Of the many stresses that people with HIV disease endure, perhaps none has received less attention than the impact of serious financial loss and the psychological consequences of adjusting to a constricted standard of living. In developed countries, HIV disease has disabled people at relatively early points in their careers, particularly gay men, who are often without dependents and who have not made it a priority to acquire assets like life and disability insurance. In addition, as they lose their jobs, most people risk losing their medical insurance. People disabled by HIV disease face a dramatic change in standard of living, complicating their psychological adjustment to HIV disease and increasing stress.

Because much of benefits counseling involves a special body of knowledge, most providers will need to refer clients to benefits specialists. Nevertheless, it is important for therapists to understand the practical impact of these issues in order to handle the emotional responses of clients: fear of material loss, anger at “the system” for its inadequacies, feelings of dependency, and grief over the loss of future opportunities. This article describes the financial benefits available to people with HIV disease and portrays two clients—one with a stable work history and one without—and the likely benefits outcome for each.

The Benefits System

For clients with HIV disease, obtaining benefits in the United States is tricky for three reasons. First, the course of HIV disease is unpredictable, and a person may recover from a disabling, even life-threatening, condition and resume daily activities, or indeed, maintain “normal” functioning for many years.

Second, health care and income maintenance usually flows from a complicated system that integrates public and private benefits with each other in different combinations at different points during the course of disease and disability.

Finally, as HIV infection status is disclosed, access to some forms of private health, life, and disability insurance diminishes, ultimately frustrating efforts to protect or expand the restricted assets of people with HIV disease.

Most people in the U.S. are covered by private, employer-sponsored, health insurance. These benefits usually suffice until a person becomes too disabled to work, and it is at this point that the interaction between public and private benefits comes into play. Over time, however, most people disabled by HIV disease rely increasingly upon public benefits for health coverage and income maintenance.

Private Benefits

Health coverage comes in one of three forms of insurance:

- **Indemnity Plans**, like those run by Blue Cross or Prudential, reimburse providers or patients for specific forms of care, subject to certain limitations—for example pre-existing conditions and experimental treatments—and may also limit the share of the cost of services that they will pay.

- **Health Maintenance Organizations (HMOs)** provide all care through a single institution or through a finite network of physicians and hospitals. Treatment is rationed by a “primary care provider” whose referral is necessary for specialized services and procedures and who, in this way, limits the cost of care.
Money and death are old baggage. It’s easy to see why many of us postpone unlocking such heavy valises and the inevitable discovery of a Pandora’s box of fear, anger, desperation, and indecision. This is especially true in the context of HIV disease, where it becomes easier for clients to immerse themselves in immediate issues—treatment information, medical appointments, and social support—than to approach distant issues like these.

In such an atmosphere, it becomes the role of counselors to raise these issues early in the course of HIV disease. What financial resources can clients command once they become disabled? Under what circumstances can they continue to work, and what happens when they become unemployed? How will they adjust their lives to diminishing discretionary income, increasing medical costs, and the apparently remote possibility of losing the material goods that most of us take for granted?

How do clients want to orchestrate their dying if and when this end becomes inevitable? Who do they trust to represent their health interests when they are no longer conscious or mentally competent? What is the balance when they weigh quality of life with staying alive?

In this issue, John Yarling offers a detailed examination of private and public benefits available in the United States, and Susan Hunt defines, from a physician’s perspective, advance directives and durable powers of attorneys for health care and the issues they raise. Both articles offer ways of framing and answering these questions and provide the reader a sense of the technical information that practitioners will need to deliver the best care.

But it is in Pandora’s box that counselors will find their greatest ally: in some versions of the myth, Hope is mixed in with Hate, Envy, Revenge, and Greed. By presenting the weighty issues portrayed by Yarling and Hunt to clients early in the course of disease; by acknowledging the difficulty of dealing with the systems involved; and by giving clients the factual tools to master these systems and the time to explore them, counselors may preempt the worst of these plagues, transforming information into power, and power into hope.

**Self-Insurance Programs** are organized and paid for by businesses for their employees, are usually exempt from strict state regulations, and increasingly limit or exclude coverage for conditions such as HIV disease.

The following case example illustrates the benefits commonly available to clients who are employed at the time they become disabled with HIV disease.

