The Costs of AIDS: A Review of the Estimates

by Jane E. Sisk

Prologue: Societal costs associated with acquired immunodeficiency syndrome (AIDS) are obviously on the rise as more individuals contract the deadly disease and others are found to be infected by the virus. The cases of AIDS reported thus far are only the beginning of the projected toll, because the damage the virus inflicts on the immune system generally is not apparent until years after initial infection. Beyond this grim reality, the epidemic is growing every day, partly because persons who may not know they are infected are spreading the virus.

In this paper, economist Jane Sisk of the U.S. Congress Office of Technology Assessment (OTA) provides a comprehensive review of the cost estimates that have been made regarding AIDS and other related infections. Sisk, who holds a doctorate in economics from McGill University, is a veteran OTA analyst, having worked at the agency since 1976, with time out (1978–1981) to participate in the scholar’s program of the Veterans Administration. Over the years, Sisk has participated in a variety of OTA-sponsored studies around health financing and prevention issues, including—most recently—an examination of payment for physicians’ services under Medicare. Other works have included a study of the medical devices industry and cost-effectiveness studies of vaccines against influenza and pneumococcal pneumonia. As an agency, OTA will be devoting more resources to the AIDS phenomenon in the future because some of its congressional stewards, including Rep. Jerry Lewis (R-CA)—a member of the House Appropriations subcommittee, which approves OTA’s budget every year—believe the agency should be centrally involved in the coming war against AIDS.
Estimates of the costs associated with acquired immunodeficiency syndrome (AIDS) have varied tremendously. Reports of hospital costs over the lifetime of an AIDS patient range from $24,517 to $147,000.\(^1\) Reports of the financing of AIDS patients range widely as well: Medicaid has been said to pay for the care of 7-65 percent of AIDS patients and private insurance to cover 13-65 percent of patients.\(^2\)

The Subcommittee on Health and the Environment of the House Energy and Commerce Committee requested the Office of Technology Assessment (OTA) to analyze the reasons for these different cost estimates. This article reports on that analysis. The article identifies specific factors that have accounted for differing cost estimates in eighteen studies, discusses problems in predicting costs associated with AIDS, and raises issues related to future cost estimates.

Because of the great variation in methods used, the results are not strictly comparable across studies. Taken together, the studies suggest that, with past survival and treatment patterns, AIDS lifetime hospital costs have most likely been under $100,000, and annual treatment costs for patients alive at any time during the year were mostly under $40,000.\(^3\) However, the studies give a far from complete picture of costs, since they generally excluded most services outside the hospital and pertained only to adult AIDS patients, not to pediatric patients or to people with other manifestations of human immunodeficiency virus (HIV) infection.\(^4\)

The most comprehensive and rigorous study of national costs attributed costs of $8.7 billion to AIDS in 1986 and predicted costs of $66.5 billion by 1991.\(^5\) More than 80 percent of these costs stemmed from losses in productivity, a reflection of the fact that AIDS has afflicted primarily working-age adults. Great uncertainty surrounds these and other cost projections because knowledge and treatment of the disease are constantly changing. Moreover, transmission of the virus has not yet peaked, and the percentage of the HIV-infected population that develops outright AIDS continues to increase.

Policy Issues

**Paying the high costs of illness.** How to pay for the treatment of AIDS is but a recent example of the continuing issue of how to pay for illnesses with high treatment costs, high in absolute terms and as a percentage of income. AIDS patients for the most part have been working-age adults. But studies have shown that about 17 percent of people in their prime working years have been uninsured for all or part of the year and that about 22 percent of the population under age sixty-five are at risk of being unable to afford necessary medical care because they were uninsured, underinsured, or otherwise medically disadvantaged.\(^6\) In such cases, the patients and their families as well as the providers who care for
them are financially vulnerable in the face of catastrophic expenses.\textsuperscript{7}

Although it is beyond the scope of this article to examine thoroughly payment of catastrophic costs, on its face the financing of AIDS treatment costs appears similar to that of other very expensive illnesses. For example, treatment costs have averaged $158,000 over a four-year period for patients with end-stage renal disease who are undergoing dialysis and about $30,000 (in 1984 prices) in the terminal year for nonelderly people with certain cancers.\textsuperscript{8} But AIDS and HIV infection are unusual in their increasing prevalence and in the age groups afflicted. Based on estimates of present infection rates, from 1984 to 1991 AIDS cases in the U.S. are expected to rise from 3.96 to 68.63 per 100,000 people, and deaths from 1.49 to 25.74 per 100,000.\textsuperscript{9} If direct medical costs for AIDS rise, as projected, to about $7.0 billion by 1991, they will account for 1.4 percent of U.S. personal health care expenditures, up from 0.2 percent in 1985.

