A RAND NOTE

The Costs of Treating AIDS under Medicaid: 1986-1991

Anthony Pascal

May 1987

RAND

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PREFACE

This Note was prepared for the RAND/UCLA Center for Health Care Financing Policy Studies, operating under a cooperative agreement with the Health Care Financing Administration, U.S. Department of Health and Human Services. It is intended to inform policymakers and other interested persons about the impending costs of treating AIDS (Acquired Immunodeficiency Syndrome) patients and about the portion of those costs likely to fall on the Medicaid program.

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SUMMARY

A large share of the rapidly escalating costs for treating victims of the AIDS epidemic will fall on the Medicaid program. Reported here are the results of a five month exploratory research effort, using available information, that attempted to estimate these costs. The findings contained in this Note are only best guesses given current knowledge, not definitive answers.

The research concentrated on people meeting the Centers for Disease Control (Public Health Service) definition of the disease. They become eligible for Medicaid reimbursement because, under current policy, AIDS has been "strongly associated" with federally defined disability. Victims of AIDS Related Complex (ARC) and some other impairments associated with AIDS are usually excluded, at least in the early stages of illness.

Using the Public Health Service forecast as a base, it is estimated that 220,000 cases (weighted for the periodicity of AIDS costs) will require treatment between 1986 and 1991. The PHS figure is now thought by many to be too low, particularly because it employs a very conservative estimate of HIV (Human Immunodeficiency Virus) incubation or latency, which determines how many seropositives convert to symptomatic AIDS over a period of time. Others think that underreporting of AIDS cases is even more egregious than the official corrections would suggest and that the extent of heterosexual transmission has been underestimated. Thus, although 220,000 cases might serve as a low-range estimate, case load numbers of 400,000 and 750,000 in 1986-1991 are more credible mid- and high-range estimates.

It is necessary to project the shares of case load accounted for by various patient groups (often called risk groups), because they vary in initial health and insurance coverage, and diagnoses, because each requires different treatment. Such variations have distinct cost implications, particularly for Medicaid. Patient group share trends show increasing proportions of IV (intravenous) drug users and the heterosexuals they infect (who may then infect others) and declining

proportions of homosexual/bisexual males. Cancers of the soft tissue will decline, relatively, as an associated pathology whereas pulmonary infections and neurological impairments will increase.

AIDS patients qualify for Medicaid when they meet state income and resource limitations. Since most cease earning income and have only modest assets, use of Medicaid depends largely on the adequacy of private health insurance coverage. A substantial fraction of patients have no coverage because they are unemployed; another large fraction may lose coverage because of the gaps in continuation guarantees under the Consolidated Budget Reconciliation Act of 1986 (COBRA), which improves the insurance situation only for members of large group health plans; others may exhaust these COBRA protections. Employer and insurance company discrimination against actual or potential AIDS patients threatens to deprive some victims of coverage. Public hospitals, the treatment site for a disproportionate fraction of patients, are, as time goes on, likely to qualify an increasing number of them for Medicaid.

AIDS ranks near the top of the list of major impairments in terms of average lifetime medical costs. Published estimates of average lifetime treatment costs for AIDS patients range between $70,000 and $150,000. The variation is due largely to the differences in hospitalization periods for AIDS treatment, for which there is no standard medical model. Extension of the low-cost case management model to places outside San Francisco, which may not be feasible, would substantially lower average costs. In some high-impact communities, AIDS could force the construction of new skilled nursing facilities or, less likely, new hospitals.

Medical interventions--e.g, azidothymidine (AZT) and other therapies--promise lower per period treatment expenditures but may raise lifetime costs by increasing the survival rate. AZT does tend to delay access to Medicaid, since it helps keep people at work.[1]

Policy changes would likely have major cost consequences. For example, widening the official definition of AIDS would raise Medicaid costs; ending automatic disability status for victims would lower them.

[1]The development of a vaccine would have little effect on expected treatment costs over the 1986-1991 period.

Successful promulgation of the case management approach would reduce treatment costs. Current Medicaid reimbursement policies are thought to tilt treatment toward hospitalization. Pressure to raise reimbursement rates also seems likely. The virus's long incubation period and growing life expectancies mean, under current policies, more AIDS patients for Medicare over time. The overall cost consequences of a diversion from Medicaid to Medicare are as yet unpredictable.

The interplay of pathology, treatment model, and the personal finances of patients have important implications for total and Medicaid treatment costs. COBRA, for example, works to relieve Medicaid of the heavy early expenses for AIDS treatment in the case of protected patients.

Combining assumptions as to case load, Medicaid eligibility, average treatment costs, and Medicaid reimbursement rates yields a range of estimate for cumulative Medicaid costs in 1986-1991. The intermediate estimate amounts to about $10 billion, although the most optimistic string of assumptions would yield an estimate as low as $2 billion and the most pessimistic would produce an estimate as high as $47 billion. The intermediate estimate for total national medical costs over this period is about $38 billion, with corresponding extreme estimates of $15 billion and $113 billion. Using the intermediate estimates, AIDS will account for about 1 percent of total national spending on health and about 3 percent of Medicaid program costs. If the most pessimistic scenario comes to pass, AIDS spending will absorb 13 percent of Medicaid dollars.

Important questions remain unanswered. How will cost burdens be shared among individuals, private hospitals, health maintenance organizations, insurance companies, local governments, the states, and the federal government? Will access to appropriate care be equitable? Studies in representative communities on actual cohorts of AIDS patients, combining retrospective and real time data collection, promise to produce highly reliable cost estimates and will help resolve such questions.

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I. FRAMING THE ISSUES

The costs of treating victims of the epidemic known as AIDS--Acquired Immune Deficiency Syndrome--are mounting relentlessly. Many of these costs will fall upon Medicaid, a state program with federal matching designed to cover medical expenses for the dependent and indigent. This Note reviews current knowledge of the disease, its incidence and prevalence, and the characteristics of those stricken to estimate the costs of treating AIDS patients under Medicaid during the next five years.

The study that led to this Note was an abbreviated and exploratory effort, budgeted at less than $32,000. During its five month course no primary research was undertaken. Instead the author reviewed the published and unpublished literature, interviewed knowledgeable analysts, clinicians, and observers, and analyzed available statistics to estimate what AIDS might cost the Medicaid program.

Because there still remain vast areas of uncertainty with respect to epidemiology, the demographics of current and potential patient groups, the effects of medical interventions, appropriate treatment models, and the course of policy, all estimates presented here must be considered tentative and preliminary; best guesses, as it were. Only an analysis that tracks samples of AIDS patients, noting the patterns of costs incurred over time by payment source, can produce definitive estimates. Section IX of this Note presents some guidelines for such a new study.

To assess the costs of AIDS to Medicaid, several questions must be answered:

- How many people will have contracted AIDS, as officially defined, over the period 1986-1991?
- How many with AIDS diagnoses will qualify for coverage under state Medicaid programs?

- How much will it cost Medicaid to treat an AIDS patient, from diagnosis to death, over this time period?
- What policy changes will most affect the cost burden on Medicaid for AIDS treatment?

The sections of this Note explore these questions and some important subsidiary topics such as private insurance coverage for AIDS victims, the potential effects of medical interventions on costs, the interplay of clinical, treatment, and financial considerations over the course of the disease, and necessary further research.

II. ESTIMATING THE NUMBER OF AIDS CASES

CLINICAL EVENTS

In reality, AIDS constitutes a continuum. People become infected as a result of exposure to the blood, semen, or other bodily fluids of a carrier of the HIV (Human Immunodeficiency Virus) infection.[1] Transmission into the blood stream is thought to be the most common, and, by some, the only means of exposure. Months or years may go by before any symptoms appear. Early symptoms are usually minor--fatigue, night sweats, thrush, lymph gland swelling, diarrhea, and the like. Immune system deterioration often follows but sometime precedes these early symptoms. Opportunistic infections in the respiratory system, such as *pneumocystic carinii* pneumonia (PCP), may ensue. Kaposi's sarcoma (KS), a rare form of soft tissue cancer, may appear. There is increasing evidence that the virus eventually passes through to the brain of the victim, inducing damage to the central nervous system (CNS) and various forms of neurological dysfunction and impairment, including dementia.

