Studying the Cost of HIV-related Illnesses: Reflections on the Moving Target

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THE END OF WHAT MAY BE CONSIDERED THE FIRST phase of the acquired immunodeficiency syndrome (AIDS) epidemic—more accurately, the human immunodeficiency virus (HIV) epidemic—can be roughly dated as late 1987. Changes in treatment, notably the use of azidothymidine (AZT) and of aerosol pentamidine in the treatment of AIDS, more effective treatment of AIDS in general as more clinical experience was gained, and a trend toward earlier treatment of HIV infection before the development of AIDS have transformed the disease from an acute condition with rapid progression to death into a chronic condition that, though still incurable, permits patients to live longer and less disabled lives. In addition, the disease is slowly changing from one affecting primarily homosexual and bisexual white males to one affecting intravenous drug users (IVDUs) and their sexual partners and children, who are predominantly blacks and Hispanics. Finally, the epidemic is spreading beyond the metropolitan areas where it was concentrated in the early years—New York, San Francisco, Los Angeles—to other areas of the United States.

After a brief survey of the current state of knowledge of the medical care costs of HIV-infected persons, this article will explore the effects these changes are likely to have on the major economic aspects of the epidemic: its direct medical care costs, the medical and other services

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required to cope with it, and the problem of how to finance the care of HIV-infected persons. In addition, the article will make some recommendations regarding the types of studies of the costs of medical care and the resources required for HIV-infected persons that are needed in the future in view of the changing nature of the epidemic.

Summary of Current Knowledge of the Medical Care Costs of HIV-infected Persons

As background for the discussion, it is useful to summarize very briefly what we have learned to date about the costs of medical care for HIV-infected persons. (For the sake of simplicity, I shall use the term "costs" throughout this article, regardless of whether the data are in terms of costs or charges.) Although the first AIDS cases were diagnosed only eight years ago, about a dozen empirical studies of the medical care costs of persons with AIDS (PWAs) have already been conducted to date. Their results are shown in table 1. The comparability of these estimates is limited. They refer to different time periods and are in dollars of different years; some are limited to hospital costs while others refer to total costs; and some are in terms of costs while others are in terms of charges. Despite these limitations, it is generally agreed that the early estimate by Hardy and colleagues (Hardy et al. 1986) of average lifetime hospital costs of $147,000 per person with AIDS was much too high, and that in recent years—1986 and 1987—the lifetime medical care costs of a PWA ranged somewhere between $40,000 and $80,000 and were most likely about $50,000 to $60,000.

There have also been a number of estimates of the national medical care costs of AIDS, which are shown in table 2. These also vary widely because they differ in their assumptions about both the medical care costs per PWA and the number of PWAs in any given year. The most recent estimate, by Hellinger (1988), of $6 billion in 1991 (in 1988 dollars), is the only one which includes the costs of AZT and is generally regarded as the best that can be made at this time. To give this estimate some perspective, it amounts to about 1.2 percent of estimated total personal health care expenditures in 1991.

We also have some data showing that the costs of treating PWAs have declined since the early days of the epidemic. For example, table 1 shows the decline in the lifetime medical care costs of PWAs in Califor-

TABLE 1
Empirical Studies of the Medical Care Costs of Persons with AIDS: Lifetime Costs

Investigator	Locality	Year	Estimated costs
Hardy et al. 1986	U.S.	1981–1985[1]	$147,000
Berger 1985	Maryland	1979–1985[1]	26,828
Kizer et al. 1986	California	1985/86	91,000
Kizer, Rodriguez, and McHolland 1987		1986/87	70,000
Kizer et al. 1988		1987/88[2]	63,000
Scitovsky, Cline, and Lee 1986	San Francisco	1984[1]	27,571
		1984[1]	41,499
Seage et al. 1986	Boston	1984/85[3]	54,578
Lafferty et al. 1988	Washington State	1984/85[1,3]	34,754
Kaplowitz et al. 1988	Virginia	1983–1986[1]	27,264
Thomas and Fox 1988	New York	1985[1]	38,200
Hiatt et al. 1988	Northern California	1984–1987	35,054
Andrulis et al. 1987	U.S. (teaching hospitals)	1985[1,3]	22,013
Andrulis et al. 1989	U.S. (teaching hospitals)	1987[1,3]	19,403

[1] Estimates refer to hospital inpatient costs only.
[2] Converted from their monthly estimates, using their estimate of an average lifetime of 17.87 months.
[3] Converted from their estimates of costs per person per year assuming an average lifetime of 13 months.

nia between 1985/86 and 1987/88 (Kizer et al. 1986, 1988; Kizer, Rodriguez, and McHolland 1987). Similarly, the 1987 national hospital AIDS survey by Andrulis, Weslowski, and Gage (1989) shows that costs per patient per year in most of the teaching hospitals covered by both their 1985 and 1987 surveys declined. Data on changes in the average length of hospital stay—a major determinant of costs—are presented in table 3 and also show a decline over time.