AIDS has afflicted mostly young men in their prime working years who are either homosexuals or intravenous (IV) drug abusers. This age/sex group historically has had low mortality rates and low medical expenditures, a pattern on which insurance companies have relied in calculating health and life insurance premiums. AIDS has disrupted that pattern and added a new layer of medical expenses that was totally unexpected only a few years ago. To the extent that HIV continues to be transmitted, increasing rates of AIDS and HIV infection will fuel even higher medical expenses.\textsuperscript{10}

\textbf{Sources of payment.} The sources of payment have varied widely. Reports estimate that Medicaid has paid for the care of 7–65 percent of patients (depending on the type of hospital); Medicare has covered 1–3 percent of patients; private insurance, including Blue Cross/Blue Shield and commercial policies, has covered 13–65 percent of patients; and those with no insurance, including indigent people, have ranged from 2 to 40 percent of patients. Researchers at the Health Care Financing Administration (HCFA) have estimated that, combining federal and state costs, Medicaid has paid about 23 percent of AIDS medical costs and that by 1991 direct medical costs of AIDS will consume 2.5 percent of federal Medicaid payments.\textsuperscript{11} These estimates assume that Medicaid covers 40 percent of AIDS patients.

Like the cost studies from which they are drawn, the estimates of payment source generally include inpatient care but vary in the scope of other services included. All estimates seem to exclude long-term care and (except for one) home care—types of care that may not be covered by insurance—and some exclude physician services and ambulatory drugs as well.\textsuperscript{12} Moreover, the known data fail to indicate the cost burden on various payers, including patients and their families, private insurers, and government programs, because the data relate to a moment in time, not to payment for AIDS treatment over the course of the disease.
Also noteworthy is the different distribution of payment for AIDS expenditures compared with payment for total U.S. hospital and physician services.\textsuperscript{13} In 1985, private insurance paid 36 percent of all hospital care and 45 percent of all physician services, in the same range as estimates for AIDS payments. But Medicaid seems to pay a much higher percentage and Medicare clearly pays a lower percentage for AIDS than for overall health care. In 1985, Medicaid paid 9 percent of general hospital care and 4 percent of general physician services, compared with HCFA estimates of 23 percent of AIDS costs (for 40 percent of AIDS patients).\textsuperscript{14} In that same year, Medicare paid 29 percent of general hospital care and 21 percent of general physician services, compared to estimates of 1 to 3 percent for AIDS.\textsuperscript{15} Medicare’s lower share reflects the younger age groups that have contracted AIDS and their short survival time, which has made it unlikely that AIDS patients live long enough to qualify for benefits as disabled persons. Medicare’s share will rise to the extent that AIDS patients survive longer and qualify for coverage.

**Allocating resources.** Another longstanding policy issue is how much to allot to a particular disease and, within that total, how to allocate resources between prevention and treatment. Prevention entails not only medical research to develop vaccines or drugs, but also epidemiological research to describe and predict the spread of the disease and educational efforts to interrupt viral transmission. During 1986 an estimated $542 million was spent on AIDS activities that relate mostly to prevention; research received 43 percent, blood screening 51 percent, and education 6 percent. More than twice as much, $1 billion, was spent in 1986 to treat AIDS.\textsuperscript{16} In considering the appropriate amount to allocate for prevention and the appropriate mix of preventive activities, one should note that there is no indication that transmission of HIV infection has peaked.

To the extent that intensified preventive activities could reduce HIV transmission and future AIDS cases, the allocation of expenditures has implications not only for future medical costs and their sources of payment but also for who bears the burden of the disease. Screening of donated blood for HIV infection is intended to arrest HIV transmission through the blood supply, the route by which hemophiliac AIDS patients and other transfusion-associated cases have contracted the disease. Continuing the present pattern of disease would put a substantial burden onto employers of people who become ill from HIV infection, since so much of the total AIDS costs stems from illness and premature death among people in their working years. Certain groups, such as homosexual and bisexual men and IV drug abusers, have been identified as being at high risk of AIDS. In addition, a disproportionate percentage of AIDS patients have been black and Hispanic—39 percent of AIDS patients versus only 18 percent of the general U.S. population. Blacks and Hispanics have accounted for an enormous share of female and
pediatric AIDS patients, 73 percent and 80 percent respectively. Some countries, such as Switzerland and Britain, have undertaken more widespread and more intensive educational efforts to prevent HIV infection than the United States. But recently the Surgeon General of the Public Health Service, members of Congress, and the Institute of Medicine have called for expanded education to prevent the spread of the virus in the United States.