OFFICIAL DIAGNOSIS

For the purposes of the current analysis only people with "officially defined" AIDS need be considered. This condition is deemed to "equal" the Title II Listing of Impairments, although AIDS is not yet actually on the Listing. Thus an individual who has CDC-defined AIDS and is not working applies for disability under Title II (Disability Income) or Title XV (Supplemental Security Income) and disability status will be granted immediately.[2]

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[1]In fact it is as yet unclear whether there is a single HIV virus, or several. Some researchers have concluded that a second virus HIV-II, found in Central Africa, is an additional deadly agent; others argue that, on the contrary, HIV-II works to immunize against HIV.

[2]The source is a memo to the author from an official of the Health Care Financing Administration. The granting of presumptive disability confers SSI benefits only for three months pending formal disability determination.

Of course people eligible for Medicaid on other grounds--e.g., coverage under Aid to Families with Dependent Children (AFDC) or who are declared medically indigent--may fall victim to the disease and receive Medicaid reimbursement for medical expenses without an official AIDS diagnosis. The numbers of such people is thought to be quite small at present but may grow substantially in the future because of increasing seroprevalence among intravenous (IV) drug users, thereby inflating any numbers developed below in this Note.

The Centers for Disease Control (CDC) of the Public Health Service, U.S. Department of Health and Human Services, define AIDS as suppression of the immune system with the presence of one or more opportunistic infections. To date, people who present the symptoms that precede the onset of immune-system-suppression-plus-opportunistic- infection, a condition often labled AIDS Related Complex or ARC, or who evidence neurological deficit but no opportunistic infections, are not officially diagnosed as AIDS victims.[3]

CASE LOAD PROJECTIONS

The range of currently available projections of the number of people who will develop AIDS between now and the early 1990s varies widely. The most authoritative published estimates were presented at the Coolfont conference, organized by the Public Health Service, earlier this year. (See Public Health Service, 1986.) A mid-range estimate of 270,000 cases, cumulative, by 1991 was reported at Coolfont. The predicted numbers by patient group (adjusted for overlaps) would be roughly as follows:

- Homosexual and bisexual men--190,000

[3]The HCFA official cited in the preceding footnote also reports that "victims of ARC and other AIDS-related disorders are not necessarily excluded [from Medicaid]; if their impairments are severe enough...they may be found disabled through the normal sequential evaluation process." There are no available data on how frequently the latter occurs.

- Intravenous drug users--55,000
- Heterosexual men and women--24,000
- Victims infected perinatally or through contaminated blood or blood products--2,000[4]

In the appendix is shown the method whereby 270,000 cumulative cases yields a weighted estimate of 220,000 cases for which treatment will be rendered during the 1986-1991 time span. This smaller number reflects adjustments for treatment expenses that do not occur within this period.

According to recent research, the Coolfont numbers now look much too low. First, evidence suggests that the fraction of seropositives who can be expected to develop AIDS symptoms is considerably higher than the 5 to 19 percent on which the Coolfont report was based. Clinical evidence indicates an increasing hazard function, meaning that, for seropositives, the probability of illness increases with each passing year.[5] Monotonic declines in T-cell function are noted for virtually all seropositives tested and there are very few cases of seropositive reversal on record.

A number of clinical studies have pointed to a higher case rate among HIV-positive individuals. Some observers now fear that 75 percent of those infected will, over a seven year period, develop full-scale AIDS, and that 50 percent will do so in five years. (See Johnstone, 1986, reporting on work by E. B. Helm of the Center for Internal Medicine at the University of Frankfort, published in the *Deutsche Medizinische Wochenschrift*, 1986, Vol. 32, p. 32.) The Institute of Medicine report (1986) suggests on pages 85 and 94 a high-side estimate of the conversion rate of 50 percent over 10 years. (See also Blattner et al., 1986; De Grutolla et al., 1986; Goedert et al., 1986; and "Who Will Get AIDS," 1986, for other high estimates of the rate of conversion to frank AIDS.)

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[4]The Institute of Medicine (1986, p. 8) projects different figures: 7,000 heterosexuals and 3,000 pediatric cases.

[5]The hazard function in this case is the rate of symptomatic AIDS at time t for those who have had no symptoms up to time t.

As many as 1.5 million Americans may be infected with the HIV virus, according to Institute of Medicine (1986, p. 91). The combination of extensive seropositivity and high conversion rates means a much higher case load than previously projected.

Second, researchers now recognize that underreporting of the numbers infected, the numbers with AIDS symptoms, and the numbers dying of AIDS is widespread. The 17 percent underreporting rate found by the California Department of Health Services study published in early 1986 (Kizer et al., 1986) may itself be an underestimate.[6]

Third, evidence mounts pointing to the efficiency of heterosexual transmission and increasing prevalence of HIV seropositivity in some heterosexual populations. For example, comparisons of the seropositive proportion for military service applicants in the greater New York area shows that the rate for women, six in a thousand, is almost as high as it is for men, eight in a thousand. (See Barnes, 1986a.) Data from Central and East Africa, scanty as they are, indicate as many infected women as men. ("Is Nobody Safe...," 1986.) AIDS, it may well turn out, is as infectious as any other sexually transmitted disease.

For such reasons, this Note is based on the conclusion that the Coolfont-based figure of 220,000 cumulative cases (weighted for treatment cost) should be considered a lower-bound estimate. An intermediate estimate for cumulative cases by 1991 would be closer to 400,000. The most pessimistic scenario would generate 750,000 cases between now and 1991. (See Sec. VII below and the appendix for a discussion of methodology.)

None of these estimates take into account the development of a vaccine against AIDS in this time period. A vaccine seems a long way off and the vast majority of the people who will present AIDS symptoms over the next five years have already been infected. However, therapies could emerge that lower the probability of full-blown AIDS among seropositives.

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[6]Personal communication from Andrew Moss, public health researcher at the University of California, San Francisco.

Distribution Across Patient Groups[7]

The distribution of the disease across patient groups is also expected to shift. (Sections III and IV below discuss why different patient groups impose different costs on Medicaid.) The rate of increase of both infection and disease among homosexual/bisexual men in San Francisco has already slowed appreciably but the disease is increasingly prevalent among drug users there. The drug user HIV population had been concentrated in the New York/New Jersey metropolitan area because that region contains a large fraction of the nation's heroin addicts and because the infection seems to have occurred there first. More than 50 percent appear to be infected. But if the recent San Francisco figures are representative (10 to 20 percent seroprevalence), large numbers of IV drug users across the country will be become infected. Many will eventually be stricken with AIDS.

Drug users have proven to be the chief source of infection among women. Consequently we can expect to see the proportion of AIDS patients composed of gay men peak in most places and the proportion composed of heterosexuals, whether or not they themselves inject drugs intravenously, expand. The number of children with perinatal AIDS infections will also grow as a result.

Some media reports seem to indicate that in populations with high rates of infection, such as the San Francisco and New York gay communities, sexual practices have shifted radically, slowing the spread of infection. Whether sexually active heterosexuals have yet adapted to the crisis remains unknown.[8] Assessment needs to be undertaken of both sentinel heterosexual populations (non-IV-drug-using) and gay populations outside San Francisco and New York.

If the HIV test continues to be effective in identifying blood contaminated with the AIDS virus, the fraction of cases made up of transfusees and hemophiliacs will continue to fall. A rapidly mutating virus may produce a different story, however.

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[7]Personal communication from Andrew Moss (see previous footnote) provided data reported in this and the following subsection.

[8]For a negative view of the likelihood of behavioral change, among both gays and straights see, for example, Leishman (1987).

Distributions Across Pathologies

The shares accounted for by the various AIDS pathologies are also shifting. (Section V below discusses how different pathologies have different treatment cost consequences.) Relatively fewer cases of KS and relatively more cases of PCP and other opportunistic infections are showing up in San Francisco.[9] This shift is partly due to the change in patient (i.e., risk) group proportions--gays have until recently been more likely to contract the former and drug users the latter--but may also indicate a mutation in the virus or a change in the time pattern of some as yet unidentified co-factor. Nobody knows.

It does seem clear that more and more patients with dementia, neurological impairment, and other kinds of cancers, such as lymphoma and leukemia, will seek treatment. Medicaid eligibility trends, discussed in the next section, will reflect these phenomena.

