

Economic consequences for Medicaid of human immunodeficiency virus infection

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Medicaid is currently a major source of financing for health care for those with acquired immunodeficiency syndrome (AIDS) and to a lesser extent, for those with other manifestations of human immunodeficiency virus (HIV) infection. It is likely to become even more important in the future. This article focuses on the

structure of Medicaid in the context of the HIV epidemic, covering epidemiological issues, eligibility, service coverage and use, and reimbursement. A simple methodology for estimating HIV-related Medicaid costs under alternative assumptions about the future is also explained.

Introduction

Human immunodeficiency virus (HIV) attacks the body's immune system, causing progressive disability and death. Since the disease was first recognized in 1981, more than 139,000 cases of the most severe form of HIV infection, acquired immunodeficiency syndrome (AIDS), have been diagnosed in the United States and more than 85,000 people have died (Centers for Disease Control, July, 1990).¹ These numbers represent not only human tragedy but a significant new financial burden on a health care system in which rising expenditures are already a concern.

The Medicaid program is bearing a major share of this burden, and its share is likely to increase as the epidemic continues. In this article, Medicaid's current and future role in financing HIV-related health care are explored. The article focuses on the disease, associated health service use and cost, and sources of financing. Medicaid's coverage of HIV-infected patients is described, and the policy issues the epidemic raises for Medicaid are highlighted. Finally, a simple methodology for estimating HIV-related Medicaid costs under alternative assumptions about the course of the epidemic, treatment patterns, and the structure of Medicaid, is described.

Disease overview

Certain features of the virus and its clinical manifestations are particularly important because of their impact on the financing of HIV-related care. First, the disease is infectious. Transmission of the virus occurs through sexual contact, through contact with

contaminated blood and blood products (e.g., through blood transfusions or sharing of needles in intravenous drug use), and perinatally, from an infected mother to her infant.

Shortly after initial infection, there is often a brief flu-like illness. An asymptomatic period follows, lasting for years (the median time from infection to serious illness is currently estimated at 7 to 10 years) (Moss and Bacchetti, 1989). During this period, a sequence of simple blood tests can usually establish that infection has occurred. Although information on the natural history of the disease is not complete, the expectation is that all of those infected will eventually become seriously ill and die as a result of their infection.

Once symptoms begin, the spectrum of clinical manifestations is very broad. In the early years of the epidemic, two "opportunistic" illnesses (conditions seldom seen in people with normal immune systems) were especially common—pneumocystis carinii pneumonia (PCP) and Kaposi's Sarcoma (KS). However, many others occur as well, and many patients experience multiple illnesses.

The spectrum of care required is equally broad (Bilheimer, 1989a). During the asymptomatic period, psychological counselling and monitoring of immune system functioning may be indicated. Treatment with drugs such as azidothymidine (AZT) (the first drug to demonstrate effectiveness against the HIV virus) may help to delay the onset of symptoms. As the disease progresses, a typical patient needs care spanning the entire range of medical, dental, personal and psychological services. Moreover, the patient's needs can fluctuate widely from one week to the next. Many people with AIDS (PWAs) do not simply decline steadily until death, but experience periods of acute illness and periods of chronic disability, interspersed with periods of relative well-being during which they may even be able to work.

The length of time from onset of symptoms until death varies with clinical manifestations, but patients generally have not lived more than a year or two after a diagnosis of AIDS. Life expectancy seems to be increasing, however, with the introduction of AZT and improvements in the clinical management of opportunistic infections, especially PCP.

Because of the modes of transmission, the disease has so far been concentrated among homosexual and bisexual

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¹Cases meeting the Centers for Disease Control (CDC) definition of AIDS must be reported. The incidence of asymptomatic HIV infection and HIV-related conditions that do not meet the surveillance definition can only be estimated, based on a few small-scale studies and assumptions about the relationship between the incidence of these conditions and reported AIDS. CDC estimates that as of early 1989 there were approximately 1 million individuals infected, but emphasizes the lack of a firm basis for this estimate.

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males, users of intravenous drugs who share needles, and recipients of infected blood products. The sexual partners of these people and children born to infected mothers are also at high risk. Close to 90 percent of reported AIDS cases are in the 20 to 49 age group, although the incidence of pediatric cases is increasing. Black and Hispanic populations have been disproportionately hard hit. Most experts believe this to be the result of a higher incidence of intravenous drug use and needle sharing in these groups (Selik, Castro, and Pappaioanou, 1988).

The disease has been highly concentrated geographically. About 42 percent of reported cases have occurred in New York and California, and within these States, most cases are in the cities of New York, San Francisco, and Los Angeles. The number of cases outside the original foci of the epidemic is increasing, however, and is expected to continue to increase.

Service use and cost

The earliest estimate of the lifetime cost of medical care for AIDS, based on the first 10,000 patients, was \$147,000 and included only hospital care (Hardy et al., 1986). This estimate is now considered to be much too high. Recent estimates of lifetime cost have ranged between \$40,000 and \$80,000, with \$50,000 to \$60,000 considered most likely (Scitovsky, 1989). The estimates are, however, very approximate. The studies on which they are based are small in scale, survey unrepresentative samples of patients, and usually omit significant cost items, such as expenditures for drugs and home-based care and the opportunity cost of volunteer services. Most cover only costs associated with surveillance definition AIDS; very little is known about the costs associated with other stages of the infection. Detailed information on the use and cost of particular services and how these vary with patient characteristics and financing sources is even more limited. The changes in treatment patterns that have occurred as clinicians have gained experience with the disease limit the value of retrospective studies.

