Before I began to do AIDS work in 1985, I worked as a social worker with Holocaust survivors and their families. Recently, I have found myself reflecting on that work as I see us beginning to emerge from the shadow of a permanently life-altering traumatic event.

I know that the epidemic is not yet over, and maybe it is premature to think in terms of post-traumatic stress at a time not yet “post.” I also know well that many people living with HIV do not have adequate access to quality health care and expensive medications. But to the degree that the epidemic is shifting, we are faced with the challenge of envisioning a future beyond AIDS and learning what we can from the experiences of previous survivors.

The Holocaust

In reflecting on the experience of survivors of the Holocaust, we are reminded that there is a long, rich, complex history of human survival. Much of what we have experienced in this epidemic is universal. We are not the only people in history who have survived or witnessed massive trauma; our clients and friends are not the only people who have returned from the edge of death to another chance to build their lives. In the wake of massive trauma, “back to the future” has never meant “back to normal,” and it has always been hard to reconstitute life when so many people from the past have not survived.

To survive trauma, some people numb themselves and aren’t always able to reopen to the whole range of human emotions. For some, the trauma becomes so enveloping that it is hard to figure out how to live without it. Some people are so wounded that they never really recover; not everyone is able to heal enough to live with wisdom and grace.

We know that those who resist and stand up (or “act up”) for themselves and for others, even in small ways, often do better afterwards. We know, too, that it helps people to stay connected to the community of others who have gone through the experience, although it is these connections that some people most want to flee.

We know a lot about memory: that it is essential to remember, but not to live only in the past; that it is important for people to tell their stories; and that people remember for their lifetimes who stood with them and who did not. We know that we all need to remember and honor those who died, participating in individual and communal ritual and acts of affirmation and renewal.

Working with Survivors

As clients focus their energies on reconstructing their lives, providers can facilitate and participate in this process. We can assist with the concrete tasks of assessment, priority-setting, and planning. Some of this involves the psychological adjustment to new expectations, formulating a new sense of “normalcy,” and recreating a future orientation. We need, also, to help people grieve.

Grieving in the face of AIDS has become intimidating to some people—there is simply too much of it—and it has become easy to feel that so much has accumulated that we will never be able to catch up with ourselves. People need to grieve not only for those who have died, but also for shattered dreams, missed opportunities, and lost hopes. It is easy to understand why someone would want to run in the other direction from all that grief. But for some, going
Editorial: Knocking on Wood
Robert Marks, Editor

It is barely acceptable in this age of hope—and I’m a little embarrassed to admit it—but I find myself hesitating when I consider joining the jubilation about the new treatment paradigm. After 16 years, I am wary of breakthroughs.

As Michael Shernoff memorializes in this issue of FOCUS, I have heard—we have all heard—the boy cry wolf so many times, each time rushing helter-skelter but meeting only disappointment. I’m too tired to chase that kid to yet another apparent sighting.

I don’t blame myself for being skeptical. In fact, I’m amazed that more of us aren’t (despite the affirmation of success embodied by friends revived). Yet, I can’t help feeling that I have misunderstood everything, and it does feel a little lonely being left after everyone has run off to save the boy from what might well be a real wolf.

Am I being a little extreme? Perhaps. People have been comfortable talking about important concerns such as access to drugs, difficult regimens, and the failure of treatment for some people. Some have even stated emphatically that combination therapy has not meant an end to AIDS.

But, it remains the case that few have gone beyond these qualifications and wondered out loud whether this bubble will burst as it has so many times in the past.

Silence Equals . . .

There’s another reason behind my reticence. I think it’s true for many of us, even in our self-actualized present, to fear that if we express hope, the desired end will be foiled. We whisper instead of shouting our hopes, if we articulate them at all. It’s funny, but the opposite also seems to be true: a potential disaster acknowledged is a tragedy that will undoubtedly occur. Silence equals . . . well, knock on wood.

In this issue of FOCUS, Avi Rose says that hope cannot be false, so I fight my inclination to replace it with doubt. He suggests that hope remains potent and authentic even if outcomes are not perfect. And when the outcomes are—well, even the most agile skeptic must acknowledge the evidence that hope has already been fulfilled by the undeniable changes in the health of so many people.

Still, I can’t go another day without admitting that tiny voice of doubt—anchored by history, but perhaps fueled by nothing more noble than fear—finding that I must take it on faith that this recognition will not endanger our efforts.

So, it is no surprise that I am both a closet skeptic and an equally private optimist.

