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# Cost and Financing of Care for Persons With HIV Disease: An Overview

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*This article explores the impact of new combination drug therapies on the cost and financing of human immunodeficiency virus (HIV) disease. Evidence indicates that the proportion of costs attributable to drugs has increased significantly since the diffusion of new combination drug therapies, and that the proportion of costs attributable to hospital inpatient care has decreased. The absence of timely data is the major difficulty in analyzing the impact of recent changes. Only two studies have examined costs since the diffusion of new combination drug therapies, and there are no recent studies of the insurance status of persons with HIV disease.*

## **INTRODUCTION AND BACKGROUND**

The recent approval of four protease inhibitors by the Food and Drug Administration initiated a new period in the treatment of persons with HIV disease. The first protease inhibitor, Invirase, was approved in December 1995. The second and third protease inhibitors (Crixivan and Norvir) were approved in March 1996, and the fourth protease inhibitor (Viracept) was approved in March 1997.

The rapid growth in the number of drugs approved to treat persons with HIV disease accompanied by improved techniques to monitor the quantity of virus in patients have transformed the treatment of

persons with HIV disease. Today, there are 11 antiretroviral drugs approved to treat HIV disease including the 4 protease inhibitors, 5 nucleoside reverse transcriptase inhibitors, and 2 non-nucleoside reverse transcriptase inhibitors, and there are hundreds of possible drug combinations. Uncertainty about how best to treat patients and the high cost of many drugs have enormous consequences for those who forecast the economic costs of this epidemic. Holtgrave and Pinkerton (1997) assert that, "Despite their promise to prolong survival and improve the quality of life of persons with HIV, the new therapeutic regimens are also much more costly than their predecessors. Moreover, as persons live longer, they consume greater health care resources, driving the overall health care costs associated with HIV infection even higher."

The new combination drug regimens (often referred to as drug cocktails) normally include one protease inhibitor and two reverse transcriptase inhibitors. This regime quickly became the drug regimen of choice for persons with HIV disease, and its rapid diffusion has had a dramatic impact on the number of deaths attributable to acquired immunodeficiency syndrome (AIDS). (Centers for Disease Control and Prevention, 1997b).

Before 1996, the death rate from AIDS had increased every year since the early 1980s when statistics on AIDS deaths were first compiled by the Centers for Disease Control and Prevention (CDC). In 1996 the death rate from AIDS dropped 23 percent. (In 1995, the number of persons who died

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with AIDS was 50,700, whereas 39,200 persons died with AIDS in 1996) [Centers for Disease Control and Prevention, 1997a].

Moreover, the number of deaths from AIDS continues to fall. During the first 6 months of 1997, the death rate from AIDS was 44 percent lower than it was during the first 6 months of 1996. (During the first 6 months of 1996, the number of persons who died from AIDS was 21,460, whereas 12,040 persons died with AIDS during the first 6 months of 1997).

Recent findings from a cohort study of 1,255 HIV-infected patients, the HIV Outpatient Study, highlight the effect of combination drug therapy (Palella et al. 1998). This study examined patients treated at nine clinics (seven private and two public) in eight cities (Portland, Oregon; Tampa, Florida; Oakland, California; Washington, DC; Chicago, Illinois; Stony Brook, New York; Atlanta, Georgia; and Denver, Colorado) who had at least one CD4+ count below 100. From 1995 to the second quarter of 1997, mortality in this cohort fell 70 percent (from 29.4 deaths per 100 person-years in 1995 to 8.8 deaths per 100 person-years in the second quarter of 1997). This study also found that by June 1997, 94 percent of the patients were on antiretroviral therapy and 82 percent received a protease inhibitor as part of this therapy.

The decreasing death rate from AIDS, however, has not been accompanied by a decrease in the number of persons newly infected with HIV disease. The CDC estimates that 40,000-80,000 persons are infected with HIV each year (Centers for Disease Control and Prevention, 1996a), and that this number has remained about the same for the past several years. Evidence supporting this conviction includes the finding that the number of persons reported with new HIV infections in the 26 States with mandatory HIV infec-

tion reporting remained virtually unchanged between the periods July 1995-June 1996 (13,371) and July 1996-June 1997 (13,111) (Centers for Disease Control and Prevention, 1997a).