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[9]Currently, 60 percent of U.S. AIDS patients suffer from PCP, according to Barnes (1986b). In the Kizer et al. study based on 1983-1985 data from California, PCP was the cause of death in only 30 percent of the cases.

III. FORECASTING MEDICAID QUALIFICATION EXPERIENCE FOR AIDS PATIENTS

ELIGIBILITY CRITERIA

A sizable portion of AIDS patients are likely to end up on Medicaid. To qualify, a patient must establish disability status under current federal guidelines and must then meet the eligibility requirements of the state of residence. The former is virtually automatic at present for anyone meeting the official CDC criteria for AIDS, since presumptive disability for all victims is the current policy.[1]

State requirements typically impose maxima on income and assets, net of equity in own home. At present, the majority of AIDS patients leave the labor force and for most that means the cessation of income.[2]

Although there are no available statistics on the asset positions of AIDS victims, a recent publication in the Current Population Reports series does illuminate the wealth status of male householders (men living without spouses) by age. For such males under 55, the average value of net worth, exclusive of equity in own home, is estimated to be only $5,121.[3] Even though there is evidence that homosexual men have a somewhat higher socioeconomic status than the population in general (see below in Sec. IV) and thus might be expected to have accumulated more wealth, it is unlikely that, on average, their net worth is sufficiently

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[1]See statement of Elmer Smith, Health Care Financing Administration, U.S. Department of Health and Human Services, in U.S. Congress (1985, pp. 343-357).

[2]A CDC study found that 86 percent of AIDS patients had stopped working. (See Hardy et al., 1986.)

[3]Net worth by age group and type of assets for male householders is given in U.S. Bureau of the Census (1986a, p. 6). Net worth is the difference between all assets--including cash, bank accounts, securities, equity in real estate and businesses, motor vehicles, etc.--and all liabilities. In making the above estimate, weights for the various age groups of AIDS patients were derived from Kizer et al. (1986, pp. 7-11), where the patient base was primarily homosexual/bisexual men.

high to prevent them spending down within a few months of contracting the illness. And, AIDS patients from the drug user population are likely to have very few assets at all. Finally, with the spread of knowledge about eligibility requirements and the so far inevitable course of the disease, more and more patients may opt to disperse or exhaust their assets in anticipation of Medicaid coverage. (Clearly, those with adequate private health insurance coverage are unlikely to avail themselves of Medicaid. Section IV explores insurance issues.)

Public Hospitals

A large fraction of AIDS patients are treated in public hospitals. Kizer et al. (1986), for example, found that almost two thirds of the cases in California were in county institutions (p. 24). (Some states of course have few public hospitals; some states have none.) At San Francisco General Hospital, for example, where the history of AIDS treatment is relatively venerable, about six in ten patients were found to be on Medicaid.[4] As the AIDS case loads grow and as public hospital administrators outside New York and San Francisco learn the rules for qualifying their patients, we can expect to see larger and larger fractions of those patients receiving Medicaid reimbursement.

There is some evidence that nonprofit and even for-profit hospitals are following suit. Administrators in these institutions are beginning to press for a more direct link with the Medicaid eligibility process.[5]

MEDICAID COVERAGE OVER TIME

We find, then, that shares accounted for by different patient groups are changing. Patients are spending down their assets and exhausting health insurance protection. Public hospitals are learning how to qualify AIDS patients for Medicaid. Such considerations account for the following trend:

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[4]Personal communication from Ann Scitovsky based on her cost study data. (See Scitovsky et al., 1986.)

[5]Personal communication from Dr. Georges Vernez, former Executive Deputy Administrator for Program Operations of the New York City Human Resources Administration.

- An early study of victims in California showed 12 percent of those dying of AIDS on Medicaid (Kizer et al., 1986, p. 51).
- Stephen Gamble, President of the Hospital Council of Southern California, testified in the November 1985 House hearings on the AIDS epidemic that 23 percent of patients were on MediCal in a survey of Southern California hospitals conducted by his organization. (See U.S. Congress, 1985, p. 247.)
- A recent personal communication from Gary McHolland, actuary in the California Department of Health Service and a coauthor of Kizer et al. (1986) revealed that 25-30 percent of AIDS patients were on Medicaid at death in a later analysis of California MediCal (the state's Medicaid program) records.
- Luehrs et al. (1986, pp. 21, 24) reported fractions on Medicaid in the range of 30-40 percent.
- Brent Nance, an insurance specialist with AIDS Project Los Angeles, testified that his group believes that more than 60 percent of the area's AIDS patients will qualify for Medicaid coverage. (See U.S. Congress, 1985, p. 333.)
- At these same hearings Jo Ivey Boufford, acting President of the New York City Health and Hospitals Corporation, stated in testimony that 65 percent of New York City patients were Medicaid recipients.[6] (See U.S. Congress, 1985, p. 262.)

As the share of AIDS patients originating in the IV drug user population, and their mates and children, continues to grow, so will the proportion of patients who can qualify for Medicaid reimbursement. Prostitutes, who often contract the infection from shared needles or from drug user sexual partners, are thought by some to constitute a second important source of the disease in the heterosexual population. (See "Is Nobody Safe...," 1986, and, on the efficiency of heterosexual transmission, Fischl et al., 1987.) If a disproportionate share of the infected clients of prostitutes are low income, the cost consequences for Medicaid will loom even larger.

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[6]The high New York figure is in part a result of the relatively liberal welfare eligibility policies there and the fact that a large proportion of the city's case load are IV drug users.

However, it must be noted that the situation with respect to private health insurance may be improving in some respects--constituting a counterweight to the growing burden on Medicaid--thanks to the recent enactment of the Consolidated Omnibus Budget Reconciliation Act (COBRA), adopted April 7, 1986. This and other issues are discussed in the next section.

IV. ASSESSING THE EFFECTS OF PRIVATE INSURANCE COVERAGE

PATIENTS WITHOUT INSURANCE COVERAGE

Sixteen percent of Americans have no health insurance coverage; 23 percent of poor Americans have no such coverage. (See Dallek and Dorn, 1986.) A large group of AIDS patients--the drug users and their associates in particular--are likely to find themselves in this situation. And, a significant fraction of AIDS patients are young adults. According to Kizer et al. (1986), about 11 percent of California AIDS victims are between 17.5 and 28.5 years old. Many of these young people will not yet have secured permanent employment and consequently may have no health insurance coverage.[1]

Where state antidiscrimination enforcement is lax, potential AIDS patients may find themselves frozen out of the job market as employers seek to avoid health insurance premium escalation. Individual health policies will be more expensive or more difficult to acquire for those thought likely to fall into the recognized risk groups. The recent ruling by the U.S. Department of Justice sanctioning dismissals of AIDS victims[2] may worsen the situation for discharged employees enrolled in plans that lack continuation or conversion guarantees.

Increasingly, complaints have been voiced over gaps in insurance coverage for actual and potential AIDS patients. In California, the District of Columbia, Michigan, and Wisconsin insurance companies are proscribed from using the results of antibody tests on applicants' blood

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[1]Suggestive is the fact that of all Americans aged 18-24, almost 22 percent had no health insurance coverage, whereas of the age group 25-54 about 12 percent had no coverage, according to Kasper et al. (n.d.).

[2]Memorandum for Ronald E. Robertson, General Counsel, U.S. Department of Health and Human Services, from Charles J. Cooper, Assistant Attorney General, Office of Legal Counsel, U.S. Department of Justice, June 20, 1986, states "...we have concluded that an individual's (real or perceived) ability to transmit the disease [AIDS] to others is not a handicap within the meaning of the statute [Rehabilitation Act of 1973, 29 U.S.C. 794] and, therefore, that discrimination on this basis does not fall within section 504 [of the statute]."

as a condition for insurance; in other states there are no such proscriptions. It is alleged that some insurers of individuals and small groups also test applicants directly for immune system impairment (e.g., lymphocyte subsets) or ask them questions about AIDS symptoms, life style, and health history with respect to sexually transmitted diseases in the attempt to screen out those who may someday make claims for treatment of AIDS. Alternatively, insurers may attempt to insert prior condition exclusions into policies. (In general on this topic, see U.S. Congress, 1985, pp. 203ff.)

