The $147,000 Misunderstanding: Repercussions of Overestimating the Cost of AIDS

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Abstract The increasing incidence of AIDS in the 1980s prompted inquiry into the resources required to meet projected needs. In the first economic study to appear on the illness, the Centers for Disease Control (CDC) estimated that the costs of inpatient care were $147,000 per AIDS patient, heightening concern that the health care system would be overwhelmed by the epidemic. However, every study published subsequently has produced much lower cost estimates. As a result, many have concluded that treatment costs declined due to improved delivery of AIDS care. We offer an alternative interpretation, based on evidence demonstrating that the CDC's methods and assumptions yielded a figure about three times too high. The CDC's erroneous estimate had significant policy repercussions. Using the $147,000 figure, the health insurance industry lobbied successfully for the right to screen applicants for HIV. Next, when a study of San Francisco AIDS patients found local hospital costs per case to be $27,571, many concluded that billions of dollars could be saved if the "San Francisco model" of care (emphasizing home and community-based services and case management) were universalized. Since then, most programs for AIDS services have provided funds for community care. While such programs improve access to vital services, they are unlikely to guarantee "better care for less money." A more informed understanding of the cost of AIDS should lead to programs that also strengthen inpatient care.

The human toll of AIDS in the early 1980s confronted society with a major public health crisis. The severity and rising incidence of the illness also engendered fears that its economic impact, particularly on the health care system, could be overwhelming. When researchers from the Centers for Disease Control (CDC) (Hardy et al. 1986) published the first cost study of AIDS-related care, apprehension increased further. The CDC re-
port estimated that charges for inpatient medical care from diagnosis to
deat for the first 10,000 persons in the United States reported to have
AIDS were $147,000 per case, among the highest costs ever estimated for
treatment of a specific illness. However, the CDC study findings (which
appeared in January 1986) have never been replicated. Empirical studies
published since then have consistently produced much lower estimates of
the cost of AIDS care (Table 1), but the first of these findings did not
appear in print until December 1986 (Scitovsky et al. 1986; Seage et al.
1986), almost a year after Hardy et al. published their findings. During
nearly all of 1986, key AIDS-related health policies then being formu-
lated were influenced by the belief that, on average, an AIDS patient’s
hospital costs were $147,000.

Some analysts have interpreted the discrepancy between the CDC esti-
mate and subsequent research as evidence of declining costs due to the
widespread adoption of a more efficient service delivery model. In this
article, we offer a different interpretation. We first present a critique of
the methodology used to obtain the $147,000 estimate and then offer evi-
dence that the result was about three times too high. The remainder of the
paper is devoted to a description and evaluation of the consequences of
this overestimate to AIDS policy. In presenting this assessment we seek
to cast no aspersions on the efforts of others. We recognize that the very
first attempt to quantify the cost of this new disease was performed under
difficult circumstances, with limited data, and at a time when AIDS re-
search was still largely an uncharted realm. We offer our critique in part to
provoke reexamination of some key assumptions about AIDS and also to
illustrate the important role that even very inaccurate numbers may play
in the formation of public policy.

**How the Estimate Was Made**

The $147,000 figure, representing the lifetime cost of hospital care for a
person with AIDS, was derived from a model utilizing three elements:
duration of an initial hospitalization, days for total lifetime readmissions,
and per diem charges (Table 2). Specifically, the average number of days
spent in the hospital per patient was estimated as the sum of two compo-
nents: the patient’s initial hospitalization (estimated at 31 days) plus all
subsequent hospitalizations (estimated at 137 days). The sum, 168 days,
was multiplied by an estimated charge per day of $878, yielding $147,000
(Table 2). All three elements in this model appear to have been overstated
to different degrees. Comparison with subsequent reports (Andrulis et al.
Green et al. (1989; Green et al. 1987; Grabau et al. 1991) suggests that the figures for length of initial stay and charge per day were high, but these elements contributed only slightly to the overestimate. By far the chief source of error was the procedure used in estimating a mean of 137 readmission days.

This estimate was derived from a survey of physicians conducted in 1984 by the New York City Department of Health (Rivin et al. 1984). The survey followed up the first cases of AIDS reported in New York City from July 1981 to January 1984, a total of 1,410 individuals. Only one survey question dealt with hospitalization. Physicians were asked to recall the “percent of time” each patient had spent in the hospital after the initial hospitalization. Respondents could choose one of four answers: 0–30 percent, 30–50 percent, or 50–100 percent of the time since the initial hospital stay, or no readmission because the patient died during the first hospitalization. The CDC study estimated the mean number of lifetime readmission days for each of these response groups by multiplying the range midpoint (e.g., 75 percent was used for the 50–100 percent category) by 361 days, the average survival time for AIDS patients beyond initial hospitalization (Table 3). In this procedure, two methodological assumptions were made that led to substantial overestimation of the lifetime cost of AIDS.