Although limited, some data are also available on the sources of payment for PWAs. It has been estimated that on a national basis, Medicaid covers about 40 percent of all PWAs and pays for about 25 percent of their total medical care costs (Winkenwerder, Kessler, and Stolec 1989). Data also show that the vast majority of PWAs hospital-

TABLE 2
Estimates of the National Medical Care Costs of AIDS

Investigator	Year	Estimated costs (millions of dollars)
Hardy et al. 1986[1]	1981–1985	$1,470
Scitovsky and Rice 1987[2]	1985	630
	1986	1,119
	1991	8,544
Pascal 1987[2]	1986–1991	37,600
Hay, Osmond, and Jacobson 1988	1987	1,530
	1989	1,721
	1991	2,205
Andrulis et al. 1987[1]	1985	380
Hellinger 1988	1988	2,600
	1991	6,000

[1] Estimates refer to hospital inpatient costs only.
[2] Medium estimates.

ized in public hospitals are covered by Medicaid or are "self-pay," which generally means they have no insurance coverage, while the majority of PWAs hospitalized in community hospitals have private insurance (Andrulis et al. 1987; Andrulis, Weslowski, and Gage 1989; Graves 1988).

Considerable data gaps remain, however. There are practically no data on the use and costs of medical services by IVDUs, homosexual and bisexual males having been the primary study subjects to date. There is some evidence that IVDUs are heavier users of care than homosexual and bisexual males because a smaller percentage have Kaposi's sarcoma (KS), which is less expensive to treat (because it can be treated largely on an ambulatory basis) than Pneumocystis carinii pneumonia (PCP). But conclusive data on possible cost differences between IVDUs and other PWAs are lacking.

Similarly, there are no data on the use and costs of medical care for women with AIDS. Women appear to have a shorter life expectancy than men (Rothenberg et al. 1987; Lemp et al. 1988). It is not clear,

TABLE 3
Average Length of Stay per AIDS Hospital Admission

Area	Year	Days
U.S. teaching hospitals[1]		
Northeast, Public	1985	26.7
	1987	24.5
Northeast, Private	1985	19.4
	1987	18.2
Midwest, Public	1985	16.9
	1987	13.7
Midwest, Private	1985	22.0
	1987	13.1
South, Public	1985	16.5
	1987	13.7
South, Private	1985	12.1
	1987	13.2
New York State[2]	1983	23.4
	1984	21.8
	1985	21.2
	1986	19.2
	1987 (incomplete)	19.5
California[3]	1985/86	13.1
	1986/87	11.9
	1987/88	11.2
San Francisco, West Bay Hospitals[4]	1982	18.2
	1983	13.9
	1984	12.3
	1985	12.1
	1986	12.2
	1987	10.6

[1] Andrulis, Weslowski, and Gage 1989.
[2] State of New York 1988.
[3] Kizer et al. 1988.
[4] Strychaz 1988.

however, what effect this difference in length of survival has on the medical care costs of women with AIDS.

There are some limited data on the costs of HIV-infected children (rather than children with AIDS). These are summarized in table 4 and

TABLE 4
Estimated Costs of Children with HIV Infection

Type of cost	Costs
Mean lifetime hospital costs per child[1]:	$90,347
Mean annual cost per child hospitalized all year[2]:	219,000
Estimated annual Medicaid cost per child[2]:	18,000–42,000

[1] Hegarty et al. 1988.
[2] U.S. Department of Health and Human Services 1989.

suggest that pediatric AIDS cases may be more expensive than adult cases. It is of interest to note that two studies indicate that a large part of pediatric hospital costs is medically unnecessary and due to the difficulty of finding foster homes for such children (Hegarty et al. 1988; Kemper and Forsyth 1988).

A further limitation of the studies conducted to date is that except for those by Andrulis and colleagues (1987, 1989) and Graves (1988), which are national in scope, most of them come from either California or East Coast cities like New York and Boston so that there are few data on the costs of PWAs in other parts of the country. The national data from the 1987 study by Andrulis and colleagues, presented in table 5, show that inpatient hospital costs were highest in the Northeast and lowest in the South, while average length of hospital stay was

TABLE 5
Average Inpatient Costs per AIDS Patient per Year and Average Length of Hospital Stay by Region, 1987[1]

Region	Cost per patient per year	Average length of stay (in days)
Northwest	$20,661	20.8
Midwest	16,315	13.3
South	14,410	13.8
West	16,075	12.6

[1] Andrulis et al. 1989.

highest in the Northeast and lowest in the West (Andrulis et al. 1989). The data on average length of hospital stay in the study by Graves (1988) show similar differences by region.

Finally, there are practically no data on the costs of medical care of HIV-infected persons other than PWAs. There are fragmentary data on the costs of persons with AIDS-related complex (ARC), which because of recent changes in treatment are already outdated (Kizer et al. 1987; Seage et al. 1988; Strychaz 1988). With regard to asymptomatic HIV-infected persons whose number has been variously estimated at between one and one-and-a-half million persons, there are no data either on the number who seek care or on their medical care costs.

In addition to these serious gaps in our knowledge of the use and costs of medical care of PWAs and other HIV-infected persons, all of the empirical studies conducted to date have the serious limitation that they are retrospective and therefore considerably outdated by the time they are published. Moreover, most of them are based on the medical and financial records of hospitals and are therefore limited to hospital inpatient services or at best to hospital inpatient and outpatient services.