PATIENTS IN SMALL GROUP PLANS OR WITH INDIVIDUAL POLICIES COMPARED WITH PATIENTS IN LARGE GROUP PLANS

There seems little evidence however that outside insurers of large groups have attempted such screening.[3] However, employers who self-insure under the Employee Retirement Income Security Act (ERISA) usually operate in a less restrictive regulatory environment and may be able to employ such screens in the attempt to protect themselves against high-cost policy holders.[4] Representatives of the insurance industry argue for the legitimacy of screening for AIDS in the case of individual and small group policies.[5] They posit the necessity to protect themselves and their policyholders against the financial consequences of ignoring proper risk group assignment. And even if an AIDS victim had been able to secure an individual or small group policy, he may, having lost his job at the onset of the disease, find himself unable to retain coverage.

COBRA protects members of large group plans. Public Law 99-272[6]

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[3]See the testimony of Mary Nell Lenhard, Vice President of Blue Cross/Blue Shield, in U.S. Congress (1985, p. 290). (The cutoff point for large group policies is generally at the level of 20-25 members.)

[4]Personal communication from Peter Groom, California Department of Insurance.

[5]See, for example, American Council of Life Insurance and Health Insurance Association of America (1985). Karen Clifford, a spokesperson for these groups, stated at a conference of state insurance commissioners in Orlando, Florida, that 10 percent of all health insurance purchasers have individual policies. (Reported in Reich, 1986).

[6]1000 STAT. 82.

guarantees that any employee terminated other than for gross misconduct can continue his health insurance coverage for 18 months at a premium of no more than 102 percent of what it would have cost his employer to cover him. This protection applies to both third-party-insured and self-insured plans with 20 or more members that began after July 1, 1986.

Lacking this COBRA shield, workers with individual or small group policies appear particularly vulnerable to coverage failure and are thus more likely to succeed to Medicaid. Are homosexual/bisexual men disproportionately likely to have such coverage? The answer may well be yes in the case of individual policies; for small group policies the evidence is ambiguous. Table 1 shows the socioeconomic characteristics of residents of "gay" census tracts in Los Angeles, New York City, and San Francisco and compares these characteristics to those of all the residents of these three standard metropolitan statistical areas (SMSAs).

The residents of the selected tracts appear to be almost twice as likely to be self-employed as is the average metropolitan area resident. That finding probably implies a higher fraction with individual health insurance policies. Many believe that the corporate world tends to discriminate against homosexuals in hiring. (See, for example, Hager, 1986.) This suggests that more gay men are likely to work in small enterprises and thus enroll in small group plans. But the statistics in Table 1 indicate that the residents of the selected tracts have considerably higher educational, occupational, and income attainments than the other residents of these SMSAs. Does that imply that more of them work for large organizations? Only further research can answer that question.[7]

As things now stand, AIDS patients in large group plans can expect 18 months of COBRA protection, covering them for most for the period in which medical bills are accumulating; the current life expectancy of patients diagnosed with AIDS is itself less than 18 months. But medical interventions (see Sec. VI) may soon begin extending the life of victims beyond this period. COBRA provides no guarantees of conversion to

[7]Whether the residents of these selected tracts are representative of all homosexual/bisexual men is not known, of course; neither is it known how representative they are of gays infected with the AIDS virus.

Table 1

CHARACTERISTICS OF A POPULATION WITH EXPECTED FRACTIONS OF SEROPOSITIVES HIGHER THAN NORMAL
(1980)

Characteristics of Residents	Unweighted Averages	
	SMSAs: LA, NY, SF	6 Selected Tracts*
Proportion college graduates in population 25 and over	.21	.42
Proportion of workers employed as:		
Managers and professionals	.28	.45
Technicians, salespersons, and administrators	.35	.37
Service workers	.10	.09
Crafts workers	.11	.09
Unskilled workers	.14	.05
Proportion of workers who are self-employed	.07	.12
Median household income	$17,700	$20,600
Per capita income	8,600	16,800

SOURCES: U.S. Bureau of the Census, 1983a, 1983b, 1983c; in each source, Tables P-1, P-9, P-10, P-11.

*The tracts selected were the two in each SMSA that registered the highest fraction of men over 15 who were single, separated, or divorced in the total tract population. In the three SMSAs together, the average tract had 17 percent in that category; these six tracts averaged 50 percent single, separated, and divorced males over 15. The six tracts also had significantly higher proportions of nonfamily and single person households and smaller households than their SMSAs but about the same fractions of householders under 65. The tracts selected were numbers 7003 and 7005 in the Los Angeles SMSA, 69 and 75 in New York, and 169 and 170 in San Francisco. Not surprisingly, the tracts were found in the communities of West Hollywood, West Greenwich Village, and the Castro, respectively, all known as "gay ghettoes."

individual policies nor any cap on the premiums attached to such conversion polices. Although many could afford the $100-$150 per month cost of the guaranteed continuation coverage, they may find it difficult to meet the $700-$800 per month premiums that conversion policies could well cost.[8]

For those who can obtain but cannot afford conversion policies, it has been suggested that state departments of health might subsidize the premiums. Even a $10,000 per year premium may be cheaper for the states in the long run than bearing full treatment costs in public hospitals or approximately half the cost burden under Medicaid programs.

As yet there has been little attention paid to the potential plight of victims who belong to health maintenance organizations. Smaller HMOs may have inadequate facilities for treating high volumes of AIDS patients yet may be loathe to refer-out patients needing treatment because of the cash drain involved. The high costs of AIDS treatment could soon begin to force HMOs, and eventually even some health insurance carriers, into serious financial difficulties.

Some portion of the AIDS patients who are eligible for treatment by the Veterans Administration choose to undergo care in VA facilities. It is estimated that to date the VA has cared for about 5 percent of all known AIDS cases. ("VA Joins Study...," 1987.) VA treatment is likely to be particularly attractive to the uninsured and inadequately insured. The more who choose the VA, the larger the offset to the Medicaid burden. At present there are no data to indicate how many HIV-positives are veterans or what their insurance situation is.[9]

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[8]Personal communication from Brent Nance, insurance advisor, AIDS Project Los Angeles. Even the continuation coverage could present difficulties for nonworking AIDS patients faced with expenses for housing, food, transportation, and nonreimbursed medical costs.

[9]The fraction of current seropositives who will be treated in Defense Department facilities is likely to be quite low because the services have been screening them out.

V. CALCULATING POTENTIAL COSTS OF TREATMENT

What is the value of the resources expended for treatment of an AIDS patient between diagnosis and death? Here again, the available estimates vary enormously. The variations arise from several sources: the mix of cases studied differ from place to place; the definition of direct costs varies across studies; and most important, there as yet exists no standard treatment model. It has, in fact, been alleged that for those with AIDS, professional decisions on hospital stays and therapies are more likely to depend on the availability of an empty bed or the presence of a third party payor than they are on the requirements of the patient.

TOTAL TREATMENT COSTS

The following estimates indicate the range of diagnosis-to-death direct costs per patient that have been reported:

- By the Medical Director of American Insurance Consultants.....$200,000[1]
- By researchers at the Centers for Disease Control.....$147,000[2]
- By the California Department of Health Services.....$91,000[3]
- By analysts at the Institute for Health Policy Studies, UCSF.....$67,500[4]

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[1]"All direct costs"; based on observations in California. Personal communication from Roy Goodman, M.D.

[2]Hospital costs only; based on first 10,000 AIDS cases in the United States. Hardy et al. (1986, p. 210).

[3]Hospital inpatient charges; 2,860 AIDS cases reported in California by July 30, 1985. Kizer et al. (1986, pp. 19-25).

[4]Midpoint of interval estimate for hospital inpatient and outpatient charges, adjusted for national case mix; experience at San Francisco General Hospital on 445 AIDS cases. Scitovsky et al. (1986, p. 3106).

The first estimate above, by an experienced physician, is based on observation, not on analysis, and may reflect early AIDS treatment experience. The CDC estimate may also reflect the early phases of the illness, when heavy hospital, and particularly intensive care unit (ICU), use was more common. Finally the IHPS estimate is based on experience at San Francisco General Hospital, where an outpatient approach, heavily dependent on volunteer services, has been developed.[5]

A recent study issued by the Minnesota Department of Health used cost figures from the California DHS study.[6] Efforts are now under way in both the New York and New Jersey departments of health to determine costs for treatment of AIDS.[7] Both studies will use billing data on AIDS patients as they progress through the stages of their illness; it is not known whether these efforts will employ comparable definitions and procedures, however.

