THE ECONOMIC IMPACT OF AIDS IN THE UNITED STATES

by Anne A. Scitovsky

Prologue: In less than a decade, the dread disease acquired immunodeficiency syndrome (AIDS) has become a major influence on the consumption of medical care resources in the United States. In this paper, Anne Scitovsky discusses a subject on which she is acknowledged to be the leading American expert-the economic cost of AIDS. Scitovsky is currently the lone social scientist researcher at the Palo Alto Medical Foundation/Research Institute. The organization devotes most of its resources to the pursuit of biomedical research. Scitovsky, who holds a master's degree in economics from Columbia University, has for many years been contributing highly valuable studies to the medical literature. During World War II. she worked at the Social Security Administration with the late Selma Mushkin, one of the early pioneers in health economics. Before Scitovsky initiated her work on AIDS in 1984, she had carried out studies of changes in the costs of various illnesses, which enabled her to estimate the impact on costs of changes in medical technology. She also published a well-known study evaluating the various studies of medical care costs in the last year of life, warning against premature conclusions regarding wasteful or inappropriate use of medical resources that were being drawn from them. Long before The RAND Corporation launched its national health insurance study and documented that demand for medical care is greatly influenced by what people have to pay for it, Scitovsky had arrived at a similar conclusion in a much less expensive and smaller research study. The Palo Alto Medical Clinic had for years offered some of the employed group that received care there comprehensive coverage without any cost-sharing requirements. When utilization reached unacceptably high levels, the clinic introduced a more modest package of benefits that required a patient cost-sharing contribution of 25 percent. Examining the results of this natural experiment in the late 1960s, Scitovsky determined that people who are required to pay for a portion of their medical care do indeed use it more sparingly than they would if it were free.

Really ten years have passed since the first cases of acquired immunodeficiency syndrome (AIDS) were reported in the United States. Because of the virulence and deadliness of the disease, which has generally required acute hospital care, serious concerns about its impact on health care costs were raised almost from the beginning. Yet only in the past three or four years have some data on its costs become available from a number of studies that have estimated the economic impact of AIDS. Even now, serious data gaps remain.

Because we appear to have reached the end of the first phase of the medical management of AIDS, with its heavy reliance on inpatient hospital care, it is timely now to review the studies and estimates relating to the costs of the epidemic and its economic impact that have been made to date. Although the evidence is not yet conclusive, new methods of medical treatment, notably the use of drugs such as zidovudine (AZT), appear to make it possible-to treat many persons with AIDS (PWAs) on an ambulatory basis. In addition, providers of care, third-party payers, and some local communities are making concerted efforts to find ways of managing the care of PWAs in an ambulatory setting. To evaluate the effect of both the new medical tools available for the treatment of PWAs and the new methods of managing their care, it is useful to review past studies and estimates so that these data can be used as a kind of benchmark against which to set the costs of AIDS in this new phase of providing medical care to PWAs.

In this article I review the principal studies and estimates to date of the personal health care costs of PWAs, how these costs compare with the costs of some other diseases, and the expected impact of the epidemic on hospitals. After very brief sections on estimates of direct nonpersonal costs of the epidemic (that is, for research; screening for human immuno-deficiency virus, or HIV, infection; blood screening and replacement; education; information; and various support services) and of indirect costs (that is, the value of lost output due to illness and premature death), I discuss the limitations of the estimates of personal health care costs of PWAs made to date and the major data gaps that make better estimates difficult. I conclude with some suggestions regarding the type and contents of future studies of the costs of AIDS.

The Personal Health Care Costs Of People With AIDS

Empirical studies and estimates. All the empirical studies of the personal health care costs of PWAs made to date have been retrospective and based on patients' medical and/or financial records. Seage and colleagues in Boston, Scitovsky and colleagues in San Francisco, and

Berger in Maryland conducted studies in which data were collected and analyzed for a number of cohorts of PWAs.¹ The California State Department of Health Services, using MediCal (Medicaid) claims data, has made two estimates of the lifetime costs of PWAs in California in 1984-1985 and 1985-1986.² A study published in summer 1987 by Andrulis and colleagues reports on a survey of 169 metropolitan public and private teaching hospitals that treated PWAs in 1985.³ They collected and analyzed data on hospital utilization (that is, number of patients and admissions, length-of-stay, and total inpatient days) by risk group, and, for smaller subsamples, data on costs, revenues, and sources of payment. In addition, a dozen or so other empirical studies are currently being conducted or have been completed but have not yet been published. Additional data on costs of treating PWAs can be found in unpublished reports by state and local health departments, hospital associations (such as the Hospital Council of Southern California and the New York Health and Hospital Corporation), and some individual hospitals.