First, the use of a single estimate of survival time (361 days) for all AIDS patients was insufficient, given evidence in the survey report itself (Rivin et al. 1984) and elsewhere (Moss et al. 1984), which demonstrate a wide variation in duration of survival. An alternative hypothesis might have proposed that patients who spent the greatest percentage of their time in the hospital were among the most severely ill and most likely to die after a relatively brief illness. Such a hypothesis would have greatly reduced the number of hospital days attributed to those patients. In fact, empirical evidence to support the latter supposition now exists. A study of 381 early AIDS cases in Oregon found a statistically significant inverse relationship ($p < .001$) between duration of survival and the percentage of time spent in the hospital (Hulman et al. 1989). The Oregon data suggest that, contrary to Hardy et al.’s assumption, patients who spent a large percentage of time in the hospital did not spend a large number of days there, because they died within a few months of diagnosis.

Second, the technique for estimating lifetime readmission days (multiplying percentage of time in the hospital by mean survival time) should not have been applied to patients who had recently been hospitalized and were still alive when the data was collected. Consider a patient who was still alive at the time of the survey, who had been discharged from an ini-
<table>
<thead>
<tr>
<th>Study</th>
<th>AIDS Patients Sampled</th>
<th>Basis for Economic Valuation</th>
<th>Lifetime Inpatient Charges or Costs</th>
<th>Lifetime Inpatient Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hardy et al. 1986</td>
<td>Various sources, principally AIDS cases reported in New York City for July 1981–Jan. 1984</td>
<td>1984 charges</td>
<td>$147,000</td>
<td>168</td>
</tr>
<tr>
<td>Scitovsky et al. 1986</td>
<td>San Francisco General Hospital patients who died in 1984</td>
<td>1984 charges</td>
<td>(a) $27,571 (b) $41,499</td>
<td>25.8 52.2</td>
</tr>
<tr>
<td>Seage et al. 1986</td>
<td>Deaconess Hospital (Boston, MA) patients diagnosed and alive as of 1 Sep. 1984</td>
<td>1984 costs</td>
<td>$46,060b</td>
<td>67.1c</td>
</tr>
<tr>
<td>Study</td>
<td>Patients</td>
<td>Year</td>
<td>Charges</td>
<td>Lifetime Hospital Days</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>--------</td>
<td>---------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Kaplowitz et al. 1988</td>
<td>Patients treated at Medical College of Valley Hospitals (Richmond, VA)</td>
<td>1987</td>
<td>$27,264</td>
<td>27.5</td>
</tr>
<tr>
<td>Hiatt et al. 1990</td>
<td>Patients diagnosed at Kaiser Permanente (northern California)</td>
<td>1986</td>
<td>$26,811</td>
<td>40.3</td>
</tr>
<tr>
<td>Thomas and Fox 1988</td>
<td>Patients hospitalized in 1985 at four New York City hospitals</td>
<td>1982-1985</td>
<td>$55,655^d</td>
<td>62</td>
</tr>
<tr>
<td>Padgug and Eisenhandler 1990</td>
<td>New York metropolitan area patients with Blue Cross</td>
<td>1982-1983</td>
<td>$44,334</td>
<td>64</td>
</tr>
</tbody>
</table>

a. Scitovsky et al. (1980) reported (a) unadjusted and (b) adjusted lifetime hospital days and charges for patients in their sample who died in 1984 and had all their professional care at San Francisco General Hospital. The adjustment was made to account for the fact that sampled patients survived only 7.5 months, whereas the expected survival given the case mix of this sample was 11.2 months.

b. Annualized inpatient costs times life expectancy in years: \((42.5 \times 13)/12 = 46.060\).

c. Annualized inpatient days times life expectancy in years: \((61.9 \times 13)/12 = 67.1\).

d. Costs were also reported ($38,169).
Table 2 Components of the Centers for Disease Control Estimate of the Lifetime Cost of AIDS Care

<table>
<thead>
<tr>
<th>Component</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Hospitalization</td>
<td>31 days</td>
</tr>
<tr>
<td>Hospital Readmissions</td>
<td>+ 137 days</td>
</tr>
<tr>
<td>Lifetime Hospital Use</td>
<td>168 days</td>
</tr>
</tbody>
</table>

Charges per Day × $878

Total Lifetime Cost $147,000

Source. Hardy et al. 1986.

