There is little doubt that in the last few years a substantial change has taken place in the prognosis of HIV infection for those living in developed countries or in the richer social groups of the less developed ones. In the 1980s and early 1990s, having HIV meant living through a period of generally healthy but slowly declining physical status, followed by inevitable and progressive deterioration, often punctuated by medical crises, and culminating in a variable but fatal end. Since 1996, however, individuals with HIV infection who have had access to highly active antiretroviral therapy (HAART) have benefited from marked reductions in the rate of progression to advanced symptomatic disease and mortality. It is not surprising that some optimists in 1997 were heard to predict that HIV was about to enter a new phase, becoming manageable “like any other chronic disease, such as diabetes.”

Today, we do not often hear such statements, and it may be useful to examine in some detail the assumptions involved in those earlier claims and the degree to which they reflect today’s reality. To undertake this exploration, it is important to understand the difference between chronic and acute illnesses and the ways in which perceptions of severity affect the way in which people categorize diseases.

**Chronic Illnesses: What Are They?**

Chronic illnesses can be regarded as the diseases of affluence. In the days when life was harder than it is now and when working and living conditions, malnutrition, infectious diseases and the perils of childbirth meant that only a minority reached old age, there was limited opportunity and little time for people to develop chronic disorders. Improvements in standards of living and working conditions, better diet, cleaner water, and adequate sewage facilities have all contributed, together with advances in medical treatments, to increases in survival and longevity. These improvements have, in turn, allowed the burgeoning of new problems, for example, heart disease, diabetes, obesity, arthritis, cancer, and degenerative neurological disorders.

The umbrella term *chronic* is a label used in opposition to “acute,” a time-limited, self-contained disease. It hides a wide range of diseases with few things in common: they do not go away easily, they last for a long time, and on the whole, they are never successfully eradicated. It is useful to realize that HIV infection has always been a chronic illness, in the sense that it develops over a number of years. In the early days of the epidemic, it was calculated that only about 50 percent of HIV-infected individuals would develop HIV-related opportunistic conditions within 10 years of infection, although once these problems appeared, decline tended to be rapid, survival after an AIDS diagnosis sometimes lasting less than two years. HIV infection is still a chronic disease, but one where the time span has extended beyond these original expectations.

What is the relationship between chronicity and other features of a disease? The time scale of an illness (chronic or acute) tells us little about its severity: diseases can be chronic and severe as well as chronic and mild, or acute and severe as well as acute and mild. Many chronic diseases such as multiple sclerosis, are indeed severe, even if they have periods of remission when the disease is quiescent; others, such as diabetes or hypertension, require close monitoring of treatment effects. Unfortunately, this distinction between chronicity and severity is sometimes lost when discussing diseases,
Editorial: Chronic Unease
Robert Marks, Editor

Chronic. Manageable. Disease. These three words represent the holy grail of HIV treatment, a prize that many have too quickly judged to have been secured.

Today, HIV is chronic, because as José Catalan, Lucinda Green, and Flick Thorley observe in this issue of FOCUS, it has always been chronic. But, as Richard Goldman also writes here, while it is better managed than it has ever been, HIV is hardly a manageable condition.

Catalan and his colleagues define the nature of chronic illness and put HIV into this context. They point out that what has confused many is that while HIV has always been chronic, there was a time when it was uniformly more severe. For people who have access to HIV antiviral treatment today and for whom treatment works, HIV is certainly a less severe condition. In that sense, it is more manageable. But, it is not any more chronic than it was, and alas, not any less so: there is still no cure for HIV, so seropositive people will continue to have HIV for their entire lives.

I suspect that is what is behind the word chronic for many of us: the sense that it is almost as good as a cure, the hope that HIV can be controlled with one pill a day and with no side effects and no treatment failure. But Goldman’s experience speaks to the real story behind HIV as a chronic illness.

