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This article presents an overview of cost issues related to AIDS. Data from the Massachusetts Cost of AIDS Study are combined with epidemiological projections to estimate the cost of treating people diagnosed with AIDS in New England. Aggregate inpatient, ambulatory, and home care costs are estimated to be $96.9 million and $524.8 million through 1987 and 1991, respectively. These estimates represent a relatively small percentage of total health care costs for all illnesses over the same time period.

The authors find that the cost of treating AIDS does not affect all health care providers uniformly and therefore argue that appropriate measures must be developed to assist those impacted disproportionately. Reduction of inpatient hospital days through the creation of subacute care centers, subsidy programs for medical care providers serving large numbers of uninsured or underinsured AIDS patients and education to prevent new cases are recommended to continue the availability of medical care for people with AIDS.

The rapidly growing number of AIDS cases in the United States has generated an increased interest in the cost of treating patients with HIV infection. Projections of future cases — the number is expected to exceed 270,000 for the nation as a whole by 1991 — are a warning to legislators, insurers, employers, health care and policy planners, hospital administrators, private practitioners, and health care activists to prepare for the economic impact of AIDS.[1] One of the most frequent questions asked of public health officials regarding treatment programs for people with AIDS is, How much will it cost?

The health care needs of people with AIDS are usually considered from the perspective either of cost or of utilization. With regard to cost, the key questions are, How much will it cost? Who will pay the cost? To what extent can society afford to pay the cost? From the perspective of utilization, the important issues are related to the availability of resources: What types of resources do AIDS patients need? Are these resources available currently? Will they be available to meet future demand?

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Questions about cost and utilization of services merge in the areas of planning and budgeting. While there is little doubt that the resource utilization and the accompanying cost of treating people with AIDS are large and will get significantly larger, it is also likely that, given adequate planning, cost-effective resources can be identified to meet this need.

In this article, the authors stress that information about cost is critical to planning for the provision of AIDS care. The text is divided into three main sections. The first section reviews information currently available on the cost of services in New England, specifically in Massachusetts. Inpatient, ambulatory, and home care costs are described. The indirect costs of care are discussed. These indirect costs include some hidden costs that may represent the largest costs of the epidemic. Changes in the cost of treating people with AIDS are discussed. The section concludes with estimates of the cost of treating AIDS in New England up to 1988 and cumulatively through 1991.

The second section describes the payer mix of AIDS patients and the anticipated impact of the projected AIDS crisis on each type of payer. People with AIDS must do battle with private and public insurance programs to receive coverage for their care. Public and private insurers, as well as hospitals providing free care, struggle to act responsibly in the face of this epidemic without overextending themselves financially.

The third section discusses the implications of health care costs in planning for the provision of health care for people with AIDS. The section addresses issues of insurability, cost containment, and prevention, and targets specific areas where planning is necessary to provide humane, comprehensive, and quality care to persons with AIDS.

The Cost of Treating Patients with AIDS

The initial report on the cost of treating patients with AIDS estimated a cost of $147,000 per patient.[2] Subsequent studies in San Francisco and Massachusetts found that medical care costs were significantly lower.[3, 4] A review of cost studies by the federal Office for Information Technology reported lower costs in studies from Maryland, New York, New Mexico, Alabama, Minnesota, Florida, and California.[5] Research from a hospital in Virginia[6] and the first two national studies with a wide sample of data[7, 8] provide further confirmation that direct medical care costs are lower than the initial estimate, probably in the range of $20,000 to $60,000.

Cost in Massachusetts

In Massachusetts, a study to determine the costs of treating AIDS was begun in February 1985. The study was sponsored by the state Department of Public Health and was conducted by the public health AIDS program of the Boston Department of Health and Hospitals. In that study, the authors of this article and their colleagues evaluated forty-five AIDS patients seen at the New England Deaconess Hospital between March 1984 and February 1985.[9]

Inpatient and outpatient medical and billing records were reviewed to obtain cost, utilization, and demographic data. Data from the Massachusetts Rate Setting Commission were used to convert inpatient charges to costs. Charges for ambulatory care were converted to costs through the use of Blue Cross customary reimbursement rates.

On the basis of these data, the researchers calculated an average hospitalization cost of $14,189 and an average length of stay of 21 days per hospitalization. To answer a variety

of questions, the authors also calculated cost per patient per annum (twelve-month period) as $46,505, and costs per case, from diagnosis to death, as $50,380.[10]

Analyses of the data also yielded the number of hospitalizations per patient as 1.6; hospitalizations per patient per annum, 3.3; hospital days per patient, 33; and hospital days per patient per annum, 62.