The decrease in the death rate attributable to AIDS combined with the steady flow of persons newly infected with HIV disease has increased the number of persons living with HIV disease. The most recent CDC estimate is that the number of persons living with HIV disease is 650,000-900,000 (Karon et al., 1996). The CDC estimated the number of persons living with AIDS increased from 196,000 in 1994, to 215,000 in 1995, to 239,000 in 1996, and to 259,000 in early 1997 (Centers for Disease Control and Prevention, 1997a).

The next section of this study examines how advances in the treatment of HIV disease have affected the cost of care. In particular, this section examines how treatment changes have affected the components of care (e.g., hospital, outpatient, and drug), and what is known about the relationship between race, gender, injection drug use, and costs. Estimates of the lifetime cost of care also are reviewed here. The third section discusses the financing of care for persons with HIV disease, and examines how third party payers set payment rates for services provided to patients with HIV disease. The last section discusses the economic implications of recent changes in treatment and presents some final remarks.

## **COST OF MEDICAL CARE FOR PERSONS WITH HIV DISEASE**

### **Monthly Treatment Costs**

In 1993, the author presented estimates of the cost of treating persons with HIV disease for four stages of illness: (1) AIDS (1987 definition); (2) HIV infection without

**Table 1**  
**Estimated Monthly Cost of Treating a Person With AIDS (1987 Definition)**

Category	Dollars	Percent
Total	\$2,764	100
Inpatient	1,890	68
Outpatient	380	14
Home Health	174	6
Drugs	265	10
Long-Term Care	55	2

NOTES: AIDS is acquired immunodeficiency syndrome. See Technical Note for 1987 AIDS Definition.

SOURCE: Hellinger, F.J., 1993a.

AIDS with a CD4+ cell count less than 200 (this stage is AIDS under the 1993 definition); (3) HIV infection without AIDS with a CD4+ count of 200 or higher and less than 500; and (4) HIV infection without AIDS with a CD4+ count of 500 or higher. (See Technical Note for 1987 AIDS definition and 1993 AIDS definition). These estimates were based on treatment patterns during the first 6 months of 1992. The estimated monthly cost of treating a person with AIDS was \$2,764 (Table 1). More than two-thirds of this cost was attributable to inpatient hospital care (\$1,890). Drug costs accounted for only about 10 percent (\$265) and outpatient costs accounted for about 14 percent (\$380).

The estimates presented by the author used data from interviews conducted during the late spring and early summer of 1992 with 1,164 respondents with HIV disease who were treated at 26 sites (hospital clinics, freestanding clinics, physicians' offices, and hospitals) in 10 cities (Baltimore, Chicago, Houston, Los Angeles, Miami, Newark, New York City, Philadelphia, San Francisco, and Tampa). That study, funded by the Agency for Health Care Policy and Research, is referred to as the AIDS Cost and Service Utilization Survey (ACSUS).

Table 2 compares the author's estimate of the monthly cost of treating a person with AIDS to more recent estimates. Except for the estimate from researchers at Tower Infectious Disease Medical Associates (TIDMA) in Los Angeles (Ruane et al., 1997), the estimated monthly cost derived by the author is similar to the more recent estimates.

There are two key trends in the monthly cost of treating persons with AIDS. First, the proportion of costs attributable to hospitalization is falling; and, second, the proportion of costs attributable to drug therapy is increasing.

### **New York State**

To illustrate these trends, the author examined the cost of treatment for persons with AIDS in New York. In 1988, hospital costs in New York accounted for 88 percent of the monthly cost of treating a person with AIDS. This figure fell to 78 percent in 1990 and to 67 percent in 1994 (New York State Department of Health, 1995). At the same time, the percent of costs attributable to drug therapy in New York increased during this period. In 1988 drug costs accounted for only 5 percent of the monthly cost of treating a person with AIDS. This

**Table 2****Estimated Monthly Cost of Treating a Person With AIDS, by Disease Stage: Selected Years**

Year	Disease Stage	Monthly Cost
1992	PWA (1987 Definition)	\$2,764
1994	PWA (1987 Definition)	2,579
1995	T-Cell <50	2,103
1992-95	T-Cell <50	2,436
1996	T-Cell <50	1,885
1997	PWA (1993 Definition)	3,274-4,084

NOTES: AIDS is acquired immunodeficiency syndrome. PWA is person with AIDS. See Technical Note for 1987 and 1993 AIDS Definitions.