Collecting adequate cost data. Issues more specific to AIDS concern data collection and hospital payment for AIDS cases. The difficulty of identifying AIDS cases in claims files and hospital records has greatly hampered estimating AIDS costs and the impact of HIV infection. In July 1986, new codes for AIDS and other HIV infections were added to the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). As medical providers and insurers begin to use the new codes, researchers and policymakers will find it easier to identify and track treatment of the disease. ICD-9-CM codes form the basis of Medicare's diagnosis-related groups (DRGs), which in turn determine Medicare's payment for hospital operating expenses. Although the new ICD-9-CM codes became effective October 1, 1986, HCFA stated in the Federal Register notice that it did not expect their use to change the classification of cases in the DRG system.

Some hospital cost studies have found that payments for AIDS cases have fallen far short of the costs incurred, primarily for inpatient services. For example, daily care for an AIDS inpatient in New York City municipal hospitals costs $800, but the hospitals received only $500 in payment. For certain Alabama hospitals, Potts and colleagues reported that Medicaid revenue fell far below hospital costs, while Medicare’s payments exceeded hospital costs. Although it is not clear what underlies this shortfall—low payment rates of certain payers, nonpayment of charges by patients (bad debts), inefficient management of patient care, or hospital accounting methods—Medicaid's low payment rates are well known. This situation raises policy issues concerning adequate compensation of hospitals providing care to poor people.

Better data on costs and payment rates could improve public and private policy making. The amount and method of payment provide incentives regarding how and where AIDS cases are treated, such as intensive care units, outpatient clinics, hospices, or homes, and these decisions in turn may well influence the total costs associated with the disease and the quality of life of the people affected. Distributive justice and rational policy making also require adequate compensation of medical providers that care for a disproportionate share of AIDS patients who cannot afford to pay for their own care.
Costs Of AIDS And HIV Infection

By far the most comprehensive and rigorous study of national costs was performed by Anne Scitovsky, Dorothy Rice, and their colleagues for the Centers for Disease Control (CDC). According to their estimates, in 1986 the average cost of the personal medical expenses of an AIDS patient alive at any time during the year was $35,592, and lifetime hospital costs in 1984 prices ranged from $60,000 to $75,000. Scitovsky and colleagues also estimated that in 1986 total costs associated with AIDS, including direct and indirect costs, were $8.7 billion and will reach $66.5 billion in 1991. In these calculations, indirect costs (productivity losses) of sickness and death dwarf direct medical costs, reflecting primarily the premature deaths of working-age adults. The great increase in total costs by 1991 stems from projected increases in the prevalence of AIDS cases, 172,800 in 1991 compared with 31,440 in 1986.

The studies reviewed give a far from complete picture of costs. Primarily because of data limitations, many studies have excluded the cost of most services used outside the hospital, such as drugs, long-term care, hospice or home care, ambulatory physician visits, ambulatory ancillary services, counseling, and community support services. These nonhospital services will account for a larger part of direct medical costs if hospitalizations are avoided or shortened and if medical developments extend the lives of AIDS patients. Furthermore, estimating the cost of nonhospital services is necessary to calculate the total medical cost of different approaches to managing AIDS and to analyze fully the cost implications of relying less on hospitalization and more on community support services, as exemplified by the San Francisco model.

Also, these studies give an incomplete accounting of the costs of HIV infection and the spectrum of symptoms it causes. For example, with one exception, the studies reviewed here pertain only to AIDS, and none included pediatric cases. In part, this incomplete accounting has resulted from reliance on incomplete records of public health departments, hospitals, and insurance companies. Also, AIDS, HIV, and the manifestations of HIV infection have been detected so recently that classification and recording systems are still evolving. Another reported factor is the reluctance of people with HIV infection or symptoms to participate in studies, mainly because they strongly guard confidentiality.

Existing studies also do not indicate how costs and sources of payment change over the course of AIDS or other symptoms of HIV infection. It has been theorized that costs peak around the time when AIDS is first diagnosed and again when the patient is close to death and that, as the disease progresses, patients without insurance spend their own assets and may come to rely on Medicaid and other government programs. However, the total cost burden on different payers and how it changes over
the course of the disease are not known.

**Changes in cost patterns.** Several studies projected the costs that would be associated with AIDS in future years on the assumption that present patterns of costs will continue. As some of the authors noted, great uncertainty surrounds these estimates because conditions are constantly changing. Knowledge and management of the disease are changing rapidly in ways that will almost certainly affect incidence and transmission of HIV infection, prevention of infection, treatment of symptoms, and survival of patients.