The Changing Nature of the HIV Epidemic and Its Effects on Costs

While the data that have been accumulated over time are most useful, recent changes that are likely to grow more pronounced in the near future are fundamentally altering the economics of the epidemic. The principal changes affecting costs are (1) changes in the medical treatment and management of the disease, (2) changes in the composition of the AIDS population by "exposure category" as defined by the Centers for Disease Control (CDC), and (3) the diffusion of the epidemic beyond the so-called "first-wave" cities, that is, the metropolitan centers where it was concentrated in the early years.

Changes in Treatment

Increase in Life Expectancy. One of the principal effects of the use of AZT and aerosol pentamidine and of the generally more effective treatment of PWAs is an increase in their life expectancy. While everybody seems agreed that life expectancy of PWAs has increased, however, hard data on the extent to which it has increased are scarce. Table 6

TABLE 6
Survival Following AIDS Diagnosis by Year of Diagnosis, San Francisco, 1981 to August 31, 1987[1,2]

Year of diagnosis	*N*	Median survival (in months)	*P* value
1981	27	10.2	
1982	100	12.5	
1983	287	11.2	<0.001
1984	557	10.9	
1985	820	10.8	
1986	1164	12.2	
1987[3]	860	15.0	

[1] Lemp et al. 1988.
[2] Cases reported under the new 1987 CDC definition of AIDS were excluded.
[3] This figure is an estimate. Followup for 1987 cases was limited to 15.4 months and was too short for a median to be calculated.

shows that Lemp and colleagues estimated that the median life expectancy of PWAs in San Francisco increased from 10.2 months in 1981 to 15.0 months in 1987. Rothenberg et al. (1987), in a study of 5,833 subjects diagnosed with AIDS in New York City before 1986, found the cumulative probability of survival to be 48.8 percent at one year and 15.2 percent at five years. When comparing subcohorts of this study population based on the year of diagnosis (1981 through 1985), however, he found a significant improvement in the one-year cumulative probability among subjects with PCP but not among subjects without PCP. Whether a longer life expectancy as a result of new treatments lowers or raises the lifetime costs of PWAs depends on the effects of the new treatments on overall costs and on the course of the patients' condition over their longer lifetime.

Effects of the New Drug Treatments on the Costs of PWAs. The annual costs of the full dose of AZT (200 mg. every four hours) has been estimated at between $8,000 and $10,000, although a recent estimate, taking account of recent price cuts and the fact that many PWAs cannot tolerate the full dose, puts it considerably lower, at about $5,500 (Hellinger 1988). This does not include the costs of the physician visits and the laboratory tests required to monitor possible side effects of the drug, which may add another $1,000 or possibly somewhat

more. The cost of the drug and associated other medical services may be offset to a greater or lesser extent, however, if it prevents or reduces the number of serious episodes of illness.

The only study of the effects of AZT on costs is a very small one conducted by us at San Francisco General Hospital (SFGH) (Scitovsky, Cline, and Abrams 1989). In this study, we matched seven of the nine AIDS patients taking part in the Phase II AZT trial at SFGH with a control group of seven comparable patients who would have qualified for the trial but did not participate because of lack of interest or space in the trial. One AZT patient refused to participate in the cost study, and another dropped out of the drug trial in its seventh month. We followed these seven pairs of patients for twelve months or until death if this occurred sooner and collected data on all their use of and charges for medical services obtained during this time. The AZT patient who dropped out of the drug trial and his control were followed for the first six months. We found that the controls had substantially higher monthly costs than the AZT patients (including the costs of AZT in the costs of the latter). This difference was due solely to the significantly lower hospital inpatient costs of the AZT patients in the first six months after starting on AZT ($P < .03$). While their costs continued to be lower in the second six months, the difference was no longer statistically significant, although this may be due to the small number of patients.

It must be borne in mind, however, that our data are for the first twelve months only. All but one of the controls and none of the AZT patients died in the course of the first twelve months while all but one of the AZT patients died in the course of the second twelve months. (One AZT patient lived beyond the end of the study and according to our last check of his record was still alive 29 months after having started to take AZT.) While we were not able to obtain data on the AZT patients' use and costs of medical services during this later stage of their illness, it is very likely that in their terminal months they incurred costs similar to the high terminal costs of the controls—and of persons in their terminal months in general. This hypothesis is borne out by a Canadian study that found that AZT decreased the short-term hospital use by PWAs but that "this honeymoon effect is, however, short lasted and appears to wane within a year" (Ng et al. 1989). Thus, it seems likely that the PWAs taking AZT will have much the same

lifetime costs over their longer lifetime as PWAs had over their shorter lifetime before the advent of AZT, i.e., about $50,000 to $60,000.

On the basis of the results of clinical studies of aerosol pentamidine for prophylaxis against PCP begun in 1987 and the opinions of members of a panel of experts, the Public Health Service issued guidelines on June 16, 1989, recommending the use of the drug for any HIV-infected adult who had already had an episode of PCP, even if the patient had been receiving AZT, and for HIV-infected patients who never had an episode of PCP if their T4 cell count was below 200 (Centers for Disease Control 1989). Assuming the recommended dose of 300 mg. every four weeks, annual costs per PWA including the cost of the drug ($120 per vial), the nebulizer and the associated physician visits would come to between $2,500 and $4,000 (Dr. Donald I. Abrams, personal communication, August 1989).

