretz had to answer truthfully that he had been blessed with numerous friends and family who had been actively supportive. Leonard then told Peretz that he had no family or friends left alive. He had never been career-oriented; he had a relatively undemanding job that minimally interested him but paid well. Peretz asked, “If you are feeling so hopeless, helpless, and powerless, why have you contacted me?” Leonard’s answer posed a tremendous professional challenge to Peretz.

“I was hoping to find someone with whom I could talk about all of this without his wanting to fix me. I know that I could try taking antidepressants in order to feel better, but to what end? I have had a wonderful life, filled with love, friendships, and lots of rich memories. I no longer have the energy or desire to do anything but to keep
going for as long as I am alive. I am not suffering greatly; I am only lonely, tired, and sick, but I have no desire to try and meet new people to begin new relationships. After my cat died and I did not even consider getting a new animal, I realized that I was preparing for the end of my life. Are you willing to work with me on these terms?”

In recounting this session to his supervisor, “Sam Carter, LCSW,” later that same week, Peretz reported telling Leonard that he wanted to think this over before reaching a final decision. Peretz told Carter that he felt confused about his ethical responsibilities. But Peretz came to believe that if Leonard were to try antidepressants – an outcome that might result from therapy – there might be the possibility that Leonard might feel better. If, however, Peretz refused to work with Leonard, there might not even be this one small chance for Leonard to change his mind. Peretz agreed to work with Leonard on Leonard’s terms.

Peretz felt challenged not to impose his own values onto Leonard and to support Leonard’s right to choose his own life’s course. Peretz worked with Leonard for a little more than a year, during which time Leonard never chose to begin antidepressants or antiviral drugs, despite escalating pressure from his doctor, whom he eventually fired. At their final session in the hospital, shortly before Leonard died, Leonard thanked Peretz for having accompanied him on his journey. “I know that my choices were not the ones you felt would have been in my best interests. But I really respected and grew to value you for supporting me at all times and even going so far as to advocate with the hospital staff for my right to choose this way. You were my last and greatest friend and ally. I can never thank you enough.”

**Conclusion**

As the science of HIV treatment continues to evolve, treatment decisions may become easier, even obvious. But for the foreseeable future, these decisions will require a laborious process of weighing risks and benefits. Mental health providers – armed with an awareness of their own cultural and countertransferential biases – are in a good position to facilitate this process.
3

Psychosocial Issues of Antiviral Treatment

My first year on combination therapy was focused on regaining my health. The second year was about allowing myself to slowly develop a cautious optimism that these treatments were going to benefit me on a long-term basis. This third year has been about the challenges of improving my quality of life in terms of resuming my career and attempting to regain some kind of financial stability for the rest of my life, no matter how long that will be.

— Christophe

Combination therapy offers real – and unprecedented – hope to people with HIV. It also presents some distinct challenges, notably coping with side effects, that can be debilitating, and sustaining dosing regimens which demand strict adherence. Whether or not any particular patient will benefit from combination therapy cannot be predicted, and some whose therapy at first succeeds later experience the emergence of resistant strains of HIV. Complicating the picture is the need
for both the counselor and client to construct a view of treatment success that acknowledges the ambiguity of treatment outcomes. As Avi Rose, a San Francisco therapist and the Executive Director of Project Inform, notes, this situation breeds both hope and uncertainty, as each individual faces a different prognosis and challenge.60

Although it is widely understood that antiviral medications are not a "cure," the all-or-nothing thinking implicit in the concept of cure continues to influence the way in which we discuss outcomes of antiviral therapy. Indeed, it is common to create a dichotomy between "treatment success" and "treatment failure," a shorthand that this monograph adopts. However it is important to recognize that treatment outcomes actually represent a continuum: on one end of this spectrum is viral suppression that results in a viral load beneath the level of detection; in the middle is symptom reduction but incomplete viral suppression; at the other end is a high level of viral activity and CD4+ cell depletion. Indeed, no treatment so far has succeeded in eradicating HIV. Likewise, there is a growing body of evidence suggesting that even people whose viral suppression is incomplete or short-lived may see benefits from combination treatment: a weakening of HIV and a strengthening of the immune system. This chapter reviews many of the mental health issues raised by these complex and confusing realities.

**Unexpected Hope: A New and Disorienting Horizon**

For those lucky enough to benefit from the new treatments, the life-prolonging benefits of combination therapy often provoke "unexpected soul-searching among patients who had pretty much given up on life."61 Therapists must not begin sessions with such clients with any preconceived ideas of how clients should be feeling about this new development. This is a prime example of "beginning where the client is."

Throughout this chapter, quotations from people with HIV disease give voice to the dilemmas raised from the struggle to wrestle with HIV-related treatment issues. As Marcus, quoted below, so eloquently expresses, even the potential to suddenly have a change of health and outlook can be profoundly disorienting for some people. This is especially true for clients who have known they were infected for many years and who have accepted that they had a life-threatening illness. Marcus explained some of his initial ambivalence about taking combination therapy:
I had two friends who died, despite beginning on combination therapy. I have had so many ups and downs over the years with the promise of new treatments that initially it was difficult to muster up excitement for these new drugs. For the five years before beginning combination therapy, I had been living my life planning and expecting to die. Now I am faced with needing to learn to believe that I have the potential to rebuild my life, jump start my career and no longer feel like a prematurely aged man. This often seems like a bigger leap than I have the energy for.

After initiating combination therapy, Robert reported similar feelings of unease:

[I have experienced] continuous psychological damage that I have to undo. Everyone I knew that took more than two or three pills a day died. I feel that they basically did not die of AIDS, but from the treatments for AIDS. I want to believe that these new drugs are the better drugs that I have been hearing were on the way for the past several years. I want to believe that, and I try to listen to my inner voice that says that this is not just another pharmaceutical scam.

Martin, who is a long-term survivor, said he feels as if he has been balancing a level of supportive denial about having a potentially life-threatening illness with the realities of medically managing the condition. He has never stopped saving for his retirement or ceased to make long-term plans. One particularly difficult time for him occurred three years earlier, the period immediately following the death of his partner from an HIV-related lymphoma. Martin said he wondered at the time if he would ever have another long-term relationship. He now feels that he has had to make a significant emotional accommodation to live with the paradox of absolute uncertainty. “Most of the time I allow myself to really believe that I do have a chronic, yet manageable health condition [but one] that could be fatal,” Martin said. Even with the new improved treatments Martin feels both blessed that his viral load is below the level of detection and anxious about how long he will retain his health.

Many people who experience benefits from combination therapy say that they are most concerned about financial security. While the thought of living on a fixed income was tolerable when combined with the expectation of a limited life span, this prospect has become more daunting as life expectancy has increased. It is no longer an
not the only people who have returned from the edge of death to another chance to build their lives.” Rose goes on to suggest that it is useful for clinicians to remind both themselves and their clients who are experiencing a resurgence of health that “Back to the future has never meant back to normal, and that it has always been hard to reconstruct a life when so many people from the past have not survived.” In terms of clinical work with people who are restructuring their lives after benefitting from combination therapy, Rose explains that counselors can assist with the concrete tasks of assessment, priority setting, and planning: “Some of this involves the psychological adjustment to new expectations and formulating a new sense of ‘normalcy,’ and recreating a future orientation.”

Not all survivors experience guilt. Tommy explained his feelings this way. “I don't feel at all guilty about being alive while so many of my dearest buddies and two lovers did not survive this plague. Actually, I feel survivor triumph at still feeling healthy. I am not happy that all those people died and did not live long enough to benefit from the new medical treatments, but I rejoice in my own good luck.” Henry said:

It's not like, hey, I deserved to live and him and her deserved to die from AIDS. No one deserved to die from this thing. We all deserved to survive it, but for some reason, the luck of the draw has it that I am here and doing well. I'm devastated that so many other people died. But quite frankly, I am thrilled and tickled pink to have lived long enough to be here now and benefit from these new drugs.

