Afterword: New Treatments, New Hopes, and New Uncertainties

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In 1996 something extraordinary occurred in the clinical care of persons with HIV/AIDS, which had stagnated after years of only moderate biomedical gains through the use of zidovudine (ZDV, AZT, Retrovir) and many disappointing clinical trials: The testing and licensing of new kinds of antiretroviral drugs, and the use of new combinations of drugs, began to suggest that improved and longer lives were possible, and there were hints that sometime in the near future the virus could be eradicated.

It seemed that everyone knew someone whose life had been renewed by use of a newly licensed drug or a combination of drugs that included newly licensed antiretrovirals. Newspapers were reporting miraculous recoveries from debilitation caused by HIV/AIDS. Some persons with AIDS, using new combination therapies, gained weight, found new energy and improved health, and decided to go back to work after months or years of disability. Vatical services, which paid AIDS patients for their life insurance policies on the bet that they would die relatively soon, had to rethink their positions.

A new mood was everywhere. A Bronx physician, who works with HIV-positive patients in a methadone program, reported that people who had shunned zidovudine were intrigued by the combination therapies,
and that medical providers were enthusiastic about the new drugs after years of prescribing zidovudine.

Yet virtually all knowledgeable persons modulated their hopes and expressed skepticism or plain reluctance to become disappointed again. Very close to the surface of the optimistic reports is a very complicated reality, freighted with remarkable psychosocial and spiritual considerations that will comprise a large component of mental health care for persons affected by HIV/AIDS in the next decade.

"I'm very skeptical about the new class of drugs. Perhaps this is a defense mechanism so I don't get disappointed," said one HIV-positive man, an advocate for improved HIV/AIDS care. When interviewed, he was taking a protease inhibitor and reported moderate side effects. He told me, "Even if I get better in the next three years, the protease inhibitor is not a cure. I'm not thinking about my retirement plans or the house I'll be buying when I'm sixty. For me the psychological aspect of all this is a balance between my knowledge, fears, and hopes. Others less knowledgeable than me may grab onto the headlines. Their sense of hope is based on a lot of advertising."

This man expressed the disconcerting uncertainty that most felt in reaction to the new drugs. From the beginning of the HIV/AIDS epidemic, many would seek to move from uncertainty to a psychological state of knowing, typically saying something like this: "I am glad now that I have been diagnosed with AIDS; the other shoe has fallen. Now I know what to expect." Later in the epidemic, "knowing" was too often expressed by way of quoting group statistics: \( x \) percentage number of infected people will have symptoms by year \( a \); \( y \) percentage will be dead by year \( b \). Those group-based numbers, which did not pertain to any specific individual, seemed to offer certainty.

Psychologically, the new therapies return persons affected by HIV/AIDS to uncertain times. The new therapies, rushed to market after limited testing, offer great uncertainties in exchange for the hope: It is unclear whether side effects will force discontinuation. It is unknown how long positive effects will last; prospects of continued improvement can be shattered overnight with side effects, dropoffs in efficacy, and unforeseen consequences. Clients may embrace the new therapies, but always echoing in the psyche is the question, "Who knows?"

Other psychosocial repercussions of the new therapies are noteworthy:

- Will everyone have access to these therapies, or will some people be excluded? The cost of a year's therapy in mid-1996 was esti-
mated to range from $15,000 to $20,000. Will pharmaceutical companies reduce prices? Will insurance companies and other payors, such as Medicaid, decide not to pay, leaving these drugs only to the wealthy and those in clinical trials?

- The new regimens have rules that are difficult to follow. Combination therapies require many pills to be taken on a very strict schedule, and some with meals and some between meals. Scientists are concerned that poor adherence to regimens may increase the possibilities of viral mutations, leading to drug-resistant strains of HIV, as occurred with tuberculosis.