Possible Increase in Other Diseases Rarely Seen before in PWAs. It has been hypothesized that as PWAs live longer, they are likely to develop some diseases most of them previously did not live long enough to develop, such as serious neurological complications, virally related cancers, retinitis leading to blindness, or tuberculosis. The medical experts I consulted, however, said they found no evidence to support this hypothesis. Dr. James W. Curran, of the Centers for Disease Control (CDC), believes that PWAs now have fewer episodes of acute illness per month but the same number, or possibly a few more over their lifetime (personal communication, February 1989). All the experts agreed, however, that there was an increasing need for long-term care as AIDS was becoming a chronic condition and some treatments formerly provided on an inpatient basis, such as intravenous drug therapy, are moving to the home.

More Aggressive Treatment of PWAs. A less direct effect on costs of the availability of new drug treatments and generally more effective care for PWAs may be a renewed trend toward more aggressive treatment, such as an increase in the use of intensive care units (ICUs). A 1986 study conducted at SFGH showed that while in the early years of the epidemic the use of ICU care for PWAs increased steadily with the increase in AIDS hospital admissions, it declined steeply after the second quarter of 1984 despite the continued rise in AIDS admissions (Wachter et al. 1986). The authors attribute this decline to the physicians' awareness of the poor prognosis of AIDS patients in the ICU, es-

pecially those with PCP, and to the practice at SFGH of discussing the options for care in critical situations with their patients. Our own studies at SFGH (Scitovsky, Cline, and Lee 1986; Scitovsky, Cline, and Swan 1989) found a similar decline in the use of ICU care between 1984 and 1986/87. In 1984, 17.8 percent of the hospital days of the 445 AIDS admissions were ICU days; by contrast, in 1986/87, less than 1 percent of the hospital days of our AIDS study population were ICU days.

There is some evidence that more recently the use of ICU care has again been increasing, although good data on this subject are not yet available (Dr. Robert M. Wachter, personal communication, April 1989). This increase may be due partly to the fact that the outcome for PWAs receiving intensive care appears to have improved (Wachter et al. 1989; Montaner et al. 1987; El-Sadr and Simberkoff 1988), and partly to the availability of new and more effective treatments that promise to extend the life expectancy of PWAs. It seems quite likely that nowadays PWAs are not willing to give up as readily as when there was practically no hope of survival and intensive care in most cases merely prolonged dying. The effects on costs of such a move toward more aggressive treatment are considerable. Our 1984 SFGH study showed that the average charge per hospital day for a PWA in the ICU was more than twice that of a patient in a regular room ($1,399 compared with $660).

Therapeutic Intervention at Earlier Stages of HIV Infection. A recent study (ACTG 019), conducted under the auspices of the National Institute of Allergy and Infectious Diseases (NIAID) at a number of medical centers across the country, found that the use of AZT can delay the onset of AIDS in people who are infected with HIV but have no symptoms. On August 18, 1989, Dr. Louis W. Sullivan, the Secretary of Health and Human Services, announced the findings of the study (*New York Times* 1989). The results of the study have not been published as of this writing, but according to the same *New York Times* report, asymptomatic HIV-infected persons with T4 cell counts from 200 to 500 are now recommended to be treated prophylactically with AZT.

Some preliminary estimates of the costs of therapeutic intervention at earlier stages of HIV infection have already been made by Arno et al. (1989). They estimated the total annual "treatment" costs, including AZT and primary PCP prophylaxis, at approximately $9,637 per per-

son. On this basis, they made three estimates of the total national costs of early intervention, assuming that 25 percent (low), 50 percent (medium), and 100 percent (high), respectively, of all estimated HIV-positive individuals other than those with AIDS would be treated. If such treatment had been begun in 1988, they estimated that total national costs would have ranged from $2.6 billion (low) to $5.1 billion (medium) to $10.2 billion (high). To give these estimates some perspective, the authors state that their medium estimate of $5.1 billion "is less than 1 percent of the $550 billion expended on health care in 1988." It should be noted, however, that this medium estimate of the costs of early intervention is almost twice the $2.6 billion estimated medical care costs of persons with full-blown AIDS in 1988 (Hellinger 1988).

It is difficult to predict how many of the potential candidates for prophylactic treatment will actually seek or obtain such care. It is most unlikely that all of them will seek care. National data show that persons differ considerably in their health-seeking behavior, especially when it comes to their use of preventive care, and that there are wide differences by age, sex, race, income, and geographic location (National Center for Health Statistics 1988). Nor is it likely that all those who would like to get prophylactic treatment will be able to obtain it. Access to such care may be limited not only by financial barriers (which will be discussed below) but also by the lack or at least shortage of medical care facilities to provide it. The public hospitals in the metropolitan centers with heavy concentrations of PWAs are already at the limits of their capacity to take care of the sick HIV-infected patients. In San Francisco, for example, Dr. Donald I. Abrams stated that the AIDS clinic at SFGH will concentrate on providing care for AIDS and ARC patients and does not plan to provide prophylactic care for asymptomatic HIV-infected persons (personal communication, August 1989). A certain proportion of them may be able to afford care from private physicians and hospitals. But the majority will depend on their local communities, notably the health departments, if they are to obtain early care.