Components of Inpatient and Ambulatory Care

In the aforementioned cost study, the researchers analyzed the components of inpatient and ambulatory care to determine where the medical expenses of treating AIDS patients are concentrated. The results of this analysis (table 1) show that inpatient costs, constituting 89 percent of total costs incurred by AIDS patients, are dramatically higher than ambulatory costs.

Total ancillary services, including laboratory services, were responsible for 47.9 percent of all inpatient care costs for the patients with AIDS studied. This percentage for ancillary services is not unusual for patient care costs generally. However, the high laboratory component of ancillary services is greater for AIDS patients than for non-AIDS patients. Room and board (routine and intensive care) and laboratory services comprised the two largest categories of cost, representing 45 and 22 percent, respectively, of total inpatient care costs.

Cost for laboratory services and cost of professional services accounted for 56 and 16.9 percent, respectively, of all ambulatory care costs. The large percentage of cost in laboratory services is related to the close monitoring of patients' immune status for diagnostic and palliative purposes.

Home Care and Support Services

Very few studies have analyzed both the cost and the cost-effectiveness of services that allow people with AIDS to spend more time at home and, presumably, less time in acute care settings. However, a study of thirty-seven pediatric AIDS cases in New York City identified 1,909 hospital days that the researchers labeled "social admissions" — that is, patient days in acute inpatient care facilities resulting from lack of appropriate available placement.[11] These so-called social admissions represented 31.2 percent of hospital days for this cohort of pediatric AIDS cases. Thus, if adequate services were available outside the hospital, the number of hospital days could be drastically reduced for this cohort.

A San Francisco study of both paid and volunteer home care services showed that home care was significantly less expensive than hospital-based care.[12] Among the resources evaluated was a home-based hospice program. This program provided a range of home care services to persons with AIDS which enabled them to spend most of the duration of their illness, including the terminal stage, at home. For the 165 persons with AIDS who received care under this program, the study found that they required an average of 47 hospice days per person, at an average cost of $4,401 per patient. The average cost per day of hospice care was $94, compared to an inpatient cost per day at San Francisco General Hospital of $773.[13] Additional data from San Francisco estimate the cost of acute inpatient care at $800/day; subacute care at $500/day; skilled nursing facility at $300/day; residential hospice at $100/day; and nonmedical group residence at $50/day.[14]

To evaluate home care needs and utilization, clients of the AIDS Action Committee of Massachusetts were surveyed.[15] A questionnaire was mailed in the spring of 1986 to 115 clients of the AIDS Action Committee and was returned by 43 individuals. The purpose of

Table 1

Total Cost per Patient for AIDS Medical Care*

Total Cost by Components

Service Area	Cost (U.S. $)	(%)
Inpatient cost	22,097	(89.2)
Outpatient cost	1,907	(7.7)
Outpatient cost (related to research protocol)	760	(3.1)
Total	24,764	(100)

Inpatient Cost by Components

Service Area	Cost (U.S. $)	(%)
Room cost	9,176	(41.5)
Laboratory	4,786	(21.7)
Pharmacy	2,958	(13.4)
Supplies	1,126	(5.1)
X-ray	1,099	(5.0)
Professional cost	1,016	(4.6)
Intensive-care room cost	845	(3.8)
Therapy	622	(2.8)
Operating room cost	454	(2.1)
Miscellaneous	15	(0.1)
Total	22,097	(100)

Outpatient Cost by Components

Service Area	Cost (U.S. $)	(%)
Laboratory	1,493	(56.0)
Professional charges	452	(16.9)
Surgery	254	(9.5)
Pharmacy	229	(8.6)
Therapy	136	(5.1)
X-ray	64	(2.4)
Miscellaneous	29	(1.1)
Emergency room visits	11	(0.4)
Total	2,668	(100)

*George R. Seage III, Stewart Landers, et al., unpublished data from study of cost of treating 45 AIDS patients at New England Deaconess Hospital 1984–85.

the questionnaire was to determine the average weekly utilization of home care services. The results indicate that 65 percent of respondents used or needed some home care services. The researchers determined a mean utilization cost of $107 per week, applying Blue Cross reimbursement rates to estimate the cost of these home care services. Assuming that persons with AIDS receive home care except when they are hospitalized, the cost of home care services for a person with AIDS from diagnosis to death may be estimated to be $4,985.[16]

This figure may be based on an underestimation of home care utilization. Those individuals needing the greatest amount of care were the least likely to respond to a question-

naire. However, the estimate is almost identical to the estimated cost of home-based hospice care in San Francisco and may be used as a rough approximation of home care costs. A thorough, population-based study of the utilization of home care health services by AIDS patients needs to be performed.