Useful as these studies and data are, none of them covers all medical services used by PWAs, many of the studies being limited to inpatient services or at best to inpatient and outpatient services provided by hospitals. In addition, many of them report data for relatively small numbers of cases. The Boston study by Seage, for example, included forty-five cases; the Maryland study by Berger, twenty-six cases. The San Francisco study by Scitovsky had inpatient and outpatient data for 201 cases, data on 445 hospital admissions of PWAs, and data on lifetime hospital costs of eighty-five cases.

Despite this scarcity of data, five estimates have been made of the medical care costs of PWAs in the United States. The first (which received a great deal of publicity at the time) was made in early 1985 by Ann Hardy and colleagues at the Centers for Disease Control (CDC).⁴ They estimated the lifetime hospital costs of the first 10,000 patients with AIDS reported in the United States at about \$1.5 billion, or \$147,000 per AIDS patient.

In early 1986, Scitovsky and Rice, at the request of the CDC, made estimates of the direct and indirect costs of AIDS in the United States in 1985, 1986, and 1991.⁵ Because of the uncertainty of much of the data, three estimates of the direct personal costs of PWAs were made for each of the three years–low, medium, and high. However, for each of the three years they used the CDC estimates of the number of PWAs alive at any time during the year, increased at the suggestion of the CDC by 20 percent to take into account underreporting. They consider their medium estimates the best possible at the time: \$630 million in 1985, \$1.1 billion in 1986, and \$8.5 billion in 1991, all in current dollars.

More recently, an estimate. was made by Anthony Pascal, of The RAND Corporation.⁶ In connection with estimating the impact of the AIDS epidemic on the Medicaid program for the Health Care Financing Administration (HCFA), he made three estimates of the total costs of treating PWAs in the five-year period 1986 to 1991. His estimates range from a low of \$15.4 billion to an intermediate estimate of \$37.6 billion (which he regards as the most likely) and a high of \$112.5 billion. Another recent estimate, by Andrulis and colleagues for 1985, based on their findings from the hospital survey mentioned earlier, put total hospital inpatient costs of PWAs in the United States at \$380 million.

The latest estimate has been made by Hellinger, who states that it takes account of "the wider use of AZT," although he gives no details regarding his assumptions about the effect of the use of AZT on costs.⁷ He forecasts the personal medical care costs of PWAs to be \$2.2 billion in 1988 and \$4.5 billion in 1991.

There are several reasons for the wide-differences in these estimates. One source of difference is the fact that some of the estimates are incidence-based (Hardy, Pascal, and Hellinger) while others are prevalence-based (Scitovsky and Rice, Andrulis). Incidence-based estimates attribute all the medical care costs incurred over a person's lifetime to the year when the patient was diagnosed; while prevalence-based estimates cover the costs of all medical care received by persons with the disease in a given year, regardless of when the condition was diagnosed and of whether they lived the full twelve months, died during this period, or were newly diagnosed in the course of the year. This source of difference, however, is not a major obstacle to comparisons when average life expectancy is relatively short, as it has been in the case of AIDS at least until very recently (about thirteen months from diagnosis to death).

The principal reasons for differences between the estimates are differences in the underlying assumptions regarding (1) medical care costs per PWA and (2) the projected number of cases with AIDS. Hardy's estimate of average lifetime hospital costs of \$147,000 for the first 10,000 cases of AIDS reported in the United States (with an average life expectancy of thirteen months) compares with Pascal's estimate of lifetime costs of \$94,000 in the period 1986-1991 (assuming an average life expectancy of twelve months) and Hellinger's estimate of \$61,800 in 1991 (assuming an average life expectancy of twenty four months). The medium estimate by Scitovsky and Rice for 1991 can be converted to an estimated lifetime cost of about \$70,000 (assuming an average life expectancy of thirteen months). The latter two estimates are in 1985 prices, that by Pascal apparently in 1986 prices.