When I first approached Julie Frank and Steve Lynch, the clinicians who run the AIDS Health Project’s HIV-positive support group program, I asked if they could suggest an AHP client who might be willing and able to write about living with HIV as a chronic illness, a person who had had a miraculous turn-around on combination treatment; you know, the ones that the popular media have been heralding for the last four years. Julie and Steve told me that of the hundreds of clients they see, we did not really have any who fit that description, that the “chronic illness” story that I was seeking seemed to be, well, a myth.

Goldman’s story is the more usual one. Treatment has been particularly in the context of HIV infection: describing HIV as a chronic illness implies that it is a less severe condition, a manageable if not altogether curable condition.

To summarize, chronic illnesses are long-term disorders, usually the result of success in the treatment of formerly acute and sometimes rapidly lethal conditions. But apart from this common characteristic, little can be assumed regarding the actual severity, course, or symptoms of a particular chronic disease. Most definitely, chronic does not equate with mild.

The Nature of HIV as a Chronic Illness

Is HIV infection a chronic illness? To the extent that it lasts years and, to date, cannot be cured, it is a chronic illness and has always been one. It has appeared to be an acute illness sometimes, because of the difference in manifestation and severity between early illness and later acute illness. Today, however, the term chronic has acquired new meanings in the context of advances in HIV management. Describing HIV as chronic illness implies a less severe manifestation throughout its course; it suggests not only that survival is extended, possibly considerably, but also that people with HIV can start “thinking about living . . . without having to call it denial.”1 It is true that there has always been a small proportion of HIV-positive individuals with a good prognosis, with few complications, and with minimal or, in the case of long-term non-progressors, no treatment. But the phenomenon of long-term survivorship as open to many—as long as a person has access to treatment—is a new development.2

As a result, people with HIV confront a number of complex issues involving

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Is HIV a chronic illness? To the extent that it lasts years and cannot be cured, it has always been one. It has appeared to be an acute illness, because of the difference in severity between early illness and decisions about their care and the psychological consequences of survival at the same time as they face the risk of opportunistic conditions. Discussed below are the most prominent issues related to the evolving meanings of chronic HIV disease, including stigma and "reverse stigma," multiple medical pathology, and the adverse effects of antiviral treatment. Interestingly, many of these issues are characteristic of other diseases such as diabetes mellitus, which could also be called chronic.

Stigma and Stigma in Reverse. HIV is not the only disease carrying multiple meanings and leading to social consequences beyond its purely medical effects: tuberculosis, leprosy, cancer, and syphilis have had similarly bad press. While the old stigma has not entirely disappeared (how many people with HIV can discuss their illness freely with neighbors as they might do if they had diabetes?), there is now the added expectation that since HIV is "only a chronic illness," the HIV-positive person should get on with life. This "reverse stigma" expresses itself not only as a societal expectation, but also as a self-imposed demand that leads people with HIV to undertake the superhuman efforts of holding a full-time job while dealing with complex treatment regimens and side effects.

One Chronic Illness or Many Chronic Illnesses? The experience of many people with HIV today—living rather than dying—is that of a gradual accumulation of ailments that require regular monitoring and treatment. Among these ailments are gastric and intestinal symptoms, skin disorders, neurological disorders, cancers, and respiratory complications. Such patterns of multiple pathology can be seen in many other chronic disorders, like diabetes mellitus or heart disease, but with HIV, the list of complications is ever longer.

Treatment and Its Less Desirable Consequences. While the debate about when to start HIV antiviral treatment continues, the adverse effects of combination therapy are becoming more apparent. Among the most common of these effects are a generalized toxicity with multiple manifestations occurring in up to 30 percent of patients, hypersensitivity reaction in up to 20 percent, and lipodystrophy in about 50 percent. Treatment adherence, always a problem when high levels of compliance are required, is bound to be strained when the consequences of taking medication are so mixed. HIV as a longer-term chronic disease begins to resemble relapsing conditions—like some forms of leukemia or other malignancies—that require regular and intensive treatments with substantial side effects, rather than well-controlled conditions—such as late onset diabetes—that respond to minimal lifestyle changes involving diet or weight loss.