“Survivor triumph” occurs when an individual does not feel any guilt or ambivalence about his or her having survived a situation that killed or maimed other people, and in fact rejoices in his or her own good luck. For instance, Raul explained his feelings about beginning combination therapy in the following way:

It's a little like living on death row and getting a stay of execution. I had a date when I knew I was going to die, and now all of a sudden I'm going to be allowed to live for a while longer. Who knows how much longer? Will I live to be an old queen? Will the virus mutate sometime in the future, making the current treatments ineffective? Obviously I don't know. I do know that instead of being overjoyed, I feel like I'm being jerked around.
After finally deciding to begin taking the new drugs, and experiencing a remarkable drop in viral activity with a corresponding increase in his energy level, Mario had similar feelings: “It’s hard to put these feelings into words. I feel like I am simply supposed to be ecstatic that I am feeling better, and of course on some level I am. But this kind of about-face brings up multiple emotional issues. It’s been impossible to say, ‘Hooray, all of my problems have disappeared.’”

**Responding to Ambivalence**

When asked what mental health providers should know in order to be most helpful to people on combination therapy, Martin, the long-term survivor quoted above replied: “Therapists should seek to find out just how disconcerting the uncertainty is. [T]hough I trust the new treatment, I only trust it to a point. There is still an emotional ‘sword of Damocles’ hanging over my head.” Martin continued by explaining how life has become a daily game of balancing the desire to succumb to irresponsible urges with the need to plan for a possible future. “Therapists should never underestimate the constant levels of anxiety present, and how those can surface in an instant, surprising even the most well-adjusted and balanced person.” As one final and sobering caution, he added that therapists should not assume that they can “really empathize with what the patient is experiencing,” even if the therapist is him or herself HIV-infected.

Mark Thomas, former coordinator of group services at the Gay Men’s Health Crisis (GMHC) facilitated a group for HIV-infected people who became visually impaired from cytomegalovirus (CMV). Group members who were doing well on combination therapy were generally pleased to be feeling better. But, when faced with the prospect of an extended life, many said that being blind was something they felt they could adjust to and cope with only within the context of not expecting to live a long time.65

The case of Eric, who became completely blind at age 23 from CMV, provides a poignant illustration. Successfully responding to combination therapy, Eric began once again to make short-term plans, for example, learning to walk independently with a cane, joining a gym to regain weight, beginning a primary relationship, and organizing a support group for the visually impaired, all the while becoming a role model for other group members. Despite his improvements, Eric admitted that his motivation to rebuild his life
still hinged on the thought that his time was limited. He had not come to terms with the thought of growing old as a blind man. In discussing this case, Thomas noted that Eric was initially inspired to enjoy his life despite his disability because of the “now-or-never” perspective that resulted from his expectation of a shortened life span.65

Most clients with improved health describe being cautiously or guardedly optimistic. They express a determination not to get too excited about living until 70 because of all the potential obstacles and limitations they still face as people living with HIV. Thomas observes his clients integrating thoughts of living longer as they begin to contemplate career options, returning to work, and retirement funding. “Subtly, their minds are thinking of a long-term future, and that is both exciting and scary.”66 One couple, for instance, decided to go ahead with plans to move out of New York City to a country home, plans that had been shelved when one partner had first tested HIV-positive. A key dynamic that contributes to the uncertainty is the lack of knowledge about what the long-term effects of taking the drugs will be on a person’s body. “I feel that all of us who are taking combination therapies are guinea pigs for medical science, and are participating in the largest uncontrolled clinical study in the history of the world,” one person explained in an article in the New York Times.51

Thomas also cautions that an additional source of anxiety for individuals who are doing well on combination therapies is the fear that many people now think that the AIDS epidemic is over. One reflection and result of this widespread misconception has been the decline in both public funding, private donations, and volunteering for AIDS service organizations, many of whose budgets and programs are being cut throughout the United States.

**Returning to Work and Financial Concerns**

Perhaps the most palpable change resulting from the success of HIV treatment is the return of the ability to fully participate in living. For some, this has meant going back to work, and for many who do, this change has brought joy and fulfillment. For others, however, the excitement of returning to work is mitigated by a range of psychosocial challenges.

San Francisco therapist Michael Bettinger discusses a variety of intrapsychic and interpersonal issues affecting a person with HIV disease who is considering returning to work.67 Among these are:
sense of failure and regret, a fear of having lagged too far behind to
catch up, grief at the loss of dreams and opportunities, anger at him
or herself for not trying harder to overcome disability, and psycho-
logical paralysis. These feelings may be fed by the practical chal-
 lenges of dealing with resumes that are no longer so impressive and
with professional skills that are no longer current. In addition, peo-
ples re-entering the job market may now be competing for jobs with
people who are younger than they are.

When envisioning a normal life span, financial instability can be
frightening and may heighten anxiety about the pressure to return to
work and the process of job hunting. For some people, a “clean
slate” may be inspiring, but for most, extended life brings with it the
unsettling prospect of trying to recapture the means and form of a
previous life. Added to this confusion is the uncertainty about
whether or not health recovered by combination therapy will be
permanent, and the understandable fear that returning to work may
mean the loss of disability income or other entitlements forever.

Many people disabled by HIV disease have grown used to a dif-
f erent way of life: a greater control over time; a slower pace and
more adaptable schedule; a healthier balance of work and rest; and
the absence of the dysfunctional interpersonal “dramas” that arise in
every work setting. For some, adjusting to disability, uncertainty,
and a threat to life also nurtures clarity about what is important and
what is unimportant, including a deeper understanding of the pre-
ciousness of life and a desire to live in the moment. This change in
perspective is often reflected in terms of work and career. So it has
not been unusual to hear stories about a person with HIV who was a
lawyer and who returns to school to become a therapist or about a
business person who becomes an artist. But recovering health,
regaining ability, rejoining the work force, and undertaking activities
previously deferred may end this way of living, transporting a per-
son back to where he or she was before becoming ill. Further, stay-
ing in or returning to the job a person previously held can, under
these circumstances, lead to feeling trapped, frustrated, and disap-
pointed.67 Therapists may also need to explore with HIV-positive
clients any regrets they may now have about having abandoned
long-term plans, either when they first found out they had HIV or
when they began to experience disease progression. For example, do
they now regret having dropped out of graduate school to travel?
According to Bettinger, “The prospect of returning to work involves a host of practical questions, but it also raises psychological issues related to the meaning of work in a person's life, the changes in perspective that follow the adjustment to a life-threatening disease, a person's relationship to the future, and the difficult process of changing one's self image, [all of which] are fertile areas for therapeutic exploration in counseling and therapy.” Issues of whether or not to return to work can raise strong feelings. As one client said: “Do I have hopes of returning to work? I think the way I feel now is that I am definitely not able to put in eight hours a day. I am saddened by hearing how wonderful everybody is, and that they are all thinking about going off disability, and that there is a whole movement of going back to work, and that is the answer to AIDS. I feel that AIDS is my full-time job. I feel that I am at work and that this is my job.”

Facing Practical and Psychological Tasks

Mental health providers can help clients who are considering returning to work appreciate the practical and emotional tasks they face and sort through the conflicts inherent in wrestling with these complex issues. Part of this process is psychological and part is practical. To deal with the practical aspects of resuming a career or training for a new one, providers may want to refer clients for vocational counseling. Some AIDS service organizations and government agencies sponsor seminars and workshops on issues related to returning to work. For instance, materials published by Body Positive, a New York-based AIDS service agency, cover a broad range of considerations, including researching rules and regulations, checking into private insurance plans, anticipating technicalities of insurance plans, exploring volunteer work, running a “reality check” about the advantages and disadvantages of returning to work, assessing credit and debt, regularizing deferred taxes, clarifying personal values, budgeting, conducting a career inventory, and rewriting a resume.