Roger is a 35-year-old bank branch manager, who has worked for his employer for 10 years. Six months ago, Roger had a bout of *Pneumocystis carinii* pneumonia (PCP). After recovering, he returned to work on a part-time basis and recently resumed a full-time work schedule. In response to its planned acquisition by another firm, the bank has notified Roger that his branch will be closed and he will lose his job.

Roger is as concerned about his employer as he is about himself. Loyalty toward his employer, concern that his employer’s disability insurance rates will rise, and the belief that the layoff is justified by the company’s economic situation combine to make Roger feel uncomfortable about pursuing his legitimate benefits options. At the same time, Roger fears that his employer might resist helping him attain the benefits to which he is entitled due to disability.

In response to such feelings, counselors should first encourage clients to take control of the situation, and to focus on defining what they need rather than what their employers or colleagues need. Clients can then work to resolve feelings that may interfere with their satisfying these personal needs. It is important to note that while many people believe the company system is hostile, many employers are happy to work with employees to help them get the benefits they desire.

**Integration of Public and Private Benefits**

The Consolidated Omnibus Budget Reconciliation Act of 1985, or COBRA—which applies to employers with 20 or more employees—requires Roger’s company to offer to continue his health coverage for 18 months after job termination at Roger’s own expense, but at no more than 102 percent of his employer’s premium. Under COBRA, Roger has up to 60 days to exercise these rights.

In addition, under the 1990 Omnibus Budget Reconciliation Act (or OBRA), people like Roger who leave work due to disabling conditions may extend coverage for an additional 11 months at a cost of 150 percent of their employer’s premium.
Using COBRA and OBRA, disabled people may extend coverage for a total of 29 months, the time that must elapse before they qualify for Medicare.

Since Roger's medical condition is considered disabling, he may discontinue his employment due to disability. This option permits him to extend his health coverage using COBRA and OBRA to ensure continuity with the federal Medicare program. It allows him to qualify for benefits through his state's disability insurance program, a level of benefits higher than that for which he would have qualified through the unemployment insurance compensation program if he had been laid off from his job. Roger also gains access to the disability retirement benefits offered by his employer.

Under the provisions of Title II of the Social Security Act, Roger is also entitled to income benefits from the Social Security tax fund. Social Security Disability Insurance (SSDI) benefits are available, following a five-month, non-payment waiting period, to disabled people who have made sufficient payments into the tax fund. Everyone in the U.S. who works, except federal employees, pay into the tax fund; however, for people with low earnings, the resulting SSDI benefits may be inadequate.

To apply for these benefits, Roger must have stopped working—though he need not have formally “terminated” employment—and must establish through medical records the point at which he became disabled. If he elects to leave work due to disability, Roger should initiate the Social Security claims process as early as he can. Even though benefits may not be distributed to him for some time, his certificate of disability will be needed for his COBRA and OBRA extensions. He will also be required by his employer-sponsored disability income program to prove that he has applied for Social Security disability benefits and the amount he will receive.

In addition, Roger may be eligible to convert his employer-sponsored life insurance policy to individual coverage, and he may be able to attain a “waiver of premium.” Roger has 31 days to make this conversion if his employer's policy permits it. In order to apply for this benefit, Roger should write a letter to his employer including evidence of his disability. If Roger has the option to convert his group life coverage to an individual policy, he may later be able to sell, or “viaticate,” his insurance either to the company that issued the policy or to a broker.

Roger's options would be substantially inferior if his employer had fewer than 20 employees. He would not be covered by COBRA: while he could convert his group health coverage to an individual policy, his coverage could be significantly reduced or limited and his premiums could be subject to unlimited increases.

Public Benefits

During the earliest phase of the AIDS epidemic, nearly 80 percent of HIV-related care was financed by the private sector. Today, three factors are changing this situation: the epidemic is increasingly affecting the poor, under employed, and unemployed; people are living long enough first to lose their jobs and then to spend down their financial resources; and as treatment becomes more varied, available, and expensive, public benefits are becoming central to HIV-related care.

The following case example illustrates the benefits available to disabled clients who must rely on the public sector.