Psychological Consequences: There Is a Future, but Will It Last? While organic brain syndromes such as HIV-associated dementia and new onset mania have become extremely rare, other psychological and psychiatric problems have become apparent. Facing the possibility of extended life expectancy can lead to major difficulties and questions, for example, how does one pick up the threads of a career or explore alternative training and employment, start to feel hopeful about developing relationships, or simply have the confidence to start living again? Efforts to normalize emotional and sexual relationships can be frustrated by problems with trust and intimacy as well as sexual dysfunction. Uncertainty about the long-term benefits of treatment, especially when side effects are evident, can lead to emotional paralysis, the inability to make decisions, anxiety, and depression. Concerns about when to start and when to stop combination therapy—the question of strategic treatment interruptions or "drug holidays"—in addition to the difficulties of treatment adherence add to these problems.

At the start of the epidemic, mental health providers tended to work in a framework of crises. These crises unfolded, for example, after HIV diagnosis, with the onset of social stigma and rejection, and when dementia or mania descended. But today, the focus of intervention has shifted towards more persistent and complex difficulties. Paradoxically, in developed countries there has been a downsizing of psychological and social services, rather than a reassessment of the nature of the care provided and the development of new services. In this context, it is not surprising to learn that for some people with HIV living has become more difficult.

Implications for Comprehensive Health Care. The changes in the pattern of HIV disease require changes in general medical care and the type of support needed to respond to the psychological consequences of care. Fewer people need urgent intervention for sudden, acute illness, or for palliative care, but more individuals need prolonged intervention for long-term complications and medical monitoring.

There is an extensive literature on the impact of disease on psychological and social well-being. Can this literature and the practical experience it reveals be of help in dealing with the new challenges of HIV infection? In the context of effective responses to specific psychosocial problems, there are three shared principles that apply to HIV disease, as well as to cancer, diabetes, heart disease, or any other serious physical disorder. First, there is always a psychological dimension to physical problems, and providers must be willing to engage in dealing with these concerns. Second, care requires easy access to mental health providers with skills ranging from the psychological to the pharmacological, and with a familiarity with the medical intricacies of HIV infection. Finally, care is improved if there are strong patient organizations or lobbying groups that influence health care provision and public policy. But beyond these broad principles, HIV infection—like all chronic illnesses—raises particular problems, and interventions need to be responsive to specific issues for specific individuals in their specific social context.

Conclusion

HIV infection, always having been a chronic disorder, has in the last few years shown a changing pattern of disease with improved outcomes (longer survival, possibly more disease-free periods, the chance to normalize life). But, longer survival has also meant more time for more adverse consequences to develop, some of them resulting from treatment itself.

As HIV infection acquires the characteristics of other chronic severe disorders and the label becomes commonplace, it is essential to highlight that chronic is not the same as mild or unimportant. Furthermore, comparison with other chronic conditions reveals just as many differences as similarities, so that the lessons that can be gleaned from other illnesses are limited. Comprehensive care for HIV needs to adjust to these changes but there are few good models to follow: as has been true for HIV all along, people living with HIV and their caregivers will need to create their own models of support and care.

Sadly, many of these challenges apply to only a minority of people with HIV. The large majority live in developing countries where access to treatments, old as well as new, is severely restricted by complications that are more political and economic than medical and psychological.

Clearinghouse: Chronic Illness

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Authors

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At a time when it is all the rage to speak of HIV as a chronic illness, my experience may illustrate both the silver lining of what appears to be a manageable illness and the cloud that remains for many people who live with HIV. I enjoyed 40 years of active, productive, and healthy living, including 15 years of a career in health care. I exercised regularly. I socialized a lot. I had lots of sex. I cooked frequently and ate well. But, I have only a shadow of a memory about what it felt like to be in this body during that part of my life.