Differences in the projected number of cases of AIDS parallel the

differences in estimated lifetime costs per case of AIDS. Scitovsky and Rice used the projections of the CDC, increased by 20 percent to take account of underreporting. Pascal, using a different forecasting model, arrived at an estimate of cumulative cases by 1991 that is about 50 percent higher than the CDC estimate and about 23 percent higher than the adjusted CDC estimate used by Scitovsky and Rice. By contrast, Hellinger, using yet another forecasting model, estimated about 18 percent fewer newly diagnosed cases for 1991 than the CDC estimates indicate, allowing for a 20 percent increase in both his and the CDC's estimate for underreporting.

The Hardy estimate of lifetime hospital costs is now generally regarded as much too high. It was based on very fragmentary data, and there is considerable evidence that the medical care costs of treating PWAs have declined since the early days of the epidemic. For example, Kizer (in the studies cited earlier) found that average lifetime costs (over an eighteenmonth average life span) for PWAs in California declined from \$91,000 in 1984-1985 to \$70,000 in 1985-1986. But statistically sound estimates of lifetime costs of PWAs are currently not possible, and all we can say is that they range somewhere between \$60,000 and \$90,000, with a strong possibility that they are closer to the lower range since all (with the possible exception of Hellinger's) are based on data from retrospective studies that do not yet reflect more recent changes in treatment, which may be cost-saving to some extent. With regard to the projections of the number of AIDS cases in the next five or more years there is also considerable uncertainty, and any cost estimates therefore must be based on a range of estimates of the number of future cases.

Because the estimates of the national costs of AIDS by Scitovsky and Rice lie about halfway between the high estimates of Pascal and the low estimates of Hellinger, I use them for comparing the costs of AIDS with other health care expenditures and for evaluating the impact of AIDS on the nation's hospitals.

Comparing the costs of AIDS with other health care expenditures. Scitovsky and Rice's medium estimate of \$8.5 billion represents 1.4 percent of estimated total personal health care costs in 1991. By comparison, their medium estimate for 1985 represents a mere 0.2 percent and that for 1986, 0.3 percent of personal health care expenditures in these two years. In 1985 and 1986, their estimated annual medical care costs of PWAs, high as they are, are considerably lower than those of patients with some other diseases. For example, based on 1980 data, they have estimated that persons with end-stage renal disease had total expenses of about \$2.2 billion; persons injured in automobile accidents, \$5.6 billion; with cancer of the digestive system, \$3.4 billion; cancer of the lungs, \$2.7

billion; and cancer of the breast, \$2.2 billion.⁸

Comparing their estimates for 1991 with estimates of the medical care costs of some other diseases in 1991 is rather problematic since the base year for other diseases is 1980, and the prevalence of these conditions is bound to change over this eleven-year period. But assuming neither drastic changes in the prevalence nor in the treatment of other conditions, they believe that it is likely that the medical care costs of PWAs will exceed those of patients with cancer of the digestive system, cancer of the lung, and cancer of the breast, and be exceeded only by the costs of persons injured in automobile accidents.

Data on the lifetime costs of other diseases are not available. However, Scitovsky and Rice estimated, on the basis of Medicare data, that the lifetime costs of persons with end-stage renal disease who are on dialysis are about \$158,000, assuming an average lifetime of four years for these patients. Thus, the lifetime costs of these patients are considerably higher than those of PWAs.

