Financing the Care of Patients with the Acquired Immunodeficiency Syndrome (AIDS)

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The problem of financing care for patients with the acquired immunodeficiency syndrome (AIDS) and other illnesses resulting from the human immunodeficiency virus (HIV) is symptomatic of the larger problems of financing health care in this country. Although most often the term “patients with AIDS” is used in this paper for simplification, our statements and recommendations apply to patients with all HIV-associated illnesses. The AIDS crisis places in bold relief inadequacies that are felt throughout our health system, such as inadequate care for persons who have neither private nor public coverage, limited access of the poor to care, inadequate funding for preventive health measures, insufficient home health care and other alternatives to institutionalization, and inadequate care for the chronically ill. If solutions to these more general problems were formulated by our society, they would contribute significantly to resolution of the specific challenges posed by the AIDS epidemic.

The American College of Physicians is hesitant to single out a disease for policy purposes from the many other devastating diseases that cause large numbers of deaths and disabilities. Cancer, for example, can progress rapidly and leave a patient who has no Medicare or private health coverage without the means of paying for care, except by becoming impoverished to qualify for Medicaid. We believe that all Americans should have access to high-quality care in an appropriate and cost-effective setting, whoever the patient or whatever the disease. Nonetheless, because we cannot assure that kind of care now and because of the severe dislocative impact that AIDS is having on the population and on the provision of health care—particularly in certain areas—we feel it is necessary to make recommendations on the question of financing care for patients with AIDS. These recommendations can point the way to further steps to provide all Americans with access to care. Perhaps the urgency of the need to respond to the AIDS epidemic will move the nation in that direction.

General Principle

The American College of Physicians believes that the AIDS crisis demands a spreading of responsibility and financial risk. For this reason, we recommend that a national policy be developed that uses all existing mechanisms for health coverage but adds appropriate new authority and resources to those mechanisms, so that each patient with AIDS has coverage for health care provided in the most efficient way possible throughout the course of his or her illness.

Several elements of this principle are important:

1. We believe that care should be financed largely through the existing mechanisms of employer-provided coverage, individual health policies, Medicare and Medicaid, and public health programs. That is, while policy direction from the national level is essential, implementation and financing will depend on all levels of government and the private sector.

2. Although these existing mechanisms can form the basis for financing the cost of caring for patients with AIDS, inadequacies in all of these mechanisms must be corrected through legislative or regulatory action and modifications to insurance policies. New resources will be necessary at all levels.

3. We believe that each patient with AIDS should have coverage for appropriate care from one or more financing sources, and that mechanisms should be developed to assure that patients take advantage of whatever health coverage is available to them.

4. Care must be provided in the most efficient manner possible, building on a network of professional and voluntary organizations, both public and private, and incorporating the best approaches to community-based care.

5. Strong central direction will be needed to develop and coordinate implementation of necessary improvements in each component of the health system.

We believe that this approach has the advantage of not requiring a massive infusion of money from any single source. Care for patients with AIDS will require large amounts of money—$8 billion to $16 billion per year by 1991 for medical care alone, according to Public Health Service estimates (1). Our recommendations to strengthen existing mechanisms will spread the increased cost of providing care among private entities, all levels of government, and patients themselves.

Finally, the additional resources necessary for the care of patients with AIDS must not be at the expense of existing health programs. We are particularly concerned about Medicaid, which now finances care for about 40%

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of patients with AIDS at an estimated federal and state cost of $400 million for fiscal year 1987 (2). Adequate financing must be available for existing services, and new resources must be made available for the care of patients with AIDS. We will oppose any effort to divert existing funds from current Medicaid beneficiaries (for example, high-risk mothers and infants) or any other health program.

Components of Financing Care for AIDS

Because our recommendations depend on the pluralistic, decentralized system of health financing in this country, coordinated planning and implementation will be needed. Actions to weave all the components together to deliver and finance care for patients with AIDS must be taken by many people and organizations at many levels, including public and private payers, all levels of government, a wide array of health care providers, patients, employers, community organizations, and others. For this approach to work, we believe it requires direction at the national level, which could be provided by the existing Presidential Commission on the HIV Epidemic or by another entity. The issue of financing is expected to be considered by the Commission (3). This body would be charged with identifying weaknesses in each of the health financing components, developing recommendations to correct these problems, and promoting and overseeing implementation of those recommendations. Strong leadership will be necessary to bring about the concerted action of all levels of government and the private sector.