The full range of analyses done to date reveal remarkably little variation in average daily hospital charges. About $825 per day appears to be typical.[8] Whether or not AIDS patients incur higher than normal hospital expenses per day is still open to question. Kizer et al. (1986) find no such pattern. Jo Ivey Boufford (U.S. Congress, 1985, p. 208) argues that in New York City at least, extra expenses result from the need to isolate AIDS patients and provide more intensive nursing, special equipment, and sterilization.[9] It is also likely that

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[5]Seage et al. (1986) estimated lifetime per-patient cost of medical care at $50,380, using data on 45 AIDS patients from the New England Deaconess Hospital. They state, however, that their figure could underestimate costs because the patients studied "...may have been less ill than the others in the state [Massachusetts]...and some patients may have received care at other sites" (p. 3109).

[6]See Schultz et al. (1986).

[7]Personal communication from Thomas Fanning, Director of Policy Analysis and Management Reports, DMA-PAUR, State of New York, and from George Logusch, Consultant, Division of Medical Assistance and Health Services, State of New Jersey.

[8]See Scitovsky et al. (1986). See also Ann Hardy testimony in U.S. Congress (1985, p. 275).

[9]See also Graham and Ricklefs (1987) on AIDS treatment costs in New York City.

Medicaid's limits on out-of-hospital services and the lack of outpatient service networks in most cities work to raise the total lifetime cost of treating the victims of the disease; they make for longer hospitalization.

AIDS Treatment Models

Most of the difference between the two estimates published in *The Journal of the American Medical Association*--i.e., Hardy et al. (1986) and Scitovsky et al. (1986)--are due to the substantial differences in the average number of days of hospitalization reflected in the databases employed: 168 days compared with 20 days.

The low level of hospitalizations in San Francisco is a result in large part of the evolution there of the so-called "case management" model. In that approach to treatment, hospitalization--particularly in intensive care units--is minimized while outpatient care is stressed. Although not reflected in the Scitovsky et al. (1986) costs, in-home care,[10] hospices, and social, psychological, and homemaker services figure prominently in the case management approach. Proponents believe that case management not only reduces the need for hospitalization, lowering costs, but enhances the quality of life for AIDS victims.

Even though aspects of the low-hospitalization approach, developed in the Bay area by such groups as Shanti and the Hospice of San Francisco, are bound to spread elsewhere,[11] it is an open question as to whether case management, as now practiced, is fully exportable or even sustainable in San Francisco. It depends heavily on the continued participation of unpaid volunteers. (See Arno, 1986, for example.) The city's well-organized gay community has played a major role in making case management work. How soon before the San Francisco pool of volunteers is drained? At what point will volunteers suffer burn out? How likely are cities with smaller and less organized gay communities to

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[10] In-home care, it should be noted, is not necessarily inexpensive: residential intravenous administration of antibiotics may cost as much as $1,500 per week.

[11] Scitovsky and Rice (1987) present some evidence for convergence in approach to treatment across hospitals in various parts of the country.

generate the same commitment? Who will perform such services for the drug-user population and the people they infect? Even if volunteers could be found, would liability considerations lessen their use? And many in the impending case load (i.e., drug users and their associates) will have no proper home in which to administer home care.

Some New York City experience is relevant here. Dr. Georges Vernez, formerly with the New York City Human Resources Administration, concluded that home health care costs can run as much as $30,000 per year for 60 hour a week service using minimum wage employees. New York City was also concerned about extending home care to AIDS patients while denying it to other Medicaid eligibles.[12] Such considerations might well discourage state and local governments from including home care in reimbursable services. The incentive to keep patients in the hospital will then continue.

Cost Trends

Trends in per patient costs for AIDS treatment are ambiguous. Kizer et al. (1986, p. 21) note that average per patient costs were 20 percent higher in 1985-1986 than in 1983-1984. (As time has passed, physicians have learned to diagnose AIDS earlier in the course of the disease, resulting in the inclusion of a larger fraction of patient expenses under the AIDS diagnosis; the Kizer findings may thus be a statistical artifact.) On the other hand, the spread of the case management model or, at least, some elements of it, would work to lower average costs.

The large number of empty hospital beds in the United States makes it unlikely that the AIDS epidemic will stress the nation's hospital capacity except, perhaps, in very high impact communities such as San Francisco and New York and in circumstances more extreme than the scenarios examined below in Sec. VII.[13] Building new hospitals would increase the real costs of AIDS treatment dramatically.

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[12]Personal communication from Dr. Georges Vernez (see above).

[13]However, American Medical, a private hospital chain, plans a new hospital in Texas devoted exclusively to AIDS treatment, according to Shiver (1986). And Steinbrook (1986) presents a pessimistic view of the strain on hospital capacity in San Francisco. Finally, *The Wall Street Journal* reports that in St. Vincent's Hospital in New York City's Greenwich Village, AIDS admissions have helped push the general occupancy rate up to 97 percent and that at Bellevue Hospital AIDS

Extension of the case management approach will also depend on the availability of nursing home facilities, especially in cities lacking volunteers to act as home visitors. To date, these facilities have been reluctant to accept AIDS patients; they anticipate high costs for maintaining them and fear that acceptance of AIDS victims will frighten off their traditional geriatric clientele. Again, if new nursing facilities become necessary, costs will escalate.

Expenses are also dependent on pathology, both because medical needs differ and because life expectancies differ by type of illness. PCP patients who had been surviving, on average, nine months after diagnosis, often use a larger total of medical resources than KS patients who tend to live for 21 months after diagnosis. (See Moss et al., 1984, on life expectancies.) (Some representative cases are discussed below in Sec. VIII.) The unknown future of KS as a presentation mode and the lack of knowledge with respect to pathologies attendant on heterosexual transmission complicate any attempt to forecast pathology/cost interactions.

Costs for Treating AIDS Compared to Costs for Treating Other Major Impairments

AIDS imposes lifetime direct costs comparable with some of the other major impairments. Table 2 contains estimates for several.

The low estimate of AIDS costs reported by Scitovsky et al. (1986) is near the treatment costs for myocardial infarction and auto crash-induced parapalegia for men in the modal age group for AIDS. Digestive system cancers and leukemia in this age group appear to be less expensive to treat than AIDS.[14]

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patients now occupy more than a third of the beds in the internal medicine service (Graham and Ricklefs, 1987).

[14]These figures are offered only for purposes of very rough comparison. Variations in costs included, inflation adjustments, and analytic methodology are obvious.

Table 2

LIFETIME PER PATIENT DIRECT COSTS
FOR SELECTED SERIOUS IMPAIRMENTS

Impairment	Risk Group	Cost
Myocardial Infarction	Men 35-44	$66,837
Cancer of the digestive system	Men 35-44	47,542
Leukemia	Men 35-44	28,636
Parapalegia from auto crash	Total population	68,700

SOURCES: Hartunian et al. (1981, pp. 33, 37, 95, 113, 223, 231, 316); U.S. Department of Commerce (1986); U.S. Bureau of the Census (1986b).

NOTE: For the first three impairments, published present values were converted to actual costs using the discount rate and respective life expectancies given in the source. 1975 dollars were converted to 1986 dollars using the ratio of Consumer Price Index values for medical care. For these impairments direct costs include emergency assistance, initial inpatient hospital care, inpatient physician and surgeon services, vocational and physical rehabilitation, nursing home and home attendant care, drugs, medical supplies and appliances, outpatient medical and surgical care, rehospitalization, home modifications, paramedical and miscellaneous expenses, insurance administration, and legal and court expenses.

MEDICAID-REIMBURSABLE COSTS

Even after a patient qualifies, not all of the costs he incurs are reimbursed by Medicaid. The experience in California--where MediCal has been paying about $500 of the $800 per day hospital costs (Kizer et al., 1986)--appears typical.[15] Overall, about 60-70 percent of inpatient charges appear to be reimbursable under Medicaid. But only about 10

[15]At Bellevue Hospital in New York City, however, Medicaid reimbursement appear to equal 75 percent of the $800 per day cost, according to Graham and Ricklefs (1987).

percent of the MediCal reimbursements have gone for outpatient services; the case management approach would seem to require a larger share for this type of treatment.