SOURCES: Hellinger, F.J., 1993a; New York State Department of Health, 1995; Gable, C. et al., 1996; Moore, R.D. and Chaisson, R.E., 1997; Ruane, P.J. et al., 1997; and Holtgrave, D.R. and Pinkerton, S.D., 1997.

figure rose to 6 percent in 1990, and to 16 percent in 1994.

Data from the New York State Department of Health indicate that the monthly cost of treating a person with AIDS in 1994 was \$2,579 (New York State Department of Health, 1995). Hospitalization costs accounted for 67 percent of this amount, and drug costs for 16 percent. The New York State Department of Health used data from the statewide discharge data system and other sources to estimate the cost of treating this population.

**Maryland Medicaid Cost Estimates**

Moore and Chaisson (1997) examined data from Maryland Medicaid claims on 606 patients who were treated at the Johns Hopkins University AIDS Service from July 1, 1992, through June 30, 1995. Estimates of the cost of care were provided for four disease stages defined using CD4+ counts. For patients with CD4+ counts equal to or below 50, Maryland Medicaid paid claims averaging \$2,436 a month. Inpatient hospital costs accounted for 56 percent of these costs (\$1,355) and drug costs accounted for 21 percent (\$515).

**Expert Panel Cost Estimates**

Gable et al. (1996) estimated that the monthly cost of treating a person with HIV disease with a CD4+ cell count below 50 was \$2,103 in 1995. Of this amount, drug costs accounted for 38 percent (\$797). This estimate was constructed using advice from an expert panel comprised of five physicians who specialized in the treatment of HIV disease from Washington, DC, Los Angeles, Dallas, Chicago, and New York City. This panel produced treatment protocols for each opportunistic infection and for primary antiretroviral therapy. They also estimated the rates of opportunistic infections for each of four stages of HIV illness defined using CD4+ cell counts. Data on charges for health care resource were obtained from a variety of sources including Medicare fee schedules, surveys, and insurance databases.

The drug costs in this study are higher than in other studies that apply to the period before the diffusion of protease inhibitors because the drug costs in this study were calculated using expert panel recommendations that patients with CD4+ cell counts below 50 receive prophylactic drug therapy for herpes, fungal infections, and mycobacterium avium complex in addition to primary antiretroviral therapies. Cost estimates derived from expert panels have the advantage of reflecting recommended treatments at the time of the study but they do not reflect the actual experience of patients. Instead, they ascertain the cost of an ideal treatment regimen.

**Cost Estimates After Protease Inhibitors**

Holtgrave and Pinkerton (1997) recognized that many patients do not receive ideal treatment, and they derived estimates

of the cost of care under three scenarios that reflect varying degrees of access to care. Their estimates apply to the period just after the introduction of protease inhibitors and were derived using treatment practices recommended by an international panel (Carpenter et al., 1996). The authors derived estimates of the monthly and lifetime cost of treating patients with low, intermediate, and high access to care. Their monthly estimates varied from \$3,274 to \$4,087 in 1996 dollars for persons with AIDS defined by a clinical condition.

In a recent study, Haburchak (1997) used a similar methodology to estimate the monthly cost of treating a person with HIV disease after the approval of protease inhibitors. He estimated that the additional monthly drug costs associated with current treatment guidelines is \$1,033, and that the monthly cost of treating a person with AIDS was \$3,797 in 1996.

The monthly cost of treating a person with HIV disease treated by TIDMA who had a CD4+ cell count of 50 or below was calculated to be \$1,885 in 1996 (Ruane et al., 1997). Only 81 of the 467 persons treated at TIDMA in 1996 had a CD4+ cell count of 50 or below. Ninety percent of the patients were male and there were no known injection drug users. The great majority of patients were privately insured and highly compliant. The average monthly cost for drug therapy was \$485 (26 percent) for those with a CD4+ cell count of 50 or below.