Although all of these factors in turn have implications for costs, the direction of change is unclear. Preliminary results of a two-year study in Massachusetts support the general impression that the cost of treating AIDS patients has declined. This study of 75 percent of the living AIDS patients treated in Massachusetts found that the cost of treating AIDS decreased at all five hospitals. Other factors, though, may increase treatment costs. Neurological symptoms such as dementia, which may require long-term institutional care, have only recently been identified in AIDS patients. The drug azidothymidine (AZT) has only recently been found to improve the condition and prolong survival of AIDS patients with certain symptoms. Other drugs are being tested in the hopes that they will arrest the progression of AIDS-related complex (ARC) to AIDS. How these developments on balance will affect treatment, the course of the disease, and the costs of AIDS is not yet clear. Expenditures associated with AIDS and HIV infection will clearly rise as viral transmission continues largely unabated. Expenditures may also rise if drugs that prolong survival must be continued throughout life.

**Variations In Cost Estimates**

The great variation in methods used by the studies reviewed make comparisons of cost estimates difficult and often impossible. The studies varied in their definition of AIDS, scope and definition of costs, time period, and geographic area. Furthermore, projections of the costs of AIDS and HIV infection in future years are handicapped by the continuing spread of the virus and the dynamic nature of treatment regimens.

**Definition of the health problem.** The costs to be included in an analysis depend on the definition of the health problem under study and the perspective taken. For national reporting purposes, the CDC has restricted the definition of AIDS to people who have antibodies to HIV, a deficiency of T helper cells, and certain opportunistic infections, presumably because HIV had impaired their immune systems. Under this definition, people who are infected with HIV and have symptoms attributed to the virus are not considered AIDS patients unless they have had one of these specific infections. People with ARC, for example, have
symptoms that range from swollen lymph glands, recurrent fevers, and unintentional weight loss to dementia and fulminant disease that leads to death. In addition, many people have been infected with the virus but have no symptoms of disease. Although it is not clear what percentage of infected people are likely to develop AIDS or ARC, the Public Health Service has estimated that 20 to 30 percent of the 1 to 1.5 million people in the United States thought to be infected in mid-1986 will develop AIDS within five years. Estimates of the percentage of people with HIV infection who are likely to develop AIDS have risen as infected cohorts have been followed over time, and the percentage may well increase as people are followed for longer periods. Based on such observations, some researchers have estimated that over 50 percent of the people infected with HIV will eventually develop AIDS, and a researcher in Germany has predicted 75 percent will develop active AIDS within seven years.

All of the studies reviewed in this paper documented costs associated with AIDS, but only the survey by the Health Insurance Association of America and the American Council of Life Insurance collected information on ARC. The results of that survey give only a partial picture of ARC costs, since the data pertain only to claims paid by the insurance companies surveyed and exclude costs paid by other payers, such as patients and government programs. These same limitations apply to the survey’s estimates of AIDS costs. The survey’s estimates of direct medical costs for AIDS were similar to those for ARC, $36,159 compared with $33,332 per case. However, disability claims for ARC patients fell substantially below those for AIDS ($8,293 versus $29,566). These figures should not be considered definitive. The survey left the definitions of AIDS and ARC to the respondent companies and asked for information from fall 1985 and before, instead of for a specific time period. Nor was information available on benefits and lengths of coverage, factors that could have accounted for the different levels of disability claims.

None of the studies reviewed attempted to document the costs of people who are infected with HIV but have not developed AIDS or ARC. These people are likely to obtain initial counseling and, over time, may seek and receive more medical care in order to rule out serious disease. Only the study by Scitovsky and her colleagues included costs related to general HIV infection. Their estimates included the costs of screening blood for HIV, research on HIV, and general education to prevent the spread of the infection, but not the personal medical costs of individuals infected with HIV.

Scope of costs. A comprehensive study of AIDS costs would include all of the costs associated with the use of resources for the disease, regardless of where they occurred or who paid for them. Costs directly attributable to AIDS consist of direct medical costs, which are incurred for the care of specific patients, and direct nonpersonal costs such as
research, education, and screening of donated blood, which are targeted more generally to the disease or to groups in the population. Indirect costs, which are intended to calculate the effects of sickness and death, are often measured by the losses in worker productivity that result from illness, disability, and death.\(^{34}\) Although it is well recognized that the burden of illness also includes the suffering of patients, their families, and their friends, no appropriate method has been developed to calculate these costs, and they are usually left out of quantitative estimates.\(^{35}\)

The perspective of the analysis affects the costs to be included. The perspective of society is the broadest and encompasses total resource costs, while the costs to a government program or to an insurance company would be more limited.