To provide some direction to this approach, the College has formulated recommendations to strengthen each of the major components of our health financing system: employer-provided group coverage, individual coverage, Medicaid, Medicare, and public health support. Some of these recommendations will require federal legislative changes, others will require state legislation, and still others will depend on action by the private sector (for example, employers and insurance companies). The College is ready to work with public and private leaders to explore these and other alternatives in crafting a national strategy.

We recognize and are encouraged that several initiatives have been undertaken recently to improve AIDS financing. Some of these are similar to recommendations made in this paper. In particular, the five states with the highest incidence have appropriated state money for patient care, as well as for education and prevention, surveillance, research, and other AIDS activities (4). These and other initiatives, which have been surveyed and described in the excellent work of the Intergovernmental Health Policy Project at George Washington University, will serve as important learning experiences in developing a coherent national strategy (5).

EMPLOYER-PROVIDED GROUP COVERAGE

Our recommendations for improvements in employer-provided coverage apply to all mechanisms of providing coverage, including self-insurance. They are:

1. Restructure policies to improve coverage for care that is more appropriate for AIDS and may be less expensive (for example, home health care, skilled nursing and intermediate level care, custodial care at home or in an institution, and hospice services). A case-management approach may be useful in directing patients to appropriate care.

2. Employers should neither condone mandatory HIV testing nor deny coverage or drop from coverage employees who may be HIV-positive.

3. Increase the period for the extension of coverage mandated by the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 (P.L. 99-272, Title X), in which an employee leaving work can pay the group-rate premium for up to 18 months of additional coverage. If the 24-month waiting period before a Social Security disability recipient is eligible for Medicare is not lowered, then the COBRA extension should be for at least 24 months to prevent a gap in coverage.

4. Provide government subsidies for the premium of a person exercising the COBRA extension, based on income and resources, so that the person does not lose the coverage because he or she cannot afford the premium.

INDIVIDUAL COVERAGE

1. Provide incentives through the tax system or other favorable treatment for insurers to increase the availability of community-rated, open-enrollment policies. Premiums can be subsidized so that lower-income individuals can purchase these policies.

2. Protect the financial integrity of these insurers from adverse selection, either through direct government assistance or through a system of spreading costs to other insurers, including consideration of the use of reinsurance.

3. Increase the availability of risk pools to spread the insurance cost of covering individuals who are otherwise medically uninsurable, including patients with AIDS or AIDS-related complex and HIV-positive persons, and others who cannot obtain insurance. States should take necessary steps to establish risk pools, and the federal government should promote their development through actions such as legislation that allows states to include self-insured employers currently exempted by the Employee Retirement Income Security Act, as well as employers with no health coverage. Legislation to establish risk pools has been enacted in 15 states, although not all had been implemented by the end of 1987; they cover a small fraction of uninsured individuals: approximately 21,000 persons in six of the fully operational plans as of mid-1986 (5). Patients with AIDS can be assisted through such actions as preferential treatment for eligibility and subsidized premiums based on income. The Minnesota and Oregon risk pools have granted "presumptive eligibility" to patients with AIDS; Wisconsin is the only state to subsidize premiums; this assistance is not limited to patients with AIDS (5). Governments should consider assistance for losses incurred by the pool, and the feasibility of a national risk pool should be studied.

4. Provide federal, or state assistance, or both for the purchase of private catastrophic illness coverage.
5. Prohibit denial of insurance, under either individual or group policies, on the basis that an individual is thought to be at risk for becoming infected by HIV.

MEDICAID
1. Increase the use of the Medicaid waiver authority, which allows states to target patients with AIDS for a wide range of home- and community-based services that can constitute appropriate and cost-effective care. New Jersey was the first state to be approved for a waiver to provide home- and community-based services for patients with AIDS and AIDS-related complex who would otherwise require institutional care; New Mexico also has an approved program, and several states are developing applications (5).

2. Increase the federal matching share for the cost of Medicaid services to patients with AIDS and the AIDS-related complex to relieve the financial burden on states with the highest incidence. This recommendation will help to protect Medicaid resources for other beneficiaries, as discussed previously.

3. Allow patients whose income is above the eligibility standard, but below a specified level, to “buy into” Medicaid or to a catastrophic illness protection under Medicaid.