Charles is 27 years old and has lived for three years without steady employment or housing. He experiences repeated bouts of irrational behavior, which—complicated by alcoholism—include hallucinations, paranoia, and extreme emotional outbursts of verbal and physical anger. His health has rapidly deteriorated since Kaposi's sarcoma has spread to his throat and lungs. He has appeared twice at a local public hospital's AIDS clinic but has not kept medical appointments and has received no regular care.

When Charles comes in for counseling, managing a life on the streets is about all he can handle. His mental status is seriously compromised, and his poor memory has made it difficult for him not only to maintain his health care, but also to pay his rent on time. Like many other people who live on the streets, Charles's time is controlled by other forces, for example, getting to a soup kitchen or to a shelter. Charles's desire for immediate services may be the biggest challenge for counselors, since agencies and physicians will require him to be punctual and available.

Because Charles has no recent history of stable employment, his only options

Benefits are not gifts or acts of charity. They are property to which people with HIV disease are entitled and for which they are responsible to use and protect.

*Six states—California, Hawaii, New Jersey, New York, Puerto Rico, and Rhode Island—have state disability programs, all of which provide benefits better than unemployment compensation.

†While they must disclose COBRA-related information to their employees, employers are not required to disclose information regarding other benefits, such as OBRA and “waivers of premiums.”
for public support are his state or county’s General Assistance (GA) program and the Supplemental Security Income (SSI) program. GA, which is available in some states, is meant as a temporary economic bridge toward employment for people with low income and assets, and is less useful as a bridge from employment to disability. Unlike SSI, GA does not include medical coverage, its payments are low and often time-limited, and it may impose work-related requirements. Charles can use GA as a bridge until he begins to receive SSI; he cannot receive both at the same time.

SSI can supplement low SSDI payments for retirees and disabled people, or can be the only source of federal support for disabled people with little or no earnings history or significant assets. Both SSI and SSDI are administered by the Social Security Administration (SSA), which defines disability as being unable to perform work for a period of 12 months or longer. Recipients of SSI also automatically qualify for health services financed by Medicaid.

SSI differs from SSDI in terms of important eligibility standards. For example, SSDI does not consider an applicant’s income or assets as a condition of eligibility. SSI, however, limits assistance to individuals with very low income and assets.

Social Security Regulations

For people like Charles, who experience severe mental impairment or who have lacked consistent medical care, getting Social Security benefits, particularly “presumptive eligibility,” may be difficult, especially in light of recent changes in regulations. The SSA grants presumptive eligibility—that is, expedited benefits within approximately six weeks—to some people with serious medical conditions. It then continues to collect evidence over six months to confirm that presumptively eligible people are in fact disabled.

To qualify for presumptive eligibility, applicants must present evidence of an AIDS “indicator” disease (as defined by the SSA and not the Centers for Disease Control). Failing this, applicants must present a combination of disease, immune system deterioration, and marked limitation in their abilities to carry out daily activities.

Because the criteria to categorize these limitations are subjective, and because many providers lack a long-term medical relationship with their clients, it may be difficult to sufficiently document these functional limitations. Further, with regard to Charles’s case, SSA no longer considers KS to be an indicator disease.

Conclusion

Navigating among the holes in the so-called “safety net” is a difficult process. Many benefits are “perishable,” so clients must exercise benefits rights in a specified and often short period of time or they will lose them. One means of helping clients through this process is to expose them to people who can share knowledge and experience negotiating the benefits system. Most of all, people with HIV disease must learn that the benefits for which they are eligible belong to them; they are not gifts or acts of charity, but in every way property to which they are entitled and for which they are responsible for using and protecting.

Clearinghouse: Benefits and Documents

While little has been published in professional journals regarding benefits, documents, and counseling about these issues for people with HIV disease, several books, pamphlets, are available.

References and Special Publications


Advance Directives
Susan Hunt, MD

People facing serious illness appropriately focus most of their attention on seeking medical treatment and emotional support—actions that are firmly connected to the present and to overcoming illness. However, as part of our increasing understanding that optimal medical care does not always entail the automatic and unlimited use of medical technology, the United States Congress enacted, effective December 1991, the Patient Self-Determination Act. This act requires hospitals, nursing homes, and hospices to inform patients on admission of their rights to accept or refuse medical care, and to formulate advance directives.