Users of data on current patterns of service use and cost must also remember that these patterns may be far from optimal. People with HIV-related morbidity face multiple service access problems (Bilheimer, 1989a). Because of fear of contagion and the social stigma attached to the behaviors associated with transmission of the virus, many health care providers are unwilling to treat those infected, even when the cost of treatment is fully reimbursed (and often it is not) (Intergovernmental Health Policy Project, 1987; Dan, 1987; Zuger and Miles, 1987; Institute of Medicine, 1988; Intragovernmental Task Force, 1988). Fluctuations in a PWA's health status can affect eligibility for services when eligibility depends upon a permanent minimum level of disability or dependency.

In addition, people infected by HIV often have other health and social problems. Those who are chemically dependent need service providers who can address their drug and alcohol problems as well as their illness. Racial minorities have traditionally experienced difficulty in obtaining access to care for ordinary health problems. Homelessness (or inability to stay in an existing living situation) is an increasing problem among people with

HIV-related conditions. This has a profound effect on the services that can be provided and leads to excessive hospitalization because of the lack of other alternatives. Substance abusers and children are particularly likely to be hospitalized for long periods for want of an appropriate place to which they can be discharged.

The complexity of these patients' health and social needs demands a flexible, coordinated approach to care. Ideally, a cost-effective package of services based on individual need is chosen from a continuum of acute and long-term medical and social services, and financed. It is often difficult to achieve this ideal, however, given the current structure of the financing system.

The best information on current patterns of service use by PWAs is for hospital inpatient care. The available studies show that use of this care varies with risk group, presenting diagnosis, and place of residence (Scitovsky, 1989). Much less information is available on other services and the usefulness of such information is limited by an absence of comparability in the definition of specific services and of cost (Bilheimer, 1990).

New studies are under way, and attention is being given to incorporating data collection activities into service delivery. Nevertheless, information on service use and cost will remain problematic in the immediate future.

Financing human immunodeficiency virus-related services

The U.S. health care financing system is built on private group health insurance for the employed and public sector coverage for the elderly and certain categories of the disabled and the poor. These financing sources are supplemented by a patchwork of other public and private payment mechanisms, largely at the State and local level. Gaps in the system leave an estimated 32.7 million people with no private or public third party payment at all (Congressional Budget Office staff estimates based on 1989 Current Population Survey). Many others have coverage that is inadequate in the face of serious illness.

This system is now struggling to finance the new costs associated with the HIV epidemic. Estimation of the current and potential costs is difficult, given the profound uncertainty surrounding both the cost of caring for each person infected and the number of persons cared for in any given year. Nevertheless, estimates have been made of expenditures for surveillance definition AIDS. For 1991, the best estimates range between 1 and 2 percent of estimated total personal health care expenditures for that year (Scitovsky, 1989). This is a substantial but not catastrophic burden on the system as a whole. Its impact is greater than the numbers suggest, however, because of the way the burden is distributed.

A review of studies to date shows a consistently small share of AIDS-related hospital care financed by the Medicare program (.5 to 3 percent) but large variations in the share of Medicaid and private insurance, depending on the location of the study, the type of hospitals included, the composition of the patient populations by risk group, and the definition of coverage (Wooldridge, Bilheimer, and Baily, 1989; Baily, 1989; Scitovsky, 1989).

The Health Care Financing Administration (HCFA) (Klemm, 1989) estimates that in fiscal year 1988, about 2 percent of PWAs were eligible for Medicare, and Medicare paid about \$30 million for their care. This is about 1 percent of estimated total expenditures on AIDS health care, and only .0004 percent of Medicare's budget for that year.

These estimates are small in comparison to those for Medicaid. HCFA estimates that the program covers about 40 percent of AIDS patients and pays about 23 percent of AIDS health care expenditures, amounting to \$640 million in fiscal year 1988. The estimate for fiscal year 1991 is \$1.7 billion, assuming no change in Medicaid's percentage share. AIDS expenditures as a percentage of total Federal Medicaid expenditures will increase from 1.1 percent to 2.0 percent from fiscal year 1988 to fiscal year 1991.

There are no estimates of total expenditures on non-AIDS HIV-related health care, or of the relative shares of various payer sources in these expenditures. It is probable, however, that Medicare and Medicaid play a significantly smaller role in financing such expenditures. As discussed later in the article, most HIV-infected persons qualify for Medicaid and Medicare only after they meet the disability requirement by receiving a diagnosis of AIDS. The notable exception is that of poor women and children.

Estimates of Medicaid and Medicare expenditures are very approximate because of the limited information available at this point in the epidemic (Wooldridge, Bilheimer, and Baily, 1989; Langwell, 1989; Bilheimer, 1989c). The goal of the study on which this article is based (Baily et al., 1989) was to provide information and analysis to assist HCFA in understanding the factors that influence Medicaid and Medicare expenditures on HIV-related care, now and in the future. This required a review of private insurance as well as Medicare and Medicaid. The next three sections summarize the findings, explaining why Medicaid's role is so important and highlighting major issue areas.

Private insurance

Private insurance plays a major role in financing HIV-related health care. Nevertheless, it has significant limitations.