Hospitals may soon begin to complain about the low fraction of charges reimbursed for AIDS patients; already, preferred panel hospitals, heretofore content to accept $450 per day from MediCal, are pressuring for higher reimbursements for their AIDS case loads.[16]

Many services that outpatients need are not reimbursable or are reimbursable only with strict limitations. Hospice of San Francisco, for instance, provides a range of at-home services to AIDS victims but claims that on average only about 15 percent of its costs are reimbursed through MediCal.[17] Costs incurred in skilled nursing facilities are reimbursable at percentages comparable to those for hospitalization but custodial nursing care expenses and homemaker services appear to be nonreimbursable. In general, psychiatric and social worker services for AIDS patients are not reimbursable; however, a Medicaid-eligible patient diagnosed with central nervous system damage, which will be the fate of an increasing number of the AIDS population, will be reimbursed for 80 percent of these expenses. Medicaid programs do not generally reimburse for all prescribed medications. Reimbursement is governed by a list of permissible medications. (But see below in Sec. VI for the differences in California.)

The burden on Medicaid for treating AIDS patients is critically dependent on the point in the course of the disease at which eligibility occurs. The time profile of costs is intensely U-shaped. In California, monthly costs in the first four months after diagnosis ran at about $12,000 and for the last four months at about $10,000. In the intervening ten months, costs were incurred at an average rate of only about $1,000 per month. (Kizer et al., 1986, p. 21.) Thus a patient who becomes eligible in month 1 is going to cost Medicaid a lot more than an identical patient who becomes eligible in month 5 or later.

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[16]Personal communication from Brent Nance, AIDS Project Los Angeles.

[17]Personal communication from Jeannie Martin, Director. There appears be a $6,500 per patient limit on hospice expenses, according to Kizer (1986).

Should the prevalence of HIV infection rise appreciably in the AFDC population--e.g., through needle-sharing, sexual association with drug users, or prostitution--the cost consequences for Medicaid would be magnified. Even before the appearance of clinical AIDS, seropositives would suffer immune system damage and a greater likelihood of illness.

Medical interventions can affect total costs and may alter their time profile as well. They are discussed in the next section.

VI. APPRAISING THE EFFECTS OF MEDICAL INTERVENTIONS ON COSTS[1]

Researchers in the United States and Europe are working on medical interventions--drug treatments--that show therapeutic promise for AIDS patients. These interventions may suppress symptoms, enhance functioning, and improve the quality of life for those treated, although none so far has been billed as a "cure" for AIDS. Successful therapies can be expected to reduce the need for other kinds of treatment, such as hospitalization, to extend life, and to enable AIDS patients to continue working, thus lengthening the period during which private health insurance policies remain valid.

Since all of the potential interventions--azidothymidine (AZT), ribavarin, dideoxycytidine, HPA-23, interferon alpha, and others--are so new, substantial uncertainties attach to their efficacy, costs of administration (including treatment of side-effects), and their implications for patient life expectancy and functioning. The discussion below explores some of the potential consequences of drug therapies, using AZT as an example.

EXTENT OF EFFICACY

Definitive results from the early phases of clinical trials with AZT are available so far only for AIDS patients suffering from PCP. The results have been gratifying both as to relief of symptoms and extension of life. (See Barnes, 1986b, for example.)

Fragmentary evidence suggests that patients with KS are also helped; AZT does not induce remission of the cancer but it does seem to diminish the likelihood of additional opportunistic infections. Whether the drug will delay spread of the cancer to internal organs remains unclear as yet.

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[1]Dennis Causey, M.D., the director of the AZT clinical trials program at the medical school of the University of Southern California, provided preliminary information helpful in writing this section.

A very small sample of patients with CNS damage showed some reversal of milder forms of dementia. Barnes (1986b) reports that AZT does seem able to transit the blood/brain barrier, but others suggest that the AIDS virus may mutate once lodged in the central nervous system and "outwit" the therapeutic agent by invading monocytes there rather than the T-helper cells it targets in other parts of the body. (See Streicher and Joynt, 1986.)

TREATMENT EXPENDITURES UNDER DRUG THERAPIES

Federal officials testified at a recent hearing of the Subcommittee on Health and the Environment of the Committee on Energy and Commerce, House of Representatives, that AZT therapy charges could amount to $10,000 per month, just for the medication. (See Cimmons, 1987.) In the AZT trials, it was found that to combat the lowering of red and white blood cell counts patients needed weekly transfusions for the first eight weeks and biweekly transfusions thereafter, at a cost of about $400 each. Necessary transfusions would thus add $12,000 to first year costs and $10,400 in subsequent years.[2]

The combined costs--more than $20,000 per year--do not include expenses of, for example, the chemotherapy still necessary for the cancer patients or custodial care for those with dementia. And some think that administration of AZT may ultimately necessitate bone marrow transplants. Thus if AZT were to extend a patient's life to only three years,[3] his lifetime costs would likely exceed those shown in Scitovsky et al. (1986) for patients before the development of AZT. The reduction in mortality and longer periods of morbidity for AIDS patients could result in their consuming even more medical resources than had been the case.

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[2]Personal communication from Dennis Causey, M.D.

[3]The early and dramatic success of AZT therapy during the few months of clinical trials in 1986 caused the trials to be truncated; thereafter AZT was provided to all AIDS patients who met the clinical criteria. (See Barnes, 1986b; currently more than 4,000 patients are receiving AZT, according to Cimmons, 1987.) Therefore, no estimates of life expectancy for patients on AZT are available.

The status of AZT therapy under Medicaid seems to vary state by state. William Roper, the Administrator of the Health Care Financing Administration, stated at these same hearings that "prescription drugs are an 'optional benefit' under state Medicaid programs, with many of those states setting dollar limits on the amount they are willing to reimburse." According to Cimmons (1987), he went on to report that Medicaid does not pay for drugs taken on an outpatient basis, as AZT would be administered (although in California MediCal pays for any AIDS drugs, such as AZT, that have been approved by the Food and Drug Administration.) But Medicaid may be obliged to reimburse for transfusions, bone marrow transplants, and the other expenses incurred by the longer-surviving patients on AZT.

ABILITY TO FUNCTION

Early results indicate that from one-quarter to one-half of patients on AZT can continue working if therapy begins early in the course of the disease. Contrast this with the one in seven of the AIDS population who had remained on the job in the study by Hardy et al. (1986). Hence for those with jobs and health insurance policies, AZT and other interventions promise to lengthen the period before which Medicaid reimbursement begins.

Of course, for those AIDS patients who lack jobs and health coverage, improved functioning may have no important financial implications. Intravenous drug users and many of the people they infect often fall into this category. Moreover, it may be unrealistic to expect that those already granted disability, with its concomitant Medicaid coverage, will rush back into the job market.

Public policies with respect to eligibility and other matters are treated in the next section.

VII. JUDGING THE CONSEQUENCES OF POLICY CHANGES

Many of the policies now in force with respect to AIDS have important consequences for the total costs of treatment and for the proportion of those costs that Medicaid will eventually pay. These are briefly reviewed below.

DEFINITION OF AIDS

People die of AIDS Related Complex and central nervous system damage. If the official definition were expanded to include ARC and neurological impairments without opportunistic infections, the total costs falling on Medicaid could rise substantially. Although some ARC patients with severe impairments are now on Medicaid, many with lesser disorders are not.[1] There may be an order of magnitude more ARC victims than AIDS victims.[2] No conclusive evidence exists with respect to the proportion of the case load with CNS impairments but increasing numbers are showing up in practice.

DEFINITION OF EXPERIMENTAL TREATMENT

Virtually all AIDS treatment can be considered experimental because the disease is so new that few standards have emerged. Officially, Medicaid does not reimburse for experimental treatments; should that limitation be strictly enforced, much of current treatment would cease to be reimbursable.

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[1]Should new interventions and therapies lessen the severity of ARC symptoms, even fewer would qualify for Medicaid under current policy.

[2]There are no published studies of the costs of treating ARC. The range of symptoms thought to characterize this condition is so wide as to make it near impossible to search hospital records by diagnosis, a common procedure in analyzing treatment costs. ARC patients generally have less severe symptoms but their life expectancy is considerably longer. Thus lifetime costs for ARC could be even higher than for AIDS.