Demand for HIV Antibody Testing. This new evidence that progression to AIDS can be prevented or at least delayed by intervention at earlier stages of HIV infection may also lead to an upsurge in the demand for HIV antibody testing. In fact, Dr. Anthony Fauci, the director of NIAID, is quoted as having said that "now people who are at

risk for AIDS, even if they have 'absolutely no symptoms, it behooves them to get themselves tested'" (*New York Times* 1989). Similarly, the Gay Men's Health Crisis (GMHC) (1989) placed advertisements in seven publications announcing its plans for an expanded campaign "to encourage more voluntary HIV-testing among the estimated 180,000 to 360,000 HIV-infected New Yorkers," now that drugs are available "which can prolong life by slowing the development of AIDS and preventing some HIV-related illnesses."

Good data on the costs of such testing are not available. A survey of local health departments in March 1987 found estimates of the costs per test including counseling ranging from $4 to $123 (Paringer et al. 1988). The National Center for Health Statistics estimates that about 4 million persons have had the HIV antibody test voluntarily, the vast majority of those tested being in the age group 18 to 49 years (National Center for Health Statistics 1988). But this number could increase dramatically, especially if concerns about confidentiality are resolved. Again, as in the case of early intervention in HIV disease, actual demand for testing may be attenuated by personal attitudes about seeking preventive care, financial obstacles, and shortages of facilities for testing and counseling, so that it is difficult to estimate the volume of this service that will be demanded and available.

Effects of New Methods of Treatment on Financing the Care of HIV-infected Persons. In the following discussion, it is assumed that current government policies affecting the financing of care of HIV-infected persons remain unchanged. Clearly such changes as a new definition of AIDS which would include all HIV-infected persons, a reduction in the waiting period for Medicare coverage, an increase in Medicaid waivers for ambulatory care, an extension of the current federal program to pay for AZT for HIV-infected persons who cannot afford the drug beyond the end of September 1990 when it will expire would alter the economic aspects of the epidemic profoundly. But in the absence of clear indications of future government policies, we can only speculate about what may happen, given the current situation.

PWAs. The effect of the new treatments and the longer life expectancy of PWAs on the financing of their costs depends partly on their functional status over a longer lifetime and partly on the types and location of the medical services they use. With regard to their functional status, two scenarios can be envisaged. If they are more or less disabled

during their longer lifetime, more of them will exhaust their private insurance and personal means and become dependent on Medicaid or their state and local governments. Some of them may live long enough to become eligible for Medicare, which has a 2-year waiting period before a disabled person becomes eligible for coverage. Alternatively, they may remain in relatively good functional status until shortly before death, in which case they may be able to go on working. If they are covered by an employer's health insurance plan, they are likely to continue to be covered by private insurance. Even when they finally become disabled, they may be able to continue their group health insurance coverage for another 18 months under the provisions of COBRA (Consolidated Omnibus Budget Reconciliation Act), although they will have to pay the full premium plus an administrative fee which some PWAs may not be able to afford. In addition, this 18-month extension of coverage may not be long enough in view of their longer life expectancy. Many small employers either offer no health insurance or undergo yearly turnovers in insurers, however, and the new underwriter often inserts prior condition exclusions. Those without insurance will face financial problems as they exhaust their savings. The two scenarios are not, of course, mutually exclusive; some PWAs will probably be more or less disabled during most of their lifetime, while others may be able to continue as members of the labor force for quite some time.

The other major factors that will affect who pays for the care of PWAs are the types and location of the medical services they use. It is clear that pharmaceuticals will play an increasingly important role in the treatment of AIDS. Insurance coverage of pharmaceuticals is very limited, however. According to the Health Care Financing Administration, in 1987 private insurance paid for 14 percent of all drug expenses and public programs for another 11 percent, with 75 percent being paid out of pocket (Letsch, Levit, and Waldo 1988). It is therefore quite possible that even PWAs who are able to continue their employment and maintain their private insurance coverage will face problems in paying for their drug treatments, while those too disabled to work will have to "spend down" to Medicaid coverage. In addition, coverage of ambulatory care by both private insurance and Medicare is less comprehensive than that of inpatient hospital care. This will intensify financing problems as a larger part of the medical care of PWAs moves from the hospital to an outpatient setting. Taking all these factors together, it is likely that in the future Medicaid and state and local com-

munities will have to bear a larger share of the costs of PWAs unless there is a drastic reform in the methods of financing the care of HIV-infected persons.

Other HIV-infected Persons. Persons with HIV infection other than those with AIDS will face the same problems regarding health insurance coverage, in general, and coverage for ambulatory care and drug expenses, in particular, as persons with AIDS who are able to continue to work. In addition, at least at present, because they do not meet the CDC's definition of AIDS, they are not necessarily automatically considered disabled, which would make them eligible for Medicaid and, after the 2-year waiting period, for Medicare. Moreover, as long as they are employed, their income is likely to be too high for Medicaid coverage. How many of them will be able to pay for drugs and uncovered ambulatory expenses out of their own pockets is the big question.