Many of those at high risk of HIV infection are also at high risk of lacking private insurance—Most Americans under 65 years of age who have private health insurance obtain their coverage through the workplace, as workers or dependents of workers. Employer-provided coverage receives favorable tax treatment, and those who have it are insured on a group basis (unless they work for very small firms). This generally means lower premiums and no medical screening. Those who purchase insurance as individuals pay higher premiums for lesser benefits, and must usually undergo screening for health risks. Evidence of HIV infection or high risk status generally means

rejection (Office of Technology Assessment, 1988).²

This structure means the unemployed are especially likely to be uninsured. Nevertheless, since not all employers offer insurance and not all employees offered it participate in their employer's plan, more than one-half of uninsured adults are working. Part time workers and workers in small firms are especially likely to be uninsured. Low income, under 30 years of age, and black or Hispanic ethnic background are also associated with lack of private insurance.

The significance of this structure is in the overlap between the uninsured population and the expected future incidence of HIV infection. The incidence of HIV infection in homosexuals and those who have received blood products is falling, and the disease is spreading most rapidly among intravenous drug users (who are likely to be unemployed), their sexual partners and their offspring. To the extent that heterosexual spread accelerates, it is likely to accelerate first among young adults in the low-income, disproportionately minority areas in which many intravenous drug-users (IVDUs) live.

Those who have private insurance when they first become infected may lose it later in the illness—Those who test positive for HIV can usually renew individual coverage already in force, but cannot obtain new or increased coverage. The surest route to adequate coverage is through employment with a firm offering good health benefits. Obtaining employment may be a problem, however, if risk status is known, and changing jobs may subject a worker to a waiting period for coverage of pre-existing conditions. Moreover, some people have been fired or their individual insurance cancelled on some pretext once their infection status became clear (Densford, 1988; Schatz, 1987; Simross and Johnston, 1988).

Coverage linked to employment can pose problems when a person becomes too sick to work. Traditionally, loss of employment meant loss of group insurance. Legislation in 1985 (Consolidated Omnibus Budget Reconciliation Act, or COBRA) guaranteed many workers the opportunity to continue insurance at group rates for at least 18 months; in late 1989, this was extended to 29 months for those who left employment or reduced their hours because of disability. They must, however, be able to afford the premiums without work income (employers can charge premiums up to 102 percent of the full group premium for the first 18 months, and up to 150 percent for the remaining 11).³ Once diagnosed with AIDS and unable to work, most people don't live beyond the extension period. Those who do may be eligible for Medicare.

²Fifteen States offer special "risk pool" coverage to the medically uninsurable, with benefits comparable to group coverage. The policies are too expensive for most of the target population, however, even though premiums are subsidized (U.S. General Accounting Office, 1988).

³Some States have introduced pilot programs that use Medicaid or State indigent care funds to pay these premiums for AIDS patients who are, or are likely to become, Medicaid-eligible (Intergovernmental Health Policy Project, 1990a).

Private insurance often does not provide adequate coverage for the services HIV patients need—Private insurance policies have limits on coverage, especially for out-of-hospital care, drugs, mental health care, personal care, experimental treatment, and nursing home care. Limited coverage means high out-of-pocket costs, which increases the likelihood that patients will exhaust their resources and require public assistance. Recent recommendations for AZT treatment of asymptomatic HIV-infected persons will create dilemmas for many, since the treatment is expensive and many insurance policies will not cover it.

As the epidemic continues, the private insurance share of HIV-related expenditures is likely to decrease relative to the public share—The epidemic is expected to spread in populations with lower than average rates of private insurance coverage. Increases in life expectancy after severe disability sets in will increase the likelihood of losing private insurance. Treatment patterns seem to be changing away from care that is well-covered by private insurance. Thus, in the absence of major new initiatives to extend private insurance coverage, the burden on public sources of financing will probably increase.

This tendency will be exacerbated if private health insurers deliberately seek to avoid bearing HIV-related expenses. So far, there is limited evidence of such avoidance. Nevertheless, employers and insurers may respond in this way if their HIV-related costs increase significantly. Employment discrimination against HIV-positive individuals is of particular importance, given its implications for access to group health insurance (Bailey, 1989).

Medicare

Medicare, the Federal health insurance program for the elderly, the permanently disabled, and persons with end stage renal disease, plays a relatively small role in financing HIV-related care (Langwell, 1989).

Few people infected by HIV can establish eligibility for Medicare—Most are under 65 years of age, so must qualify on disability grounds. They must be unable to work because of a disability expected to last for at least 12 months or to result in death, have enough experience in covered employment to qualify for Social Security disability insurance (SSDI) payments, and then wait 29 months (5 months for SSDI payment, 24 months more for Medicare coverage). Intravenous drug users may lack the necessary work experience. More important, currently, most HIV-infected persons who are too sick to work die before the end of the 29-month waiting period.

For those who do qualify, Medicare does not provide full coverage for the services needed—As in private insurance, there are limits on coverage and out-of-pocket payments for coinsurance and deductibles. Experimental treatment, long-term care, out-of-hospital drugs, mental health care, and dental services are major categories of services not covered at all or covered to a very limited extent.

If eligibility and benefit structure remain unchanged, Medicare is unlikely to become a major source of payment for HIV-related health care—The disease is expected to remain concentrated among those under

65 years of age. Treatment advances are prolonging lives, but this does not automatically imply a commensurate increase in the number of PWAs on Medicare, since the issue is how long HIV-infected people live after they can no longer work. Treatment may preserve ability to function as well as prolonging life, thus postponing SSDI and Medicare coverage.

Medicaid

Medicaid, the Federal-State program that finances health care for certain categories of the poor, is a major source of financing for AIDS-related health care, and to a lesser extent, for other HIV-related health care. Unlike Medicare and private insurance, Medicaid frequently covers more of the services especially needed by PWAs. Administrators and providers have exercised energy and creativity in using Medicaid to meet the needs of those affected by HIV, and many innovative programs are already under way. However, issues remain, associated with the structure of the program and with budgetary constraints.