None of the studies reviewed included the full scope of costs associated with AIDS. There was a great deal of variation in what was and was not included. All seemed to include inpatient hospital costs, either explicitly or implicitly, by stating that they included direct medical costs. In general, inpatient hospital services are the most likely medical care to be covered by insurance, but cost estimates based on claims submitted to private insurers and public programs may include only part of inpatient expenses, depending on patient cost sharing and benefit limitations.\(^{36}\) It is not clear whether some of the estimates from specific hospitals included inpatient physician charges. A minority of the studies included ambulatory physician and ancillary services. Only Kizer and colleagues reported expenses for ambulatory drugs, home health, and long-term care, and the extent of coverage for these service categories was not clear.\(^{37}\)

Only the national estimates of AIDS costs by Hardy and Scitovsky and Shultz’s estimate of AIDS costs in Minnesota added indirect costs connected with sickness, disability, and premature death.\(^{38}\) As Scitovsky and colleagues stressed, these indirect costs have dwarfed direct ones. For 1986, indirect costs were estimated at $7.0 billion for the entire United States and $32.2 million for Minnesota, compared with direct costs of $1.7 billion for the United States and $5.8 million for Minnesota.\(^{39}\) The estimate of U.S. costs by Scitovsky and Rice was the only study to calculate the nonpersonal direct medical costs of general activities to further knowledge or prevent infection.\(^{40}\) This is an important omission from other studies, since Scitovsky and Rice estimated that such costs in 1986 amounted to $542 million, almost one-third of all direct medical costs.

While Scitovsky and Rice and Shultz and colleagues took the perspective of the total society in their cost estimates, other studies were less broad. Most enumerated costs to specific hospitals or inpatient hospital charges to payers, especially third-party payers, such as Medicaid. Although Bowen did not include indirect costs, he calculated total charges billed, regardless of who paid for them.\(^{41}\)

**Time periods.** The studies also varied in the time periods considered.
Three studies (the two by Scitovsky and others and one by Seage and colleagues) calculated annual costs, that is, the costs associated with AIDS during a twelve-month period. Five studies, including one by Scitovsky and colleagues and one by Hardy and colleagues, estimated the “lifetime” costs of AIDS patients from diagnosis to death. The lifetime estimates by Scitovsky and Hardy were limited to hospital and physician inpatient services, but the ones by Bowen and Kizer included a range of ambulatory services as well. In general, the other studies reported data for more than one year, often according to what was available in the data.

**Geographical differences.** The cost estimates covered many different geographical areas. Because of their high incidence of AIDS, New York City and California (San Francisco, Los Angeles, and the state) were the most frequently studied. These areas and others were also the sources of data for Hardy’s and Scitovsky’s national estimates. Taken together, the studies provide information from areas of high (New York City, California, Florida), medium (Boston, Maryland, Minnesota), and low (Alabama, New Mexico) numbers of reported cases.  

AIDS patients in San Francisco have had the shortest average lengths of hospital stay, even for patients on Medicaid. It also appears that San Francisco patients have the lowest lifetime hospital costs. This experience has been widely attributed to the support services and the different patient mix in San Francisco. It has been suggested that, since 97 percent of San Francisco AIDS patients are homosexual or bisexual men, they are more likely to have social support to enable earlier discharge from the hospital than AIDS patients in New York, for example, where 30 percent have been IV drug users. However, no significant differences were found in lengths-of-stay or hospital costs between IV drug users and other AIDS patients in New York. There is more support for the possibility that Kaposi’s sarcoma, more common among male homosexual AIDS patients, is less likely to require hospitalization than other opportunistic infections, such as pneumocystis carinii pneumonia, more common among IV drug abusers with AIDS. Also, community services to shorten or avoid hospitalization are more available in San Francisco.

Average lengths-of-stay reported in New Mexico; Alabama; Belle Glade, Florida; and Los Angeles were also below Scitovsky’s national estimate of twenty days. The information presented in these studies is insufficient to draw further conclusions about the relative cost of hospital or other medical services. It is clear that the average length-of-stay of thirty-one days and the average lifetime hospital costs of $147,000 reported by Hardy for the first 10,000 AIDS cases were much higher than subsequent reports. Scitovsky and her colleagues estimated that lifetime hospital costs in 1984 prices most likely ranged between $60,000 and $75,000. Perhaps, as some suggest, it took longer to diagnose and determine the treatment of the early AIDS patients that provided the
basis for Hardy's estimates. And as the high fatality rate of the disease became widely known, people in the terminal phase of AIDS may have been treated less intensively and hence less expensively.\(^{48}\)

## Predictions Of AIDS Costs

Five of the studies reviewed made projections of the costs that would be associated with AIDS in future years. Only those by Scitovsky and her colleagues related to the United States as a whole; Hull projected costs for New Mexico, Kizer for California, and Shultz for Minnesota.\(^{49}\) Since the 1987 Scitovsky study incorporated more recent CDC predictions of AIDS but used the same methods as her 1986 study, only the latter estimates will be discussed here.