Hope and Doubt Forever

My mistake is in thinking that I must commit to either hope or doubt, that they are in some way forever mutually exclusive. Instead, they co-exist, dependent on interpretations of the same facts, but independent of each other: they are irrebutably, undeniably separate, each distinct in its own unambiguous moment. One does not triumph over the other any more than stillness might triumph over motion.

When I am still I know that I will move again; when I am in motion, I know that I will stop. To pit these states against each other—or to fight them myself—is futile and ultimately unnecessary. I can move and simultaneously believe that I should be still without impeding my motion. I can hope and then doubt and then know that I will hope again. I can’t stop doing either, so I’ve decided to practice both with intention.

into that well of grief is the only thing that will make it possible to recover resilience, faith, and a full-hearted commitment to life.

Some of this grief is hard to get at individually, and is more easily accessible in the context of community rituals. We all need opportunities to remember the people we’ve known and loved, recalling them as they really were, not limiting ourselves to a saintly romanticized version of them. We need to celebrate the lives of those who have died, but not in a way that doesn’t allow us to feel our sorrow.

While listening to and assisting people spill out their pain, providers need to be clinically vigilant about each person’s psychic limitations in coping with trauma. In light of such overwhelming loss, the role of the counselor may be to help people contain their grief as well as express it. Those who feel as if they were drowning in sadness, especially those who experience little or no respite from intrusive thoughts and images of death, may benefit from a range of therapeutic techniques or from the creation of rituals that may help define boundaries of grieving.

For mental health and medical providers working with survivors, our simple yet formidable challenge is to be deeply present, respectful, and compassionate with those we serve. This work is formidable primarily because many of us carry our own numbness and despair. In the face of overwhelming loss, trauma becomes normalized, and we tend to minimize people’s losses, including (or especially) our own. With each other’s support and through
formal structures such as consultation, we as providers need to summon reserves of fresh energy and open-heartedness to enable us to offer full attention to our clients' tales of survival. We will all be telling these stories for the rest of our lives.

Past, Present, and Future

None of us came to AIDS as a blank slate. Each of us already had his or her own history, circumstances, and character. For people living with HIV, the nature of going back to the future depends in part on what the future looked like before their lives were changed by the epidemic. If you were feeling good about yourself, doing fulfilling work, had loving relationships with friends and family, felt connected to the community, felt that you had control over your own destiny, and had a sense of purpose and direction in your life, going back to the future probably looks wonderful.

But if you were doing work you hated, felt isolated, anxious, or depressed, were struggling with major addictions, or were barely able to make ends meet, going back to the future may be daunting. On the one hand, anything is possible; on the other, obstacles are frightening and demoralizing. For many people living with HIV disease, dealing with the loss of government benefits or the impact of new immigration policies may make it difficult to feel hopeful about the future, no matter how promising the new HIV treatments are.

Facing the future is sometimes complicated by people having felt left behind by their uninfected friends in the past. Understandably, people with HIV disease measure themselves against their uninfected peers. For those with middle-class opportunities and expectations, this means looking at those who have settled down to careers, families, financial security, and retirement planning. This is especially difficult for the large number of people whose lives were interrupted by HIV during a stage of life when they ordinarily would have been building the foundation for a seemingly secure future. It is important, though sometimes difficult, to face feelings of envy, anger, and resentment, mourning lost opportunities in a way that makes it possible to move forward.

A sense of abandonment is even more evident among people for whom combination therapy is not working. There have always been disparities in antiviral success among people with HIV disease, but these differences have never been so sharply delineated. Successful treatment is likely to bring exhilaration; antiviral failure may lead to shame, inadequacy, and isolation. This is particularly true in communities hardest hit by the epidemic, where the celebratory atmosphere is inescapable. Shared adversity often fosters camaraderie, and for those who have not yet been doing well with new treatments, the treatment success of others can engender a feeling of being left behind by their treasured comrades. For those who are doing well, it can be difficult to not succumb to survivor guilt, even if survival still feels precarious.

As mental health and medical providers, it is especially important for us to ensure that community and emotional support embrace everyone. We must be particularly careful not to abandon those who might make us feel impotent and uncomfortable when they do not do as well as they are “supposed to.” We need to somehow ensure that there is ample room for the despair of some of our clients, the excitement of others, and the community and solidarity which is still crucial to everyone.

Living with Uncertainty

The success of triple combination therapy and protease inhibitors has indeed been exhilarating. But while exhilaration is hopeful and exciting, it can also leave people feeling dizzy and disoriented. There is still so much uncertainty—not a new challenge in the epidemic or, for that matter, in life, but a challenge nonetheless. It is hard for people to tolerate, let alone embrace, uncertainty. Over the years, I have seen people get into trouble pursuing certainty and the “either/or” thinking that comes with it.