Later in this article, we highlight the structural aspects of Medicaid that are important for persons infected by HIV. Note that, unlike Medicare, which is nationally uniform, Medicaid's eligibility requirements, service coverage, and reimbursement methods vary significantly from State to State. As a result, where a person lives greatly affects the assistance that can be obtained. This complicates discussion of the program, as well as raising questions of equity.

Many impoverished HIV-infected persons have difficulty establishing Medicaid eligibility—Rules for eligibility are complex and, as noted, vary across States. Applicants must meet both categorical and financial eligibility requirements.

The categories are primarily based on certain federally required welfare programs: Aid to Families with Dependent Children (AFDC), serving members of such families (usually mothers and their children); and Supplemental Security Income (SSI), serving persons who are elderly, blind, or disabled. Additional women and children are eligible as a result of recent legislation requiring States to extend Medicaid coverage to all pregnant women, and children up to 6 years of age with family incomes up to 133 percent of the Federal poverty level (States may, if they choose, raise this to 185 percent for pregnant women and infants). These rules mean that, except for HIV-infected women and children, who may already be eligible for Medicaid when they become seropositive, the most likely way HIV-infected persons become eligible for Medicaid is by first qualifying for disability under the SSI program administered by the Social Security Administration.

The financial eligibility requirements consist of limits on income and assets. The limits vary substantially across eligibility groups and from State to State, especially for the AFDC and SSI categories. In the 36 States with medically needy programs, a person who falls into an appropriate group but whose financial resources exceed the limits may qualify as medically needy if income net of incurred medical bills meets a State-determined medically needy level, which can be up to 133 percent of

the AFDC payment level. Given the high cost of AIDS treatment, this program is extremely important in the context of the HIV epidemic.

Because Medicaid is means-tested, coverage is interrupted if there is an increase in income or assets. However, the increased resources may not be sufficient to pay for needed care.

Medically needy persons must first obtain care, incurring sufficient expenses to meet the spend-down requirements on a periodic basis (the period varies from 1 to 12 months, depending on the State). With limited resources, they may have difficulty obtaining the care to spend down. Although they need not pay for the care themselves, Medicaid will not pay. Frequently, the cost is borne by non-Medicaid State programs⁴ or by public or private providers as uncompensated care. This can contribute to access problems, as providers are uncertain about payment.

A particular issue has arisen for disabled AIDS patients on SSI who have applied for SSDI payments. When their 5-month waiting period for disability insurance payments ends and payments begin, they may no longer be eligible for SSI. In that case, Medicaid eligibility ceases, but Medicare coverage does not begin for 24 months.

Variations in eligibility rules cause the number of HIV-infected persons who are Medicaid-eligible to vary significantly by State. The risk group configuration of the epidemic within the State is also important. The probability that an infected person will qualify for Medicaid and the duration of time on the program varies by risk group. As noted, women and children, especially those whose infection is related directly or indirectly to IV drug use, often have Medicaid eligibility already. Intravenous drug users who are uninsured and unemployed and have few assets and little work history are likely to become eligible as soon as they meet the disability standard. Other adult patients may be more likely to become eligible further along in the course of the illness, after they have not only become disabled but also exhausted their own resources.

Complex Medicaid rules make for a complex application process. The application form can be as long as 52 pages, and the process can take as long as 6 weeks (Wooldridge, Bilheimer, and Baily, 1989). A diagnosis of AIDS confers presumptive eligibility for SSI and Medicaid during processing. Those with HIV-related symptoms that do not meet the CDC surveillance definition of AIDS must wait for a disability determination. Managing the application process is a severe burden on people who are seriously ill, especially if they are socially isolated, as many PWAs are, and have no family or friends to help them.

Those who do qualify for Medicaid often have difficulty obtaining the services they need—Some services must be covered by all Medicaid programs, while others are at the discretion of the individual States. Mandatory services of particular importance to PWAs are inpatient and outpatient hospital services, physician services, lab and X-ray services, skilled nursing facility (SNF) services for

persons 21 years of age or over, home health services, and early and periodic screening, diagnosis, and treatment (EPSDT) services for children only. Optional services of importance are intermediate care facility (ICF) services, prescription drugs, dental care, clinic services, transportation, personal care, private duty nursing, diagnostic and screening services, case management, and hospice.

States may impose limitations on required and optional services—limitations that can be extremely restrictive—and service coverage varies significantly across States. Among the optional services, services important for AIDS patients but frequently not offered or severely restricted are dental care, community mental health services, prescription drugs, and personal care. The last is extremely significant for the maintenance of low-income PWAs in the community rather than in institutions, yet as of 1989, only 26 States covered personal care services (19 for both categorically and medically needy Medicaid recipients and 7 for the categorically needy only) (Intergovernmental Health Policy Project, 1990b).

When a service is covered, it may not be structured to meet the needs of PWAs. Until 1987, the hospice benefit, for example, had limits on inpatient days that failed to account for the volatility of PWA health status and the instability of many of their home situations. Hospice programs also, as part of their philosophy, expect patients to forego the use of all aggressive treatment, something many PWAs are unwilling to do.

Like Medicare and private insurance, Medicaid usually does not cover experimental treatment. An issue currently under debate is coverage of drugs with FDA "treatment investigational new drug (IND) status." Such coverage would have major cost implications. States already differ significantly in the extent of their coverage of fully approved drugs. As more new drugs are developed, disparities across States are likely to increase, possibly leading to migration of PWAs to more liberal States.