An advance directive is a tool that enables patients to decide upon the range and magnitude of medical care they will accept, and, as a written statement of future medical preferences, ensures that their wishes will be honored even if they become unable to communicate them. Although specific legislation varies from state to state, congressional action on this issue represents a societal acknowledgment that patients mean when they describe these preferences. In formulating advanced documents such as the advance directive and the durable power of attorney for health care deserve attention while patients are still relatively healthy. This article examines the formulation of these documents for people with HIV disease.

An advance directive—also known as a medical directive or living will—may take several forms, ranging from a description of general preferences to a specific check list of interventions that a patient would choose when faced with terminal illness or irreversible mental incapacity. Companion to the advance directive is the durable power of attorney for health care. This document allows a patient to designate a “health care proxy” or “surrogate decision maker” to make medical decisions for the patient in case of future incapacity and to ensure the implementation of the patient’s advance directive.

Formulating Documents
The formulation of these documents is an integral part of the physician-patient relationship, and should begin at the initial outpatient visit. Postponing these documents until a patient’s hospitalization is the equivalent of deliberately choosing an emergency procedure over a carefully planned elective one.

Discussion about these issues may be initiated by asking patients if they have lost anyone to AIDS or if they foresee a time when they might want to limit medical intervention. The initial conversation serves as a point for patients to begin thinking about preferences, and for their physicians to begin to understand what patients mean when they describe these preferences. In formulating advanced

During the course of HIV disease, patients develop new insights in response to ever changing conditions. Advance directives must reflect this evolution.


Wood GJ, Marks R, Dilley JW. AIDS Law for Mental Health Professionals (Updated Version). San Francisco: UCSF AIDS Health Project, 1992. To order the 306-page book, send $19.95 (California residents include 8.25 percent tax) plus $3.00 shipping and handling to: UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884, or call (415) 476-6842.

Contacts
John Darragh, 723 Humboldt Street, Santa Rosa, CA 95404, (707) 579-5303. To receive a list of vithal companies, a copy of the article by David Petersen summarized in Recent Reports, and other materials, send a self-addressed stamped envelope with your request.

Susan Hunt, MD, Pittsburgh AIDS Center for Treatment, c/o Presbyterian University Hospital, University of Pittsburgh, DeSoto and O’Hara Streets, Pittsburgh, PA 15213-2582, (412) 647-7228.

David Petersen, 429 East 52nd Street, Apartment 4G, New York, NY 10022-6431, (212) 371-4741.

Social Security Administration, 800-772-1213. Available between the hours of 7:00 AM and 7:00 PM. In addition to providing general information on SSA programs, operators can make appointments for applications, determine what benefits are available to callers, or clarify the status of particular claims.


See also Recent Reports cited in this issue.
directives, patients should consider, for example, the point at which they would rather die than be maintained on life support, procedures they would consider to be too invasive, and the quality of life they would accept over death.

Traditionally, advance directives are defined in terms of what is not desired, for example, “No CPR” or “Do Not Resuscitate.” Equally important are discussions and instructions about what patients do want. For example, some people with HIV disease prefer to die at home, even if it means foregoing hospital-based medical interventions. Others want to ensure that they receive adequate pain medication if and when they need it.

Discussions about advance directives should occur as dialogues. Instead of simply recording patient preferences, physicians should play an active role in helping patients clarify choices and understanding the implications of these choices. Mental health providers may play a key role in encouraging patients to participate in these discussions and providing psychological support for tackling the difficult issues involved.

A person with HIV disease may have a significant other who is not a legal spouse. For such a patient, the legal designation of a surrogate is particularly important, since an unmarried partner may not be recognized by the patient’s blood relatives. A patient without a partner may designate a close friend or relative as surrogate. The patient should discuss his or her medical preferences with the surrogate, and it may be helpful for the surrogate to accompany the patient to meet the patient’s physician before there is a medical crisis.

**Resolving a Medical Crisis**

It is critical to remember that the formulation of advance directives is an ongoing process. During the course of HIV infection, patients develop new insights in response to ever changing circumstances, and advance directives must reflect this evolution. The value of such ongoing discussions is clear from the following case.