CONTINUATION OF PRESUMPTIVE DISABILITY

As interventions, such as AZT (discussed in Sec. VI), become more widely available, the administrative practice of deeming AIDS "equal to the listings" may come into question. The automatic association of AIDS and disability may no longer be valid. People suffering from AIDS may be able to retain their jobs and thus their health insurance policies. A larger fraction of treatment costs would then devolve on private insurance carriers and a lower fraction on the Medicaid program.

STANDARDIZATION OF TREATMENT MODALITIES

The case management approach (described in Sec. V) offers lower treatment costs and, perhaps, preferable treatment from the victims' standpoint. Even if costs cannot be kept to the level experienced in San Francisco to date, substantial savings could still ensue. Medicaid may have to rethink its reimbursement standards to accommodate the out-of-hospital emphasis of this modality.

OPENING MEDICAID TO UNINSURABLES

Advocates at the Waxman hearings (see U.S. Congress, 1985) urged that Medicaid become the insurer of last resort for "uninsurables." Such people would pay premiums to the program on the basis of their incomes but, presumably, would not have to meet the strict financial maxima imposed by state Medicaid rules. It is difficult to estimate how many people might avail themselves of such an opportunity but clearly the result would be to raise the Medicaid cost burden.

DIVERSION TO MEDICARE

Currently, AIDS patients, like other disabled, become eligible for Medicare only after a two year waiting period beginning with commencement of Supplemental Security Income and an additional five month waiting period while on Disability Income, unless, of course, they qualify because of age. But few with AIDS have been surviving two years and AIDS, up to now, has been rare even among people over 50.[3] For such reasons, the Southern California hospital survey reported by Gamble (see

[3]Few cases have occurred among those over 50, according to Kizer et al. (1986, pp. 7-11.)

Sec. III above) in U.S. Congress (1985) found only 3 percent of AIDS patients on Medicare.

The promise of longer survival for AIDS patients and the new estimates of the length of the incubation period between infection and symptoms make it certain that more and more AIDS cases will be Medicare-eligible over time. How the Medicaid/Medicare cost shares may ultimately break down is difficult to forecast because we still know so little about the demographic and pathologic characteristics of the long-surviving and elderly AIDS populations. However, states can be expected to begin pressing for an easing of Medicare eligibility rules; they pay something like half of Medicaid costs but none for Medicare.

QUALIFYING PUBLIC HOSPITAL PATIENTS FOR MEDICAID

Whether the proportion of AIDS cases treated in public hospitals will rise or fall is also difficult to predict. The initiation of COBRA will work to keep more on the private side but the growing share of drug users in the AIDS population implies more public treatment. Longer survival will carry some beyond their COBRA guarantees, by which time they may also have exhausted the assets that had precluded Medicaid eligibility. As AIDS case loads grow, states will almost certainly begin to urge public hospital administrators to qualify as many patients as possible for Medicaid (and, as time goes by, for Medicare). The administrators of nonpublic hospitals may follow suit.

VIII. AIDS TREATMENT COSTS UNDER MEDICAID: A RECAP

The preceding sections depict a future for AIDS costs rife with uncertainties and ambiguities. This section concludes with low-, intermediate-, and high-range estimates that attempt to provide a perspective on the problem, based on the material discussed earlier in this Note. But first is presented a useful device for summarizing how clinical events, treatment phases, and financial considerations interact to generate costs, for the nation and for the Medicaid program.

THE GENERATION OF COSTS IN REPRESENTATIVE CASES

Figures 1 and 2 sketch the interplay of clinical, treatment, financial, and cost events for two representative AIDS cases. The cases were chosen to reflect differences in patient group membership, pathology, and approach to treatment. They are in no sense to be construed as "average" cases. The illustrations are presented to show how the situation of the patient and the treatment he receives affect the costs he generates rather than as a base on which to project costs into the future.

Figure 1 depicts what could well occur in the case of, say, a 35-year-old homosexual, employed when stricken, and middle class as to socioeconomic status, if he were treated according to the case management approach (referred to as case type 1). Figure 2, on the other hand, portrays the case of, perhaps, a 30-year-old unemployed and destitute IV drug user receiving treatment according to the more usual heavy- hospitalization model (referred to as case type 2).

The first line of each figure simply shows the months as they unfold. On the second line are clinical events as they occur over time. The third line displays the phases of treatment, with the width of each phase roughly proportional to its duration. The last line indicates the financial state of the victim as it affects his eligibility for Medicaid. These considerations are used in lines four and five to derive the cost implications, in total and for Medicaid, respectively. The height of the bars on the Medicaid cost line are roughly

proportional to the reimbursement rates applying to each type of service. The figure at the right-hand end of the cost lines aggregates the costs shown in the segments of that line.

Various assumptions, suggested in interviews with knowledgeable observers and researchers,[1] were used to construct these representative cases and to cost out the services implied. The assumptions are listed below

ASSUMPTIONS EMPLOYED IN FIGURES 1 AND 2

Charges:
- Hospital at $750/day for room, meals, pharmaceuticals (including for outpatient periods), and ordinary services
- Intensive care unit at $3,000/day
- Residential hospice at $125/day
- Home care costs at $100/day
- Outpatient services at $10/day, hospital or physician's office

Medicaid reimbursement rates:
- All inpatient at 70 percent
- Skilled nursing facilities (including residential hospice) and outpatient visits at 60 percent
- Home care at 15 percent

Course of treatment for case type 1:
- First hospitalization after KS diagnosis of 7 days, including 3 days ICU, for chemotherapy
- 20 month period of intermingled out- and inpatient care, including 30 days of hospitalization for chemotherapy
- 15 days of hospitalization, including 5 days ICU, after diagnosis of opportunistic infection, for chemotherapy and antibiotic therapy
- 30 days of home care
- 30 days of residential hospice

Course of treatment for case type 2:
- First hospitalization after PCP diagnosis of 10 days, including 5 days ICU, for oxygen and antibiotic therapy
- 10 month period of intermingled out- and inpatient care, including 100 days of hospitalization, for various therapies
- 15 days of hospitalization after onset of neurological impairment for further diagnosis and stabilization, including 5 days ICU
- End period of 45 days hospitalization for lack of alternative facilities in which to place patient

[1]They included Chris Matthews, M.D., of the Robert Wood Johnson Foundation's Clinical Scholars program at UCLA; Jeannie Martin, Hospice of San Francisco; and Alice Moed, San Francisco General Hospital.