Indirect Costs

Scitovsky and Rice have divided the indirect costs of AIDS into two types: morbidity costs (productivity lost on account of illness) and mortality costs (future earnings lost for those who die prematurely).[17] They estimated the total direct and indirect cost of AIDS in the United States in 1985 alone to be $4.8 billion. Of this cost, the researchers calculated $3.9 billion, or 81 percent, as indirect costs. Thus, while indirect costs are less obvious in terms of impact upon the health care system, the overall economic impact of such indirect costs is immense.

Mortality costs account for 94 percent of indirect costs. These costs are very high, owing to the young age of AIDS patients and the associated large numbers of years of life lost. Not included in this accounting is the fact that many persons with AIDS may not pay premiums to health insurance, taxes, Social Security, and so on, during what are usually a person's most productive years.

Other indirect costs related to the cost of AIDS include added infection control precautions, nursing care, and supplies, as well as complex case management services.[18] The difficulty of caring for AIDS patients consists in increasing personnel costs, owing to the need for additional support services for personnel. This article will not include the indirect costs of AIDS in its projections of direct medical care costs in New England.

Changes in the Cost of Treating AIDS

The cost of providing medical care to a person with AIDS is not static. There is evidence that the cost may be declining. New and costly therapies for persons with AIDS, as well as experience in the treatment of AIDS, will affect the cost of care.

Evidence of reduction in cost. In July 1985, the study of the cost of treating persons with AIDS in Massachusetts expanded to include five hospitals and to evaluate patient utilization over the two-year period March 1984 through February 1986.[19] Two hundred and forty patients were enrolled over the two-year period. This cohort represented 55 percent of all AIDS patients alive in Massachusetts during the study period. The cohort was representative of all AIDS patients reported to the Massachusetts AIDS Surveillance Program with regard to risk group status, gender, geographical distribution, and race.

Preliminary data on cost over the two-year period showed a decline in total inpatient and outpatient cost from year one to year two at each of the five hospitals studied. The researchers attributed the observed decrease both to shorter lengths of stay (mean reduced from 19.2 days/hospitalization to 15.7 days/hospitalization) and to a decrease in the mean number of hospitalizations (mean reduced from 2.2 hospitalizations/patient to 1.9 hospitalizations/patient). Future analysis of these data will attempt to evaluate additional factors related to the decline in cost, such as the availability of support services and home care programs.

The effect on cost of AZT. As antiviral and other therapies are developed, the direct medical care cost of treating AIDS is likely to change. One therapeutic agent that may have a significant impact on cost of care is the drug Azidothymidine (AZT). It is uncertain whether use of this drug, which has been shown to decrease the frequency of life-threatening pneumonia in AIDS patients, will increase or decrease utilization of health

care services.[20] AZT may reduce the length of stay for AIDS-related hospitalizations and the overall number of hospital days for AIDS patients, by decreasing the severity of opportunistic infections. AZT may also keep AIDS patients healthier longer and allow them to continue working longer.

On the other hand, by allowing patients to survive more bouts of *Pneumocystis carinii* pneumonia (PCP), AZT may result in more lifetime hospitalizations and an increased number of total hospital days. In addition, physicians may become more aggressive in their treatment, knowing there is a drug that may significantly extend the patient's life once any immediate crisis is forestalled.

One thing is certain: AZT is an expensive drug. A one-year supply of AZT is currently estimated to cost between $8,000 and $10,000.[21] Once on AZT, an AIDS patient needs to continue taking the drug as long as he or she is alive, unless serious side effects occur.

Experience with AIDS patients. The extent of an institution's experience with AIDS patients may alter the cost of services to persons with AIDS for a number of reasons, including familiarity with the disease; adoption of an oncological modality of treatment; and recognition of the particular out-of-hospital services that AIDS patients may require.