The impact of AIDS on hospitals. Because inpatient hospital care has been and continues to be the driving force behind the costs of AIDS, it is important to examine the likely impact of the epidemic on hospitals. Scitovsky and Rice's \$8.5 billion estimate of total medical care costs of PWAs in 1991 assumes 5.9 million hospital days. This is equivalent to 2.6 percent of all hospital days used in 1985, almost four times the number of hospital days used in 1985 by patients with cancer of the colon (1.6 million) or cancer of the breast (1.5 million), and twice the number of hospital days used by patients with cancer of the lung (2.8 million). Only patients with acute myocardial infarction (7.2 million days), pneumonia (6.8 million days), and normal infant deliveries (12.6 million days) used more inpatient days in 1985 than their estimate for AIDS patients in 1991.⁹

Their estimate of 5.9 million hospital days needed by AIDS patients translates into a requirement of just over 16,000 beds in 1991, which represents 1.2 percent of all hospital beds available in 1985. Although there is an excess of hospital beds in the United States (possibly as much as 20 percent), the AIDS epidemic will impose a serious strain on hospitals, especially public hospitals, in metropolitan areas with large numbers of PWAs. On the basis of Scitovsky and Rice's assumptions regarding hospital use by PWAs and the CDC estimates of the prevalence of AIDS in New York and San Francisco in 1991, increased again by 20 percent to account for underreporting, I have estimated that in 1991 AIDS patients would require about 2,100 beds in New York, or about 5 percent of all hospital beds in the New York metropolitan area in 1985, and 648 beds in San Francisco, or about 9.5 percent of all hospital beds in

that city in 1985. Other metropolitan centers such as Los Angeles, Washington, D.C., Miami, Houston, and Newark would face similar demands on their hospital systems.

Public hospitals in these centers, however, will face the most serious problems if they continue to provide inpatient care for the same percentage of PWAs they currently care for and if they have the same number of hospital beds as they do now. I have estimated (again using Scitovsky and Rice's assumptions regarding hospital use) that under these conditions PWAs in 1991 would require between 10 percent and 13 percent of all public hospital beds in New York City and about one-third of all beds in San Francisco General Hospital. In fact, according to a report presented at the Fourth International Conference on AIDS in Stockholm in June 1988, 30 percent of all acute care beds in one public hospital in New York already are occupied by patients suffering from HIV-related illnesses. Clearly there is a limit to the number of beds that public hospitals can provide for PWAs because they have an obligation to provide many other essential medical services to their cities' populations.

In addition to the strain on their physical resources, the public hospitals also face the most serious financial problems posed by the AIDS epidemic because of the high percentage of their AIDS patients either who are covered by Medicaid, which generally reimburses the hospitals for less than their costs, or who are self-pay, which frequently turns into uncollectible bills. According to a 1987 report, of the PWAs hospitalized in the public hospitals of the New York Health and Hospital Corporation, 70 percent were covered by Medicaid, 6 percent by Blue Cross, 1 percent by Medicare, less than 1 percent by commercial insurance, and 12 percent were self-pay.¹⁰ Somewhat earlier data collected by the West Bay Hospital Conference (which collects data for San Francisco Bay Area hospitals) showed that of the PWAs hospitalized at San Francisco General Hospital, 71 percent reported Medical (Medicaid) as their expected source of payment, 3 percent Medicare, 4 percent other public programs, 15 percent private insurance, and 8 percent self-pay. By contrast, the corresponding figures for PWAs hospitalized in other San Francisco hospitals (including a Kaiser hospital) were 16 percent Medical, 5 percent Medicare, 2 percent other public programs, 75 percent private insurance, and 2 percent self-pay.¹¹ Andrulis and colleagues found that of the responding hospitals, public hospitals reported 62 percent of their AIDS admissions covered by Medicaid, compared to 35 percent of the admissions in private hospitals; 1 percent covered by Medicare compared to 3 percent of the admissions in private hospitals; 7 percent compared to 45 percent covered by private insurance; 18 percent compared to 13 percent self-pay; and 12 percent compared to 4 percent with other

payment arrangements.

While these data clearly indicate the need for community hospitals to play a greater role in providing inpatient services to PWAs, it is equally clear that in view of the financial and insurance situation of PWAs currently being treated by public hospitals, private hospitals may not be eager to treat large numbers of AIDS cases. Moreover, there is some evidence that the proportion of PWAs covered by private insurance has been declining, with payment responsibilities shifting to the public sector, primarily Medicaid and local communities.¹² This highlights the increasingly urgent need for comprehensive planning on how to finance medical care for PWAs. One way or another, the medical care costs of PWAs will be met. But unless the present piecemeal system is drastically reformed, the AIDS epidemic will cause severe economic hardships for and place disproportionate financial burdens on not only many PWAs and their families but also public hospitals and local communities.