- Will some classes of individuals be automatically excluded because of problems following drug protocols? The author of an op-ed piece in the New York Times has suggested that the risk of creating drug-resistant mutated strains of HIV may justify withholding these drugs from “those who have demonstrated an inability to take medications consistently” (G. Rotello, The risk in a “cure” for AIDS, July 14, 1996, sec. 4, 17). If persons are excluded from available therapies, they are likely to be the powerless and those already oppressed and deprived of too many resources. As one physician said, “If that happens, they have every right to be pissed.”

- These drugs have side effects. What will be the psychological response of someone who has to stop these medications because of side effects?

- The long-term effects of these treatments are still unknown.

Some point out social repercussions: That the new combination treatments may lull society into thinking that HIV/AIDS has been adequately addressed, thus eliminating funding for alternative strategies. As dangerous may be the belief by some HIV-positive persons treated with the new therapies that their HIV has disappeared and they can return to unsafe sexual practices.

**Professional Practice in the Next Decade**

Each of these issues, and many more, will be in the hearts and on the minds of HIV-affected clients who seek mental health care, including psychotherapy, in the years ahead. The advent of these therapies and the psychosocial and spiritual implications underline the need to be not only compassionate but competent, utilizing the techniques and adapting mod-
models of care described in this book: Conceptualizing HIV/AIDS using a biopsychosocial model; becoming knowledgeable about the medical aspects of care; employing a “bending the frame” style of care that combines psychotherapy with other aspects of needed care, including support of adherence to the new therapies; attention to clients’ spiritual aspects; applying new models of care that respond to clients’ needs, and competently evaluating those models and clinical practices to determine what works and why.

Practitioners will need to keep current with the pace of new scientific developments. One practical tool for maintaining knowledge is the website of the National AIDS Clearinghouse. With a computer, modem, and web access, it can be reached by typing http://www.cdcnac.org. This bulletin board has links to many sources of information, and one can search several databases using its gopher. (See also Appendix B.)

Tools for Clinical Practice

Skillful providers will respond to the new therapies by considering the following:

- As with all aspects of HIV/AIDS care, the skillful practitioner should know his or her opinions and feelings related to the psychosocial aspects of the new therapies — feelings regarding quality versus quantity of life, hope versus skepticism, among other aspects — but will refrain from influencing the client.

One example may indicate how a client may be injured by a therapist’s attitudes. Let’s say that the therapist is a believer that life should have quality rather than quantity, and that the therapist is fairly clear what quality entails. The client facing this therapist is unfamiliar with quality of life as the therapist conceptualizes it. The client may want to live long simply because that is a tenet of his or her religion. The client may want to live, in the hope of a cure, despite being a chronic drug user. The client may want to live to see children grow older, even if his or her existence seems marginal. If the therapist were to engage in a debate over the client’s quality of life, or suggest in some subtle way that the client’s life is subpar, it could be experienced — accurately — as an attack. The reverse may also be true: A client’s life may appear to the therapist to have quality, but may seem poor to the client.
The skillful therapist knows that attitudes and opinions about issues such as quality of life are personally and idiosyncratically derived, and that therapy is not about foisting one's opinions onto clients.

- *The client may need help with his or her cost-benefit analysis. The therapist should ensure that psychosocial/spiritual variables are included.*

Everyone makes a cost/benefit analysis, or tries to sidestep one. The therapist's delicate task is to assist the client in weighing all of his or her unique variables, and not to tilt the scales unfairly.

In response to headlines and marketing, clients may want to rush, unthinking, into use of new therapies. Or, alternatively, some may say they can't make a decision, which is a decision, of sorts, in itself. If the new therapies are available to a particular client, the therapist should raise the issue if it doesn't surface. Then, therapeutic tasks may include:

- Exploration of taking a new therapy in the context of the larger question of the client's philosophy regarding quality of life versus quantity of life. This can lead to very rich discussion. It surely is appropriate for the therapist to ask such thought-provoking questions as, "What do you value, above all things?" or "With your partner dead, you seemed not to have much motivation to continue living. Does that influence your decision to bypass the new therapy?"