To approach the psychological issues, clinicians should be aware of two sources of potential conflicts and ambivalence regarding returning to work or retraining: one is intrapsychic, and the other is systemic. Providers can begin to effectively address the intrapsychic issues by asking clients to explore the meaning of work and working (or not working) in their lives. Clinicians should pay particular attention to the effects of not working on a person's self-
image and self-esteem, and to the emotional issues that might make returning to work difficult. For clients who want to return to work, the psychological task is to move in a direction in which they will be able to redefine themselves as workers, while acknowledging but disengaging from the image of themselves as being disabled. Exploring the meaning of work with clients can help them locate internal emotional strengths and resources that can help in keeping them on track in this often difficult period of change.67

On a broader level, clients face changes in the structure of their lives and their interactions. Some clients with HIV disease may find it difficult to readjust to a world defined beyond medical appointments, medication schedules, and other HIV-related activities. They may want to change from a primary identity as a person living with a chronic and life-threatening illness, but they may not want to have to act or be different from how they have been. For instance, many who have been on long-term disability have gotten used to sleeping late and to having total control of their schedules. They may have also gotten used to receiving special support services such as free meals and complimentary tickets to cultural events. Some clients struggling with returning to work experience difficulty letting go of what has become normal, even when the familiar is a painful reminder of their health condition.67

In addition, many people have realistic concerns about what will happen to their insurance policies and other benefits if they do return to work. Although a person may feel significantly healthier than he or she did in the past, that does not necessarily mean that he or she is prepared for the challenges of a full-time job with fixed hours, which may also conflict with demanding medication schedules. In addition, many HIV-infected people left their jobs in the first place because workplace-associated stress was compromising their health, and it might do so again. Perhaps the biggest unknown variable is how durable any improvements in health may be. Setting aside disability entitlements is a major step to take in the midst of such uncertainty. For example, clients who have moved into residences for people with AIDS may jeopardize their status as “worthy” recipients of continued support. Some people facing the loss of disability benefits may confront the ethically difficult situation of exaggerating their symptoms in order to maintain their disability benefits in the face of uncertain health.
For non-professional clients like migrant workers, unskilled workers, or those who have been chemically dependent for much of their adult lives, the loss of social supports offered to people with HIV disease can create a sense of dread, and many face a return to a life with few options for stable income, medical support, or housing. For clients with families or dependent children who may or may not also be infected, the potential loss of supportive services can be especially daunting. (Undocumented immigrants face a related concern: they rarely even access social service agencies because they fear deportation, and HIV only complicates this situation.)

People who believed that they had permanently retired and who have not worked for several years, have had no reason to keep up with current developments in their professional fields. They are worried about returning to work and not having the state-of-the-art expertise required to be employable. In addition, returning to work manifests very differently for white-collar versus manual workers: it is one thing to have a desk job and quite another to return to the factory floor. The hypothetical case of John (a composite of actual cases using a fictional name for the client and his lover) offers the perspective of a professional who has deferred his dreams and feels trapped in his present.

**John: Confronting Deferred Dreams**

“John” is a 47-year-old gay, White, HIV-positive man with a doctorate in art history. While he was completing his dissertation, his lover, “Jean-Pierre,” died of AIDS. John has made his living writing and doing translation work for art museums and academic presses. At the time Jean-Pierre died, John taught a class at one of the major universities in his field; but his illness undermined his teaching, and he was not asked to apply for a permanent position when one became available.

Three years later, after combination therapy led to a full regaining of his health and vitality, the department at which he earned his doctorate invited him to apply for a teaching position. As one of the finalists for the job, John had to give a lecture, but since the position was not in his main area of expertise, John did not get the job.

John came to believe that he would never get a job: he was 47 years old, had had his doctorate for eight years, had never formally taught, and was known to have AIDS. In therapy, John sought other career options, because freelance writing and translating made him
feel isolated, especially since virtually all of his gay male friends and his partner were now dead. John wrestled with the anger and frustration that arose from his failure to achieve his professional dreams through no fault of his own.

To complicate matters, John earned just enough money to support himself, had to let his private health insurance lapse because he could not afford the premiums, and was saddled with student loans and a high level of debt he incurred while caring for his deceased partner. “I now feel that I have the energy to pursue my career, but I also think realistically that my time has passed,” John said. “There is another whole generation of hot shot PhDs out there who can be hired.”

**Relationships with Significant Others**

With greatly improved health, increasing numbers of people with HIV disease find renewed interest in having sex, dating, and relationships. Doug told his therapist, “I knew that my body was really rebounding when I had an erection again, and then discovered that I could masturbate and even have an orgasm.” But the challenge of rediscovering sexuality raises many concerns, including facing hopes and fears about finding relationships, handling disclosure and rejection, dealing with issues of sexual function, and maintaining long-term relationships in the context of increased life expectancy.

Single clients often report that while they had felt satisfied with a life composed of meaningful friendships when they thought they did not have long to live, the prospect of an extended life without a primary partner is saddening. Men and women who have stopped seeking dates, relationships, or sex due to illness are often shy about beginning to meet people for romantic possibilities. “I haven’t flirted with a man in over two years,” confided Sabrina. “I just hope that I haven’t forgotten how, and that if things do take off it will be like riding a bike, something you never forget how to do.” For single people with HIV disease, there is the ever-present fear that they will meet someone they like only to be rejected because they are infected. Most clients who are once more open to dating and sexual intimacy admit that this raises anxiety, but they also recognize that dealing with such issues is a luxury.

Many people with HIV who stopped dating have an understandable insecurity about meeting new people based on several factors. Regardless of sexual orientation, a major concern is being out of
practice in the variety of interpersonal skills required by the dating and courtship rituals. Other concerns include low self-esteem because of a distorted body image and forced disclosure of HIV status because of medication use during a date.

Benefitting from combination therapy can have a variety of effects on long-term relationships. The change in the caregiving and care-receiving balance may bring not only relief but also a tension as the partners struggle to redefine their roles as two healthy adults. Advanced HIV disease has led to the continuation of some relationships that would have ended if both people had been healthy. For example, “Joe” and “Andrew” had only been dating for two years when Andrew became so seriously ill from HIV-related complications that he stopped working, and it seemed as if he was going to die. Andrew moved into Joe’s apartment in order to make it easier for Joe to care for him. Six months after combination therapy brought him back to robust health, Andrew told Joe that he wanted to end their relationship. Though Andrew loved Joe and was grateful for all that Joe did for him when he was ill, he confided that he had never been “in love” with Joe and would have stopped seeing Joe a long time ago had he not gotten sick. Now that he felt healthy, he did not feel it was fair to either of them for him to stay with Joe just out of gratitude.

Such scenarios can also unfold with the caregiving partner artificially sustaining the relationship. “Harry” and “Carl” had been lovers for seven years and had been experiencing problems almost from the beginning of their relationship. Carl wanted a sexually exclusive relationship, and Harry had no desire to be monogamous. The partners were companionable and loved each other, but Harry’s sexual infidelities were a constant source of pain and disappointment to Carl. Harry was HIV-infected when they met, and he told Carl about this on their first date. When Harry developed an HIV-related lymphoma and required frequent hospitalizations and chemotherapy, Carl focused much of his time on caretaking. It was coincidental that before Harry’s lymphoma diagnosis, Carl had decided to end the relationship, but in light of the illness, he did not tell Harry. Several months later, Harry’s lymphoma went into remission, and after a year of viral load levels below the level of detection, Carl finally told Harry that he was ending their relationship.

While some relationships end when one partner feels better, other relationships find a new “lease on life” as the infected partner’s
health improves, allowing the couple a chance to reinvent the relationship. Two case studies (composites of actual cases using fictional names for both clients and therapists) illustrate such events.

**Nellie and Robert: HIV as a Defense Against Relating**

“Nellie” is a 36-year-old Puerto Rican woman born and raised in poverty in the Bronx; “Robert” is a 32-year-old African American man from a middle-class family in Washington, D.C. Both are in recovery from substance abuse, and they became a couple after meeting in a 12-step program. Theirs is the first sober relationship for either of them.

Nellie and Robert had been a couple for two difficult years before Nellie was first hospitalized due to a severe HIV-related gynecological problem. Robert was not infected, but before they began to date, he knew that Nellie was HIV-positive.

Robert worked as a paralegal in a large law firm and earned a good living. At the same time, Nellie struggled to complete her high school equivalency and try to get herself off of public assistance. The financial and class differences between them were a constant source of tension. Nellie comes from a very large and close Latino family. Robert is an only child and has been estranged from his parents for ten years. Nellie’s proximity to her family and the frequency of interactions and visits with her family were difficult for Robert to understand or embrace. He found Nellie’s family to be very intrusive. In addition, Nellie was a vocal feminist who was deeply ambivalent about being financially dependent on anyone. This caused problems because Robert financially supported the couple, and he was resentful that Nellie expected him to share housekeeping while she did not share in providing income.

Seeking to resolve some of their differences, Robert and Nellie entered a group for couples in which one or both partners have HIV. When they first began the group, they spoke of constantly fighting and feeling hopeless about the relationship. Initially when asked to describe the problems that were making them unhappy, both blamed their difficulties on the fact that they were a mixed HIV-status couple. After the group asked them to give specific examples of how HIV status affected them, they described concerns that were unrelated to HIV – always somehow managing to bring the focus...
back to HIV. The other group members told Nellie and Robert that it sounded like they were using HIV as a way to avoid dealing with a variety of complicated interpersonal issues. The group leaders reinforced this interpretation and helped offer illustrations to support it.