### **Gender, Race, and Drug Use**

Gender, race, and drug use are related to the cost of treating persons with HIV disease. Three large studies reveal that, in general, females with HIV disease are less costly to treat than males with HIV disease. The primary reason for this is that females with HIV disease spend fewer days in the hospital.

The Boston Health Study enrolled patients treated at three sites: a public hospital HIV clinic, a private group practice at a major teaching hospital, and a multicenter health maintenance organization (Weissman et al., 1996). Patients who met the 1987 CDC definition of AIDS and who were treated at one of these sites during 1990 were asked to enroll. There were 305 patients enrolled in the Boston Health Study. Information about them was acquired from interviews, hospital bills, and medical charts. This information indicated that females with HIV disease spent an average of 10.8 days in the hospital whereas males spent an average of 14.2 days in the hospital during the four-month period immediately preceding the patient interview.

Data from New York State and from ACSUS also demonstrated that females consume fewer resources. The average monthly cost of treating a female with HIV disease in New York State during 1994 was \$2,257, whereas the average monthly cost for a male was \$2,970 (New York State Department of Health, 1995). Data from the ACSUS indicated that the cost of treating females was less than for males because females spent fewer days in the hospital (Hellinger, 1993b).

Evidence from the Boston Health Study, ACSUS, and Maryland Medicaid indicates that the cost of treating white persons with HIV disease is slightly lower than the cost of treating persons who are not white. The average number of hospital days for white persons in the Boston Health Study was 12.5 days, and it was 15.3 days for persons who were not white. Moore and Chaisson (1997), in their study of Maryland Medicaid recipients, found that it was 7 percent more expensive to treat persons with AIDS who were not white, and data from ACSUS indicated that white persons with AIDS were 8 percent less likely to be

hospitalized than persons who were not white (Hellinger, 1993b).

The relationship between drug use and the cost of treating persons with HIV disease is less transparent. Data from New York State indicated that the cost of treating persons with AIDS who were injection drug users was virtually the same as the cost of treating persons who were not injection drug users (\$2,992 per month for injection drug users and \$2,970 for male adults). Moore and Chaisson (1997) also found that the cost of treating persons with AIDS who were drug users was about the same as the cost of treating those who did not use drugs. However, the Boston Health Study found that injection drug users with AIDS were hospitalized 21 percent fewer days than those who did not inject drugs.

Two new studies shed light on the role of gender, race, injection drug use, and insurance status in obtaining new drug therapies and tests (Palella et al 1998; Denning 1998). Data from the HIV Outpatient Study (Palella et al., 1998) revealed that gender and race were not related to a patient's ability to secure protease inhibitors or to morbidity or mortality, and that although injection drug users had poorer access to protease inhibitors, they had similar morbidity or mortality rates. This study analyzed the experiences of 1,255 patients between January 1994 and June 1997 who were treated at nine clinics in eight cities. This study also found that privately insured patients had better access to drug therapies, lower mortality, and lower morbidity than publicly insured and uninsured patients.

However, data from the Viral Load Surveillance Project (Denning, 1998) found that females, black people, and injection drug users had poorer access to viral load tests. This study examined the HIV/AIDS case reports and medical records of 2,092 persons over 13 years of

age who were newly reported with AIDS in Los Angeles, San Francisco, and New Jersey from January through October 1997. This study also revealed that privately insured patients had better access to viral load tests.

## **Geographic Variation**

The cost of treating persons with HIV disease varies significantly across geographic regions, and is lower on the West Coast than on the East Coast, particularly in the Northeast (Hellinger, 1991). This is primarily because of the shorter lengths of hospital stay on the West Coast. Wennberg (1993; 1996) has shown that there also are large variations in treatment patterns between areas within small regions, as well as large variations across regions of the Nation.

In 1993, the average length of stay for AIDS patients in New York State was 16.1 days (New York State Department of Health, 1995) whereas it was 6.2 days for AIDS patients treated at TIDMA. Similarly, AIDS patients stayed an average of 19.6 days in 1989 in New York State and 11.6 days in California (Hellinger, 1991).