After recovering from two occurrences of *Pneumocystis carinii* pneumonia, Tom, 28, told his doctor, Hazel Musick, on several occasions that he preferred no intubation in the case of a recurrence. Near the end of his illness, Tom was admitted to the hospital with respiratory failure and faced intubation or death. He was awake and alert, and he told Dr. Musick that he was too frightened to make any decisions. Dr. Musick told Tom that, although he always had the option to change his mind, on the basis of their earlier discussions, she thought that he would prefer to avoid intubation. Tom thought for a while, and then said, yes, that had been his preference, and he wanted no intubation now.

The long-term relationship and communication between doctor and patient allowed Dr. Musick to remind Tom what he had told her. In this way, she was able to provide support for his making his own decision at a critical moment.

**Hard Decisions**

Both patients and practitioners face challenges in formulating and implementing these documents. For patients, advance directives are obviously complicated by the inherent difficulty of understanding options and making choices in the present for future medical circumstances. For patients, surrogates, and providers, subjective and value-laden terms frequently used to describe medical situations or interventions—“hopeless” and “extraordinary”—may become difficult to interpret.

Physicians may not always be in agreement with advance directives. They may anguish over their patients’ suffering when patients choose aggressive medical interventions, or they may wish to treat conditions more aggressively than directives allow. Ongoing dialogue about advance directives, however, can ensure that patient preferences are clearly understood, that documents are insightfully and carefully prepared, and that wishes are faithfully carried out.

In the end issues regarding advance directives remain complex, but this must be so. Any attempt to make these decisions overly simple risks diminishing the value and complexity of human life, and the importance of human choices.

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**Comments and Submissions**

We 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, including a summary of the idea and a detailed outline of the article. Send correspondence to:

Editor, *FOCUS*
UCSF AIDS Health Project, Box 0884
San Francisco, CA 94143-0884
Income from Sale of Life Insurance Policies

Petersen D. Viatical settlements: Living benefits for the insured, terminally ill patient. The Bulletin (New York City Association of Life Underwriters). April 1991: 1-4. [Privately revised May 1992; see Clearinghouse for information on how to receive this article.]

In 1989, companies began to purchase life insurance policies from the terminally ill to allow them to collect benefits before they died. This new industry offered cash—a "viatical settlement"—in return for being named the irrevocable beneficiary of a life insurance policy. Viatical settlements offer people with HIV disease disposable income that would otherwise accrue to their beneficiaries.

Viatical companies typically purchase life insurance policies at 60 to 80 percent of face value; this payment increases if life expectancy is shorter. Companies generally acquire policies valued at $50,000 to $500,000 and are reluctant to buy a policy if minor children or other dependents are reliant on the policyholder for financial support.

To meet the requirements of a viatical settlement, terminally ill people must release their medical records for review to the viatical company, which will use these records to estimate life expectancy. Group life insurance coverage can be viaticated only after it has been converted to an individual policy, but some group policies preclude viatication. The entire viatication process can take three to four months.

Viatical settlements are considered taxable income. Receiving a viatical settlement also disqualifies recipients from any means-based entitlements such as Medicaid or Supplemental Security Income.

More than 90 percent of the policies purchased in 1991—an estimated value of $100 million—were purchased from people with AIDS. For individuals who have no disability insurance but substantial life insurance, viatical settlement is a good option. Viatical settlements should be distinguished from accelerated benefits, by which terminally ill people can receive proceeds, based on the value of their life insurance, directly from their insurers. Accelerated benefits offer a much better income option, and terminally ill people should investigate loans from personal friends or their policy beneficiaries, and other alternative sources of money, before selling their life insurance policies.

Catastrophic Financial Loss


Catastrophic financial loss led to major depressive disorder and general anxiety disorder as defined by standard diagnostic criteria (DSM-III), according to a controlled study of people who lost significant assets as a result of bank fraud. Subsequent to the loss, few of the subjects sought out or received mental health care.

Researchers interviewed 72 people out of 113—whose average age was 54—who lost their retirement savings. During the first 16 to 20 months following the financial loss, 29 percent reported major depression; among 48 percent of respondents, the episode lasted more than six months. Twenty-seven percent experienced generalized anxiety disorder. Subjects rated themselves as being less healthy than members of a control group. Subjects also reported more tranquilizer use and functional bodily complaints including headaches, heart palpitations, and chest pain than control group members.