It also emerged that prior to entering the group, Nellie and Robert did not know any other couples grappling with HIV. The partners began to use the group to try to figure out different approaches to the problems they faced. They were often frustrated, angry, and hurt, and after six months, they still wrestled with whether or not to break up. As part of their continued exploration, they decided to remain a couple but to live apart.

Around this time, Nellie began to deteriorate physically and experience a variety of HIV-related illnesses. When she initiated combination therapy, her HIV-related symptoms ceased and her health and energy improved. Robert began to talk about about loving someone with HIV, a concern that he had never before acknowledged. He said he was afraid of losing Nellie, that she had become family to him. A breakthrough occurred when Robert admitted to the group that it was easier to scapegoat HIV than to do the painful work of figuring out how to reach mutually acceptable compromises in their relationship. He also began to see how Nellie’s HIV was an excuse he used to protect himself from getting more deeply involved with the woman he loved. With Nellie’s improved health, Robert talked for the first time about daring to hope that they might have a long future together.

Hearing this brought Nellie to tears. It prompted her to describe how her need to be a vocal political feminist may have been an effort to have control over at least one part of her life; and she realized how at times she treated Robert unfairly by testing his love for her in terms of his willingness to do “woman’s work.” Nellie also told Robert that the way he had worked with her family to take care of her while she was sick meant a lot to her and made her feel that the disparate parts of her life were beginning to come together. Though there remained significant obstacles to work out, Nellie’s success with combination therapy had become the impetus for both partners to become less rigid, allowing them to begin to address conflicts through a more honest expression of their love, and with more humor and less anger.
Marty and Beau: Sexuality as Camouflage

“Marty” and “Beau,” both HIV-infected, are both successful professionals and gay White men in their early fifties. They met in a leather bar more than fifteen years ago. Neither man has progressed to AIDS, and both have been on antiviral treatment for several years, beginning combination treatment soon after it became available.

Marty and Beau met and first began dating after each knew he was HIV-positive, a fact they disclosed to each other prior to their having sex. Because neither was interested in a long-term commitment, they dated other people for the first year of their relationship. “A few weeks after meeting, we each talked about how neither of us expected to live very long or even become middle aged,” Beau said. At the end of the first year, they decided to become monogamous and have since remained sexually active with one another.

Marty and Beau undertook an initial course of psychotherapy with “Frank Goldstein, LCSW” in the first year they defined themselves as a couple, and periodically they returned to counseling when a few sessions seemed to be useful. In 1998, they resumed therapy to deal with two issues, according to Marty:

> It was clear from the beginning of dating Beau that he was 99.9 percent a “bottom.” While I considered myself to be versatile, I always thought of myself as more of a bottom than a “top.” I remember thinking that I could temporarily be top for several years, but now I am faced with the possibility of an extended life with no possibility of being bottom again. Additionally, it has suddenly dawned on us that we have the potential to live to become old men. We have some serious planning and adjusting that we need to do as a couple if we don’t want to wind up as two poor old queens.

Beau then explained his concerns:

> About six months ago, when we passed the fifteen-year mark of our relationship, we decided it was time to come back in for a “relationship tune-up.” From the beginning of our work with you, you have helped us see what each of us is unable to get from one another. You have helped us accept that we can either give up wanting these particular things, accommodate ourselves to not getting them, or look elsewhere to have those needs satisfied. Previously, this was primarily about Marty’s need to be more social than I felt comfortable. Neither of us was really open to the possibility of not being monogamous, until recently. Also, so
much of our early work with you was learning to adjust as a couple to coping with all of the uncertainty that accompanied living with HIV. But we are now faced with a completely different health and emotional landscape that has left us thrilled, but also confused.

At the beginning of therapy, Marty and Beau focused on the sexual issue. What soon became apparent was that it was far easier for them to talk about sexual incompatibility than it was to look at their feelings about being middle-aged men, about growing older – both as individuals and as a couple – and about planning for a financially secure future. Each time Goldstein reminded them that these issues also were given as reasons for returning to therapy, one or both of them would steer the discussion back to the sexual arena of their relationship. Over the course of therapy, the couple decided to experiment with becoming non-monogamous. Several weeks later, Goldstein finally pointed out to them that whenever he attempted to get them to talk about their feelings about aging or financial planning, they somehow managed to bring the topic back to sex. Goldstein suggested that perhaps talking about sex and their differing sexual needs, while important, seemed to function as a defense against dealing with more difficult issues.

Marty and Beau were both stunned at this not so gentle confrontation, but soon acknowledged its accuracy. This opened up a path that allowed them to begin to share with each other and the therapist their fears about growing older, bodily changes that they were beginning to experience, and how to manage changing their lives in order to save money. They also took Goldstein’s suggestion to make an appointment with a financial planner.

**Clients with Children**

For clients with children, the prospect of extended life due to treatment success may exacerbate their emotional turmoil. “Three years ago I was not sure that I was going to live to see my son’s confirmation,” said Milagros, a 47-year-old HIV-positive woman. “Now I am thinking it is quite possible that I might see him graduate from high school. Who knows, perhaps I will even bounce a grandchild on my knee.”

For other parents, improved health may increase the potential for not dealing with custody planning and the possible need for future care of their children. Mildred Pinot, a staff attorney with the Legal Aid Society HIV/AIDS Representation Project in New York, explains:
"The best way to broach the subject of custody planning to HIV-positive parents is similar to that for any parent: all parents, regardless of medical status, should have a documented plan for their children's future in the event of the parent's illness or death." If clients themselves do not raise this issue, mental health professionals need to initiate conversations. Such a sensitive matter is best raised initially with the client alone, and then, depending on the particular family, it may be helpful to support the client by bringing the issue up during a family session. The family session can provide an opportunity for all concerned to express their feelings and fears, while balancing hope with the reality that HIV could take the life of the parent. In all cases where a parent has a potentially terminal illness, it is important for the parent's wishes to be known to the family before the parent's death.

It is understandable that parents may procrastinate in making these arrangements because it reminds them of their own mortality at a time when they are feeling more optimistic. Pinot correctly states that the difficulties many HIV-infected parents experience in implementing these plans involve fears of disclosing their HIV status to others and the possible resulting stigmatization, rejection, and isolation. Therapists need to be prepared to question the unwillingness of clients to discuss concrete plans for their children. It is helpful to stress to clients that by addressing these issues now, they can ensure that they will have a measure of control over what happens to their beloved children later. Because such a discussion has the potential to confront a client's denial, clinicians must be prepared to be the target of anger.

**Treatment Failure**

Between 10 percent and 30 percent of people who undertake the difficult course of new HIV medications either fail to respond or experience viral breakthrough as HIV reestablishes itself and health begins to decline. Others respond but cannot tolerate the various side effects commonly associated with antiviral therapies. Because the new treatments do not work for everyone, it is important for mental health workers to help clients modulate their expectations and hopes for a dramatic improvement in health. Many people who are doing well on combination therapy wonder if the benefits of these drugs are worth the side effects. According to Rick Sowadsky, Coordinator of the Nevada AIDS Hotline, "People suffer-
ing from severe side effects must ask themselves, ‘Which is more important . . . quantity of life or quality of life?’ Ultimately, this balance between quantity of life and quality of life is a very personal decision.” Therapists need to encourage such discussions without favoring one side or the other.

Some people who suffer from severe side effects stop taking their medications, either temporarily or permanently. They may skip a few doses, or stop taking their drugs altogether. A temporary lapse in dosing is commonly known as a “drug holiday,” and depending upon the circumstances and length, may sabotage treatment efficacy. The job of the clinician is first to elicit the feelings that caused the client to miss a dose(s) and those that arose as a result of missing the dose(s), and second, to encourage the client to discuss his or her actions with his or her primary care physician as soon as possible. If the client is feeling shame due to his or her actions, it is important to help him or her see that missing doses may represent an attempt to take control of how he or she is feeling in the short term – even if this results in long-term negative outcomes.