The lack of familiarity with the care required by persons with AIDS may lead to unnecessary cost expenditures. A report on the provision of medical care at U.S. public and private teaching hospitals found that 15 percent of responding hospitals had not yet treated an AIDS patient.[22] Familiarity with the care and support that persons with AIDS require will reduce the number of hospital days, the use of intensive care, and the application of unnecessary diagnostic techniques.

As AIDS is a new and thus far terminal illness, AIDS care may utilize a range of different treatment modalities. For example, an alternative to the inpatient hospital model is the oncological or hospice model. This model, developed for terminally ill cancer patients, attempts to maximize comfort for the afflicted individual and minimize aggressive or intrusive diagnostic and therapeutic measures. AIDS patients receiving hospice care are much less likely to be placed under intensive care — an unpleasant (albeit potentially life-prolonging) and costly form of care.

The availability of support services and home care can make a difference in the length of hospitalizations and the overall cost. In some cases, discharge planners need to familiarize themselves with the services and support groups already available to persons with AIDS. However, the absence of such services in many local communities may prevent the implementation of an effective and realistic home care plan.

Estimating Cost in New England

For purposes of estimating direct medical care costs per case, the authors have combined the mean inpatient and ambulatory cost per case, $50,380, and the mean estimated home care cost, $4,985. Our estimated total direct medical care costs per case are $55,365.

The number of AIDS cases diagnosed to date in New England is based on case reports to the Centers for Disease Control (CDC) by the six New England states as of November 23, 1987 (see table 2). Nationally, more than 270,000 cases are expected by the end of 1991. Massachusetts has consistently reported 2 percent of the national cases, and this percentage is used to estimate the case load in Massachusetts cumulatively through 1991. Projections for the other five New England states are based on the total number of cases each state has reported cumulatively to November 23, 1987, and the percentage of New England cases each such total represents. Using these calculations, the total direct medi-

cal care cost is $524.8 million for persons with AIDS diagnosed in New England during the ten-year period 1981 to 1991.

Who Will Pay? A Look at the Payers

With an estimate of $524.8 million needed to pay for the direct medical cost of treating persons with AIDS in New England through 1991 (see table 2), the most important questions are, Who is and who will be paying for this, and who will pay in the future? The simple, if somewhat naive, answer, of course, is that we all pay for the cost of treating AIDS, either through health insurance premiums, federal and state tax dollars for Medicare and Medicaid, or local tax revenue that provides services to the uninsured or reimbursements to hospitals for free care and bad debt. The reason this point of view is naive is that the exact payer mix matters greatly to each potential payer. Insurers wish to reduce their exposure to high costs; holders of private insurance policies do not want their premiums to rise; and government health care budgets need to remain responsive to a wide variety of political interests. In essence, AIDS costs highlight the classic confrontation between the private versus the public sector.

Analysis of the payer mix is key to measuring the impact of policies that will shift the cost of caring for AIDS patients among payers. The Massachusetts cost study found that 47 percent of people with AIDS had Blue Cross, 18 percent had commercial insurance, 18 percent had Medicaid, and 18 percent had no insurance.[23] These data differ from the data presented by Andrulis and Beers et al. in their nationwide study. They reported that for hospitalizations in the Northeast region, only 12 percent were reimbursed by private insurance. Instead, 65 percent of patients had Medicaid, 17 percent had no insurance, and 11 percent had Medicare, received veterans' benefits, were prisoners, or were classified as "other."[24]

Table 2

AIDS Cases and Costs* in New England States

State	AIDS Cases Diagnosed to 11/23/87[a]		AIDS Cases Diagnosed to 1991[b]	Cost of AIDS Diagnosed to11/23/87 (in $millions)[c]	Cost of AIDS Diagnosed to 1991 (in $millions)[c]
Massachusetts	997	(57.0%)	5,400	55.2	299.0
Connecticut	521	(29.8%)	2,822	28.8	156.2
Rhode Island	105	(6.0%)	569	5.8	31.5
Maine	57	(3.3%)	309	3.2	17.1
New Hampshire	49	(2.8%)	265	2.7	14.7
Vermont	21	(1.2%)	114	1.2	6.3
Totals	1,750	(100.0%)	9,497	96.9	524.8

*Costs include hospital inpatient, hospital outpatient, and home care costs.

NOTE: Projections are likely to vary by as much as 50 percent; any variation between these projections and those found in other articles is due to different assumptions about the number of infected persons, the spread of infection, and the rate at which those infected will progress to AIDS.