The housing problems of PWAs complicate the delivery of subacute care and home-based services. Many PWAs, especially substance abusers and children, need housing with supportive medical and personal care, yet there is no stable funding source for it. The low level of financial assistance provided by welfare programs limits the PWA's ability to pay for suitable housing. Use of existing nursing homes is limited by infectious disease regulations, inadequate reimbursement, constraints on bed supply, the reluctance of operators to care for PWAs (especially substance abusers), and the reluctance of PWAs to live in facilities oriented toward the needs of the elderly.

Lack of suitable housing for PWAs in need of subacute and personal care is not a Medicaid problem. Medicaid rules do, however, complicate attempts to solve the problem. Community residences for PWAs are often developed in neighborhood housing, staffed by volunteers, and do not meet the regulatory requirements for licensed facilities (for example, health and safety standards for facilities in which SSI recipients reside, set forth in a section of the Social Security Act known as the Keys Amendment, Section 1616(e), 1976). As a result, services provided in these residences may not be eligible for reimbursement by Medicaid. As a PWA's health

⁴In fiscal year 1989, an estimated \$65 million of State-only funds were spent on AIDS patient care (Intergovernmental Health Policy Project, 1989a).

status fluctuates, he or she may have to be transferred from a community residence to different sites licensed for different purposes to obtain reimbursement for the needed level of care, a process that is expensive and inhumane.

Home and community-based waivers (under Section 2176 of Public Law 97-35, the Medicare and Medicaid Amendments of 1981, as modified in 1986) have been used by some States as a vehicle for tailoring services to patient need. They allow special programs of home and community-based services to be developed for target groups of Medicaid recipients who would otherwise require more expensive care in a nursing home (or hospital in the case of AIDS patients).

Waiver programs show promise but are not without problems. One problem has been slow intake because of the volatility of patients' states of health and high death rates after identification of patients but before enrollment. This occurs because PWAs must be sick enough to require a high level of care to be eligible for the programs. Another problem has been the constraints on in-home services imposed by the Keys Amendment (Wooldridge, Bilheimer, and Baily, 1989).

Since 1986, States have had the authority to provide case management as an optional service and to target it to patients with AIDS. This provides them with a useful tool to tailor services to patient need, potentially improving the quality and cost effectiveness of care. Case management is most effective, however, when appropriate services are actually available and paid for by Medicaid or other public funds.

Medicaid often does not reimburse for the full cost of care received by AIDS patients, even for covered services—Medicaid reimbursement rates and methods are set by the States and vary widely. The program has been criticized in the past on the grounds that reimbursement does not cover the cost of services, regardless of the health problem. In consequence, many providers may choose not to participate in Medicaid rather than share in funding Medicaid services through bad debt. This issue is exacerbated in the case of PWAs, who have greater needs than the average Medicaid patient. Testifying before the National Commission on AIDS, Green and Arno cited examples of differential reimbursement in New York City: an intermediate office visit by a new patient for which Blue Cross pays \$78, Medicare \$80, and Medicaid, \$7; chemotherapy infusion, for which Medicare and Blue Cross pay \$70 and Medicaid, \$35; bronchoscopy, Medicare and Blue Cross, \$600, and Medicaid, \$60 (Green and Arno, 1989).

Some States have modified Medicaid reimbursement to respond to these problems. For example, New York and New Jersey have introduced new AIDS diagnosis-related groups (DRGs) for reimbursement of hospital inpatient care. New York has also developed enhanced outpatient rates for AIDS patients at AIDS resource center hospitals and restructured home health payments so AIDS patients can receive more time per visit. New Jersey has an enhanced Medicaid nursing home rate in an AIDS nursing home unit that opened in 1988. Medi-Cal of California pays a higher capitation rate for diagnosed AIDS cases enrolled in a health maintenance organization and Wisconsin has received HCFA approval for special rates to hospital subacute care units treating AIDS patients (Wooldridge, Bilheimer, and Baily, 1989).

This modified-reimbursement strategy is only available, however, when higher rates for AIDS patients can be reasonably related to PWA need for more extensive services. Otherwise, Federal regulations prohibit States from enacting diagnosis-specific Medicaid policies. Inadequate reimbursement rates would have to be increased for all diagnoses, not just AIDS, a costly alternative in a time of tight State budgets.

The geographic concentration of the epidemic and the variability in State Medicaid programs produce an uneven distribution of the financial burden of HIV-related care across State and local governments and health care providers—Medicaid is financed according to a formula in which the relative shares of the State and the Federal government depend on State per capita income. In 14 States, the State portion is shared with local government. New York City, for example, pays 50 percent of the State share for all services except nursing home care, for which it pays 28 percent.

The actual level of Federal Medicaid expenditures for HIV-related care depends on State-level rules on eligibility, service coverage, and reimbursement, as well as the configuration of the epidemic within each State. The two States with the highest cumulative incidence of AIDS (New York and California) have minimum Federal matching rates but relatively extensive programs. Florida and Texas, also in the top five States by incidence, have higher Federal matching rates but much less comprehensive coverage.

Indigent care not covered by Medicaid, or reimbursed by Medicaid at less than full cost, imposes a burden on government, providers, or private charity. Medicaid is often referred to as "the payer of last resort," but this is misleading. The actual payers of last resort are State and local governments, and the private charity provided, often involuntarily, as uncompensated care by private providers.

Because HIV-related expenditures are not spread evenly over the entire country, and because financing for indigent care was already a serious problem when the epidemic began, the financial impact of HIV infection is much greater than it would be otherwise. Public and private entities face difficult choices in the allocation of scarce resources between AIDS patients and others in equal or greater need in cities such as New York, Los Angeles, Newark, and Miami.