In an article subtitled “Feel Poisoned by Protease Inhibitors? Don’t Feel Alone,” Kevin Christopher proposed, “If protease inhibitors are extending your life but destroying the quality, there’s a larger question to ask: At what price survival?” He chronicled how, after a very brief period of benefitting from the new drugs, he became overwhelmed by the side effects and today is “no doubt sicker than I was before I began the new wonder drugs.” Kevin is not alone. Louis, who has not been able to tolerate antiviral medications, stated: “I don’t like to whine, but it is really difficult hearing all the good news and how these drugs have heralded the end of the plague. That has simply not been my experience. It’s very lonely not being able to talk to other people about what it’s like hearing all the good news and feeling totally left out. Even in my AIDS support group no one seems to understand how I feel.” Jeffrey Karaban, former Deputy Executive Director of Body Positive, observes, “A lot of old timers are feeling abandoned. They fear they’ll become lepers, written off by drug companies who can’t make a buck off of them.”

Mental health professionals need to be knowledgeable about side effects. They should ask clients about the side effects clients are experiencing, inquire how clients feel about their side effects, and encourage clients to discuss them with their physicians. Providing
clients with information, encouraging proactive interactions with medical providers, and, when necessary, advocating on the behalf of clients are all examples of interventions that must be considered in work with clients taking antiviral medications.

Former GMHC coordinator Mark Thomas says that when people do not respond to combination treatments, they often feel a sense of hopelessness and despair. He recommends that therapists remind clients who are not doing well on combination treatment that it is not they who have failed treatment; it is the treatment that has failed them. Helping “reframe” the perspective of clients in this way is important, but it may be complicated if a client has not adhered to treatment regimens. Thomas reports that when clients feel that it is they who have failed, this is often because they have not adhered to the required dosing schedule. Still, it is important for therapists to keep in mind that it is hard for anyone, even people fighting the flu with antibiotics, to be perfectly adherent. Clients may blame their treatment failure on even slight deviations from their regimen and may feel guilty or “beat themselves up” for every minor infraction, and this response may be counterproductive in instilling adherence over the long haul. In addition, counselors should be alert to clients who become so compulsive about following their drug-taking regimens that it seriously interferes with their emotional health. An alternative to Thomas’s reframe for clients who have not achieved viral loads below the level of detection might be for counselors to redefine such “treatment failure” as “progress but not perfection.”

The case of Christopher (a composite of actual cases using fictional names for both the client and therapist) provides an excellent example of someone who benefitted from this approach.

**Christopher: Redefining Treatment Failure**

“Christopher” is a 47-year-old, gay, White man with HIV. When he began therapy five years ago, he had just stopped working and gone on disability. He sought therapy to help him adjust to what at the time seemed to be a slow downward spiral toward death. Christopher entered one of the first clinical trials of combination therapy in New York and almost immediately began to experience a reduction in his symptoms. Despite physical improvement, for many months he remained depressed and discouraged because his viral load never decreased to below the level of detection. After a different drug com-
bination also failed to achieve an undetectable viral load, Christopher became despondent and was convinced that he was going to die. Christopher's therapist, "Shirley Jenkins, PhD," empathized with all of Christopher's feelings but chose to begin a process of cognitive restructuring after consulting with Christopher's doctor.

The physician told Jenkins that while Christopher's viral load was low but still detectable, his CD4+ cell count had risen to a normal level for the first time in years and all the rest of his blood work was also normal. Armed with this information, Jenkins began by asking Christopher what he remembered of his doctor's assessment of his physical health. Christopher accurately described what his physician had told him. The therapist asked Christopher if he trusted his doctor, even when the doctor's news was not good. Christopher replied that trust had been one of the strengths of their ten-year professional relationship.

After acknowledging Christopher's disappointment about his viral load, Jenkins expressed concern that Christopher was focusing only on this factor and not on his improved health: his Kaposi's sarcoma had gone into remission, his Cytomegalovirus was no longer progressing, he had put on weight and maintained the weight gain, he had more energy, and he was once again feeling vital and interested in sex. Jenkins challenged Christopher to think about redefining what constituted a treatment success: could he imagine success in terms of his health, not just his viral load? Christopher responded with anger. Jenkins managed to avoid becoming defensive as Christopher criticized her, and she encouraged Christopher to express all his anger and disappointment.

After a few weeks, Christopher said he realized that, because Jenkins was "real and tangible," it was easier to focus his anger, pain, and disappointment on her than it was to simply rage at this "fucking virus." As the two explored these feelings, Christopher slowly began to accept that his psychological and emotional equilibrium was dependent on redefining the meaning of treatment success and failure. "I would not now be feeling as healthy, vibrant, and hopeful if I had not been on combination therapy," Christopher said. "I guess I am not failing on these drugs after all."

**Responding to Failure and Shame**

When clients experience a sense of failure, shame, and stigma, they may isolate themselves from partners, family, and friends or
engage in self-destructive behaviors such as unsafe sex, substance use, or overspending. Recognizing that support groups might ease this isolation and address the unique set of concerns faced by people who do not respond well to combination treatment, GMHC set out to offer support groups specifically for this population. It is important to note that while until now, generic support groups for seropositive clients have been effective in handling the range of issues clients face, it may be less useful today to mix clients who are successful in treatment with those for whom treatment is not working. People not responding well may feel awkward sharing their concerns, while those who are doing well may feel bad about discussing their improved health in a group of this composition.

But, despite the fact that the GMHC support group was structured in this way, Mark Thomas reported, after a year of extensive advertisement, only a few clients registered. He said, "I think that people are uncomfortable about not being on the optimistic bandwagon, and feel further stigmatized for not benefitting from these treatments. It is as if they are a minority within the already stigmatized minority of people with HIV and AIDS, and are reluctant to come for support around these issues." 66 Scott, a man living with HIV disease for eight years, recently said in a public forum, "I don’t want to spoil the party for everyone else." 75

According to Avi Rose, "For those who are having problems with the new medications, due to viral resistance or to troubling side effects, it is difficult not to succumb to panic and despair." 60 Rose puts these reactions within a historical perspective. "It is not new for groups of HIV-positive people to experience wide disparities of success with various treatment options, often for no apparent reason. However, now the stakes of success or failure seem higher than ever, so the attendant feelings of inadequacy, shame, or despondency sometimes run deeper." Rose also sounds an important cautionary note when he says, "Special attention must be directed to not abandoning those who are not currently doing well, who may easily evoke feelings of powerlessness and impotence, which are disturbing to care providers and communities." 60 Mental health professionals working with this population must monitor their desires to avoid hearing clients share their difficult and painful feelings about not benefitting from the new drug regimens.
Abraham: Transcending Failure

"Abraham" is a 55-year-old, African American, gay man who is a judge in Manhattan. He is single and has never had a long-term relationship. He began therapy five years after learning that he had HIV, but before effective combination treatment became readily available. Initially, he was reluctant to begin taking antiviral drugs, despite his constantly dropping CD4+ cell count and a variety of minor HIV-related symptoms.

Abraham has suffered through a long history of depression and isolation, using work and – prior to that – studying and excelling in school as primary defenses. Only after joining a gay men's therapy group, where he met other people who were benefitting from antidepressants, did he agree to try antidepressants himself and experience relief from his life-long depression. Abraham also began to tentatively explore social relationships with a couple of the men from the group. He met one seropositive man who was successful in battling HIV with combination treatments, and he finally complied with his doctor's advice to begin treatment himself.

From the first day of taking the medications, Abraham was plagued by almost every possible side effect. This caught him off guard. Over six months, he changed combinations three times. He spent a lot of time in both his individual and group therapy sessions expressing his anger about how the drugs were affecting him and trying to develop strategies to manage the side effects. When he felt overwhelmed by the side effects, he was coached to call his doctor and discuss this with him, something he was often reluctant to do because he did not want to be perceived as a whiner or a "wimp." Therapy helped him reframe seeking help as an act of self-empowerment, an embracing of adult responsibility for his own well-being. Initially, Abraham had a great deal of difficulty even admitting his anger about his course of treatment; only after he heard other men in the group express their own anger at HIV for all their losses did he begin to tentatively experiment with this emotion.

Abraham's third drug combination proved to have the fewest and most tolerable side effects, but his viral load never significantly declined. Two additional combinations also failed. He complained of feeling responsible for this: "If only I had not been stubborn and agreed to go on medication sooner, perhaps I would not now be in
this position.” He was also enraged that “the protease miracle is not helping me. I really feel that this parade is passing me by.” His depression got worse, and he increased his antidepressant dosage.