[a]*AIDS Weekly Surveillance Report — United States,* United States AIDS Program, Center for Infectious Diseases, Centers for Disease Control, November 23, 1987, 2.

[b]W. M. Morgan and J. W. Curran, "Acquired Immunodeficiency Syndrome: Current and Future Trends," *Public Health Reports* 101, no. 5 (September–October 1986): 461.

[c]Costs data are based on George R. Seage III, Stewart Landers, Anita Barry, et al., "Medical Care Costs of AIDS in Massachusetts," *Journal of the American Medical Association* 256, no. 22 (December 12, 1986): 3107.

The wide discrepancy is due to the difference between the two cohorts. The initial Massachusetts study was comprised predominantly of white, gay men, most of whom were working at jobs that provided health insurance at the time they became ill. Andrulis and Beers et al. studied costs at public hospitals and teaching hospitals, and their Northeast region includes New York and New Jersey as well as New England. The number of persons with AIDS in New England who rely on the public health system may range from 36 percent to almost 90 percent.

Private Insurers

Concern about AIDS costs is not uniform among private insurers. Some private payers are devising strategies to reduce their exposure to AIDS-related costs. A quick look at the rise of widespread health insurance, as well as its recent decline, sheds light on the concerns of the industry.

The growth of health insurance in the United States from the time of World War II to the present is well documented by Rashi Fein, an expert in medical economics at the Harvard School of Public Health:

> [By 1977,] over 80 percent of total health insurance premiums went for the purchase of group coverage and over 95 percent of all group insurance was provided in the employment context. Furthermore, almost 90 percent of all U.S. employees worked in firms that provided health insurance plans and over 90 percent of employees in those firms were eligible for the insurance.[25]

However, Fein also notes:

> In 1977 over 99 percent of workers in firms with over 1,000 employees had an employment-related health insurance plan, compared with only 55 percent of workers in firms with 25 or fewer employees. . . . In general, workers in smaller and nonunionized firms were less likely to have employment-related group coverage.[26]

Group health insurance is usually provided without any physical exam or laboratory testing. After a fixed waiting period, the employee is covered regardless of any preexisting conditions he or she may have. As a member of a group insurance plan, an individual cannot be denied coverage as a result of HIV testing or other prescreening method employed by insurers for persons seeking individual coverage.

Under the Consolidated Omnibus Budget Reconstruction Act of 1985 (COBRA), persons covered by group health insurance policies in companies of twenty or more employees have the right to continue insurance for a period of eighteen months following termination of employment.[27] Individuals must pay the full cost of premiums. COBRA also requires that individuals are informed of this right, which enables AIDS patients to prolong the time period during which their financial resources are protected from the cost of high medical expenses.

In the 1980s, a significant decline in the availability of group health insurance has occurred. To protect against rising costs, employers frequently exclude family members and part-time employees from group health policies or require higher co-payments, leaving fewer individuals covered by insurance.

Furthermore, a growing number of companies, especially larger firms, no longer offer commercial policies and are self-insuring. Eighty-five percent of firms with more than forty thousand employees and 70 percent of firms with between twenty and thirty thou-

sand employees are now self-insured.[28] Self-insured groups are covered under the federal Employee Retirement Income Security Act (ERISA) and are exempt from state regulation. There has been no federal initiative to protect insurance coverage for persons with AIDS; therefore, employers that are self-insured have greater discretion regarding decisions to test for the AIDS antibody or to not cover AIDS at all. In addition, because these employers are not subject to state attempts to pool higher health insurance risks, they undermine the limited experimentation with shared risk pools.

Health Maintenance Organizations (HMOs), a relatively new entrant into the health care market, have shaped health care policy significantly. HMOs are concerned that HIV-antibody-positive persons with a choice of insurers will select HMOs to reduce the high co-payments required by many traditional health insurance policies.

Public-Sector Insurance

The reduced availability of private health insurance underscores the importance of Medicaid as an insurer of last resort for AIDS patients in New England. Medicaid eligibility is dependent upon income and assets. If a person has assets in his or her name, those resources must be depleted in order for that individual to qualify. States have a wide variety of criteria for Medicaid eligibility. For example, Andrulis and Beers et al. found that only 15 percent of AIDS cases in the South are paid for by Medicaid.[29] This figure is attributed to the restrictive Medicaid eligibility requirements common among southern states.