As the epidemic continues, Medicaid's share of HIV-related expenditures is likely to increase relative to the shares of other private and public payers—As noted, the epidemic is expected to spread within groups of people who are more likely than average to be poor, to lack private insurance, and to be ineligible for Medicare. Thus, in the absence of major new initiatives to extend private insurance coverage or expand the Medicare program, the burden on Medicaid will increase. Moreover, expenditures will continue to be higher than they would be if AIDS were evenly distributed across the States, given the concentration of the epidemic in some of the States with the most liberal Medicaid programs. Erosion of private insurance coverage among populations traditionally served by the private insurance sector would increase the burden on Medicaid even more.

This conclusion assumes that AIDS-related costs remain the largest part of the lifetime cost of HIV

infection. A major shift in the share of costs attributable to treatment before disability sets in (e.g., long-term treatment with expensive drugs to delay the onset of AIDS) would tend to offset the trends outlined. On the other hand, many women and children would be Medicaid-eligible from the start of their infection. Adult workers might find themselves with fewer resources upon becoming disabled, after years of paying for treatment, and qualify for Medicaid earlier. Finally, if effective treatment to delay the onset of AIDS were available to those who could afford it but not to the poor, there might be pressure to expand Medicaid.

Changes in eligibility, service coverage, reimbursement policy, and the financing formula could significantly increase the impact of the HIV epidemic on Federal Medicaid expenditures—Many proposals have been made to alter the structure of Medicaid to improve its ability to respond to the needs of HIV-infected persons. On eligibility, for example, proposals have been made to simplify the application process, minimize the paperwork required from the medically needy to re-establish eligibility, detach eligibility from the cash grant program, increase the income and asset cutoffs and standardize them across States, require States to have a medically needy program, and allow the poor within certain income limits to purchase Medicaid coverage. Proposals on service coverage include expansion of coverage of existing services and standardization across States, development and inclusion of new services specifically for persons with HIV-related conditions, coverage of selected experimental treatments, and greater use of “managed care” strategies such as case management and enrollment of Medicaid-eligibles in prepaid health plans. Reimbursement changes could take the form of an increase in the general level of reimbursement, or special reimbursement rates for HIV-related care. On financing, proposals have been made to change the matching rate in States with high concentrations of AIDS patients, for AIDS-related expenditures or for all expenditures. It has also been proposed that the matching rate be increased in all States for certain services especially important to AIDS patients.

The budgetary implications of these proposals are obviously substantial. The next section describes a cost model developed to help HCFA understand the impact of policy changes on Medicaid expenditures, as well as the impact of changes in the configuration of the epidemic and of treatment.

Cost estimation methodology

The cost model (Bilheimer, 1989b) was designed to be a simple, microcomputer-based tool to assist policy decisionmaking at the Federal, State, and local levels, rather than a sophisticated stochastic model. Its structure is driven by the epidemiology of the disease and the structure of Medicaid and Medicare. It is deterministic and hierarchical, with a series of breakdowns by epidemiological, service utilization, and payment variables (Table 1).

The specific variables were chosen for policy relevance and data availability. For example, risk group affects both service use and source of financing. Primary clinical

Table 1
Structure of cost estimation model

Epidemiologic categories

Risk group
 Gay/bisexual
 IVDU
 Gay/IVDU
 Other adult
 Pediatric
 Primary clinical manifestation
 KS
 PCP/other infections
 Geographic location

Service use categories

Inpatient
 Hospital days
 Physician visits
 Outpatient visits

Payment source

Medicaid
 Medicare
 Private insurance
 Other

Prevalence categories

Diagnosed and living
 Diagnosed and dying
 Diagnosed previously and living
 Diagnosed previously and dying

NOTES: IVDU is intravenous drug user. KS is Kaposi's Sarcoma. PCP is pneumocystis carinii pneumonia.

SOURCE: (Bilheimer, 1989b.)

manifestation has consequences for service use, disability, and length of life. The clinical breakdown used for the initial cost estimates is between patients presenting with Kaposi's Sarcoma (KS), and those presenting with pneumocystis carinii pneumonia or other infections (PCP/OI), since this seemed to be the important distinction in the first phase of the epidemic. (As the epidemic evolves, the model has the capability to be modified to allow for other breakdowns.) Geographic location is important because of the concentration of cases in certain geographic areas, geographic variations in service use, rates of private insurance, and State Medicaid programs (Bilheimer, 1989c). Breakdown by service type is necessary to capture the effects of shifts in treatment patterns and changes in relative unit costs of services, as well as variations in the extent of third-party coverage for different services.

Considerable attention was given to allowing for changes in the level of a patient's expenditure and source of financing over time. The numbers of importance to HCFA are annual expenditures related to the disease, but these figures depend not only on the number and characteristics of HIV patients on Medicaid or Medicare during a given year but where each is in the course of the disease. For example, early data on service use by PCP/OI patients showed a u-shaped pattern, with high utilization surrounding a diagnosis of AIDS, and then again, at the time of death. Also, a PWA's source of third-party coverage may change over the course of the illness, given the relationship between private employment-related insurance and Medicaid and Medicare.