The Direct Nonpersonal Costs Of The HIV Epidemic

To date, Scitovsky and Rice have made the only estimates of the direct nonpersonal costs of the HIV epidemic-that is, the costs of research; blood screening and replacement; screening of individuals for HIV infection; and health education, information, and support services.¹³ Their medium estimates, in current dollars, range from \$319 million in 1985 to \$542 million in 1986 to \$2.3 billion in 1991. However, these estimates should be regarded with great caution. The data available to estimate current costs of these services are even more fragmentary than those available for estimating the direct medical care costs of PWAs. It is virtually impossible to project these costs because of the uncertainties of future policy regarding the provision of these services. For example, costs will differ enormously depending on the extent of screening for HIV infection, the breadth of educational programs, and the funds made available for research of all types.

The Indirect Costs Of The HIV Epidemic

Both Hardy and colleagues and Scitovsky and Rice have made estimates of the indirect costs of the HIV epidemic–that is, the value of lost output due to illness and premature death.¹⁴ Hardy estimated the indirect costs of the first 10,000 cases of AIDS in the United States at \$4.8 billion, or more than three times her estimate of health care costs, Scitovsky and Rice's estimates range from \$3.9 billion in 1985 to \$7.0 billion in 1986 to \$55.6 billion in 1991, or more than six times their estimates of personal health care costs. Most of the indirect costs (93 percent) represent losses due to premature death. While their estimates of indirect costs represent only 1.2 percent and 2.1 percent of the estimated total indirect costs of all illness in 1985 and 1986, they rise to close to 12 percent of the estimated total costs of all illness in 1991.

These estimates, too, should be regarded as very tentative because there are no data on the earnings of PWAs. There is some evidence that of the two major risk groups, homosexual and bisexual males and intravenous (IV) drug abusers, the former have above-average earnings, while the majority of the latter are likely to have either no or belowaverage earnings or earnings from illegal sources such as drug dealing, theft, and prostitution. We assumed that PWAs had the same average earnings as others in their age and sex group. But this assumption is not based on any hard data.

Limitations Of The Estimates And Major Data Gaps

Any estimates of the costs of AIDS made on the basis of currently available data have serious limitations. I already have indicated the limitations of estimates of the direct nonpersonal costs and of the indirect costs of the epidemic. Here I discuss the limitations of the data on the direct personal medical care costs of PWAs and, more generally, of persons infected with HIV

Retrospective nature of the data. As already mentioned, all the estimates (with the possible exception of Hellinger's) are based on data from retrospective studies. Thus they do not include persons with two conditions that were added to the definition of AIDS by the CDC as of September 1987: the so-called wasting syndrome and dementia. No good data are available on how many cases this will add to the count of PWAs, although it is estimated that it may increase the total number by 10 to 15 percent. But there are no estimates available of the medical care needs and costs of persons with these conditions.

Uncertainty of projections of the number of AIDS cases. Even estimates of the number of persons with the conditions covered by the pre-September 1987 definition of AIDS are uncertain. Some epidemiologists think the CDC underestimates the number of cases that will occur over the next five years. As mentioned earlier, the intermediate estimate by Pascal of The RAND Corporation for 1991 is about 50 percent higher than that made by the CDC. Conversely, the CDC estimate may be too high, as Hellinger believes. His view is shared by epidemiologists in the San Francisco Public Health Department, whose projections of the prevalence of AIDS in San Francisco are considerably below those of the CDC. The former estimates that there will be 3,822 PWAs alive at any time in San Francisco in 1991, while the CDC estimates 8,120. (Note: This estimate was made in 1986.) The difference between the two estimates reflects differences in the methodologies the two organizations use for projecting the course of the AIDS epidemic. The CDC bases its projections largely on past trends. By contrast, the San Francisco Public Health Department, which has data from a 1978 hepatitis B vaccine study on the number of males infected with HIV, bases its estimates on estimates of the percentage of HIV-infected persons who will contract AIDS in future years. The CDC is planning a series of surveys to determine the numbers of HIV-infected persons in twenty metropolitan centers with large numbers of PWAs and in ten low-incidence areas to be able to make more accurate projections of the future course of the epidemic.