4. States should use existing Medicaid authority for “enhanced reimbursement” to provide new or more intensive services that will be of help to patients with AIDS and other beneficiaries. Florida, for example, has created a higher level of Skilled Nursing Facility care, doubling its Medicaid reimbursement to nursing homes accepting patients with AIDS (5).

5. Continue to examine regulations regarding HIV-associated conditions that qualify a person to be considered “presumptively disabled” and therefore eligible for Supplemental Security Income/Medicaid, bypassing the usual process for determination of disability. The Social Security Administration revised its regulations on presumptive disability in September 1987 immediately after the Centers for Disease Control broadened the definition of AIDS to include two conditions previously considered to be AIDS-related complex (6).

MEDICARE
1. Shorten the 24-month waiting period before a recipient of Social Security Disability Insurance can receive Medicare coverage.

2. Continue to examine regulations regarding HIV-associated conditions that qualify a person to be considered “presumptively disabled” and therefore eligible for Social Security Disability Insurance, bypassing the usual process for determination of disability.

PUBLIC HEALTH SUPPORT (FEDERAL, STATE, AND LOCAL)
1. Provide incentive payments to facilities initiating or expanding services to patients with AIDS, especially for areas of service in which the greatest inadequacies exist, such as community care, psychiatric support, long-term care, and housing.

2. Explore ways in which existing public health grant programs can be used for AIDS and areas in which additional resources are necessary, such as the block grants for maternal and child health, preventive health, and alcoholism, drug abuse, and mental health.

3. Provide assistance to public hospitals in which large numbers of patients with AIDS and other HIV-associated conditions who do not have health coverage are being cared for, through either direct grants or the provision of risk-pool or other insurance to individuals. A survey of 169 hospitals reporting treatment of patients with AIDS found that 61% of almost 5400 cases were cared for in public hospitals (7).

4. Provide support for the training of counselors, care givers, and others providing services to patients with AIDS.

5. Provide support for case management to assure that patients take advantage of health coverage available to them and receive appropriate medical and nonmedical services.

6. Provide assistance to volunteer organizations that are serving the health and nonhealth needs of patients with AIDS.

7. Provide assistance to adapt the successful components of the San Francisco network of services to other areas and other patient populations.

8. Some of the activities identified in this section are or can be appropriate initiatives for private foundations and other charitable institutions.

CONCLUSION
The College believes that there is no single solution to the problem of financing care for patients with AIDS. The proposals that we have presented can be implemented without a radical alteration of our existing health system. They require relatively modest steps to strengthen existing mechanisms of health care financing. They have the further advantage of providing flexibility to take into account variations across the country in the size of the caseload, different kinds of patients with AIDS who have different manifestations of the disease, the availability of community resources, and other relevant factors. With commitment, ingenuity, and strong central leadership, a coherent national strategy can be developed to assure that all patients have access to care and that financing is available from appropriate sources.

We have chosen to focus our recommendations on financing for health care and have not discussed financing for research and for education and prevention activities. (Priorities for research are discussed in the accompanying paper, “The Acquired Immunodeficiency Syndrome (AIDS) and Infection with the Human Immunodeficiency Virus (HIV)” [8]). We are supportive of all appropriate and cost-effective activities in these areas. The federal government has responded, particularly in biomedical research, and funding now approaches $1 billion. Much more needs to be done by all levels of government and the private sector to expand educational and preventive health initiatives to stop the spread of HIV infection.
Finally, we note that physicians can play an important role in solving the problem of financing the care of patients with AIDS. Physicians should be aggressive about developing and using cost-effective mechanisms of care. As much as possible, they should shift care away from over-burdened public facilities. Patients with AIDS should not be relegated to a small number of physicians practicing in a limited number of health facilities. Physicians should be aware that many patients will not have health coverage and may not be able to pay fully for their care.

The approach we have outlined would help resolve the problem of financing the cost of caring for patients with AIDS. It bears repeating, however, that we are uncomfortable making recommendations for a specific disease and have done so only because of the enormous and growing impact of AIDS on health care delivery. The disease dramatically illustrates the inadequacies of our patchwork system of financing health care. We believe the nation must assure care for all patients, regardless of their disease. Perhaps the current crisis will serve as the crucible in which we can search for and test means of extending health coverage to all of our citizens.

References