That shadow is further obscured by the all-too-memorable experience of living in a body that has been ravaged by HIV and anal cancer, and the treatments for both conditions. Chronic HIV infection has left me measuring my days in intervals between pill taking. How these intervals unfold depends on the day and the state of my bowels and my body. Emotionally, I am in limbo. Compared to 10 years ago, my energy level and sense of well-being have improved dramatically, but these remain erratic, and while some people with HIV have resumed working, I have not been able to do so. Before HIV “happened” I thought I would work and then retire with a home, a relationship, and a comfortable life. Most of those dreams were swept away suddenly and forever.

I have regained something of my prior existence: a sense that I will live beyond next month and a fuzzy vision of the not-too-distant future. At first, after I was diagnosed with HIV, I worried that every ache or pain or cramp was the beginning of the end. Those symptoms have become background noise, annoyances somehow tolerable, like what I imagine the process of aging must be for seniors. I don’t feel certain that the meds I am taking won’t fail, that I won’t slip into acute illness again, but I do feel that I have more options than I did before.

The Early Years

I had about three years of good health after testing HIV-positive in 1985. But first came fear and shock. I had been absolutely careful not to share bodily fluids since about 1982, so I had reason to hope that I would be uninfected. HIV tapped into the feelings of shame, the internalized homophobia, that accompanied a 1950s childhood. After all, I had gotten HIV through gay sex, not from a blood transfusion. Somewhere deep inside, I was not an “innocent” victim. For a few months I couldn’t and didn’t talk to anyone about my diagnosis. Then, I watched as friends and colleagues became ill and died all around me. I was fine physically. It was a horrific time.

I was diagnosed with AIDS-related anal cancer in December 1989. I’ve been cancer-free for 10 years now, and there is not a single day that I don’t think about having it. It was my first AIDS-related illness. My CD4+ cell counts had been gradually falling, and for two years prior to my cancer diagnosis, I’d felt “flu-ish” most of the
time, I ached a lot and was so exhausted, I had to nap every day, even at work. But I had no other maladies.

When the rectal pain started, my CD4+ cells had already fallen below 200. Chemotherapy and radiation treatments were beyond nasty and kept me in bed and incontinent. I stopped working immediately. I felt like I was dying, and I guess I was expected to go. I was in constant pain, even with a good pain management regimen. Radiation ulcers came and went inside and outside my anus. Diarrhea was nearly uncontrollable.

I lived alone, and I found solace in a “buddy” from the Shanti Project to whom I could voice my worst fears and vent about my pain. Another volunteer helped with household chores. I tapped into community support resources. I lost all sexual functioning, and the doctors told me I might never get it back. I made out my living will and stockpiled enough meds to kill myself should the pain or suffering go beyond what I felt I could handle. I needed assistance walking, cooking, and cleaning, and never ever went anywhere without a pillow to sit on. I grew to appreciate feminine hygiene products. I joined a support group, which I still attend.

I started doing some volunteer work when I was able. The loss of my identity as a “productive” member of society was and continues to be profound. At first, I longed to return to my job, and even tried, only to fail within days. I gave up and decided I needed to let go of that part of my life. I was 40 years old.

Life went on this way for six years, with an occasional opportunistic infection here and a medication side effect there. My CD4+ cell count bottomed out at 13 in 1996. Somehow, I managed to survive.

Life in Limbo

In 1996, after the first protease inhibitors were approved by the Food and Drug Administration, I began triple-combination therapy. I experienced diarrhea, fatigue, muscle and body aches immediately, but continued with the pills. The Crixivan “burps” nearly burned a hole in my esophagus and I started other meds to mitigate that. After a year, my viral load began to drop, and my CD4+ cell count slowly began to rise. I have slowly developed midsection girth from lipodystrophy and super high cholesterol and triglycerides. I am taking more pills to counteract that. The opportunistic infections have stopped, and I have gone off the antibiotics to prevent them. I have a little more energy.

My body has recovered some, but not all, of its normal functioning. The long-lasting side effects from radiation therapy, which damaged my intestinal system, are always only a cramp or a bowel movement away. I can never have anal intercourse again. My body image has changed to a variation of “Humpty Dumpty.” Ironically, even though I have gained weight, I mainly experience feelings of loss. I am in limbo, my life a compromise between side effects and an HIV regimen that seems to be keeping me alive; a process of sustaining a body that will never be well, but may very well continue to be.