- Discussion regarding the client's attitudes specific to the new therapies. Is the client suspicious, as many were regarding AZT? What are the client's motivations regarding participation or nonparticipation? Does the client really want to take these medications or is he or she responding to external pressures? What are those pressures?

- Does the client have accurate information upon which to base a decision?

- Is the decision affected or delayed by a mood disorder or continuing substance abuse that requires attention?

- Is the client sufficiently motivated for a difficult protocol? Can the client enlist support from family, friends, and others in maintaining motivation?

- Can the therapist, or the agency, create support groups or other activities to assist clients with difficult drug regimens?
— What is the client's spiritual interpretation of the availability of the new treatments? Is the availability of the new therapy seen as a new opportunity for spiritual work?

• The therapist must help the client balance hope and new uncertainties created by the new therapies.

The new therapies offer hope, which may be perceived by some as a day at a time and by others as two or three years of renewed life. But many clients mix skepticism with their hopes. This balancing act is stressful. One admits that control is relinquished to factors unknown. One takes a leap into the unknown. Psychotherapy can provide great assistance in this process, providing a medium for discussing and creating the balance, and supporting the client when the emotional balance is upset.

This assistance with balance should also extend to a client's family and friends. They too are balancing, and their feelings are shifting. A therapist tells the story of a mother who readied her children for her death, but then began a new drug and improved markedly.

• Mental health practitioners should assist clients who choose these therapies to adhere to their complicated drug treatment protocols.

Patients find it difficult to retain complicated information. Many clients will need assistance to understand their complicated therapies and to adhere to the protocols. Medical practitioners are finding that it is insufficient to explain the regimens just once. The client often has to hear about the different aspects many times. Psychosocial practitioners can assist with this.

Therapists should become active helpers of their clients' adherence to new therapies. Those who work in medical settings, such as that described in chapter 13, may want to work with primary care providers to create systems that support adherence. For example, at Montefiore Medical Center, the medical director of a primary care program in the Substance Abuse Treatment Program and a psychologist are making plans to support patients in taking protease inhibitors, and the patients are responsive. Mental health practitioners should consider the following supportive strategies:

— Creation of therapy adherence support groups.
— Creation of buddy systems, in which two or more people can telephone each other continually to remind each other to take
medication and to provide support to one another when energy flags.

— Creation of family-oriented support, in which partners, spouses, siblings, and others are enlisted to assist adherence.

— Assistance with creation of reminder systems, such as refrigerator and medicine cabinet charts and use of items such as pill boxes with alarms.

— Brainstorming and focus group sessions with clients may provide useful suggestions regarding support. One colleague suggested enlisting the assistance of *bodega* shopkeepers in the Bronx, who would be urged to ask their customers, “Did you take your medication?”

- *If clients are excluded from therapies, they will be enraged. The therapist will be a lighting rod for that rage.*

  The clients likely to be excluded from new therapies are likely to be those excluded from many resources and opportunities. These are the poor, those of minority races and cultures, people who have come to this country without adequate documentation, and persons who have addictions. The rage of the disadvantaged is all around us, and majority-culture individuals would notice if we were to drop our defenses.

  The HIV/AIDS client excluded from new therapies will be rageful, having experienced yet another assault. The therapist must absorb the client’s rage and never negate it. The therapist cannot excuse or defend the realities of our society and definitely should not dismiss the client with a statement such as, “Maybe next time.”

- *Clients who improve with the combination therapies will face issues long put off.*

  Many HIV-infected individuals, facing what to them was a certain death, opted out of many routine and troublesome aspects of life. Some exceeded their credit card limits and failed to pay bills. Others did not pay income taxes. Many isolated themselves from family members, acquaintances, and friends. And some detached themselves from their spiritual leanings. Then, they found that the new therapies renewed their bodies, and they are now concerned about renewing their psychological, social, and spiritual lives as well.