The model's structure has to yield annual estimates yet be consistent with patterns at the micro level for individual patients, and ideally, allow micro level assumptions about what is happening over time to be incorporated. The solution (inspired by Anne Scitovsky's initial studies of AIDS health care costs) is to divide persons with AIDS into mutually exclusive annual prevalence categories: diagnosed and dying within the year, diagnosed within the year and alive at the end of the year, diagnosed in a previous year and alive all year, and diagnosed in a previous year and dying during the year. A mathematical algorithm is used to generate prevalence numbers by State of residence, risk group, and diagnosis group for each of these four prevalence categories from predictions of incidence by State and probabilities of survival by risk group, diagnosis group, and State (obtained from other research).

For each prevalence category, assumptions are made about service use and source of payment. Service utilization rates are then multiplied by the number of individuals in each diagnostic and prevalence category to obtain estimates of total service utilization disaggregated by type of payer. Multiplying these estimates by cost per unit of service produces aggregate cost figures for each payer type. The geographic variable is incorporated by running the model separately for each geographic area.

In the model, it is assumed that service use is independent of payer, an unrealistic assumption, since the availability and structure of third-party coverage is likely

to affect the use of services. At this point, the data are not good enough to justify more disaggregated assumptions, but when data become available, they can be incorporated by simply running the whole model separately for each payer. Running the model repeatedly is not cumbersome, because the model is set up on a personal computer, data entry is simple, and the model runs relatively quickly. This means that additional disaggregation and separate breakouts of this kind can be done even though they are not built into the basic model run.

In its current form, the model can be used to examine, albeit crudely, the implications of alternative scenarios about the course of the epidemic, treatment patterns, and financing. To do this, the dimensions of the scenarios need only be translated into quantitative assumptions about the variables in the model.

To illustrate this process, the model was used to estimate Medicaid expenditures for California, using California data as a basis for assumptions on incidence and prevalence, service use, cost, and payer distribution. The results of several alternative scenarios are given here. The assumptions and results are explained more fully in Bilheimer (1989c) and for illustrations of the use of the cost model to explore Medicare costs refer to Langwell (1989).

The baseline estimate of the cost of hospital and physician care for AIDS to the Medicaid program in California in 1991 was \$118.1 million (Tables 2 and 3).

Table 2
Baseline assumptions for estimates of Medicaid service utilization and cost: California, 1991

Risk group	Total adult cases ¹	Risk group diagnosed with KS ¹	Diagnoses and living ¹	Diagnosed and dying ¹	Diagnosed previously and living ¹	Diagnosed previously and dying ¹	Total ¹	Number of cases eligible ¹
	Percent							
Total	—	—	38.2	15.1	20.7	26.0	100.0	—
Gay/bisexual men	81.1	18.6	31.0	12.2	17.0	21.1	61.2	30
Gay IV drug users	10.2	19.4	3.8	1.5	2.1	2.6	10.0	60
Heterosexual IV drug users	2.6	4.1	1.1	0.5	0.5	0.8	2.9	60
Other adults	26.0	23.3	2.2	0.9	1.1	1.6	5.8	30

¹Based on total number of projected AIDS cases in California for 1991 = 24,200.

²Pediatric cases were not included because the number of cases in California was very small.

NOTES: AIDS is acquired immunodeficiency syndrome. IV is intravenous. KS is Kaposi's Sarcoma.

SOURCE: (Bilheimer, 1989.)

Table 3
Baseline estimates of service utilization and cost, by Medicaid eligible persons with acquired immunodeficiency syndrome: California, 1991

Type of care	Diagnosed and living	Diagnosed and dying	Diagnosed previously and living	Diagnosed previously and dying	Total	Unit cost	Total cost in thousands
Total	—	—	—	—	—	—	\$118,130
Inpatient days	37,000	30,000	29,000	51,000	146,000	\$630	91,980
Inpatient physician visits	47,000	35,000	34,000	60,000	177,000	\$50	8,850
Outpatient physician visits	90,000	20,000	27,000	36,000	173,000	\$100	17,300

¹Medicaid assumed to pay 70 percent of total cost of \$900.

SOURCE: (Bilheimer, 1989c.)

Table 4
Medicaid service utilization and cost with 1 year increase in median survival between 1986 and 1991: California, 1991

Type of care	Diagnosed and living		Diagnosed and dying		Diagnosed previously and living		Diagnosed previously and dying		Total		Unit cost	Total cost in thousands
	Number	Percent change	Number	Percent change	Number	Percent change	Number	Percent change	Number	Percent change		
Total	—	—	—	—	—	—	—	—	—	—		\$146,860
Inpatient days	44,000	+19	17,000	-44	76,000	+167	45,000	-11	182,000	+25	\$630	114,660
Inpatient physician visits	56,000	+19	20,000	-44	91,000	+167	54,000	-11	220,000	+24	\$50	11,000
Outpatient physician visits	108,000	+17	11,000	-44	64,000	+140	32,000	-11	212,000	+23	\$100	21,200

SOURCE: (Bilheimer, 1989c).

Table 5
Medicaid service utilization and cost with 50 percent of dying non-IV drug users being Medicaid eligible: California, 1991

Type of care	Diagnosed and living		Diagnosed and dying		Diagnosed previously and living		Diagnosed previously and dying		Total		Unit cost	Total cost in thousands
	Number	Percent change	Number	Percent change	Number	Percent change	Number	Percent change	Number	Percent change		
Total	—	—	—	—	—	—	—	—	—	—		\$129,020
Inpatient days	24,000	-36	45,000	+51	18,000	-36	77,000	+51	164,000	+12	\$630	103,320
Inpatient physician visits	30,000	-36	53,000	+51	22,000	-36	91,000	+51	196,000	+11	\$50	9,800
Outpatient physician visits	58,000	-36	31,000	+51	17,000	-36	54,000	+51	159,000	-8	\$100	15,900

SOURCE: (Bilheimer, 1989c).