While so many of my friends have died, I have not; I am still here. I feel as if the world is passing me by, a dinosaur who has survived the ice age. But, I also feel that I am here for a reason. I still have some creative spark in me, and some ability to give back to the community that has helped me so much. I love life, food, people, art, culture and nature far too much to give them up yet.

A Change of FOCUS

In order to streamline our production process and take advantage of software changes, we reviewed the layout of FOCUS and made adjustments. Many of the resulting changes will be almost invisible to you, but they will subtly improve the readability of the newsletter. In addition, we have made small changes to some design elements, most prominently, the FOCUS logo.

We continue to invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
Quality of Life and Chronic HIV


Compared to people living with other chronic conditions, people with HIV experience substantially higher rates of illness and diminished quality of life, according to a large national survey.

The study included 2,864 HIV-positive adults participating in a larger probability sample of adults with HIV receiving health care in the United States. Researchers surveyed participants about physical functioning, emotional well-being, role functioning, pain, general health perceptions, social functioning, energy, and disability days. They combined these eight domains into physical and mental health summary scores—on a scale from 0 to 100—and compared these results with quality of life ratings for the general U.S. population and for people with other chronic diseases.

Physical functioning was about the same for adults with asymptomatic HIV disease (a mean score of 92) as for the U.S. population (a mean score of 90), but much worse for those with symptomatic HIV disease (a mean score of 76) or with AIDS (a mean score of 58). Physical functioning scores for asymptomatic participants with HIV were not significantly different from those of people with epilepsy and were significantly better than those of people with other chronic diseases (gastroesophageal reflux disease, localized prostate cancer, clinical depression, diabetes, end-stage renal disease, and multiple sclerosis).

Emotional well-being was comparable between participants with asymptomatic HIV disease (a mean score of 62) and participants with symptomatic HIV or AIDS (a mean score of 59). However, participants with HIV scored significantly worse than both the general population (a mean score of 75) and people with all other chronic diseases except depression. The presence of HIV-related or treatment-related symptoms was strongly associated with physical and mental health scores, whereas race, sex, health insurance status, disease stage, and CD4+ cell count were, at most, weakly associated with physical and mental health.

Life-Satisfaction among People with HIV

Tsevat J, Sherman SN, McElwee JA, et al. The will to live among HIV-infected patients. Annals of Internal Medicine. 1999; 131(3): 194-198. (University of Cincinnati; University of Medicine and Dentistry of New Jersey; and University of Massachusetts, Boston.)

A small study of life-satisfaction found that many people with HIV have a strong will to live and believe that their lives with HIV are better than they were before seroconversion.

Researchers recruited 51 HIV-positive participants who were patients at the University of Cincinnati Medical Center’s Infectious Diseases Center. Of the total sample, 49 percent were African American, 45 percent were White, and 30 percent were women; the average age of participants was 36 years.

Forty-nine percent of participants said that life with HIV was better than it was before they contracted HIV, 29 percent said that life was worse, 18 percent said that life was about the same, and 4 percent did not know. Participants who said that their lives were better were more likely to be at peace with God and the universe, to be female, and to have stopped injection drug use since diagnosis. Seventy-one percent of people who had used but no longer used injection drugs (compared with 45 percent of people who had never used injection drugs) and 73 percent of women (compared with 39 percent of men) said that their lives were better. Feelings about whether life had improved since contracting HIV were unrelated to stage of HIV disease, number of years since diagnosis, or whether the participants were receiving protease inhibitor therapy.

When asked whether they would exchange longevity for excellent health, 47 percent of participants indicated that they were unwilling to trade any life expectancy, and 14 percent said they were willing to trade, at most, nine days of life expectancy for excellent health. Factors unrelated to health that contributed to life-satisfaction and health values included spirituality and concern and love for one’s children.