Table 3 Derivation of the Centers for Disease Control Estimates of 137 Days for Readmissions and 168 Total Hospital Days

<table>
<thead>
<tr>
<th>Percentage of Time in Hospital since First Hospitalization</th>
<th>Number and Percentage of Patients</th>
<th>Category Percentage Midpoint</th>
<th>Number of Readmission Days</th>
<th>Total Lifetime Hospital Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 d</td>
<td>136 (14)</td>
<td>0</td>
<td>0</td>
<td>31</td>
</tr>
<tr>
<td>0–30</td>
<td>339 (35)</td>
<td>15</td>
<td>54</td>
<td>85</td>
</tr>
<tr>
<td>30–50</td>
<td>152 (16)</td>
<td>40</td>
<td>144</td>
<td>175</td>
</tr>
<tr>
<td>50–100</td>
<td>332 (35)</td>
<td>75</td>
<td>271</td>
<td>302</td>
</tr>
<tr>
<td>Total</td>
<td>959 (100)</td>
<td>137</td>
<td>168</td>
<td></td>
</tr>
</tbody>
</table>

a. The midpoint of each category was assigned to represent the percentage of time spent in the hospital. This step may also have caused errors, particularly the use of 75 percent to represent the 50 percent–100 percent category.

b. Category midpoint times 361 days. The 361-day figure represents the average survival time (392 days) minus the average length of the initial hospitalization (31 days).

c. Readmission days plus 31, where 31 represents the length of stay for the initial hospitalization.

d. No readmissions because patient died during first admission.

Initial hospitalization four weeks previously, and had since spent two weeks in the hospital. In response to the survey, the patient's physician would state that "50–100 percent" of the patient's time had been spent in the hospital. While that person had actually experienced 14 inpatient readmission days, the CDC model would have credited him or her for 271 such days (75 percent × 361 days. See Table 3). The implicit assumption that the percentage of time a living patient had thus far spent in the hospital could be used as an estimate of his or her lifetime use is unjustified.

Both assumptions (uniform survival time and extrapolation from living patients' experience) tended to exaggerate the number of days patients
diagnosed with AIDS stayed in the hospital during the remainder of their lives. By including data based on the experience of patients who were still alive, the CDC study tended to inflate the size of the group that was assigned the highest hospital utilization rate. Crediting this high-utilization group with the average survival time for all patients led to an extremely high estimate of 302 hospital days—for a group which, thus constituted, made up 35 percent of the entire sample (Table 3). Thus, the assumptions made in converting data on “percent of time in hospital” to actual lifetime hospital days led to the inference that more than one in three persons with AIDS would spend ten months out of a life span assumed to be thirteen months in hospital, and this conclusion greatly skewed the overall result.

**Magnitude of the Overestimate**

Subsequent reports on hospital care for those diagnosed with AIDS during the same period as the patients in the CDC study provide a basis for assessing the degree to which the $147,000 estimate differed from the costs actually incurred. For example, a study employing Blue Cross claims data (Padgug and Eisenhandler 1990) examined retrospectively the charges incurred by patients with AIDS in New York City. Those diagnosed in 1982 or 1983 on average used 64 hospital days from diagnosis to death and incurred inpatient charges per patient of $44,334, about one-third the CDC estimate of 168 hospital days and $147,000. An investigation of patients with AIDS at four New York City hospitals found that those who died in 1985 experienced an average of 62 lifetime days in the hospital and generated charges of $55,655 (Thomas and Fox 1988). Finally, a study by Scitovsky et al. (1986) of AIDS patients who died at San Francisco General hospital in 1984 yielded lifetime hospital charges per case of $27,571; even after adjusting for the atypically brief survival time of their sample patients, Scitovsky et al.’s estimate increased to only $41,499. In summary, the best empirical studies of the cost of AIDS care in the period covered by the CDC study determined that average lifetime inpatient charges ranged from about $40,000 in San Francisco to approximately $50,000 in New York City. We infer, therefore, that the $147,000 estimate was approximately three times too high.