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expectations to eventually fade and die. He had a plan, and now he needs help in coming up with a new, less “certain” one.

Those of us who do HIV-related work have also been challenged in this time of new uncertainty. It can be difficult to be fully honest with people about what we do not know. We need to face—and to honor—clients’ anger and disappointment about our unwillingness to pretend to have answers to unanswerable questions: Can I count on these treatments continuing to be effective? For how long? What if I make new life changes and then get sick again? We need to acknowledge and empathize with the fear, skepticism, weariness, and other feelings behind these questions, and to not fend them off out of our own discomfort. We need to understand how frightening it can be to not have answers. While people desire “answers,” I am convinced that people are most deeply reassured by “realness,” rather than pretense.

Conclusion

At work recently I’ve noticed an increase in people not showing up for appointments, especially mental health appointments. It seems that some people, as they feel better and more independent, want to pull away from us a bit. We may be supportive and wonderful, but we also represent AIDS to people who are trying to build new lives that don’t revolve around their health and well-being. But in most cases, we simply need to be willing to let go and let people be as independent as they desire, while making sure they know that they can come back if necessary.

We need to make sure that what we offer people matches what they currently need, not what they used to need. We need to adapt, helping people figure out what they want to do with their lives now and supporting them as they move forward, not only in terms of work or school, but also in other aspects of life—dating, quitting smoking or any other addiction, cleaning up a police record, dealing with debts, or going back to the gym. The future is filled with possibilities. We need to hold out that increased hope, for those we care for and for ourselves, without denigrating it or invalidating it as “false hope.” Hope is never false. And our proper role, at this point of the epidemic and always, is to be nurturers of people’s hopes.

References


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See also references cited in articles in this issue.
Hope is essential for all people in order to create meaning in our lives, but it is especially crucial in the depths of an epidemic. In the early days of AIDS, hope was in short supply for everyone from people with HIV disease to their caregivers and communities. As the epidemic progressed, hope emerged in the laboratory with each new experimental treatment only to be disappointed in the field. In fact, a history of hope and disappointment is tantamount to a history of the epidemic: tracing its clinical and scientific milestones and the related mental health challenges. This article briefly attempts to trace this evolution and relate it to the current treatment paradigm with the goal of learning something about frustration and resilience.

“Hope has at least two components: a positive focus and a future orientation,” according to Columbia researcher Judith Rabkin and her colleagues, who go on to explain that when young or in excellent health, it is normal to assume that life will continue into a distant future. People with AIDS do not have the luxury of anticipating time or presuming longevity. Yet, Rabkin continues, “Even in extreme circumstances, hope may shrink but it need not disappear altogether. One can think positively ahead to the coming week, the coming day, or even the coming hour.” Jerome Frank, a psychiatrist and a pioneer in identifying the therapeutic roles of hope and persuasion, affirms this notion, defining hope independent of a distant future, “as the perceived possibility of achieving a goal.”1


History Repeating

Rabkin and colleagues have identified some of the milestones in the roller-coaster history of HIV-related treatment. In 1984, Health and Human Services Secretary Margaret Heckler confidently predicted a brief epidemic with an announcement that still haunts us: “There will be a vaccine in a very few years, and a cure for AIDS before 1990.” In 1986, at the Paris AIDS Conference, Samuel Broder reported on preliminary trials of ZDV and laboratory experiments of zalcitabine (ddC) and didanosine (ddI), asserting, “I believe AIDS is curable.” For four years, ZDV and its relatives dominated treatment, but were periodically challenged by other drugs usually introduced with great fanfare. Ranging from the “alternative” to the “experimental,” these treatments included bone marrow replacement, egg lipids, interleukin 2, ribavirin, dextran sulfate, HPA-23, Compound Q, blood heating, hypericin, isoprinosine, soluble CD4, cyclosporine, and GP160.

It was not so much that these drugs were hyped in the medical literature or even among most people with HIV disease, but that somehow, each gained a vocal and committed following whose enthusiasm promised something extraordinary. Scientific claims were usually qualified by “it appears” or “this has to be proven in the field,” but these disclaimers evolved into a predictable litany, heard but dismissed as so much fine print, overshadowed by bolder and less grounded pronouncements of a brighter future, of hope. And so it was that we—everyone drawn into the orbit of AIDS—urged ourselves from one “cure” to another, raising hopes to unreasonable heights so that even when a drug actually had some positive effect, it rarely satisfied expectations.