## **Lifetime Costs**

The lifetime cost of treating a person with HIV disease from the time of HIV infection to death was estimated by the author to be \$119,000, using 1992 data (Hellinger, 1993a). To construct this estimate, the monthly cost of treating persons in each of four stages of HIV illness were multiplied by the mean occupancy time in the corresponding stage of illness and summed (Table 3).

The author's estimate of \$119,000 is compared with several other estimates in Table 4. As previously noted, Gable et al. used an expert panel in 1995 to derive cost

**Table 3**  
**Lifetime Treatment Costs, by Disease Stage**

Disease Stage <sup>1</sup>	Mean Occupancy Months	Cost per Month	Total Cost During Time in Stage
HIV+ Without AIDS T-Cell > 500	67.3	\$282	\$18,978
HIV+ Without AIDS T-Cell Between 200 and 500	44	430	18,920
HIV+ Without AIDS T-Cell < 200	12.4	990	12,276
With AIDS	25	2,764	69,100
Total	—	—	119,274

<sup>1</sup> 1987 AIDS Definition (See Technical Note.)

NOTES: AIDS is acquired immunodeficiency syndrome. HIV is human immunodeficiency virus.

SOURCE: Hellinger, F.J., 1993a.

estimates for primary antiretroviral therapy and the treatment of opportunistic infections for each of four disease stages that were similar to those used by the author. They also used the mean occupancy times in each stage employed by the author to derive an estimate of the lifetime cost of care of \$95,000.

Analysts at the New York State Department of Health estimated that the lifetime cost of care was \$95,000 for persons who were diagnosed with AIDS in 1993. Unfortunately, the analysts who derived this estimate did not provide detailed information about how their estimate was constructed.

In their study of Maryland Medicaid patients being treated for HIV disease from July 1, 1992 to June 30, 1995, Moore and Chaisson used a Markov model to calculate lifetime costs. They used four disease stages and derived probabilities of moving to the next more serious stage of illness. Applying these probabilities and the estimated cost of spending a month in each stage, they estimated that total Medicaid payment to providers would total \$133,000.

Holtgrave and Pinkerton estimated lifetime costs for patients treated after the approval of protease inhibitors. Their estimates of lifetime costs ranged from

\$71,143 for patients with low access where real costs were discounted at 5 percent per year, to \$424,763 for patients with high access where real costs were not discounted. Because this is the only study that calculated estimates where the real costs of care were discounted, the undiscounted cost estimates presented in this study should be compared with estimates from other studies.

### **FINANCING OF CARE FOR PERSONS WITH HIV DISEASE**

The race, ethnicity, and risk behavior profile of persons with HIV disease are changing. Ten years ago more than one-half of those diagnosed with AIDS were white, and more than one-half were males who reported having had sex with other males. Yet, during the period from July 1996 through June 1997, the percent of persons diagnosed with AIDS who were white dropped to 36 (from 40 percent for the period from July 1995 through June 1996), and the percent who were black increased to 43 (from 40 percent for the period from July 1995 through June 1996) (Centers for Disease Control and Prevention, 1997a; Centers for Disease Control and Prevention, 1996b). The percent who were

**Table 4**  
**Estimates of Lifetime Cost of Treating a**  
**Person With HIV Disease: Selected Years**

Year	Estimate
1990	\$85,000
1991	102,000
1992	119,000
1994	109,000
1995	95,000
1992-95	133,000
1996	71,143 - 424,763

NOTE: HIV is human immunodeficiency virus.

SOURCES: Hellinger, F.J., 1991; Hellinger, F.J., 1992; Hellinger, F.J., 1993a; New York State Department of Health, 1995; Gable, C. et al., 1996; Moore, R.D. and Chaisson, R.E., 1997; and Holtgrave, D.R. and Pinkerton, S.D., 1997.

Hispanic increased to 20 (from 16 percent) whereas the percent who were males who reported having had sex with another male fell to 38 (from 44 percent).

Persons with HIV disease who are black, Hispanic, or have a history of drug abuse are more likely to have public insurance (Bartnyska et al., 1995; Hellinger, 1991; Diaz et al., 1994), and the proportion of persons with HIV disease who are black, Hispanic, or have a history of drug abuse is increasing (Centers for Disease Control and Prevention, 1997a). Thus, the proportion of persons with HIV disease who are publicly insured is increasing.