Scitovsky and Rice predicted that by 1991 the annual total costs associated with the 172,000 AIDS patients estimated for that year would reach $66.5 billion, up from $4.8 billion in 1985 for 18,720 patients and $8.7 billion in 1986 for 31,440 patients.\(^{50}\) These estimates included direct (medical and nonpersonal) costs and indirect (mortality and morbidity) costs. In each year, indirect costs accounted for about 80 percent of the total, mostly due to premature mortality.

Shultz counted direct and indirect costs, but not nonpersonal direct costs, in his estimate that from 1986 through 1990 Minnesota's AIDS costs would total $846 million.\(^{51}\) Hull estimated that annual inhospital costs for New Mexico AIDS patients would range from $2.4 to $11.4 million in 1988 if cases doubled every twelve months, close to their current national rate.\(^{52}\) Both of these studies used Scitovsky's and Hardy's estimates of per case costs rather than the costs observed within the respective states. Hull used Scitovsky's figures for the low end and Hardy's for the upper end of his estimated range, and Shultz used an average of Scitovsky's and Hardy's figures. Kizer limited his projections to direct medical costs and used Medi-Cal (California Medicaid) claims as the basis for estimates of Medicaid and private-sector costs. Assuming that Medicaid pays and would continue to pay about 8 percent of direct medical costs, he estimated that their total would rise from $135 million in fiscal year 1985–86 to $1.2 billion in fiscal year 1990–91.\(^{53}\)

Although these studies differed in the estimated number of future AIDS cases, per case medical costs, and the types of costs included, they all based their projections on the assumption that present patterns of costs would continue. Scitovsky and her colleagues in particular realized the drawbacks of this approach but also recognized that they had no basis on which to predict changes in the direction of future costs.\(^{54}\)

Because knowledge about AIDS and its prevention and treatment is evolving at a rapid rate, many factors that affect the incidence, symptoms, and management of the disease may change dramatically over the
next five years in ways that would affect costs. As noted above, areas of uncertainty with important implications for costs are the number of infected people who will develop AIDS or other symptoms and the rate of viral transmission and spread of the disease. Conversion to AIDS seems to increase five to seven years after infection.\textsuperscript{55} Since AIDS was first identified in the United States in the early 1980s information is still unfolding on the natural course of HIV infection and the probability that an infected person will develop AIDS.

In the long run, the rate of HIV transmission may change, either by increasing or decreasing, with implications for the number of infections and the incidence of disease. The rate of transmission could be slowed by screening donated blood for HIV, hence reducing transfusions of infected blood, and by changes in sexual practices of high-risk people. On the other hand, HIV could become more prevalent among current low-risk populations, such as heterosexuals and children. And there are reports of infection with a variant of HIV termed HIV-II.\textsuperscript{56} Since tests currently used to screen donated blood do not detect infection from this slightly different virus, development and use of an additional screening test, and additional costs, may be needed to ensure a safe blood supply.

Because complications of AIDS seem to differ among high-risk groups, changes in incidence patterns could influence the manifestations and hence the cost of the disease. Higher incidence among infants may raise average and total costs. In general, these infants have become infected in utero, so more pediatric cases would be expected as HIV infection spreads among heterosexuals.\textsuperscript{57} The medical care of infants with AIDS may be especially costly if they are institutionalized for long periods because their mothers are incapacitated with AIDS.

The management of AIDS cases appears to have changed and will continue to change over time. However, the direction of the change in costs is unpredictable. Some developments lower inpatient use and probably total costs. There are reports that AIDS patients are less likely to be admitted to intensive care units than they were when less was known about the course of the disease and that the average length of hospital stay has declined.\textsuperscript{58} Seage’s preliminary data for Massachusetts, mentioned above, suggest such a decline in hospital treatment costs. Also, some services, such as blood transfusions for anemia, that formerly justified hospital admission are now provided on an ambulatory basis. Spurred by the example of community services in San Francisco, other localities are attempting to promote more supportive, less expensive alternatives to inpatient treatment, such as home and hospice care.