Chronic HIV and Neurological Disorders


Disorders of the brain, spinal cord, and peripheral nerves may play an increasing role in HIV-related health and social service needs in the “chronic-treated” phase of the epidemic. Since HIV persists in the sanctuary of the central nervous systems of people under HIV antiviral treatment,
major disabilities such as cognitive impairment, dementia, walking difficulties, and chronic pain may undermine enjoyable and independent living.

One of the more common cognitive disorders is AIDS dementia complex, a disorder characterized by cognitive impairment, motor slowing, and affective impairment. Some virologic studies indicate that 20 percent of people with AIDS suffer from AIDS dementia, while 30 percent to 40 percent of them suffer from lesser forms of cognitive disorder. Observation in outpatient HIV care departments also reveals significant numbers of people with gait disorders, including painful limping, atactic gait that requires a cane, and weakness or paralysis that requires a wheelchair. The frequency of impaired gait among residents at one chronic care facility for persons with HIV was 46 percent.

Finally, according to a convenience sample in an HIV outpatient clinic, more than 40 percent of the consultations were for problems related to chronic pain. Roughly equal proportions of consultations concerned low back pain, vascular headache, and peripheral neuropathy. The acute and new onset of headache is of particular concern because of the vulnerability of people with HIV to meningitis, intracranial infections, and primary CNS lymphoma. Distal symmetric sensory peripheral neuropathy is found in 10 percent to 35 percent of people with advanced HIV, and pain occurs in 30 percent of people suffering from this form of neuropathy.

Managing Chronic HIV Infection
Gifford AL, Sengupta S. Self-management health education for chronic HIV infection. AIDS Care. 1999; 11(1): 115-130. (University of California, San Diego; and University of North Carolina, Chapel Hill.)

A study of a health education program found that active participation in HIV disease and symptom management led to changes in attitudes and behaviors. The Positive Self-Management Program (PSMP) applied social cognitive theory and principles of disease management to the challenges of chronic HIV: living with side effects and sustaining adherence. PSMP consisted of seven, weekly, two-and-a-half-hour sessions composed of 10 to 15 HIV-positive individuals and two trained leaders. Each participant completed questionnaires assessing symptoms and functional status both at baseline and at two months after PSMP completion. From the 71 PSMP participants, researchers selected a representative group of 33 subjects for program evaluation through telephone interviews; 24 subjects actually completed the evaluation. All participants interviewed were gay men and most were White and had health insurance.

Self-management approaches to chronic disease care recognize the central role of the person being treated, and the emergence of HIV as a chronic illness increases the need for people with HIV to be effective self-managers. Among the self-management skills people with HIV need are: the ability to use and adhere to complicated regimens, the ability to monitor symptoms and act on them appropriately, and the ability to participate in medical decisions with a clear understanding of risks and benefits.

More than half of participants interviewed identified contracting—the process of articulating, planning, and achieving specific goals—as the most helpful PSMP activity. The role of the group in providing interaction and support was highly praised, as were instructional materials and the resource book, which provided flow charts that helped evaluate the causes of common HIV-related symptoms. While many of the participants found the program to be thorough and informative, others indicated that the presentation was targeted toward “beginners” and suggested that offering both introductory and advanced courses may be more helpful. The program successfully demonstrated improved living skills and motivated participants to change poor attitudes and behaviors by helping them to better organize their time, set priorities, improve diet, rely less on doctors and more on self-management, and overcome fears about the future.

Next Month
The condom continues to represent the gold standard of HIV prevention. But no matter how effective, a condom that goes unused provides no protection at all. In the March issue of FOCUS, two authors offer perspectives on alternatives. Alex Carballo-Diéguez, PhD, Associate Professor of Clinical Psychology (in Psychiatry) at Columbia University, focuses on gay men, discussing microbicide development and acceptability, and the use of the female condom. Nancy Padian, PhD, Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences at the University of California San Francisco, discusses microbicide, female condom, and cervical cap use among women.
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