The increasing number of persons with HIV disease with public insurance signifies that the financial burden of taking care of persons with HIV disease is increasingly being borne by public agencies. It also has implications for treatment. The HIV Outpatient Study found that patients with public insurance were less likely than patients with private insurance to be prescribed a protease inhibitor (Palella, 1998), and the Viral Load Surveillance Project

found that patients with public insurance were less likely to have received a viral load at the time they were reported with AIDS (Denning, 1998).

In this article, costs represent payments from insurers and patients to providers. However, different payers reimburse different amounts to providers for the same set of services. For example, both Medicare and Medicaid reimburse less than private insurers for most physician and hospital services. The Physician Payment Review Commission estimated in 1993 that Medicare paid physicians about 60 percent of what private insurers paid and Medicaid paid only 43 percent (Henke, 1994). These discrepancies are not as great for hospital services. Medicare paid about 96 percent of costs for hospital care in 1993 whereas Medicaid paid about 80 percent of costs. Consequently, payments from public insurers to providers of health care services for persons with HIV disease are less than those made by private insurers. The cost estimates discussed in this section represent the average of all payments received by providers.

Increasingly, persons with HIV disease covered by Medicaid are being moved into managed care plans (Conviser, 1997; Conviser, Kerrigan, and Thompson, 1997). Moreover, in a small number of States, Medicaid programs have designated a specific monthly rate to be paid to managed care organizations for caring for persons with HIV disease.

Maryland began enrolling recipients into its Medicaid managed care program, HealthChoice, in June 1997. In order to be accepted as a provider organization that treats persons with HIV disease under Maryland's HealthChoice program, managed care organizations must have experi-



ence in treating persons with HIV disease and offer treatment at a number of sites around the State.

Rates in Maryland are set using the ambulatory care group (ACG) methodology with special capitation rates for a few categories including persons living with AIDS. The capitation rate for treating persons living with AIDS in Baltimore (where the vast majority of persons living with AIDS in Maryland reside) is \$2,161 per month.

This rate does not include protease inhibitors, other newly approved drugs to treat HIV disease such as Viramune and Rescriptor (two new non-nucleoside reverse transcriptase inhibitors), diagnostic tests such as viral load tests, and mental health services. Managed care organizations are reimbursed on a fee-for-service basis for excluded services. Researchers at the Federal agency responsible for administering the Ryan White CARE Act, the Health Resources and Services Administration (HRSA), stated that, "The monthly cost of combination therapy and viral load testing generally have been estimated as \$1,000 to \$1,500" (Conviser, Kerrigan, and Thompson, 1997).

California reimburses a variety of managed care organization rates that vary from \$1,000 to \$1,500 a month to treat Medicaid recipients with AIDS (Dreyfus, Kronick, and Tobais, 1997). These rates do not include protease inhibitors. California reimburses patients treated by the AIDS Health Care Foundation a partially capitated rate of \$1,100 to \$1,200. This rate excludes both protease inhibitors and inpatient care.

Massachusetts began a program that reimburses providers to treat persons with AIDS in 1992. The capitation for treating this population was \$3,756 a month. The Community Medical Alliance is the chief recipient of these funds, and their costs for

treating a person with AIDS in 1993 were estimated to be \$2,950 a month (Master et al., 1995). Recently, the Medicaid program in Massachusetts adjusted its rates so that it now reimburses managed care organizations \$2,300 a month to treat active AIDS cases and \$2,998 a month to treat advanced AIDS cases (Conviser, 1997). Cases are placed in one of these two categories depending on the opportunistic infections experienced by the patient.

The changes in the racial, ethnic, risk-behavior profile, and insurance status of the population of persons with HIV disease have important economic consequences. The most obvious are the steep and well-publicized rise in the cost of drugs, and the growing concern that many persons with HIV disease who might benefit from expensive combination drug therapies have been unable to gain access to them because they are unable to afford them.

The best information on the insurance status of persons with AIDS was collected by eight States (Arizona, Connecticut, Delaware, Florida, Georgia, New Mexico, South Carolina, and Washington) and three local health departments (Denver, Detroit, and Los Angeles) in collaboration with the CDC as part of the Supplement to HIV/AIDS Surveillance Project (Diaz et al., 1994). This project interviewed a sample of 1,858 persons with AIDS who were 18 years of age or over and who were reported to have AIDS from June 1, 1990, through June 30, 1992. Of this sample, 20 percent were privately insured, 55 percent were publicly insured, and 25 percent were uninsured.