Other developments may make management of AIDS and HIV infection more costly. Neurological symptoms, such as dementia, are increasingly being detected in AIDS patients, who may require more intensive care than can be provided through home or hospice care. The drug
AZT, which the Food and Drug Administration recently approved for AIDS patients with certain symptoms, is expensive ($10,000–$12,000 per year) and often requires blood transfusions for resulting anemia, a service that is also costly.\textsuperscript{59} There is also the possibility that drugs will be developed to prevent or delay disease in infected people or to retard the progression of the disease in patients with symptoms. Any of these or other developments that change the length of the disease or the survival rate may also affect the total costs of treatment. Increased knowledge of HIV infection may also lead to higher costs. Based on the possibility that tuberculosis may be predictive of AIDS, the CDC in mid-1986 recommended that people with HIV infection be tested for tuberculosis and that tuberculosis patients in certain instances be tested for HIV infection.\textsuperscript{60} As noted above, new tests to screen the blood supply for variants of HIV would also add to the costs associated with AIDS. Treatment costs may also rise if people are diagnosed as having AIDS earlier in the course of the disease.

Another area of uncertainty in cost projections concerns how representative the data are on which existing cost estimates are based and how they can be generalized to other sites of care and areas of the country. Data have been drawn from a range of hospitals (municipal, private, and teaching hospitals), payers (government and private insurers), and geographical regions. However, in most cases, the categories of costs and disease severity have not been sufficiently standardized to permit comparisons. Furthermore, almost all the data on medical costs have centered on acute care hospitals. With the exception of data on Medi-Cal patients, no information has been available on the costs of long-term care and of ambulatory care separate from hospital outpatient clinics or on changes in costs over the course of the disease.\textsuperscript{61} And none of the studies reviewed included patients’ out-of-pocket expenses. Thus, we still do not have a comprehensive picture of the costs of AIDS.

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NOTES

1. The $24,517 estimate is from M. Belmont, “Resource Utilization by AIDS Patients in the Acute Care Hospital,” draft final report and summary of St. Luke’s-Roosevelt Hospital Center Study submitted to The Health Services Improvement Fund, Inc., December 1985; the $147,000 estimate is from A. Hardy et al., “The Economic Impact of the First 10,000 Cases of Acquired Immunodeficiency Syndrome in the United States,” Journal of the American Medical Association (10 January 1986):209–211. The cost of resources used should be distinguished from the charges to those who pay for the services performed.
Most of the studies reviewed here used charges to estimate the direct medical costs borne by patients and other payers, and the amounts derived are costs from the perspective of the payers rather than the providers of services. However, Seage and colleagues [G.R. Seage III et al., “Medical Care Costs of AIDS in Massachusetts,” Journal of the American Medical Association (12 December 1986):3107–3109] and Potts and colleagues (L. Potts et al., “The Costs of Treating AIDS in Alabama,” paper presented to the Association of Schools of Public Health, Las Vegas, Nevada, 1 October 1986) converted hospital charges to costs for inpatient care, and six other studies reported or used the average cost per hospital day.

2. The 7 percent Medicaid payment figure is from Potts et al., “Cost of Treating AIDS in Alabama;” the Medicaid figure of 65 percent is from J. Boufford, president, New York City Health and Hospitals Corporation, in testimony to the Subcommittee on Health and the Environment, Committee on Energy and Commerce, House of Representatives, U.S. Congress, Washington, D.C., 1 November 1985; the 13 percent private insurance payment figure is from S. Gamble, President, Hospital Council of Southern California, in testimony to the Subcommittee on Health and the Environment, Committee on Energy and Commerce, House of Representatives, U.S. Congress, Washington, D.C., 1 November 1985, and A. Scitovsky et al., “Estimating the Direct and Indirect Economic Costs of Acquired Immune Deficiency Syndrome, 1985, 1986, and 1990,” final report prepared for The Centers for Disease Control, task order 282-85-0061 #2, 31 March 1986; the figure of 65 percent is from Seage et al., “Medical Care Costs of AIDS in Massachusetts,” and Scitovsky et al., “Estimating the Direct and Indirect Economic Costs of AIDS.”

3. Costs per patient alive at any time during the year include costs for some people who did not have expenses for the entire twelve-month period, because they died or were diagnosed as having AIDS during the year. By contrast, cost per year for patients alive throughout the year represents the annual cost of caring for a person with AIDS and has been calculated as the cost per patient divided by the number of months each person was in the study times twelve. Seage et al., “Medical Care Costs of AIDS in Massachusetts.” Regarding the figure of $40,000, as noted later in this article, these estimates have generally excluded nursing home and home care and have varied in their inclusion of ambulatory drugs and other services.

4. Although the virus that causes AIDS has been termed human T-cell lymphotrophic virus type III (HTLV-III) or lymphadenopathy-associated virus (LAV), human immunodeficiency virus (HIV) is now the accepted nomenclature.