In this baseline case, 30 percent of non-IV drug-using PWAs were assumed to be eligible for Medicaid, rising to 60 percent for the subgroup of IV drug users, with the percentage eligible constant across prevalence groups. Medicaid was assumed to reimburse 70 percent of the assumed unit cost of hospital care and 100 percent of inpatient and outpatient physician visits. The median survival times assumed were 16 months and 9 months for KS and PCP/OI respectively (Bacchetti et al., 1988).

The effects of changing individual assumptions were then examined. For example, a 1-year increase in the median survival probability raised costs to \$146.9 million, or 24 percent over baseline, largely as a result of the increased numbers of patients in the category "alive all year" (Table 4).

The baseline case assumed a constant Medicaid eligibility rate across prevalence categories. This is unrealistic, since it is likely that many PWAs who are privately insured at diagnosis eventually become impoverished and die on Medicaid. The implications of assuming a higher percentage of dying patients covered under Medicaid compared with other prevalence categories are shown in Table 5. If the overall 30-percent eligibility rate among non-IV drug-using adults represented a 50 percent rate for dying patients, with correspondingly lower rates for the other prevalence categories, there would be an overall increase in cost of 9 percent. In this scenario, inpatient utilization increases but is partially offset by a decrease in outpatient utilization.

The implications of changes in patterns of service use can be explored. For example, the effects of assuming intensive use of in-home services by dying patients, provided through the market (rather than by volunteers) and reimbursed by Medicaid are shown in Table 6. Patients were assumed to use in-home services for an average of 30 days (a conservative estimate) at an average daily rate of 0.54 hour for nursing and counseling and 4.76 hours for attendant care. Daily use in hours was derived from the experience with dying patients in a Los Angeles study (Little, et al., 1988). Inpatient utilization was assumed to be unchanged. These assumptions add 55,000 hours of nursing and counseling and 483,000 attendant care hours to utilization in the baseline model, for an additional cost of \$1.6 million and \$2.9 million respectively. Total cost of all services for the dying becomes \$65.7 million.

Table 6
Service utilization by dying Medicaid eligible persons with acquired immunodeficiency syndrome with 30 days of intensive in-home services: California, 1991

Type of care	Diagnosed and dying	Diagnosed previously and dying	All dying patients
Inpatient days	30,000	51,000	81,000
Inpatient physician visits	35,000	60,000	95,000
Outpatient physician visits	20,000	36,000	56,000
In-home nursing and counselling hours	20,000	35,000	55,000
Attendant care hours	177,000	305,000	483,000

SOURCE: (Bilheimer, 1989c.)

A number of assumptions can easily be combined into a single scenario. The effects of assuming a higher Medicaid proportion among dying patients, intensive in-home service use and reduced inpatient utilization among dying patients, and an increase in life expectation are shown in Table 7. Inpatient utilization by the dying was assumed to be reduced by one-third; the other assumptions were as in the previous scenarios. Under these assumptions, the total cost for all services for the dying falls to \$55.2 million, 16 percent below the cost for this group in the previous scenario.

Since the data were limited, it was necessary to make a number of arbitrary assumptions to complete the model. The estimates should be considered illustrations only, with relative changes from one scenario to another of more interest than absolute levels. Nevertheless, they show how policymakers can take the few data they have, combine them with their best guesses about variables for which data are absent, make rough estimates of costs, and test the sensitivity of their estimates to variations in the data and assumptions. The examples show that the cost implications of the epidemic for Medicaid are significant, and sensitive to variations in the parameters in the model.

Conclusions

The HIV epidemic has created a new and expanding group of chronically ill persons with unusually complex

Table 7
Service utilization by dying Medicaid eligible persons with acquired immunodeficiency syndrome with 30 days of intensive in-home services, 50 percent Medicaid eligibility among non-IV drug users and 1 year increase in median probability of survival, and one-third reduction in inpatient utilization: California, 1991

Type of care	Diagnosed and dying		Diagnosed previously and dying		All dying patients	
	Number	Percent change from baseline	Number	Percent change from baseline	Number	Percent change from baseline
Inpatient days	17,000	-43	46,000	-10	63,000	-22
Inpatient physician visits	20,000	-43	54,000	-10	74,000	-22
Outpatient physician visits	17,000	-15	48,000	+34	65,000	+17
In-home nursing and counselling hours	17,000	-15	47,000	+35	64,000	+16
Attendant care	150,000	-15	412,000	+35	562,000	+16

SOURCE: (Bilheimer, 1989c.)

medical and social needs. Responding to these needs is an extraordinary challenge for the American health care financing and delivery system.

The challenge is especially great for the Medicaid program, given the role it plays now and will continue to play as a major source of payment for HIV-related health care. Much is already being done at the State and Federal level to use Medicaid creatively to help those affected by the epidemic. More will have to be done in the future, as the epidemic continues to spread among the poor and uninsured.

In this article, we have reviewed the disease, current sources of payment for HIV-related health care, and structural features of the financing system that determine Medicaid's share of the burden. Issues of Medicaid eligibility, service coverage and use, and reimbursement have been explored in the context of the needs of the HIV-infected population.

We have also described a methodology for estimating HIV-related Medicaid expenditures, and illustrated how it can be used by Medicaid administrators as they plan for the future. Given data limitations, the cost model is a very simple one. Nevertheless, the process of developing and using such a model clarifies the features of the epidemic and of Medicaid that are most important, highlights the need for better data, and serves as a guide for setting data collection priorities.

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