Changes in distribution of PWAs. Another element of uncertainty that complicates cost estimates is the possibility of a change in the distribution of PWAs by major risk group. As the percentage of PWAs who are IV drug abusers increases, costs may rise because a higher percentage of them develop *Pneumocystis carinii* pneumonia (PCP), which is more expensive to treat than Kaposi's sarcoma, more often found among male homosexuals.

Lack of outpatient data. We are slowly beginning to get good data on inpatient hospital costs. But data on the costs of ambulatory care, such as for physician outpatient and outpatient ancillary services, home health care, counseling, and similar support services are almost totally lacking.

Lack of information on payers. An important data gap is the almost total lack of information on who is paying for the medical care costs of PWAs–private insurance, public programs such as Medicaid and Medicare, the patients themselves, or local communities whose public hospitals are the main source of services for the under- and uninsured. A frequently cited estimate puts the burden on Medicaid at 25 percent of total medical care costs of PWAs; however, there is little basis for this estimate. Pascal's estimates of the cumulative Medicaid costs for AIDS treatment for 1986 to 1991 range from \$2.3 billion (or 15 percent of total national AIDS costs) to \$10.2 billion (or 27 percent of total costs) to a maximum of \$47.4 billion (or 42 percent of total costs).¹⁵

Others infected with HIV. Last, but not least, the medical care costs of PWAs are only part of the medical care costs associated with the HIV epidemic. Thus cost estimates made to date do not include costs of persons with AIDS-related complex (ARC) nor of those who are infected with HIV and have either very mild symptoms or no symptoms but are worried and seek medical care and advice. Estimates of persons infected with HIV range from half a million to as high as two million; however, I

know of no estimates of the number of these persons who use the medical care system nor of the type of care they obtain.

Similarly, there are no hard data on the number of persons with ARC. They have been variously estimated at two to five times the number of PWAs, and some estimates put them as high as ten times the number of PWAs. The only estimate of the costs of care of persons with ARC that I have found to date comes from the latest study of the California Department of Health Services.¹⁶ They estimate monthly Medical costs of persons with ARC at \$652, which converts to \$1,043 in billed charges (compared to \$3,889 a month for persons with AIDS). My rough estimates on this basis show that if we assume that in 1986 there were four persons with ARC alive at any time during the year for every person with AIDS, their medical care costs would have amounted to about \$1.6 billion, or somewhat more than the Scitovsky and Rice estimate of the medical care costs of PWAs in that year. A more conservative estimate of two persons with ARC for every one PWA would come to \$787 million, or about 70 percent of their 1986 estimate of the costs of PWAs. Thus it is clear that the total personal medical care costs of the epidemic far exceed the costs of persons with full-blown AIDS as defined by the CDC. If we add to the personal medical care costs the direct nonpersonal costs for research, screening, education and information, and miscellaneous sup port services, the Scitovsky and Rice estimate of \$8.5 billion for personal health care costs of persons with full-blown AIDS in 1991 may well have to be doubled or even tripled.

Recommendations For Future Studies

Currently available data do not permit reliable estimates and projections of the personal health care costs of persons infected with HIV Because they come from retrospective studies, they do not reflect more recent changes in the treatment and management of the disease. Moreover, they are generally limited to data on inpatient hospital care or at best inpatient and outpatient hospital care and shed little light on the costs of ambulatory care. Finally, they come primarily from a few geographic areas, which may not be representative of costs in other areas and the nation as a whole. To make plans for meeting the medical resource and financial needs of persons infected with HIV, better and more comprehensive data on their use and costs of medical care are essential. What follows are my recommendations regarding the type and content of future studies of the costs of AIDS and HIV infection in general.

Prospective studies. First and foremost, future studies should be prospective studies in which patients are followed for at least one year but preferably longer. These studies should be conducted in geographically representative areas and obtain detailed data on the use and costs of all services used rather than only of data on hospital services.