Changes in the Distribution of Persons with HIV Infection by Exposure Category

Another change that is already affecting the economic aspects of the HIV epidemic and will increasingly do so is the change in the composition of the AIDS population by exposure category. While in the early days of the epidemic the vast majority of PWAs were white homosexual or bisexual males, the trend has been toward an increasing proportion of IVDUs, women, minorities, and children. Table 7, based on CDC data (Centers for Disease Control 1984, 1985, 1986, 1987, 1988) shows that the percentage of PWAs who are IVDUs has increased from 17.3 percent of reported adult and adolescent cases in the years before 1985 to 23.7 percent in 1988. During the same period, the percentage of PWAs who are women increased from 6.6 percent to 10.4 percent, and the percentage of PWAs who are minorities rose from 39.6 percent to 44.9 percent. The percentage of all reported cases who are children has risen from 1.2 percent to 1.8 percent in this same period. The CDC has made no recent projections of future AIDS cases by exposure category, but it seems unlikely that the trend shown by the figures in table 7 will change substantially in the near future.

As pointed out earlier, there are no data on the medical care costs of women with AIDS and only limited data on the costs of pediatric cases, although what little data there are for the latter indicate that

TABLE 7
Percentage of Distribution of Reported Cases of AIDS by Selected Characteristics, 1981–1988[1]

	Percentage of reported adults/adolescents			Percentage of all reported cases
Year	IV drug users	Women	Blacks and Hispanics	Children
Before 1985	17.3%	6.6%	39.6%	1.2%
1985	16.9	6.5	38.0	1.7
1986	16.5	7.1	38.6	1.4
1987	16.9	8.0	37.9	1.5
1988	23.7	10.4	44.9	1.8

[1] Figures calculated from CDC *AIDS Weekly Surveillance Reports:* December 24, 1984, December 30, 1985, December 29, 1986, December 28, 1987, and December 26, 1988.

they are high. Nor are there data on AIDS costs of blacks and Hispanics compared with those of whites. Because 80 percent of all IVDUs with AIDS are black or Hispanic, however, the two groups may be considered identical for purposes of cost estimates.

As also mentioned earlier, there are no hard data on the medical care costs of PWAs who are IVDUs compared with the costs of homosexual and bisexual males. Whether in the past they were more expensive or less expensive to treat than the latter, however, it seems highly likely that with the changes in the treatment and management of AIDS their costs in the future will be higher than those of homosexual and bisexual males. Some of them may be unable to adhere to a rigid drug regimen such as that required for AZT and, if treated with AZT, may have to be treated in some form of institutional setting. Nor are their living conditions favorable for outpatient treatment on any large scale since many of them have nobody to care for them. As a result, a certain proportion of them may have lengthy hospital stays because of difficulties of finding a suitable place to which to discharge them. Finally, it is unlikely that community organizations staffed largely by volunteers, such as those in San Francisco and some other cities which provide services to homosexual males with AIDS, will provide much ambulatory support for them. Thus, much of the higher cost of IVDUs with AIDS is likely to be social rather than strictly medical, and due, as

in the case of children with AIDS, to the lack of a place outside a hospital or some other institutional setting where they can receive care. The financing picture of this group of largely minority PWAs is also not very hopeful. The majority is unlikely to have any private insurance and thus they will be dependent on either Medicaid or the local communities where they reside.

Because we do not even know the total number of HIV-infected persons other than those with AIDS, there are also no data on the distribution, and changes in the distribution, of asymptomatic HIV-infected persons by exposure category. But it is highly likely that among those with HIV infection, as among persons with AIDS, the percentage of IVDUs is increasing. There is some evidence that homosexual males have modified their sexual behavior (Stall, Coates, and Hoff 1988; Winkelstein et al. 1988), and that the rate of new infection among them has been low in recent years (Winkelstein et al. 1988). While some modification of risk behavior appears to have occurred among asymptomatic infected IVDUs as well (Des Jarlais and Friedman 1988), it is nevertheless likely that the percentage of asymptomatic HIV-infected persons who are IVDUs, like that of PWAs, is also increasing.

It is impossible to estimate how this possible shift in the distribution of asymptomatic HIV-infected persons by exposure category will affect the demand for and use of prophylactic care. But it is likely that IVDUs will face greater problems in obtaining such care than homosexual males who are more likely to be covered by private health insurance. Financial barriers and shortages of facilities where they can get treatment may severely limit access to care for these largely poor and minority victims of the epidemic.