7. Certain federal and state laws promote the continuation of health insurance coverage for people, such as those with AIDS, who become too sick to continue working, although the actual effect is not known. The Internal Revenue provisions of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 (EL. 99-272) require that employees who are terminated (except for misconduct) from most firms be given the opportunity to continue their health insurance coverage under the employer’s group policy for eighteen months and to convert to individual coverage after that time. In addition, California requires that, for employees who leave work because of a medical disability, health insurers...
continue group coverage for claims related to that disability for one year at no additional cost (B. Bowen, corporate economist, Blue Cross of California, personal communication, 17 March 1987). Some other states may have similar requirements.


9. Scitovsky and Rice, “Estimates of the Direct and Indirect Costs of AIDS.” As advised by the Centers for Disease Control (CDC), Scitovsky and Rice increased the CDC estimates by 20 percent.

10. One would expect health insurance premiums of private insurers to rise to the extent that AIDS causes medical expenditures to rise for age groups that have historically had low expenses.


14. DHHS, Office of the Actuary, “Revised Estimates of Medicaid Impact of AIDS.”

15. Scitovsky and Rice, “Estimates of the Direct and Indirect Costs of AIDS.”

16. Ibid.


25. Seage and colleagues are analyzing the cost of ARC patients at a Massachusetts facility. G.R. Seage III, epidemiologist, Boston Department of Health and Hospitals, personal communication, 11 March 1987.

27. IOM, Confronting AIDS; and K. Kizer et al., “A Quantitative Analysis of AIDS in California” (March 1986). In 1986, the CDC supplemented its definition for national reporting with one based on clinical expression of disease and intended for public health purposes. The 1986 classification system consists of four groups that range from acute and asymptomatic infection to persistent generalized lymphadenopathy and other disease, including overt AIDS. U.S. Department of Health and Human Services, Public Health Service, “Classification System for Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus Infections,” Morbidity and Mortality Weekly Report (23 May 1986):334–339. In addition, the CDC is considering revisions of its national reporting (surveillance) definition, such as adding a category for presumptive AIDS and expanding the diseases considered indicators of AIDS. “CDC Revising AIDS Definition, Includes New ‘Presumptive AIDS’ Category,” The AIDS Record (15 December 1986): 1.

28. IOM, Confronting AIDS.


30. P. Volberding, chief, Medical Oncology Division and AIDS Activity Division, University of California at San Francisco, personal communication, 19 February 1987; and “German Researchers Predict Higher AIDS Rate,” AIDS Record (15 December 1986):3.

31. HIAA and ACLI, “Results of the HIAA and the ACLI AIDS Survey of Member Companies.”

32. IOM, Confronting AIDS.


34. An alternative method of placing a value on health and life is to measure the amount that people are willing to pay to avoid sickness, disability, or death. The “human capital” approach using worker productivity has been more extensively used to calculate the costs of different diseases and is the only one known to have been applied to the costs of AIDS. Both approaches have drawbacks that are related to distributional issues. Since the human capital method values people’s health and lives according to their earning levels, it values groups with higher average incomes (men, whites, working age, wealthy) more highly than people with lower average incomes (women, blacks, children, elderly, poor). Similarly, people with higher incomes are more able and hence more willing to pay larger amounts to forgo illness and death.

35. What people are willing to pay to avoid a medical problem would theoretically include the effect of pain and suffering.


40. Scitovsky and Rice, “Estimates of the Direct and Indirect Costs of AIDS.”

44. S. Anderman in Scitovsky et al., “Medical Care Costs of Patients with AIDS in San Francisco.”
46. Hardy et al., “The Economic Impact of the First 10,000 Cases of AIDS in the U.S.”
47. Scitovsky et al., “Medical Care Costs of Patients with AIDS in San Francisco.”
48. It has also been suggested that Hardy’s estimates were high because much of their data on average length-of-stay came from New York City, which may have had higher than average stays (A. Hardy, Centers for Disease Control, Atlanta, Georgia, personal communication, March 1987), and that there was a selection bias toward sicker (terminally ill) patients from looking at people in hospitals over a short time period (Seage, personal communication).
50. Scitovsky and Rice, “Estimates of the Direct and Indirect Costs of AIDS.”
51. Shultz et al., “The Epidemiology and Health Economics of AIDS in Minnesota.”
52. Hull, “Projected Impact of AIDS for New Mexico.”
54. Scitovsky et al., “Estimating the Direct and Indirect Economic Costs of AIDS.”
55. Volberding, personal communication.
57. P. Selwyn, presentation to the American Public Health Association, Las Vegas, Nevada, 28 September 1986.
58. Scitovsky et al., “Estimating the Direct and Indirect Economic Costs of AIDS.”
59. Volberding, personal communication.