For the several years following Heckler’s announcement, so much was being how scientific research has raised hopes only to disappoint them and later, somehow, has contrived to renew them. This has been the path the protease inhibitors have followed. First introduced in 1991, the protease inhibitors were touted as “the next generation of antivirals,” more powerful than zidovudine (ZDV; AZT) and its relatives, only to prove in 1994 to be readily resistant and cross-resistant in monotherapy. But in 1997, in combination with other antiviral drugs and at lower doses, the protease inhibitors have spelt the most magical words of AIDS lexicon: chronic manageable condition.

A History of Hope:
The HIV Roller Coaster
Michael Shernoff, MSW
learned about HIV disease, so many theories seemed promising, that there was a sense of optimism, a belief that HIV-related research was moving forward toward a resolution. But this momentum could not sustain itself without new breakthroughs: breakthroughs—even premature or false ones—seemed (and seem even today) to be the only thing that kindled hope. Incremental advances were never good enough, and advances followed by setbacks were devastating. As optimism waned until 1995, the most positive assertion, better characterized as a consolation, was that scientists were gaining an increasingly precise knowledge about the virus and disease progression.

In 1992, an advertisement for *Time Magazine* stated, "In the mid-1980's, scientists believed a vaccine for AIDS would be ready in two years. Seven years later; no vaccine, no cure, no reliable treatment." And an Op-Ed column in the *New York Times*, written by Harvard researcher William Haseltine, concluded, "Why...does the future look so bleak? The answer is that given what we know today, it cannot be predicted when, or even if, an effective treatment will be developed and when, or if, a vaccine will be developed."1

The Berlin AIDS conference in 1993 has been acknowledged as a low point in hope. Dominated by the Concorde study’s apparent finding that ZDV was not an effective early intervention, reports of the conference focused more on negative findings than on positive ones, for instance, advances in treating opportunistic infections. In an article on the conference and this response, Stephen Follansbee and James Dilley wrote: "Confirmation of the limits of the nucleoside analogues and of the painstaking effort required by antiviral research has left resignation where only two years ago, there were high hopes."3 In a 1994 article in *The Nation*, University of California, Berkeley professor David Kirp wrote: "Hardest is acknowledging that AIDS is a momentary disaster that will be stopped by scientists who, in their quest for the Nobel Prize, will come up with the magic bullet. The hope early on was that HIV would, like polio, be tamed by knowledge, but the fact is that HIV is much more like cancer, stubbornly resistant to the ingenuity of scientists."4

**Hope and Therapy**

As a psychotherapist who has worked with people with HIV and AIDS since the earliest days of the epidemic, I have watched as the research caused hope to wax and wane. While I had not believed that I would see a cure for AIDS in my lifetime, I have never challenged a client’s or friend’s hope that a cure would be discovered in time to benefit them and their loved ones. It is not my place to challenge hopes simply because I consider them unlikely. After all, what do I have that could replace those dashed hopes?

In fact, much of my work is, in keeping with Judith Rabin’s definition of hope, trying to help people sustain hope for goals that are more imminent than a cure, for realistic and concrete objectives. Such hopes might be as tangible and specific as: undergoing an improvement in health; avoiding severe pain; or living long enough to travel, accomplish a specific goal, attend an important event, complete college, or change careers. They might be as ethereal as believing in an afterlife and the reunion with loved ones, or as simple as being remembered after death.

Hope was in short supply in 1993, when reports from the Berlin conference on AIDS translated directly into hopelessness among my clients with HIV disease: in particular, clients who were already depressed experienced an increase and worsening of symptoms of depression as a direct result of the bad news from Berlin. As these individuals lived longer and experienced improved health and increased energy, hope rebounded and depression waned.

But, hope can be a precarious entity even for those lucky enough to be achieving their goals. I am currently treating clients who have benefitted from combination therapy, but who are experiencing attacks of anxiety, feelings of unreality, depression, suspicion, and anger in response to the improvement in their health. Usually they are confused by these reactions and often are ashamed to talk...
about them. As welcome as an improvement in health may be, it cannot yet be trusted to last, and because of this, even a dramatic resurgence of good health breeds a reluctance to invest too much hope too early in the game. Previous disappointments make it increasingly difficult to muster and sustain optimism and lead in part to the well-documented emotional roller-coaster of living with HIV disease.\(^6\)

One client characterized his restored health as being "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.

Another factor that erodes hope, according to Andrew Jacobs, is the estimate that between 10 percent and 30 percent of people who try combination therapy fail to respond. Jacobs adds, "The perception that the plague is over has only compounded the misery of those who have failed on combination therapies.\(^7\)" For people who have had their hopes dashed countless times, it is crushing to be left out of this so-called success story. A client of mine put it this way:

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.