Changes in the Geographic Distribution of HIV-infected Persons

Finally, the change in the geographic distribution of the AIDS population may affect the future costs of the HIV epidemic, although it is not clear what the precise effects are likely to be. Table 8 shows how the number of new cases of AIDS reported in different geographic areas has changed over time (Centers for Disease Control 1987, 1988). In the early days of the epidemic, over one-half of all new cases were reported in five of the so-called "first-wave cities," while their share in 1988 was just a little more than one-third. By contrast, the percentage of new

TABLE 8
Percentage of Distribution of Reported AIDS Cases by Residence and Date of Diagnosis, 1981–1988[1]

Residence	Before 1985	1985	1986	1987	1988[2]
"First wave" standard metropolitan statistical areas (SMSAs)	58.6%	48.8%	44.0%	37.8%	36.0%
New York	33.1	25.6	21.9	18.2	18.3
San Francisco	10.8	9.4	8.5	7.0	6.6
Los Angeles	8.1	8.6	8.1	7.1	5.8
Miami	3.7	2.8	2.4	2.4	2.4
Newark	2.7	2.4	3.0	3.2	2.9
15 other SMSAs with largest number of AIDS cases	19.3	24.2	25.4	26.8	26.2
Rest of United States	22.1	27.0	30.6	35.4	37.8
Total	100.0	100.0	100.0	100.0	100.0
Total reported cases	9,876	10,094	17,232	24,270	22,433

[1] CDC *AIDS Weekly Surveillance Reports*, December 28, 1987 for 1985 and earlier figures; January 30, 1989 for 1986–1988 figures.
[2] Figures represent cases diagnosed in this calendar year and reported to CDC as of January 30, 1989. Figures preliminary.

cases reported in other cities with large numbers of PWAs rose from 19.3 percent in the early years to 26.2 percent in 1988, and that of cases reported in the rest of the United States from 22.1 percent to 37.8 percent.

It is difficult to predict what impact this shift in the geographic distribution of AIDS will have on the cost of AIDS. In the early years of the epidemic, it was believed (though there was little hard evidence) that costs of treating PWAs were lower in cities where the epidemic had struck early than in cities where it made its appearance later, mainly because physicians in the former had gained experience over time that helped them to treat PWAs more effectively and at less cost. Andrulis's 1987 AIDS Hospital Survey, however, does not bear out this hypothesis (Andrulis, Weslowski, and Gage 1989), at least as far as hospital costs are concerned. As Table 5 records, he found the highest hospital costs

per PWA per year in the Northeast, where the epidemic had started early, the lowest costs in the South, where it appeared somewhat later, and in between and very similar in the West, where it had started early, and the Midwest, where it showed up later. There are no data on total annual costs per PWA by geographic area, and they may show a somewhat different pattern, although this is not very likely in view of the fact that hospital costs still represent the major share of total AIDS costs.

One can hypothesize that geographic differences in the costs of treating PWAs will diminish as knowledge about the medical management of the disease becomes more widespread. Alternatively, it is possible that geographic differences will remain much the same because it is known that geographic differences in the diagnosis-specific average length of hospital stay have persisted for many years, and these are unlikely to change dramatically in the near future. Finally, assuming that PWAs who are IVDUs are more expensive to treat than homosexual and bisexual males, costs of treating PWAs in regions other than the Northeast may rise relatively more than in the Northeast if the percentage who are IVDUs rises more steeply in these regions.

CDC data already indicate that such a shift has been occurring in recent years. Table 9 shows the increase in all newly reported adult/adolescent cases of AIDS and in newly reported adult/adolescent cases who

TABLE 9
Number of Newly Reported Adult/Adolescent Cases of AIDS and of Newly Reported Adult/Adolescent Cases of AIDS Who Are IVDUs, Calendar Year 1986 and July 1988 through June 1989, by Region[1]

	All adult/adolescent AIDS cases			IVDUs		
Region	1986	1988–1989	1988–1989/1986	1986	1988–1989	1988–1989/1986
U.S. total	12,936	31,757	2.5	2,223	6,892	3.1
Northeast	5,264	11,020	2.1	1,756	4,562	2.6
Midwest	1,048	3,198	3.1	69	388	5.6
South	3,357	10,086	3.1	307	1,477	4.8
West	3,267	7,453	2.3	91	465	5.1

[1] Centers for Disease Control personal communication, August 1989.

are IVDUs in calendar year 1986 and the twelve-month period from July 1988 through June 1989. While in the Northeast between these two periods the number of new cases of AIDS doubled and that of AIDS cases who are IVDUs somewhat more than doubled, in the Midwest and South the number of AIDS cases tripled but the number of AIDS cases who are IVDUs increased more than fivefold in the former and almost fivefold in the latter. Similarly, in the West the number of newly reported AIDS cases slightly more than doubled but the number of AIDS cases who are IVDUs rose fivefold.

This trend is likely to continue in the next few years. There is some evidence, although the data are far from firm, that the AIDS epidemic among IVDUs has progressed further in the Northeast than in other regions of the country. Table 10 shows the distribution by region of the estimated number of all IVDUs and of the cumulative number of PWAs who are IVDUs reported through June 1989. The data on the number of IVDUs were obtained by the National Association of State Alcohol and Drug Abuse Directors (NASADAD) who annually contact all state alcohol and drug agencies for estimates of the number of drug

TABLE 10
Percentage of Distribution of Estimated Number of IVDUs in 36 States and the District of Columbia, and of PWAs Who Are IVDUs, by Region

Region	Percentage of estimated number of IVDUs, fiscal year, 1988[1]	Percentage of PWAs who are IVDUs 1981 through June 1989[2]
Total	100.0% (N = 1,344,713)	100.0% (N = 15,966)
Northeast	37.9	76.2
Midwest	17.9	3.9
South	18.5	14.4
West	28.5	5.5

[1] Butynski, Canova, and Jensen 1989. Data missing for:
Northeast: Vermont
Midwest: Kansas, Michigan, Ohio
South: Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Virginia
West: New Mexico, Utah, Wyoming.