**Initial Reaction**

The $147,000 estimate was the subject of intense publicity (Eckholm 1986), beginning in mid-1985 when it was first presented and in 1986 when it was published. Reports from the CDC projecting 270,000 AIDS
cases by 1991, coupled with the prospect that costs per case would average $147,000, gave rise to fears that $40 billion might be needed over five years to provide AIDS-related inpatient care (Schramm 1987). One writer attempted to convey the significance of the $147,000 AIDS cost estimate by pointing out that this was equivalent to the lifetime cost of heart transplantation, among the most intensive of medical interventions (Osborn 1986). Others portrayed the high cost of AIDS as a "time bomb" threatening hospitals with financial ruin (Powills 1986).

The Insurance Industry's Response

By the fall of 1985, corporate policymakers, particularly those in the insurance industry, began to take notice of early reports of the CDC's AIDS cost study. A front-page article in the Wall Street Journal (1985), headlined "AIDS Costs: Employers and Insurers Have Reason to Fear," cited the $147,000 figure. The New York Times (Kristof 1985) quoted a senior insurance executive who perceived AIDS "as potentially the biggest financial risk the health and life insurance business has ever faced in this country." With reports of new AIDS cases doubling every twelve to fourteen months (Institute of Medicine 1986), the insurance industry began to limit its liability by using the ELISA HIV-antibody test, then newly licensed, to screen applicants seeking individual policies (Oppenheimer and Padgug 1986).

The insurers' strategy of avoiding future claims by denying individual coverage to applicants infected with the AIDS virus encountered obstacles when states such as California and Wisconsin took legislative action forbidding the use of the HIV antibody test to determine insurability, while other states prepared to follow suit (Denier 1988). The prospect of legislative opposition to HIV testing for underwriting purposes galvanized the insurance industry to organize a lobbying campaign (Kocolowski 1985). The two leading industry trade groups, the Health Insurance Association of America (HIAA) and the American Council of Life Insurance (ACLI), prepared a white paper (ACLI and HIAA 1986) in which the $147,000 figure was used to support the thesis that testing for HIV was required to avoid an enormous financial liability.

Later, when the HIAA and ACLI conducted their own survey, with a 72 percent response rate by all health and life insurers in the country, they found that the average, per person AIDS-related health insurance claim was $36,159 (Health Insurance Association of America 1986). Yet, despite their own survey results, the HIAA and ACLI, when arguing for
the insurers' right to test applicants for HIV infection, continued to cite $147,000 as the possible lifetime cost of AIDS (Schatz 1987). This occurred in public statements (Clifford and Iuculano 1986), in the pages of the Harvard Law Review (Clifford and Iuculano 1987), and in a brief before the New York State Supreme Court, Health Insurance Association of America v. James P. Corcoran, 551 N.Y.S.2d 615 (N.Y. 1987).

Through lobbying or court suits, the industry succeeded in blocking or overturning actions to ban HIV antibody testing in several states, including Wisconsin, Washington, D.C., Massachusetts, and New York (Denier 1988). As of this writing, California is the only state that still prevents insurers from testing individual health policy applicants for HIV. Cal. H&S Code §199.21(f); Cal. Ins. Code §§ 799 et seq.

A Life of Its Own: Interpretations of the $147,000 Figure in the Literature

The $147,000 figure gained importance as it was repeatedly cited in medical and public policy journals. A systematic review of that literature, covering the period from April 1985 through the end of 1988, yields seventy-two references (Table 4), more than twenty times the average number of citations for a scientific paper (Scientific Citation Guide and List of Source Publications 1990). The published literature has imputed a variety of meanings to the figure of $147,000 (Table 4). Twenty-two percent of the articles simply cited it as the true current cost per case of AIDS in the United States. As new investigations began to report much lower lifetime costs, many writers (32 percent) continued to cite the Hardy study by simply noting that the range of available estimates extended as high as $147,000. The statement “estimates of lifetime AIDS treatment costs per patient range from $27,571 to $147,000” or words to that effect are found in most of these articles, often with little or no critical discussion. This practice created the impression that average inpatient costs for AIDS varied enormously and were therefore highly unpredictable.