When Abraham was diagnosed with an HIV-related lymphoma – his first AIDS-defining illness – he felt even more hopeless and helpless. He was greatly touched that the group members visited him during his illness and urged him to participate in group sessions by telephone. His individual therapy began to focus on life review and end of life issues.

**Conclusion**

The complexity of HIV medical treatment is matched by the complexity of the psychosocial response to it. Even the ideal treatment scenario – plummeting viral load, no significant side effects, improved health, and an optimistic outlook – may be accompanied by uncertainty, even fear, and the sense that life is still threatened. Improved health also brings with it decisions about the future that are often difficult for any person. Unimproved health, of course, leaves a person burdened with the physical challenges of active HIV disease and the psychological devastation of failure, abandonment, and isolation. Clarity about this spectrum of response is important and facilitates the work of the mental health provider.
Responding to Treatment-Related Psychosocial Issues

Just last week I told my doctor that after four years on combination therapy and four years of undetectable viral loads, I am beginning to grow confident that I will not die from AIDS. What concerns me now is that nobody can predict what the long-term effects of taking these drugs will be on the various organ systems of my body. His response to me was: “I wish I could tell you not to worry about that, but in all honesty I can not.”

— Michael

A broad range of approaches is available to mental health professionals seeking to assist their seropositive clients in responding to issues raised by medical treatment. Indeed, while psychological interventions for clients with HIV disease are well-established, there remains no single, research-based standard of therapeutic care. This chapter reviews the mental health concerns raised by the new treatments, particularly in terms of uncertainty, and the available modes of intervention.
Coping with Uncertainty

Many people who benefit from combination therapy feel uncertain about whether or not improvements will hold up over time. This uncertainty is not ill-founded — the long-term effectiveness of combination therapy has not been established — and creates a potent anxiety. Uncertainty enters into every aspect of emotional and psychological response to HIV treatment — from treatment decision making to adherence to treatment success and failure. It is crucial, therefore, to focus clinical attention on this issue.

The Relationship between Uncertainty and Long-Term Survival

Columbia University researchers Robert Remien and Glenn Wagner developed a model for counseling long-term survivors prior to the advent of combination therapy, and this work takes on increased significance in the new world of HIV treatment. They write that one challenge facing long-term survivors is coping with the uncertainty of future health, which makes it difficult to make plans. They also suggest that clinicians be alert to several other issues in this population: responding to grief and multiple loss; accessing support networks; managing romantic relationships; handling the relationship with a primary physician; navigating treatment options; attending to progressive symptoms; and confronting career matters. All of these issues remain relevant for the client who is responding well to combination therapy. Remien and Wagner go on to list the corresponding therapeutic tasks: validating emotional reactions; focusing on short-term goals; facilitating feelings of empowerment; helping clients obtain concrete services; assessing psychiatric risk and suicidal ideation; promoting adaptive coping strategies; fostering family communication and cooperation; and talking about the meaning of death and dying.

Time, both in quantity and quality, becomes a precious commodity and a powerful variable when discussing HIV infection, and it provides fertile areas for psychotherapeutic exploration. For some people, the prospect of unanticipated survival may lead to a period of difficult readjustment, with some patients feeling “overwhelmed, depressed and even suicidal.” Remien and Wagner note, “To carry on, clients may need help in finding new meanings in their lives. Sources of pleasure and satisfaction need to be reexamined so that goals become focused on obtaining the most out of the present,”
while at the same time planning realistically for an uncertain but likely future. John, the art historian described in the previous chapter, is an example of a client who requires this focus in his psychotherapy.

Studies demonstrate that an active behavioral approach to coping with HIV illness is associated with a decrease in psychological distress related to HIV infection. Remien and Wagner state, “Some use of denial as a coping strategy can be beneficial to patients with HIV infection as long as it does not prevent the individual from seeking needed medical care.” Therapists increasingly believe that it is inappropriate to confront “supportive denial” as long as it does not put the client in any medically compromised or dangerous situation. “Counselors can address this issue in a supportive manner by talking about the desire to ‘forget it’ or ‘not think about it’ for a while, while helping patients confront the reality of their disease in very concrete, practical terms.” Action-oriented problem-solving strategies, characteristic of a fighting spirit, are more consistently associated with positive outcomes than are avoidance strategies – as long as there are aspects of the disease that are within the person’s direct control. Remien and Wagner suggest that, “Counselors can assist HIV-infected patients in developing multiple coping strategies and learning how to apply them differentially to various situations that arise during the course of the disease.”

**Bending the Frame**

Thomas Eversole, Training Director of the American Psychological Association’s Office on AIDS, states that traditional psychotherapy roles are delineated by what are called “frames” of practice, dictated largely by the theory that guides the clinician’s work. He suggests that when working with people with HIV, it is often helpful to “bend the frame,” that is, as necessity demands, go beyond the ordinary limits and established boundaries of therapeutic practice. He feels that in order to practice in this manner, clinicians need to undertake two tasks. First, they need to develop a large repertoire of skills and resources with which to serve clients, encompassing advocacy, case management, and existential psychotherapy. This refers back to the concept presented earlier in this monograph about the counselor’s need to become skilled in using a mixture of traditional psychotherapy and counseling approaches to work with clients on combination therapies.
Second, they need to make deliberate, ethical, and theoretically sound selections of therapeutic responses to client needs. Bending the frame brings with it responsibilities for professionals to reexamine the legal and ethical aspects of their work, their real and therapeutic relationships, and the sources of personal authority from which they practice. This concept reinforces the need for counselors working with HIV-infected clients to have ongoing supervision, whether it be consultation with a more highly skilled professional clinician or with a peer.

Clients whose health has rebounded may also need to mourn the loss of their identity as being ill and disabled. Matthew Ignoфф discusses taking a “reality therapy” approach to “quality living when there is no cure.” He states, “AIDS clients, just like any other client, need to feel that they have regained control over their lives. In addition, they need to feel that they still belong to the world of the living. Furthermore, they need to look forward to being able to manage the rest of their lives as well as to face their eventual deaths with a sense of both responsibility and serenity. Ultimately, they need to understand that AIDS and death are not the uncontrollable terrors which they seem to be.” For some people grappling with these aspects of quality living, spiritual issues such as the meaning of life and death and the possibility of an afterlife come to the forefront.

Balancing Hope and Uncertainty

Avi Rose states that people with HIV disease who are fortunate enough to be doing very well “face a complex set of issues in going about the profound task of reconstructing the future and balancing the issues of hope, uncertainty, meaning, and survival.” He continues by noting some of the large questions that remain for all people living with HIV, even those now doing well:

- How long will the new treatments remain effective?
- Will my strain of the virus become resistant to my treatment?
- What are the short-term and long-term side effects of these new drugs, and what side-effects might develop over time?
- Will the next wave of treatment alternatives arrive in time for me to benefit from them?
- If these new treatments do arrive, will they be made available to everyone who needs them?
• What happens if I make major life changes based on how I am currently feeling, get sick again, and feel more vulnerable, physically, emotionally, and financially, than I ever did before?

Rose wisely reminds us that people with HIV do not necessarily expect answers to these questions, but they need to ask, and they deserve acknowledgment and empathy for the related feelings, which include fear, skepticism, anger, and weariness. He urges mental health professionals to "at least acknowledge the unanswerable questions, to not fend them off out of our own discomfort and to understand and reflect back to the patient how frightening it must be for neither of them to have the answers."60

It is useful for the clinician to ask clients how the uncertainty is affecting them. Rose notes that an exploration of the issues surrounding the uncertainties for people on combination therapy "brings up the issue of control, which tends to be surrounded by myths and illusions."60 Rose is referring to the myths and illusions that enable most people to believe they have control over more areas of their lives than in fact anyone can. Harvard University psychologist Steven Schwartzberg discusses this concept in detail, providing practical advice for therapists to help clients address their attitudes about the role control plays. He notes first that most people have "an illusory and exaggerated sense of control" that needs to be relinquished in order to maximize adaptive coping to life crises. He then suggests that therapists need to help clients learn to distinguish between what can be controlled within the constraints of environment, health, and economic circumstances (for example, current and future life decisions, health care choices, and personal goals) and what cannot be controlled (for example, being infected with HIV, the past, other people’s behaviors, and who your parents and siblings are). Further, Schwartzberg suggests that it is often therapeutically useful to examine the cultural meanings of control, a goal that some people pursue unrealistically, and others abandon out of a sense of despair or defeat.62

According to Rose, in the process of assisting people with the range of issues related to uncertainty, care providers need to be scrupulously honest about what they do and do not know.60 "For some, that means dealing with their own discomfort with uncertainty, the desire for control, and feeling responsible to ‘fix’ things far beyond our control. When providers don’t pretend to have the answers to
unanswerable questions, they need to be prepared to deal with people’s anger in reaction to it, trusting that ultimately clients are more reassured by honesty than by pretense, which maintains the integrity of care providers as well.” Rose also urges clinicians to remember that it can be helpful to provide the opportunity for clients to rail at the cosmic unfairness of “living in a world where so much cannot be known or controlled. Ironically, in coming to terms with uncertainty and lack of control, people usually end up feeling more empowered.”