Only prospective studies can reflect the changes that are occurring in the medical treatment of PWAs. Although AZT has now been in fairly wide use for about a year, no firm data on its effects on costs exist to date, mainly because it has not been in use long enough. While it appears to reduce medical care costs of PWAs in the short run by reducing inpatient hospital use, it is no cure, and although it seems to prolong life expectancy, patients are still likely to die and probably to incur high costs in the last months of life just as AIDS patients who died in the past did.

Similarly, only prospective studies can capture the effect on costs of new methods of managing the care of PWAs. The experience with AIDS in San Francisco has shown that medical care costs can be held down when appropriate community support systems exist that enable patients to be treated at home. However, I fear that the extent to which this "San Francisco model" can be exported to other areas is limited. PWAs in San Francisco are predominantly male homosexuals; San Francisco's wellorganized gay community rallied to the epidemic. Whether similar community services can be organized in centers such as New York City, where more than one-third of PWAs are IV drug abusers, is questionable. Moreover, the agencies that provide out-of-hospital care in San Francisco rely heavily on volunteers, who may be more difficult to recruit in other areas. Even in San Francisco, it is not certain that the present system will be able to cope with the larger number of patients expected in the course of the next few years.¹⁷ The need for volunteers will increase, and some of the current volunteers may "burn out" or contract AIDS themselves. If paid personnel has to be substituted for volunteers, home care may become no less expensive than institutional care.

The results of various experiments with case management of PWAs by third-party payers also will need careful evaluation. Under the ideal version of this system, which can take many forms, beginning with nothing more than hospital discharge planning, a medical worker (usually a nurse) is placed in charge of a patient's total course of treatment so that services are synchronized. Wherever feasible, outpatient care is substituted for hospital care and paid for by the patient's insurance policy even when such ambulatory care services are not normally covered by the policy. Again, it is not at all clear yet that this system necessarily is costsaving, although it may well improve the quality of care of the patient.

Finally, prospective studies should include not only persons with fullblown AIDS but also those with less severe manifestations of HIV infection such as patients with ARC and even asymptomatic seropositive persons. If the current trials of the use of drugs such as AZT for HIVinfected patients with less than full-blown AIDS prove successful, these persons may become major users of medical care and add considerably to the overall medical care costs of the epidemic.

The National Center for Health Services Research and Health Care Technology Assessment (NCHSR) plans to sponsor prospective studies aimed at obtaining such use and cost data. In addition, it will be interesting to learn what the various demonstration programs sponsored by the Health Resources and Services Administration and The Robert Wood Johnson Foundation will show regarding the effects on costs of different ways of managing the care of PWAs.

Data on payers for care of PWAs. It is essential that future studies obtain data on the insurance coverage of PWAs and other HIV-infected persons. This is increasingly important as the percentage of PWAs who are IV drug abusers continues to increase as it has done in recent years (from 15.3 percent of all reported cases in the year ending July 11,1987, to 22.2 percent in the year ending July 11, 1988).¹⁸ These patients are less likely to have private insurance than homosexual and bisexual males, and thus the costs borne by public programs and local communities may rise. Similarly, if life expectancy of PWAs increases, more of them may qualify for Medicare, which in the past has paid very little of the costs of PWAs because most patients did not live the two years it takes to qualify under the Medicare disability program; or they may become dependent on Medicaid as they lose their private insurance coverage. Alternatively, if their quality of life improves so that they can continue to work longer, more of them may retain their private insurance.

Finally, if HIV-infected persons other than those with full-blown AIDS become heavier users of medical care than they have been to date, this will raise serious financing problems. If drugs become a relatively important item in their costs (as seems likely), many of these patients may have difficulties paying for them since private insurance generally does not pay for out-of-hospital drugs and prescriptions. At the same time, unless such persons are automatically declared disabled for purposes of Medicare coverage, their costs are also not paid by Medicaid.

Prevalence of HIV infection. To make possible better projections of the number of persons with AIDS, better data on the prevalence of HIV infection are urgently needed. As mentioned earlier, the CDC is planning a series of surveys to obtain data on the extent of HIV infection in different geographic areas and among the different population groups at risk of HIV infection. It is to be hoped that despite the difficulties of conducting these surveys–difficulties due largely to the problems of confidentiality that this particular disease raises–they will be successful.

NOTES

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