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of mine, remarking that the failure of combination therapy to work for everyone has intensified his ambivalence about hope:

It feels somehow self-indulgent to be so caught up in relishing my own improving health. My best friend has not been able to tolerate these drugs...[But] why should I be able to get away with not having any side effects, when he was debilitated by them? It really bothers me that Tony can't take them and I can. In addition, with my knowing that they haven't been of help to him, I worry that what happened to him will eventually happen to me.

Conclusion
I am a “non-progressor,” still asymptomatic after 20 years of HIV infection. Hope has been an essential element for me in how I deal with HIV disease both personally and professionally. When I first found out that I was HIV-positive, I was 36 years old, and hoped that I would live to be 40. Now at 46, in perfect health and with no detectable viral activity for more than a year, I increasingly expect to live out my normal life.

Many people have truly come back from the dead and are, viscerally and without qualification, hopeful. But this truth cannot erase the reality that people are still dying from AIDS, and that new people are still becoming infected. Nor can it blot from memory those who have died and the belief that had they survived a little longer, they would, in the end, have lived a lot longer. And some, like the client I mention above, will remain frightened that as treatment has failed for their friends and has failed in the past, so will it fail for them now.

What is amazing, miraculous, and consistently inspirational to me is that in the midst of all this, people manage to construct belief systems that include hope at the core. The ability to maintain hope even in the depths of the most dire situations is one of the most astounding and uplifting—ultimately hopeful—aspects of the human psyche, forming the basis for most traditional religions and personal spiritual beliefs.

The ways that people with HIV disease hold onto hope and allow what they hope for to expand, contract, and evolve over the course of their illness is essential to living well with this disease. The hopes of many of my clients have offset the hopelessness and despair that is so much a part of this illness. Their hope has nurtured me, and it has enabled me to support other individuals in their struggles to search for hope in their lives and redefine illness in the face of treatment success.
Managing Sustained Uncertainty


At a time when treatment advances offer hope for people with life-threatening illnesses, therapists must continue to help people cope with sustained uncertainty, according to a study of parents of children with chronic life-threatening diseases. Uncertainty is a process rather than a single or short-term stimulus, a complex set of changing circumstances with both history and trajectory.

Researchers analyzed interviews with 10 families and 21 parents, and performed a comprehensive survey of uncertainty theory and of biographical accounts of children with similar life-threatening diseases.

Uncertainty in life is universal, but awareness of uncertainty is mediated by each person’s “assumptive world”: a relatively stable cognitive world of knowledge, values, and beliefs, plus a more mutable action world of predictable events, behaviors, and relationships. This “taken-for-granted” world provides continuity and coherence and is characterized by a deep-rooted belief that what has been true will continue to be true. Life-threatening illness ruptures this world.

Managing the resulting uncertainty involves strategies to manipulate the known, the unknown, and the unknowable. Some people do this by seeking information; others, fearing that knowledge will incapacitate them, attempt to limit or discount information they receive. A common way people manage information is to transform a “probability” into an “absolute.” For instance, a 25 percent chance of survival is simplified to either “survival” or “failure to survive.” Another strategy is to stack the odds, gathering information that supports only the desired outcome.

The Dynamics of Hoping


The dynamics of hope involve three elements related to the concept of “play”: imagination, movement, and risk. An essay on chronic illness posits that when people hope, they detach themselves from the stories of their lives, imagine new stories, draw new pictures of the world, and envision themselves in these pictures.

Psychologist Shelly Taylor found that women with breast cancer who coped best were sustained by “illusions”—unrealistically positive views of themselves and their personal control. Taylor defines “illusion” as a reinterpretation of reality, rather than the complete alteration of reality that accompanies repression or denial. Illusions enable people to derive energy from imagination without taking flight into delusion.

In contrast to a typical definition of hope—“the positive expectation of realizing desirable outcomes”—which he redefines as “wishing,” Gabriel Marcel proposes that hope transcends the particular objects or goals to which it may first seem attached. The hopeful person, rather than being defined by particular wishes, is open to the possibility that reality will disclose as yet unknown sources of meaning and value.

Similarly, Paul Pruyser sees hope as “surrender, not only to reality-up-till-now, but also to reality-from-now-on,” accommodating the unknown, possibility, and surprise. Hope introduces fluidity into constructions of the world: it is not a denial of reality, but a continued reevaluation of its content. To hope is to adopt a “playful” attitude toward reality, time, and the self; it is “a way of perceiving that sustains creative striving in the face of adversity.”

The dynamics of hoping amount to the “renarratization” of illness and require empathic interpersonal communication: the existential commitment to be with a sick person and to facilitate his or her building of an illness narrative,” that makes sense and gives value to his or her experience.
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