Individuals under age sixty-five become eligible for Medicare after they have received Social Security Disability Insurance (SSDI) for twenty-four consecutive months, followed by a processing period of three to five months. However, the median conditional probability of survival from date of diagnosis with AIDS is 347 days.[30] Thus, most persons with AIDS never qualify for Medicare. In 1985, Massachusetts determined that an AIDS diagnosis is a presumptive disability, which qualifies persons with AIDS for SSDI. However, with the recently expanded case definition, certain AIDS diagnoses, including wasting syndrome and dementia, no longer automatically qualify an individual for SSDI.

Currently, Medicare pays for the care of approximately 1 to 2 percent of AIDS patients in Massachusetts, but it could pay for more. There exists a waiver of the two-year Medicare waiting period for individuals with certain types of renal disease. If a similar waiver were available for AIDS patients, the cost of treating them would shift dramatically from Medicaid to Medicare, and consequently from the state to the federal government. Further analysis is necessary to demonstrate the magnitude of this cost shift if the waiting period were eliminated or if it were reduced to six, twelve, or eighteen months.

Implicit in a state-controlled program is the power to determine what will or will not be covered. Such decisions are likely to reflect political as well as medical realities. The decision of a Medicaid program to pay for AZT, for example, is likely to depend as much on political will as on economics. Medicaid in Massachusetts, as in most states with large and visible advocacy groups representing persons with AIDS, has decided that it will pay for AZT.

Free Care

Despite the availability of Medicaid and the advent of client advocates to help people enroll in publicly funded programs, many individuals continue to fall through the cracks and seek medical care without any insurance coverage. In Massachusetts, a reimbursement system (Chapter 572) was established to cover hospital losses resulting from free

care. The system, which expired October 1, 1987, allowed hospitals to set charges in excess of expenses in order to cover free care. Some other New England states do not reimburse hospitals for free care.

A large number of persons with AIDS do not have health insurance and therefore tax the system to reimburse free care. Thus, the AIDS epidemic has a disproportionate impact on those hospitals seeing the greatest numbers of AIDS patients. Boston hospitals reported 79 percent of Massachusetts cases, although only 47 percent of Massachusetts cases actually reside in Boston. The concentration of cases at these hospitals invalidates the equations previously used to compensate these institutions.

The AIDS epidemic will increase the need for services among uninsured, underinsured, and Medicaid patients. For hospitals that continue to provide care for indigent patients, this epidemic will mean a rise in free care. Government must ensure the willingness and financial ability of hospitals to care for indigent patients.

Issues Affecting Cost and Treatment

The direct medical care costs of treating persons with AIDS present a challenge to the fiscal planning efforts of health care planners in New England. In relation to overall national health expenditures, the actual cost of treating persons with AIDS is small. Scitovsky and Rice estimate that in 1991, AIDS will represent 1.4 percent of estimated national medical care costs.[31] This relatively small percentage could be absorbed if it were distributed evenly across all insurers and providers of care. However, in order to tame the rise in health care costs, access to health care has become unevenly distributed in society. The health care industry is developing new methodologies for cost containment. In the process, certain population groups — such as family members — have effectively been denied access to medical care; some employers provide very limited options that deny employees full coverage. These disenfranchised groups are already taxing the public health care system. With the addition of AIDS treatment, certain providers may be totally crippled.

A new movement to protect access to health insurance is developing nationwide in response to the cost containment practices in the health care industry. Advocates of compassionate health care must couple arguments for wider access to care with plans for cost containment. Without cost containment, plans to increase access to health insurance do not appear to be politically viable. In Massachusetts, Governor Dukakis has led a movement for universal health insurance but as of this writing has not succeeded in passing legislation for this purpose.[32]

Until some form of universal health insurance is enacted, the marketplace for health care will become increasingly restrictive. For persons with AIDS or who are infected with HIV, the available options may become fewer as the need for insurance becomes greater. In the next section, we look at the developments in health insurance which affect persons with AIDS or at risk for AIDS. The section concludes with suggestions for reducing the adverse economic impact of AIDS on the health care system.

Developments in Health Insurance

Various developments in health insurance may alter the source of payments as well as the cost of care. HIV antibody screening will shift responsibility for the cost of caring for AIDS from private insurance to the public sector. Insurance coverage of subacute care facilities will shift medical care services to less cost-intensive alternatives. Shared risk

pools are one mechanism for maintaining private insurer involvement in the care of persons with AIDS.