Although the results may be biased because of low response rate, the study demonstrates a causal relationship between catastrophic financial loss and two mental disorders. The researchers noted that the financial loss may have had a more powerful depressive effect on those subjects who felt guilty and blamed themselves for causing the loss. But those who became depressed were just as likely to seek social support and to use other coping mechanisms as were respondents who did not report depression.

Women and Disability

McGovern T, Stoll K, Williams S, et al. What you will need to prove disability. WORLD. 1992; No. 13: 4-5. [To receive this article and a free subscription to WORLD write: P.O. Box 11535, Oakland, CA 94611, (510) 658-6930.]

New Social Security regulations governing HIV-related disability benefits may not make it easier for women and children to qualify. Issued in December 1991, the regulations were developed in response to...
Concerns that women, injection drug users, people of color, and poor people were not properly served by the AIDS definition used by the regulations.

The new regulations provide a list of medical criteria that, if met, automatically qualify applicants for benefits. The criteria include only a few of the HIV-related conditions that primarily affect women and children, and discriminate against low-income applicants for the requirement for extensive documentation.

Living Wills


The fact that HIV disease is not considered a terminal illness in more than half of U.S. states makes it difficult for HIV-infected people to implement living wills. According to a review of the U.S. law surrounding this issue, the right to refuse treatment is often related to whether refusal is in response to a terminal illness, and, surprisingly, people with HIV disease face a great challenge proving that HIV disease is terminal. If they cannot, states may stop the implementation of their living wills.

Statutory definitions of what constitutes a terminal condition and a life-sustaining treatment tend to be circular. In most statutes, withdrawal or withholding of life-sustaining treatment can proceed only after several physicians certify that the person is in a terminal condition. A condition is defined as terminal only if “life-sustaining procedures” are employed to postpone the moment of death but do not improve life. Many common HIV-related treatments do not meet this definition.

Many HIV-related treatments do not meet other aspects of these definitions. In 11 states a life-sustaining procedure is defined as that which “sustains, restores, or supplants a vital function.” Medication is specifically excluded from these definitions in 19 states and the District of Columbia. HIV disease is not considered terminal in 11 states because death must be “imminent,” and recovery from opportunistic infections occurs too often to meet this requirement.

The courts, however, have frequently defined the right to die in broader terms than a strict interpretation of state statutes would imply. Case law, based on judicial decisions, has tended to be more flexible than statutory law. The courts have viewed the right to die in terms of the individual’s right to privacy versus the state’s need to prevent suicide, protect third parties, maintain the integrity of the medical profession, and preserve life. They have used the state’s right to prevent suicide as a means of investigating the motives of those rejecting treatments and have ruled against withdrawal of treatment if such a decision appears to be irrational.

The courts appear to be moving toward expanding privacy rights by letting mentally incompetent as well as competent patients die. Family members and patient-designated medical decision makers are being allowed to decide to withdraw treatment. The 1990 Supreme Court decision in Cruzan v. Harmon established a patient’s right to die if there is clear and convincing evidence that the patient would forgo treatment if mentally competent. This “substituted judgment test” and the "best interests approach”—by which the court makes decisions based on the best interests of the patient—mark an expansive trend in the law that may make it easier for people with HIV disease to have their living wills implemented.

Next Month

The Centers for Disease Control recently ended with a resounding squeak the roller coaster ride regarding the AIDS definition. After months of waffling, the definition remains the same. This experience and others like it—where HIV-infected people are subjected to quickly changing research, treatment, and policy information—force people to change their conceptions about HIV disease again and again. In the August issue of FOCUS, James W. Dilley, MD, Director of the AIDS Health Project and Associate Clinical Professor of Psychiatry at the University of California San Francisco, and Robert Marks, Editor of FOCUS, explore the psychological response to this constant change.

While the AIDS definition remains the same, the CDC’s actions reinforce the significance of T-helper cell testing and early intervention. Also in the August issue, Richard DiGirola, MD, a physician in private practice and co-chair of the AIDS Advisory Committee of the Washington, DC Commission of Public Health, outlines early intervention recommendations and approaches.
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