[2] Centers for Disease Control personal communication, August 1989. Data are limited to standard metropolitan statistical areas.

users. Because several of the states in the Midwest and South did not provide estimates and because these states are likely to have substantial numbers of IVDUs, the data understate the percentage of IVDUs in these regions. Despite these limitations, they can be used for a comparison of the distribution by region of all IVDUs and of the PWAs reported to date who are IVDUs. Such a comparison suggests that in the Northeast, which accounts for 76.2 percent of all PWAs who are IVDUs but for only 37.9 percent of all IVDUs, the AIDS epidemic among IVDUs has spread further than in the other regions, especially the South and West, where the corresponding figures are 3.9 percent and 18.5 percent (South) and 5.5 percent and 25.8 percent (West). Furthermore, NASADAD data as well as data from several other studies also estimate that the HIV infection rate among IVDUs is considerably higher in northeastern metropolitan centers than in other metropolitan areas. To sum up, it seems likely that the proportion of PWAs who are IVDUs will rise more steeply in regions other than the Northeast and that as a result costs per PWA may also rise more steeply in these other regions.

With regard to the geographic distribution of HIV-infected persons other than PWAs, the data are too limited to permit any estimates. Because of likely geographic differences in infection rates among both homosexual and bisexual males and IVDUs, their geographic distribution by risk group is unlikely to be the same as that of PWAs, nor will it necessarily change in the future in the same way as the geographic distribution of PWAs by risk group.

Future Studies of the Costs of the HIV Epidemic

As the preceding discussion has shown, there is great uncertainty about the effects on costs of the changing nature of the HIV epidemic. Yet, planners at all levels—public and private, federal, state and local—require more, better, and more current data if the resource needs of the HIV epidemic are to be met. Thus, there is a clear need for further empirical studies of the use and costs of medical, social, and support services of HIV-infected persons.

The National Center for Health Services Research (NCHSR) is currently in the process of launching a prospective study of the health care

use and costs of PWAs and other HIV-infected persons in selected sites in the United States with a view to obtaining a better basis for estimating the national costs of the HIV epidemic. Such a study is clearly needed. There is also a need for additional in-depth studies at the local level, however. The HIV epidemic can be regarded as a number of local epidemics, differing from each other in the characteristics of their patient populations, in the availability of the various resources providing medical and support services for such patients, in the organization of these resources, and even in the attitudes of the providers of care to HIV-infected persons. For these reasons, patterns of use and costs may vary widely between different locations, and a system of providing care that is cost-effective and satisfies patients in one location may not be successful in another.

Because of the changes in the nature of the HIV epidemic described above and the likelihood of further changes in the future, especially in the treatment of HIV-infected persons, such studies should be prospective rather than retrospective in nature, as past studies have been. In addition, while it may have been legitimate in the early years of the epidemic, when about 90 percent of total medical care costs of PWAs were hospital inpatient costs, to limit the scope of the studies to hospital use and costs, future cost studies must include the use and costs of all medical, social, and support services. Finally, special attention in these studies must be given to PWAs who are IVDUs, women, children, and minorities, and to asymptomatic HIV-infected persons for whom data are especially lacking. This type of study will require enrolling patients and following them forward over a specified period of time. Judging by our own experience with two studies of this type, this is a major task. It can be done, however, provided that the close cooperation of the patients' principal care providers is secured and some payment is made to participating patients at each contact to encourage them to remain in the study.

It might be thought desirable to follow a patient for data on use and costs of services from diagnosis of HIV infection through all stages of the illness to death. This is likely to be very difficult, however, especially in view of the probably quite extended lifetime of HIV-infected patients who are treated at an early stage of infection. Moreover, changes in treatment are undoubtedly going to occur during such a long period, so that lifetime cost data would be outdated by the time they would become available. A preferable alternative would be to en-

roll patients at different stages of infection and follow them for one year or possibly two years, with results available shortly after the end of this period.

In addition to such local empirical cost studies, focused on the local patient population and health services setting, it would be very helpful if HIV demonstration programs such as those sponsored by the Robert Wood Johnson Foundation and the Health Resources and Services Administration (HRSA) as well as drug trials for HIV-related illnesses would make provisions for the ongoing collection of data on the use and costs of services of the patients participating in the projects and trials. The additional cost of including such provisions in demonstration projects and drug trials would be low compared to the cost of conducting an independent empirical study. Interim findings could be made public in the course of these projects so that they would be quite up to date. Similarly, the ongoing collection of such data in drug trials would make it possible to conduct cost-effectiveness studies at the end of the trials.

There are obviously needs for health services studies other than cost studies. These include first of all surveys to determine the number and geographic distribution of HIV-infected persons other than PWAs. Also needed are local studies of the medical, social, and support services available for HIV-infected persons, possible alternatives to hospital care, innovative ways of providing long-term care on an ambulatory basis, and the availability of sites for testing individuals for HIV antibodies and providing counseling to those who test positive. But these topics go beyond the scope of this article.

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