Economic forecasting based upon reviews of the literature were in turn skewed by the $147,000 figure's influence. For example, in 1987 the RAND Corporation prepared an estimate of the future costs of care for AIDS and the share of these costs likely to be borne by the Medicaid program (Pascal 1987). Noting the wide range of published cost estimates, the authors of the RAND report chose, quite reasonably, to prepare low, medium, and high case scenarios. However, the resulting high estimate, which used the $147,000 cost figure, drew the headlines, with its projec-
Table 4 Citation and Interpretation of the Centers for Disease Control Study in the Medical and Health Policy Literature

<table>
<thead>
<tr>
<th>Interpretation</th>
<th>Citations by Year</th>
<th>Total Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>$147,000 is the cost of AIDS in the U.S.</td>
<td>1 6 4 5</td>
<td>16 (22)</td>
</tr>
<tr>
<td>Estimates range from $27,000 (or some other figure) to $147,000</td>
<td>1 2 9 11</td>
<td>23 (32)</td>
</tr>
<tr>
<td>$147,000 was the cost of AIDS in the early epidemic years, or was the cost of AIDS in New York City</td>
<td>0 0 2 4</td>
<td>6 (8)</td>
</tr>
<tr>
<td>$147,000 is the cost of AIDS in the U.S. except in San Francisco or except when the San Francisco model is applied</td>
<td>0 2 6 4</td>
<td>12 (17)</td>
</tr>
<tr>
<td>$147,000 estimate was too high or was based on an unrepresentative sample</td>
<td>0 3 7 5</td>
<td>15 (21)</td>
</tr>
<tr>
<td>Total</td>
<td>2 13 28 29</td>
<td>72 (100)</td>
</tr>
</tbody>
</table>

Note. A complete list of citations, classified according to interpretation, is available from the authors upon request.

a. The Centers for Disease Control study by Hardy et al. was published in January 1986. References from 1985 cited earlier public presentations of the Hardy study (Hardy et al. 1985; Hardy 1985).

b. Articles in this category described various flaws in the Hardy et al. estimate. None, however, identified the major problem, which was the calculation of hospital readmission days (see text).

tion that under worst-case assumptions a total of $113 billion (including 13 percent of the nation’s entire Medicaid budget) could be expended on AIDS care from 1986 to 1991 (Parachini and Simross 1987). Comparison with more recent economic analyses suggest that the costs of AIDS care from 1986 to 1991 would not exceed, and may well have been considerably less than, $20 billion (Hellinger 1988; Hay et al. 1988).
Further Misunderstandings: $147,000 vs. $27,571

Among subsequent reports of lower lifetime costs, the most significant in its implications was Anne Scitovsky's cost-of-illness study (Scitovsky et al. 1986) based upon a systematic review of AIDS patients' medical records. Scitovsky and her colleagues found that lifetime hospital costs of those with AIDS who had all their inpatient care at San Francisco General Hospital and who died in 1984 averaged only $27,571. (The fact that they adjusted this figure up to $41,499 within the same article to correct for an abnormal sample—see Table 1—received less notice.) The more than fivefold discrepancy with the CDC's $147,000 estimate required explanation. One hypothesis was that $147,000 represented the cost of AIDS in the first years of the epidemic, costs that had since declined (Sisk 1987). Some analysts, trying to explain why the costs were so high in the earlier period, conjectured that physicians may have taken longer to diagnose patients, or that they used more aggressive treatment. Another widely accepted interpretation is that the CDC figure represented the cost of AIDS in New York City, given that much of the data were drawn from the New York City Health Department survey noted above. Specifically, some writers inferred that the intense needs of intravenous drug users in New York resulted in very long hospital stays (Bloom and Carliner 1988).

"Except in San Francisco"

The most influential interpretation of the discrepancy between the CDC study and Scitovsky et al.'s finding, however, was that the San Francisco data reflected a dramatic achievement in health care cost containment that was unique in that city. An article in the San Francisco Chronicle (1986) attributed the Scitovsky study's low figure to "the lower treatment costs achieved at San Francisco General Hospital, the first to replace costly intensive hospital care for AIDS patients with outpatient care." A number of writers began to describe the costs of AIDS as being $147,000 in the U.S. as a whole but $27,571 in San Francisco and to attribute the difference to an innovative approach to delivering care—the "San Francisco model" (Silverman 1988).