HIV antibody testing. Insurers have sought the right to screen applicants for health insurance for evidence of HIV infection. Screening for HIV antibody status has not been initiated for group health insurance, since no eligibility screening practices are currently in place for group plans. If insurance losses due to AIDS become unmanageable, insurers may increase efforts to screen for HIV infection under group plans. In Massachusetts, hearings on proposed regulation of the use of the HIV antibody test reflected widespread consensus among all constituencies, except insurers, against the use of the test for health insurance eligibility.[33] This view is consistent with a widespread opinion in Massachusetts that health insurance is a necessity and should be considered a basic individual right.

The Massachusetts Division of Insurance had, until September 1, 1987, prohibited insurers from using the HIV antibody test at all. The division then promulgated and adopted regulations allowing limited use of the test for individual life and disability insurance plans. The regulations also provided for limited confidentiality of test results and for required counseling of persons who tested positive. Upon challenge by the insurance industry, a preliminary court decision held that the regulation is an invalid exercise of power by the insurance commissioner.[34] At the present time, it is uncertain whether courts will recognize an administrative or regulatory ban on antibody testing without special enabling legislation.

Fairness and excessive losses are the main arguments offered by insurers to justify screening out HIV-infected individuals for health insurance. Insurers argue that if they are forced to assume the high cost of insuring HIV-infected persons, individual premiums will increase. Any rise in premiums, they contend, will force individuals who are struggling to maintain individual policies to give up those policies. Therefore, if the insurability of individuals with HIV infection or AIDS is protected, other individuals may be deprived of health insurance. Furthermore, since insurance companies currently refuse insurance to "bad risks" — such as former cancer patients, women with certain types of benign cysts,[35] and others — insurers argue it would be unfair to insure HIV-infected persons who are comparably bad risks. However, state governments, for public policy reasons, have successfully constrained insurers from using other tests, including those which indicate the presence of sickle cell, Tay-Sachs, and hemoglobin C traits.[36]

Insurers are so adamant about the preceding arguments that to avoid state regulations against HIV testing, they are attempting to use other methods to screen applicants without using HIV testing per se. Some insurers have already utilized screening criteria as diverse as marital status, residence or zip code, medical history, beneficiary, and living arrangements to screen out persons who are potentially at risk for AIDS.[37]

The use of HIV screening threatens to create a class of individuals likely to be subject to discrimination in various aspects of life. Persons with AIDS or who are perceived to be at risk for AIDS have suffered discrimination in employment, housing, accommodations, and parental rights.[38] Use of HIV screening by insurers increases the risk of discrimination, particularly since safeguards to protect the confidentiality of information collected by insurance companies are inadequate. The failure of the federal government to protect individuals from discrimination on the basis of their HIV antibody status creates an atmosphere that discourages use of the antibody test.

Coverage of home care, hospice, and other forms of subacute care. Strategies need to address the coverage of cost-effective methods of caring for AIDS patients, including home care, hospice, group residences, skilled nursing facilities, and subacute care units.

As noted in the first section of this article, the daily costs of care for these services are significantly lower than acute inpatient cost.

Medicaid programs in each state may apply for a waiver that would allow the program to develop more effective reimbursement plans for a particular disease. New Jersey has received such a waiver for AIDS and has established a system for reimbursing those out-of-hospital services which are required to care for patients with AIDS in the most humane and cost-effective manner.

Beginning in FY'87, Massachusetts allocated funds to eight home health care agencies, in order to assist the agencies in developing services for persons with AIDS. The grants have been used for staff training, education, and outreach programs. The grant recipients have argued that insufficient reimbursement is still a major impediment to effective delivery of services to persons with AIDS, and have looked to insurers, primarily Medicaid, to reevaluate the services for which home health care agencies may seek reimbursement.

Case management is another approach that is receiving increased attention as a cost-effective way of coping with specific medical problems. Under this approach, a case manager helps develop a strategic plan for the patient. For example, in the case of AIDS patients, a case management approach may involve educating the family and friends in order to help them overcome fears of the disease and help them enable the patient to remain at home as long as possible. Blue Cross of Massachusetts has adopted a case management system for elderly patients but has not implemented the program for persons with AIDS. A study of the effectiveness of case management for AIDS patients is under way at the AIDS Medical Resource Center in Illinois.[39]

Shared risk pools. The problem of "uninsurables" is not a new one, and, as indicated earlier, other classes of individuals have had difficulty obtaining health insurance. In order to maintain private insurer involvement in coverage of high-risk individuals, thirteen states have passed legislation establishing risk pool programs.[40] Under these programs, private insurers contribute to a pool that provides health insurance to individuals at high risk for various diseases. The premiums are generally higher than normal, and government subsidies keep them within an affordable range. The programs have not been very successful. In 1986, the seven operating risk pools enrolled only twenty-one thousand people, and all but one of the pools lost money.[41] The addition of AIDS patients as beneficiaries of the pool would exacerbate this situation further.