One central focus of psychotherapy for clients on combination therapy is balancing hope for continued health with the fear of potential antiviral failure. As Rose states, “The work of therapy focuses on creating psychic space for ambiguity and uncertainty, hope and apprehension together. Supporting hope makes intuitive sense, but supporting apprehension is a less obvious beneficial goal. Given uncertainty about the long-term outcomes of combination treatments, holding apprehension as well as hope strengthens a client’s ability to tolerate reality, a critical skill when reality becomes harsh or uncertain. Keeping each of these aspects alive, without collapsing into either polarized state, comprises the delicate psychic balancing act of therapy.”

Developing an Eclectic Clinical Approach

While the most important treatment-related interventions may regard balancing hope and uncertainty, there are other approaches that are useful to consider. Among these are: crisis intervention; dealing with denial; prioritizing goals; anger and frustration management; and balancing quantity and quality of life. In addition, it is crucial to recognize the role of more eclectic approaches that may be more directive than traditional psychotherapy.

Crisis Intervention

Many of the initial interventions for clients with HIV – for example, antibody test counseling – incorporate traditional crisis intervention approaches. But crisis intervention is also useful during the course of ongoing clinical work with HIV-infected clients, that is, at various critical moments in the course of the disease, including the onset of an opportunistic infection; during different levels of physical deterioration or debilitation; and when coping with the numerous losses of people and things, such as a job, a sense of a future,
and hopes and dreams. Crisis intervention also has a useful application for clients on combination therapy – in response to treatment failure or overwhelming by side effects.

**Dealing with Denial**

Another important aspect of counseling people living with HIV is to help them realistically balance hope without supporting maladaptive denial. An example of maladaptive denial is if a client refuses to begin treatment for a condition that is easily treated but is very serious and perhaps even fatal if left untreated. Part of the counseling process is to help clients reframe living with HIV from a death sentence into learning how to live with a chronic, yet sometimes manageable, life-threatening illness.

**Prioritizing Goals**

Helping clients prioritize their short- and long-term life goals has been and remains an important aspect of counseling people with HIV. For many gay men with HIV, having a sexually transmitted disease such as HIV may reactivate or reinforce internalized homophobia. Prior to the onset of combination treatment, therapy included a component of helping HIV-infected clients prepare for death. While this is not required as frequently now, when people fail on combination therapy, this is still a valuable and essential component of mental health treatment.

**Anger and Frustration Management**

One dynamic that has been operative throughout the course of the epidemic and remains so is the goal of helping clients manage their anger and frustration. Therapists working with this issue face a difficult task: while encouraging clients to express their fears, providers must ensure that clients do not become overwhelmed by focusing entirely on the “what if’s” of drug failure. Therapists may also remind clients that while it is appropriate to hope and desire treatment benefits to last over time, there is value in appreciating improvement regardless of its duration. Many clients who have shown improvement experience the paradox of dealing with issues they thought they would never again face – issues related to work, feeling better, socializing, and even dating – all of which can be experienced as stressors that precipitate anxiety or depression. Work with people anticipating
or undergoing combination therapy requires providers to address early on issues of access, adherence, side effects, and maintenance.

**Balancing Quantity and Quality of Life**

It is often useful for the therapist to contextualize the client's struggles in regard to quality of life issues and the resulting treatment decisions. This may be accomplished by reminding clients that there are no hard and fast answers to the questions with which they are struggling, because treatment guidelines are changing very rapidly, and opinions about when to change treatment vary from one HIV expert to another. In addition, people with any chronic and life-threatening illness wrestle with these same issues of quantity of life versus quality of life. People with cancer, for example, often struggle with these issues as they pertain to the side effects of chemotherapy, radiation therapy, and surgery.60

**Applying Eclectic Approaches**

A number of authors have written about the need to move beyond the traditional realms of psychotherapy when working with HIV-infected clients.79-82 They suggest that traditional psychoanalysis and other means of therapy that focus only on the intrapsychic process, transference, and countertransference issues are of only limited usefulness in counseling people with HIV. More eclectic therapeutic approaches seem to be especially relevant when working with clients who are on combination therapies. Examples of these kinds of interventions include:

- Being directive at times, for instance urging a client to call his or her doctor and report side effects;
- Bringing mental health services into client's homes when clients are too ill to continue therapy at the office;
- Touching patients in a therapeutic way, for example, when a supportive hug can be encouraging and nurturing, and can communicate a deeper level of caring;
- Disclosing the therapist's serostatus if by doing so the therapist can use his or her own experience to further communicate an increased level of empathy for the client's struggle.

To be effective in providing mental health services to clients with HIV disease and those on combination therapy, it is necessary to dif-
ferentiate between when it is appropriate to provide "counseling" versus "psychotherapy." Counseling refers to a professional process specifically geared towards crisis intervention, problem solving, and the solution-focused, symptom-reduction model of brief treatment; it can certainly be a component of long-term, ongoing psychotherapy. Counseling in this context may encompass the skills involved in traditional social work, including active problem solving, prioritizing multiple problems, responding to multiple stressors, actively referring clients to appropriate resources, and managing crises. The case studies (composites of actual cases using fictional names for both client and therapist) that follow provide a detailed view of this approach.

**Kesha: Case Management Increases Social and Practical Support**

"Kesha," a 30-year-old, HIV-infected, African American woman in recovery, began consulting "John Harlan, LCSW," a hospital social worker, when her daughter, "Rosa," was also diagnosed as HIV-positive. As a case manager, Harlan provided Kesha with referrals to various services and entitlement programs. Harlan was able to establish a good relationship with Kesha by being flexible when she did not make it to their scheduled appointments; rather than trying to set limits with her, Harlan empathized with the difficulties Kesha must face as she tried to accomplish everything she needed to do while caring for her ill child. Clinically, this accomplished two things. First, it helped engage Kesha by not judging or pathologizing her for not being able to keep regularly scheduled appointments. Second, it illustrated Harlan's ability to bend the frame by finding other times to meet with her.

As both Kesha's and Rosa's health deteriorated, Harlan began to see Kesha twice a week and referred her to a support group he was running in the hospital for seropositive women. When Kesha's physician suggested that she begin combination therapy, she was very confused and discussed this with Harlan. Harlan gave Kesha a variety of educational materials to read and told her to bring all her questions and feelings to both their individual and group sessions. It took Kesha six weeks to decide that she was going to follow her physician's suggestion and begin taking antiviral drugs. "I don't feel that there is any other option for me, since in addition to my sick baby, I have two other young children who totally depend on me," she told Harlan. Harlan encouraged her to ask the other women in the group...
about their experiences taking antiviral medications and for suggestions about maintaining adherence. These discussions provided Kesha with the confidence in her decision and hope for the future. Kesha also got a lot of practical advice from the other women about managing side effects and sustaining the regimen, which helped her feel optimistic about being able to handle these situations.

The women in the group also encouraged Kesha to share with her mother the fact that she was HIV-infected. One of the other women in the group, “Sally,” attended the same church as Kesha and Kesha’s mother, and told Kesha that the pastor was very kind, understanding, and helpful. He had even preached a sermon on the need for the community to reach out to help people living with HIV.

After hearing this information, Harlan suggested that Kesha consider disclosing her infection to her mother and prepare for this possibility by meeting with her pastor and asking for his advice. The pastor was welcoming and understanding and even offered to be present at the meeting during which Kesha disclosed her infection to her mother. Kesha accepted this offer and used a "spontaneous" home visit from the pastor as the occasion to tell her mother, “Lorraine.” Lorraine was terribly upset at the news. The pastor offered to connect Lorraine with other women in their church who had adult children with HIV, women who had come together to form an informal support system for themselves. Kesha thanked Harlan for having suggested she talk with her pastor, and said that she trusted him more because he seemed to understand how important the church was to Lorraine and her.