The thesis that a model approach to caring for AIDS patients had been developed in San Francisco, which could, if replicated, offer economic relief by substituting home and community-based services for hospital care, soon became a cornerstone of AIDS policy—and has remained so ever since. In the eyes of many, the contrast was between two fundamen-
tally different ways of delivering care: the $147,000 figure represented the "traditional medical model," characterized as heavily dependent on technologically intensive, institutional hospital care, while the $27,571 figure symbolized the "continuum-of-care model," described as an integrated network of services linked together by case management that afford "more compassionate care for less money" (Kawata and Andriote 1988; Altman 1986). Although prior research, especially in geriatrics, appeared to show that adding home and community-based services, however desirable from the patient's perspective, did not contain costs (Weissert 1985; General Accounting Office 1982), many regarded AIDS as an exception, largely because of the apparent discrepancy between the CDC and San Francisco cost figures. For example, a House conference committee (U.S. House 1986a) concluded that, "the San Francisco experience shows that new community services reduce rather than expand the cost per case for AIDS patients."

**Shaping the Response**

The nation's programmatic response to the new demands for health services created by the AIDS epidemic began in early 1986 when the Robert Wood Johnson Foundation announced the AIDS Health Services Program, a $17.2 million initial investment in a series of demonstration projects to assist cities in developing consortiums of community-based AIDS care. Following the same lead, the federally funded AIDS Service Demonstration Program, legislated in 1987, also supported demonstration projects modeled on San Francisco's community-based, case-managed model of care. Other federal legislation permitted states to obtain Medicaid waivers to offer home and community-based services exclusively to AIDS patients. Act of Oct. 2, 1986, Pub. L. No. 99-509, 100 Stat. 1874. Finally, New York State, in developing its Designated AIDS Center program, opted for a model which drew many key elements from the San Francisco approach.

These vitally important programs, the first to deal with AIDS as a health care delivery problem, shared similar goals and assumptions. One was that the major unmet need among persons with AIDS was for subacute care, particularly home care. Another was that patients preferred to receive care at home rather than in the hospital whenever feasible. Thus the expansion of home and community-based care was an attempt to make the care delivery model more responsive to patients' needs and preferences. There was also a belief that case management services com-
Figure 1 Contrasting Estimates: Portrayal of the Costs of Hospitalization for AIDS Patients in the United States and San Francisco

Source. This figure appeared in AIDS Health Services Program, Robert Wood Johnson Foundation, 1986.

Combined with home care would assist patients in obtaining greater access to services and would constitute a more coordinated response. While these objectives had much merit and might have been sufficient to summon resources, the programs were also promoted as important cost containment initiatives.

Announcements describing the demonstration projects justified the expectation of reduced costs by citing the CDC and Scitovsky studies (see Figure 1) (Robert Wood Johnson Foundation 1986; U.S. Department of Health and Human Services 1987). The committee report (U.S. House 1986b) accompanying the Medicaid waiver legislation also used the CDC estimate, forecasting that the cost of AIDS care in 1991 would be $24 billion unless other cities adopted San Francisco’s continuum-of-care model. New York State officials projected that the Designated AIDS Center Program would reduce AIDS-related hospital use by as much as half (Sullivan 1985). Thus, every major effort to expand health services for AIDS patients was shaped in part by the prediction that replication of
the San Francisco model would not only improve care but also yield dramatic savings by avoiding the costly hospital utilization pattern ostensibly revealed by the CDC study.

While the AIDS initiatives were undoubtedly instrumental in expanding access to and improving coordination of services, there is little evidence that the need for hospitalization declined as had been projected. Data from the National Center for Health Statistics show that AIDS patients spent almost 1.4 million days in hospitals in the two-year period 1986-87, compared with half a million days in the two years 1984 and 1985, and that between these two periods the average length of stay for AIDS-related hospitalizations increased slightly from 15.6 to 15.9 days (Graves and Moien 1987; Moien and Kozak 1989). In addition, the notion that many hospitalized AIDS patients were being served in an inappropriate setting has not been demonstrated. For example, Andrulis et al. (1988) reported that based on national survey data only 10 percent of hospitalized AIDS patients did not actually require acute care.

Avoiding the Hospitals

As the epidemic progressed and treatment modalities expanded, a growing number of AIDS patients relied on hospitals to provide increasingly sophisticated care (Green et al. 1987; Wachter 1989). While hospitals throughout the country, particularly major teaching hospitals and urban public hospitals, responded rapidly to meet this challenge (Andrulis 1989), national survey data show that in providing such care hospitals experienced financial losses averaging $2,000 to $3,000 per AIDS admission (Andrulis et al. 1989) and incurred additional costs of instituting universal precautions. Yet, once the San Francisco model, with its emphasis on replacing inpatient with outpatient care, was adopted as a paradigm, it became easier for policymakers to authorize funds targeted for ambulatory services, home care, and case management than for inpatient care. In fact, the first major federal funding initiative prohibited the use of program funds to compensate hospitals (U.S. Department of Health and Human Services 1987). Based on the argument that funding for added community-based services for AIDS would reduce the need for hospitalization, the more recent Ryan White Comprehensive AIDS Resources Emergency Act of 1990, 104 Stat. 576, similarly allocates nearly all funds for outpatient and community-based care, with very limited support for acute care.