Access to insurance is hampered for persons with AIDS not only because of unavailability, but also because of cost of premiums, since an AIDS diagnosis is often accompanied by loss of employment and of the ability to pay for insurance. Therefore, shared risk pools *alone* are unlikely to solve the problem of providing health insurance for persons with AIDS, and may need to be combined with a subsidy or coupon-type program to allow persons with AIDS to purchase such insurance.

Suggestions for Managing the Cost of Caring for People with AIDS

Reduce acute inpatient care days. Acute inpatient care constitutes the largest single component of the direct medical care costs of AIDS patients. It is necessary to reduce acute inpatient care as much as possible without compromising the quality of care each patient receives. Reduction of inpatient care may be accomplished by establishing an organized, well-trained, and reimbursable continuum of care.

Physicians must be trained to recognize the opportunistic infections associated with AIDS in a timely way. They must be familiar with the latest treatments, particularly those

which allow patients to be treated at home or at subacute care facilities.

Subacute levels of care — including skilled nursing facilities, home health care, hospice programs, and group residences — must be developed through the utilization of new or existing resources. Reimbursements must be flexible enough to make such facilities economically feasible.

Target specific medical care providers for assistance. Those institutions or insurers which provide the greatest amounts of unreimbursed care must be identified, and subsidies must be provided to enable the continued delivery of these services. Owing to matters of geography, philosophy, or reputation or to referral networks, certain institutions are likely to care for disproportionately high numbers of AIDS patients who are uninsured or underinsured. Adequate systems must be developed to determine who is being disproportionately impacted as well as the extent of shortfalls related to AIDS care. Accurate assessments of the extent of unreimbursed care will assure the most cost-effective distributions of subsidies or program funds.

Strengthen AIDS education. Education about AIDS must be strengthened to prevent new cases. While our projections through 1991 indicate a situation that appears to be economically manageable, worst case scenarios through 1995 and beyond may present a far less manageable situation. Reducing the number of new infections and thereby reducing the number of new AIDS cases is an important and extremely cost-effective strategy.

Conclusion

The cost of treating people with AIDS, estimated to be more than $500 million for cases diagnosed in New England over the ten-year period 1981 to 1991, is an increasing burden for society and especially for the health care industry. However, this cost is only a small percentage of overall health care costs and, with proper planning, can be managed.

The largest component of AIDS health care costs is acute inpatient care, and the largest part of inpatient care costs consists of room and board. Ambulatory care and home care are significantly less expensive alternatives.

Paying for AIDS is made more difficult by the patchwork nature of the current health care reimbursement system and distribution of services. Many persons with AIDS are uninsured or underinsured, or may lose their insurance coverage during the course of their illness. Various strategies may be implemented to maintain or perhaps expand insurance coverage for people with AIDS. However, insurers, including Medicare and Medicaid, will oppose any plan that increases their share of AIDS coverage.

Particular insurers or health care providers may find themselves overburdened as they become the primary care centers for AIDS patients. Public and teaching hospitals in New England are likely to be burdened the most by the AIDS epidemic.

To guard against the deterioration of health care services for people with AIDS, the authors recommend reduction of acute inpatient care through the development of alternative levels of care, including subacute care, skilled nursing facilities, hospice programs, group residences, and home health care; the development of targeted subsidies or programs to relieve severe pressures on particular insurers or health care providers; and the strengthening of education to slow the growth of the AIDS epidemic.

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    Cost per patient = inpatient and outpatient cost = $24,764

    $$\text{Cost per patient per annum} = \frac{\sum_{1}^{N}\left(\frac{\text{Cost per patient} \times 12}{\text{\# months in study}}\right)}{N} = \$46{,}505$$

    To calculate the total inpatient and outpatient costs of treating an AIDS patient (cost per case), we multiply the per annum cost by the average life expectancy from diagnosis to death, estimated to be thirteen months. See Ann M. Hardy et al., op. cit., at 210.

    Cost per case = cost per patient per annum times survival time (13/12 of a year) = $50,380
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