Kesha had severe side effects from the protease inhibitor she began taking and had to be briefly hospitalized. During the hospitalization, Harlan raised the issue of planning for the future of Kesha’s children. Harlan suggested that Kesha discuss options for possible guardianship of her children with her pastor, who visited her regularly at the hospital. The pastor shared with Kesha that Lorraine had broached this same issue with him, but she had been reluctant to talk about it with Kesha. The pastor also told Kesha that her mother was ready and willing to be the guardian of Kesha’s children if the need ever arose. This made it easy for Kesha to raise the topic with her mother. Once Kesha told Harlan that she and her mother had talked about the custody issue, Harlan asked them if he could have an attorney from Legal Aid Society come to the hospital to begin drawing up the documents. Kesha agreed.
After beginning a different combination of drugs, which she tolerated and to which she responded, Kesha’s health improved dramatically, and she was discharged from the hospital. Harlan continued to use multiple mental health and case management interventions, approaches, and modalities in his work with Kesha. This exemplified the effectiveness of integrating interpersonal, intrapsychic, family, and systemic interventions to meet the varied needs of people with HIV.

**Patrick: Adjusting to Limitations**

“Patrick” is a 35-year-old, gay, White man who entered therapy because he had received a warning at work—a hospital where he was a paramedic—about his repeated absences on Mondays. These absences were due to his regular use of large quantities of “recreational drugs” each weekend. During an initial consultation, Patrick told his therapist, “Steve Romano, PhD,” that he often engaged in unprotected sex while using ecstasy, ketamine, and crystal methamphetamine. He had been partying like this for many years and had never been tested for HIV. During most of this time, Patrick had refused to acknowledge that his drug use was negatively interfering with his life, but the real possibility of losing his job and placing his career in jeopardy finally broke through his denial. Romano decided that the first priority of treatment was to work on Patrick’s drug use. At his urging, Patrick began to attend gay Alcoholics Anonymous (AA) meetings—but Patrick also continued to use drugs.

Initially, sessions focused primarily on drug counseling with a harm reduction approach. Although Patrick did not express a desire to stop using drugs, he wanted to learn how to control his usage so that it would not be as self-destructive as it had been. Only when one of his best friends died from a drug overdose did he become frightened enough to admit that he had never been able to adhere to his self-imposed limits. He entered a substance abuse treatment program but began to struggle with remaining drug-free. He decided to take the HIV test and learned that he was infected. Further testing confirmed that he had an extremely high viral load and a very low CD4+ count. This news reinforced Patrick’s feelings that if he continued to use drugs, he would die. His physician started him on a triple combination therapy, and Patrick and Romano began to address Patrick’s feelings about learning that he was infected.
Patrick expressed a lot of shame about having become infected: he was a health care provider and he knew well the importance of safer sex. During therapy, he explored to whom and when he would disclose his HIV status, as well as various strategies to help him adhere to his medication regimen. Patrick also described feeling depressed, and Romano suspected that Patrick's drug use was an attempt to self-medicate. Yet Patrick remained reluctant to begin antidepressants, because he was already having difficulty taking both his antiviral drugs and prophylactic medications for opportunistic infections. Patrick discontinued his drug use, but only by going to two and sometimes three AA meetings a day.

A few months later, Patrick uncharacteristically arrived a day late for an appointment with Romano. The therapist was free and saw Patrick, who was genuinely upset and confused about having gotten the day wrong. He discussed finding himself confused more often and forgetting things; he was frightened that he might endanger his patients. During this session, Patrick admitted that he had never been able to take his medications three times a day; additionally, he had been so debilitated by the side effects that he just stopped taking the medications three months ago and had not been to his doctor since. Patrick was afraid to tell his doctor that he was unable to tolerate the drugs and that he had not been adherent. Romano explained that many people were not able to tolerate the side effects and that this was an important thing to share with his physician. Upon exploration, Romano learned that Patrick could manage to take his drugs twice, but not three times, a day. Finally, since Patrick complained of memory problems, Romano wondered if this might be due to HIV infection of the brain. After hearing this, Patrick was frightened but also relieved to learn that there might be an organic component to his growing disorientation and that he was not “just going crazy.”

Having obtained Patrick's permission to do so, Romano telephoned Patrick's physician to express his concerns about Patrick's mental status. In addition, Romano suggested that the physician might consider whether Patrick should take a temporary medical leave of absence from work. Finally, Romano shared with the physician Patrick's concerns about his adherence problems.

Patrick stopped working and began to focus on his medications. As he adhered to his new antiviral regimen, his depression diminished, his confusion decreased, and his short-term memory improved.
Three months after achieving a viral load below the level of detection, Patrick remained drug-free and felt well enough to return to work.

Conclusion

The successful use of combination therapy to reduce HIV disease progression has resulted in significant changes for people living with HIV, their providers, and, perhaps to a lesser extent, people at risk for infection. The news is generally favorable, yet with change comes new challenges. Mental health providers play an important role in helping clients manage some of these issues.

Unanswered Questions

The future remains filled with unanswerable questions for people on combination therapy. How long will the drugs continue to be effective? What are the long-term side effects of these drugs? Is it possible to sustain these complex regimens over long periods of time? As people on combination therapy live longer and develop medical conditions related to aging, how will approaches for these conditions affect their HIV-related treatment? How effectively will people with renewed health as a result of combination therapy be able to adjust to resuming work? How will they adjust to new roles and relationships, and to the prospect of living longer than they had expected?

People with HIV who are lucky enough to have the money, education, and time to become sophisticated about treatment options may now have a shot at surviving AIDS. Tragically, however, a growing number of people with HIV do not have the money, education, or even the time to become as informed as they must be to survive. Health care professionals must work both with clients and within the larger system of HIV care to advocate for access to treatments for every person with HIV who wants them. In addition, clinicians need to remain knowledgeable about new treatment information as it becomes available. Mental health professionals need to merge the traditional roles of psychotherapy with counseling and social case work to assist clients in maintaining social supports as they adjust to new medications, renewed health, life-long adherence to treatment regimens, and the possibility that medications may have limited efficacy. These same integrated mental health skills are also necessary to help clients who either cannot tolerate the new treatments or for whom the treatments have not been successful.
While it is impossible to predict the future, some speculations about what might be in store for people with HIV may be useful in helping to prepare mental health providers. For example, physicians are already seeing people on combination therapy whose viral loads have risen from below levels of detection, although their immune systems and general health remain good. While relatively low levels of virus (1,000 to 4,000 parts per milliliter) were at first thought to possibly indicate treatment failure because they were still "detectable," researchers now posit that persistent low levels of virus may be sustainable and safe. But this theory remains unproven. The hardest question is: are we heading for the biggest disappointment we have experienced regarding HIV treatment? Will large numbers of people with HIV begin to fail on new treatment regimens? Or are we moving towards the grandest success: the eradication of HIV from an infected person's body?

The Struggle Continues

With many people erroneously believing that HIV is now an easily treated chronic disease, there has been a "normalization" of living with HIV, an effect that may result in an increase in the numbers of people engaging in high-risk sexual or substance-using behaviors that could cause a dramatic increase in new infections. This possibility looms even as community-based AIDS service organizations have reported increased difficulty in raising funds for ongoing programs and services. But the AIDS epidemic is not over, and although combination treatment has become a powerful weapon, it has not ushered in the "twilight of the epidemic." In fact, current treatments have not even come close to solving many of the problems routinely experienced by people living with HIV disease.

Mental health providers have the opportunity to help their clients acknowledge both the hope and the doubt involved in living with HIV—even in the context of successful treatment. Speaking up and contradicting the shame that accompanies silence is the surest way to recognize and confront uncertainty and ambiguity. Mental health professionals have many important roles to play in the new era of HIV treatment, not the least of which is helping clients understand and give voice to all of the feelings they experience in this phase of living with HIV disease.
References


HIVlnSite: Gateway to AIDS Knowledge: A comprehensive site run by the UCSF Center for AIDS Prevention Studies that covers medical, prevention, and social aspects of the epidemic, as well as community and research resources; http://HIVlnSite.ucsf.edu

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