While arguments favoring support for community-based care were per-
suasive, other responsible proposals, which would have offered hospitals economic relief, did not receive as much support. For example, one proposal called for providing AIDS patients with Medicare coverage, by waiving the twenty-four-month waiting period normally required before an applicant becomes eligible for Medicare benefits on the basis of having a permanent disability (Presidential Commission 1988). Expanded Medicare coverage of AIDS would have benefited hospitals (and patients) by reducing the proportion of patients who either had no insurance or only had Medicaid (which often pays very low inpatient rates). In addition, some called for the development of specific diagnosis-related groups (DRGs) for AIDS (Clark and McCallum 1988). This mechanism would have brought payments closer in line with hospital costs, not only for the few Medicare patients with AIDS but for many other patients in states where Medicaid or private insurers use DRGs. It was not until 1990, however, that AIDS-specific DRGs were added to the federal system, which sets the standard followed by most users of DRGs (the exception is New York State, which implemented fifteen AIDS-specific DRGs in 1988).

**Social Science and Public Policy**

The circumstances that led to such a wide acceptance of the CDC’s overestimate of the cost of treating AIDS have analogs in other cases. For example, a widely used estimate of the dollar value of property stolen by heroin users in New York City ($2–5 billion) was at least ten times too high (Singer 1971). Singer noted that when people believe a societal problem is very large they are also inclined to accept very high estimates of its economic magnitude. Fox (1987) makes an analogous point, noting that the CDC’s estimate of the cost of AIDS was believable, in part, because catastrophic cost was serving as a metaphor for many of the terrible effects of the illness.

In pulling together data for an early estimate of the magnitude of AIDS treatment costs, the CDC faced many difficulties. Nevertheless, even with these obstacles, it appears in retrospect that opportunities existed for early detection and correction of the error. First, lower estimates predating the CDC study were available; while limited in their generalizability, they might have been used to place the $147,000 figure in some perspective. An OTA report issued in February 1985 put the lifetime cost of AIDS at $60,000 to $70,000 (Office of Technology Assessment 1985). A widely circulated study by Belmont, released in December 1985, found that AIDS patients used 40 days of hospital care per year (1985). Most
important, an early version of the Scitovsky et al. (1986) study had been presented at the First International Conference on AIDS in mid-1985 (this early version reported the lifetime costs of AIDS inpatient care as $29,000) (Scitovsky et al. 1985) at the same panel session in which the CDC analysis was presented.

Secondly, there are standard methods for handling data that represent the experience of both living and deceased patients. Comparison with other studies of AIDS costs shows that within the research community similar data limitations were overcome by restricting analysis of lifetime costs to patients who had died (with adjustment for survival duration) (Scitovsky et al. 1986) or by using the lifetable method to take account of truncation that occurs when data on living patients are used to project lifetime utilization (Hiatt et al. 1990).

Once the CDC study was published, subsequent literature referred to it often but did not assess it critically. We would be remiss, however, if we did not point out that a few writers noticed early on that there was something seriously wrong with the $147,000 figure, though none identified the principal source of error. Gildea (1986), for example, pointed out as early as January 1986 that the cost estimate was “a red herring” that had distracted the insurance industry and other key players. Fox (1987) was among the first to describe the $147,000 figure as an overestimate, while Schatz (1987) took the insurance industry to task for using the $147,000 figure when it had long since been superseded. By contrast, it was widespread practice to open articles on AIDS costs by summarizing prior research as offering a range of estimates from $27,571 to $147,000, a practice that offered readers little insight into either the condition of the literature or the true cost of treating AIDS.

The $147,000 figure, as used by those who had an interest in portraying the cost of AIDS as catastrophic, had major consequences for policy. The insurance industry, as we have seen, found the estimate useful in making the case for HIV testing so they could screen out HIV-positive applicants, even after industry data no longer supported such high costs. Predictably, the private insurers’ share in financing the care of those with AIDS has declined measurably over the course of the epidemic (at least in the states that have the highest incidence of AIDS), even after controlling for demographic changes in the AIDS population (Green and Arno 1990). As a result, the burden has fallen increasingly on public financing. Now that we have more accurate estimates of the cost of treatment, the policy that allows insurers to screen for HIV should be reexamined.