  Psychotherapy issues may include:
— Financial matters such as debts, including lack of payment to medical providers, and taxes. Many areas have credit counseling services which mediate between clients and creditors, and a referral may be appropriate. Regarding taxes, a client may want to consult a tax attorney. Those unable to pay for a consultation may seek tax advice through legal-aid-type organizations.

— Psychological issues such as continuing substance abuse, untreated or otherwise ignored disorders such as depression, self-neglect in nutrition, and home environment.

— Social issues such as family members' feelings regarding the new health status. If family and friends were relating to the client as if he or she were imminently departing, with a variety of possibly mixed feelings, the social circle will have to adjust to a relatively healthier family member or friend. The healthier person may demand more power in the family system, thereby destabilizing it. Old roles, abdicated due to poor health, may have to be fought for. And, of course, if the new treatments fail, family and social systems will be destabilized once more, with the client possibly blamed for the continuing upset.

— Spiritual issues such as neglect of one's sense of immanence, feelings of despair as someone overlooked by the creator, rage and dismissal of God, and self-hate based on religious teachings. As noted in chapter 4, intractable spiritually based problems may require a referral to an empathic clergy person.

• Those who have a renewed life may want to plan again.

Perhaps many of us would welcome an opportunity to reenter life, taking the opportunity to do it in new ways — with less fear, with more love for self and more regard for others. While most of us, including some clients, would like to believe that the extended life offers a chance for a psychological “makeover,” it is more likely that individuals will return to old patterns. Nevertheless, opportunities for adjustment are available, and the renewal should include the possibilities. The therapist may explore these areas, being certain that the client is not perceiving a demand:

— Ask the client what his or her ideal self is and who, or how, he or she would rather be, even over a short time. Explore barriers to desired improvement. Help the client identify just one
small area of improvement that he or she wishes to tackle. Make this small improvement an early therapeutic goal.
— If the client believes relationships need attention, the client will need to evaluate his or her available emotional resources that can be allocated to repair, as well as barriers to hoped-for changes. One possible barrier may be that the other person is not capable of a relationship.

Moreover, the therapist should be aware of his or her own fantasies regarding reunions and not make them the client’s.
— Allow the client to do some concrete planning that may involve financial matters, scheduling of important events, remaining or moving, working or not. In all cases, exploration of the feelings and motivations are key.

• The belief of some who have found renewed lives is that they have been “saved” by God. This opens a door for exploration of their spiritual lives.

As Sister Pascal Conforti notes in her essay on spirituality (chapter 4), the therapist’s task is not to make judgments about the client’s expressions of spirituality but to appreciate the client’s revelation of something deeply personal. The therapist should listen and be open to the expressions. With the door of conversation about spirituality open, much can be discussed, including the client’s spiritual history and how he or she wants to live spiritually in the extended life.

The therapist should anticipate a crucial issue if the client interprets positive medical results as divine intervention: Will negative medical effects also be interpreted as divine intervention? And what will that mean to the client? Will it mean that God is displeased and punishing him or her?
• Until more is known, clients should be counseled to use safer sex techniques regardless of their viral load measurements.

“My viral load test indicated no measurable HIV. So why should I use a condom?” That is a question likely to be raised countless times.

There are two approaches, which ultimately converge, to this question. The first is an exploration of all the issues the client experiences around safer sex practices. As indicated in chapters 8 and 11, these issues are complicated and important. The client
should understand why he or she wants to dispense with safer sex practices. The second approach involves a concrete response: Until the time when scientists are certain that HIV can be eradicated from the body, infected persons must continue to use safer sex techniques. While measurable HIV may not be found in the blood, scientists believe it nevertheless is still present in the body. I tend to think that clients know the concrete response, but that psychodynamic issues propel them into unsafe areas.

These are just a few of the issues that are already being discussed as we enter the epidemic's new era of hope coupled with uncertainty. If these issues and others discussed in this book have intrigued you or moved you, if your heart has found its place in HIV/AIDS-related mental health practice, then I invite you to join the many compassionate and skillful practitioners in this field.