Few persons without insurance can afford to pay for HIV care, and most insurance plans provide leaner coverage for outpatient drugs and services than for inpatient drugs and services. The cost of a protease inhibitor can be as high as \$8,000 per year, and the total cost of new

combination drug therapies and associated services may run as high as \$20,000 a year. Furthermore, the costs of other drugs can easily exceed these costs. For example, the cost of prophylactic drug therapy to prevent cytomegalovirus (CMV) may add \$20,000 a year to these costs (Bartlett, 1998).

The Federal and State governments have paid for much of the cost of the new and expensive combination drug therapies through Medicaid and State AIDS Drug Assistance Programs (ADAPs) (Doyle, Jefferys, and Kelly, 1998). Medicaid covers persons with HIV disease who are poor and disabled, and the ADAPs provide access to expensive drug therapies for many low-income individuals living with HIV disease. The Federal Government funds ADAPs through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The income limits for ADAP generally are much higher than the income limits for Medicaid eligibility. The demand for new and expensive drugs early in the course of treatment of HIV disease has grown swiftly so that now several States have waiting lists for their ADAP programs. There are also persons who do not qualify for ADAP funds and who cannot afford to pay for these drugs, and there are employed persons with HIV disease with private health insurance plans that offer little or no coverage for outpatient drugs (Doyle, Jefferys, and Kelly, 1998).

Both the HIV Outpatient Study and the Viral Load Surveillance Project determined that persons with public insurance had poorer access to care (Denning, 1998; Palella et al., 1998). These studies show that good access is not a direct consequence of insurance coverage for poor patients with HIV disease.

## **DISCUSSION AND FINAL REMARKS**

Before the advent of the new combination drug therapies, most persons with HIV disease waited until their CD4+ cell counts dropped below 200 or until they experienced serious medical conditions before they began antiretroviral therapy. This is not true today. Many believe that antiretroviral drug therapy to arrest the replication of HIV should be undertaken early during the course of illness and should be continued indefinitely to prevent a resurgence of the virus.

The economic consequences of the early and continuous use of expensive antiretroviral therapies by increasing numbers of persons with HIV disease, who previously were not receiving antiretroviral drug therapy, are poorly understood because there are no comprehensive assessments of the cost and financing of care for persons with HIV disease. Yet, the diffusion of costly, new drug therapies among the population of persons with HIV disease in conjunction with the increasing number of persons living with HIV disease indicate that the cumulative cost of treating HIV disease is rising, and that it will continue to do so in the near future.

Indeed, the major impediment in the analysis of the cost and financing of HIV disease is the lack of timely data. There are no recent studies of the insurance status of persons being treated for HIV disease, nor any recent studies of the national cost of treating this disease. Moreover, only the lifetime cost estimate derived by Holtgrave and Pinkerton (1997) applies to the period after the diffusion of new combination therapies. Thus, other estimates of the lifetime cost of treating a person with HIV disease exclude the cost of new drug combina-

tions, the cost of monitoring the impact of these drugs (i.e., the cost of viral load assays), and the cost of treating their side effects. In addition, other estimates understate the expected survival period for persons with HIV disease.

Although it is unclear exactly how much longer the expected survival period is for persons with HIV disease who are being treated with new combination drug therapies, the sharp drop in deaths from AIDS experienced since 1996 suggests that it is considerable. In fact, it may be no longer meaningful to forecast the lifetime cost of treating a person with HIV disease because the expected survival period from the time of infection until death is too long and it is too difficult to foresee changes in treatment regimens that may substantially affect the cost of care. We do not estimate the lifetime cost of treating a person with heart disease, hypertension, or diabetes for these reasons. Furthermore, existing estimates of the lifetime cost of treatment do not specify whether the estimate is for persons that are diagnosed with HIV at the time the estimate is made, or for those who have been diagnosed with AIDS, or for those in the latter stages of this disease.