A careful review should also be made of policy decisions that favor
community-based care over care provided by hospitals. Programs that emphasize alternatives to hospitalization are not new: in fact, they constituted a trend in health policy well before the AIDS epidemic. During the 1970s policymakers became convinced that expansion of home and community-based services for the elderly might be a kind of “silver bullet” that could both improve quality of life (because it would reduce institutionalization in nursing homes and hospitals) and simultaneously lower health care costs (Brecher and Knickman 1985). The 1970s and 1980s were also characterized by research that questioned the appropriateness of hospital services and by cost containment efforts (such as utilization review, prospective payment, and managed care) that increasingly focused on reducing the role of hospitals (Vladeck 1990).

In light of these trends toward alternatives to institutional care, data showing that money invested in community-based care would yield significant savings had long been anticipated; but in fact no such evidence had arrived. On the contrary, study after study reported that demonstrations of community-based care increased costs, because the community-based services were supplementing rather than replacing institutional care (Kemper et al. 1987). A review of such research led Vladeck (1991) to conclude, “If we have learned anything in health economics in the last decade, it is that the cost of a bundle of medical services is primarily determined by the characteristics of the patient and the patient’s illness, not the site of care.”

The two separate studies of AIDS reporting lifetime costs as different as $147,000 and $27,571, together with suggestions that this difference was due to the community-based nature of care seemed to confirm, for once, that expanding community-based services would in fact save money and that these savings could be demonstrated empirically. As more realistic data have become available, it appears that, as with the elderly, it is far easier to associate community-based care for AIDS with important benefits to patients than with cost containment (Benjamin 1988). This suggests that a recent proposal advocating a new approach to home care policies with increased emphasis on improving the efficiency of home care delivery (Weissert 1991) should apply to home care for AIDS as well. A reevaluation of the level of support provided to hospitals caring for AIDS patients may also be required. As Cotton (1988) notes, hospitals, particularly those in major urban centers, are “the front lines” in the war against AIDS. She argues that, despite recent attempts to redefine AIDS as essentially a “primary care illness” or a “chronic disease,” the virulent nature of its manifestations, the complexity of therapeutic protocols,
and the rapid changes in accepted practice suggest that much of the care provided for AIDS is appropriately centered in acute care hospitals and, particularly, in academic medical centers.

In New York City alone, as AIDS incidence has grown dramatically, the average daily census of AIDS patients in public and private hospitals increased from 1,071 in March 1987 to 2,053 in July 1990, the latter figure representing 8 percent of the city's entire bed capacity (Greater New York Hospital Association 1991). Statistics alone cannot fully convey the challenges hospitals have faced as ever-increasing numbers of AIDS patients have arrived. In the course of just a few years, entire hospital units were transformed into specialty wards for the treatment of AIDS. Within these units health care workers were called upon to overcome constant concerns about personal safety in order to meet their patients' needs, testing the limits of their professional dedication. The numbers do not convey the extraordinary clinical achievement, much of it accomplished within these same few hospitals, that has transformed AIDS from a medical mystery into a fairly circumscribed set of conditions for which an extensive battery of therapeutic options now exist (Cotton 1991). In an era of intense financial pressure on hospitals, increased competition and the decline of cost-based reimbursement, is it reasonable to expect hospitals to absorb the unanticipated burdens of an AIDS epidemic without adequate compensation? Are policies which allocate a predominant share of the resources earmarked for AIDS services to alternatives to hospitalization sufficient, when in 1991 alone AIDS patients were expected to utilize more than $3 billion worth of hospital care?

During the course of their illness, AIDS patients experience fluctuations in health status requiring support of correspondingly varying intensity, including hospital care, long-term care, and primary care. To meet these needs as the AIDS epidemic continues, programs should aim at strengthening the entire system of inpatient and outpatient care. As Levine (1990) points out, in any realistic model for delivering care to persons with AIDS, hospitals are at the fulcrum of the system. Perhaps the second decade of the AIDS epidemic will be characterized by strategies for more equitably distributing financial responsibility and for supporting appropriate services based on a balanced assessment of the respective roles of outpatient and inpatient care.
References


San Francisco Chronicle. 1986. $60,000 or $147,000?—A Dispute over Cost of AIDS Hospital Care, 9 June, p. 28.