Instead of devoting energy to deriving better estimates of the lifetime cost of treating persons with HIV disease, investigators should concentrate on developing better estimates of the cost of treating persons with HIV disease over a specified period based on the patient's characteristics (e.g., CD4+ cell count, viral load, opportunistic infections, age, gender, and risk behavior profile). As many State Medicaid programs compel persons with HIV to join managed care plans, it is essential that Medicaid plans establish special rates for persons with HIV disease so that such persons are not discriminated against by managed care plans.

In order for the special rates for persons with HIV disease to accurately reflect the

cost of care, these rates must be based on current data. Rapid changes in the treatment regimens of persons with HIV necessitate that these rates be updated regularly to reflect changes in treatment regimens.

The only timely and comprehensive study of the utilization of resources by persons with HIV disease is the ongoing HIV Cost and Service Utilization Study (HCSUS). However, information about the cost and financing of HIV disease is not available from HCSUS at this time. HCSUS is being directed by a group of organizations that includes RAND (the primary research institution), Project HOPE, the National Opinion Research Center, and more than 15 universities. This study began in 1994 as a cooperative agreement between RAND and AHCPR. During the past few years, additional components have been funded from a variety of sources including HRSA, the National Institute on Drug Abuse, the National Institute of Dental Research, the National Institute on Aging, and The Robert Wood Johnson Foundation.

HCSUS is the first study to enroll a national probability sample of persons with HIV disease. The sampling strategy is based on a three stage design. The first stage involves sampling areas according to the number of AIDS cases reported. The second involves sampling providers based on estimates of their AIDS caseload within the geographic areas chosen in the first stage, and the third stage involves the sampling of patients from the providers chosen in the second stage. About 2,900 persons have been enrolled in HCSUS, and each person has been interviewed three times. The interviews were spaced about 6 months apart, and the last wave of interview began in August 1997 and were completed in December 1997. Billing data is being collected and a sample of providers also will be interviewed. Thus, HCSUS will

provide comprehensive information about the treatment of persons with HIV disease in 1996 and 1997.

Information from HCSUS also is needed to reconcile the findings of the HIV Outpatient Study and the Viral Load Surveillance Project regarding the proportion of patient that receive antiretroviral therapy. The HIV Outpatient Study found that 82 percent of patients received protease inhibitors whereas the Viral Load Surveillance Project found that 17 percent of newly reported AIDS patients had received protease inhibitors.

These studies examine different populations and there are good reasons for these divergent findings. First, patients in the HIV Outpatient Study were treated at primarily private clinics that specialized in treating persons with HIV disease; it is reasonable to expect that most patients at these clinics received combination antiretroviral therapy. Secondly, the Viral Load Surveillance Project studied newly reported AIDS cases in 1997. Yet, persons who took protease inhibitors when they became available in 1996 were less likely to progress to AIDS in 1997, and thus are less likely to be included in this study population. Nonetheless, the widely divergent findings of these two studies highlight the need for good population-based studies of persons with HIV disease.

In order to ensure that all patients with HIV disease receive appropriate care, it is necessary to understand more about the determinants of care. In particular, more information about how patient characteristics (both sociodemographic and clinical),

provider characteristics (e.g., experience with treating HIV disease, type of practice, and age), and facility characteristics (e.g., public or private, teaching-affiliated, urban or rural, and experience treating patient with HIV disease) are related to cost is needed to enable payers to set appropriate rates for managed care organizations. Moreover, the HIV Outpatient Study and the Viral Load Surveillance Project revealed that insurance alone does not guarantee access, and research into why publicly insured patients are less likely to receive new therapies is needed.

## **TECHNICAL NOTE**

### **1987 AIDS Definition**

For persons with laboratory-confirmed HIV infection, the 1987 definition incorporated HIV encephalopathy, wasting syndrome, and other indicator diseases that are diagnosed presumptively (i.e., without confirmatory laboratory evidence of the opportunistic disease).

### **1993 AIDS Definition**

In addition to 23 clinical conditions in the 1987 definition, the 1993 definition includes HIV-infected persons with a CD4+ count of less than 200 or a CD4+ percentage of less than 14, and persons diagnosed with pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer. All conditions in the 1993 definition require laboratory confirmation of HIV infection.

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