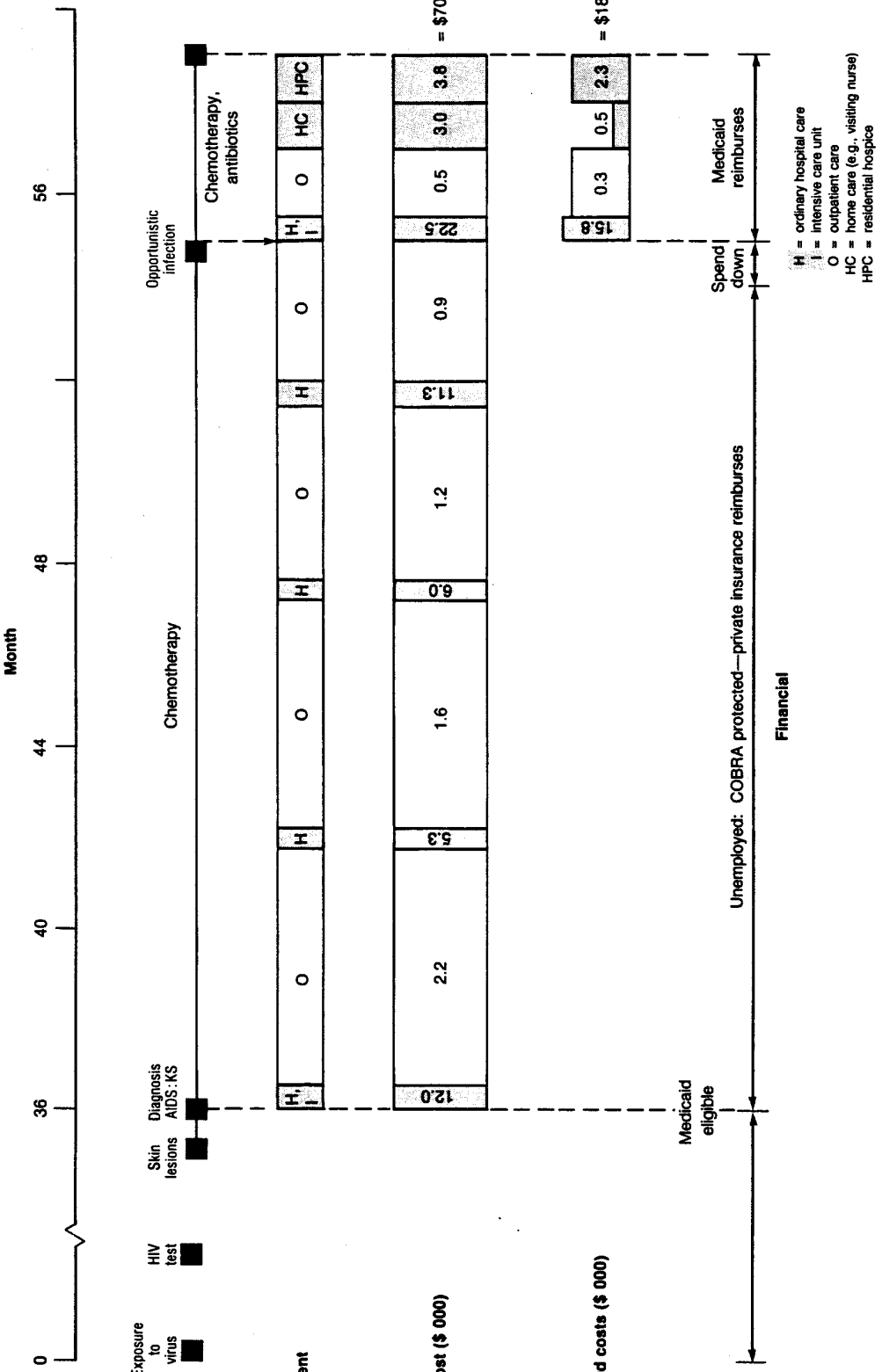

Fig. 1—The generation of costs for case type 1

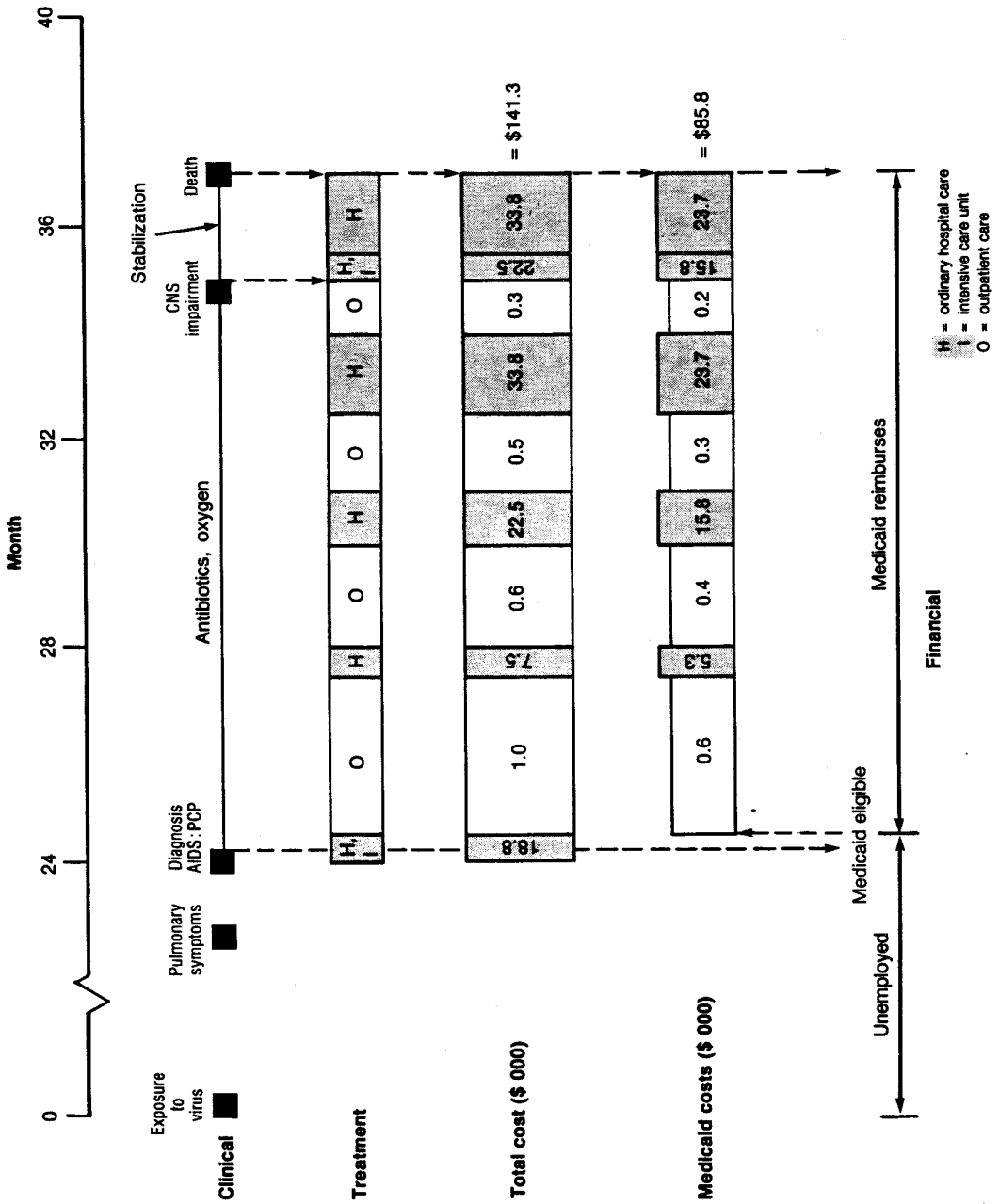

Fig. 2—The generation of costs for case type 2

Figure 1 shows a three year incubation period before AIDS symptoms appear. With the official diagnosis and granting of presumptive disability, the patient becomes unemployed but is able to continue his health insurance policy under COBRA protection for 18 months. At the end of this period he spends down his remaining assets and becomes eligible for Medicaid. He has short periods of hospitalization, at increasing frequency, over the next 20 months, when an opportunistic infection, perhaps tuberculosis, strikes. After another hospital stay, he is released for a shorter period until he requires intensive home care. He dies in a residential hospice about two years after the appearance of symptoms.

Note that in this case Medicaid reimburses only a small fraction of the victim's medical expenses because private health coverage continues. COBRA makes the difference. (Of course the patient is also likely to have to pay some medical expenses out-of-pocket as well.)

The second representative case, probably in poor health to begin with, presents PCP symptoms two years after infection. Eligibility for Medicaid comes soon after admittance to a public hospital because he begins with no insurance coverage and no private resources. Although he survives only half as long as does case 1, he spends many more days in the hospital both because he is sicker--dementia complicates the original symptoms--and because there are few care alternatives in his community.

For case 2 the total medical costs are twice as high as for case 1 and the amount reimbursed by Medicaid is more than four times as much. Financial status, pathology, and approach to treatment have dramatic implications for the Medicaid cost burden.

THE RANGE OF COST ESTIMATES

One can make "optimistic" or "pessimistic" assumptions with respect to the cost-generating factors. The scenarios developed in Table 3 string together optimistic and pessimistic assumptions to produce, respectively, low and high cumulative cost estimates over the period 1986-1991. These serve to delimit the range in a rough fashion. An intermediate estimate is also presented. Once again, it must be

stressed that these numbers are far from definitive predictions; they constitute best guesses, given current knowledge.

In fact, there is no logical reason to restrict any estimate scenario to purely optimistic or pessimistic assumptions. They could easily intermingle. In fact the ultimate cost estimates produced using the strictly optimistic and strictly pessimistic contingencies are highly unlikely to occur. The intermediate cost estimates seem considerably more likely.

The range with respect to the first factor, case load, is a result of the uncertainties noted earlier, particularly as to the disease's latency period. For the second factor, variation across scenarios results from contrasting views of the share of case load accounted for

Table 3

ESTIMATES OF CUMULATIVE COSTS FOR AIDS TREATMENT
FOR THE PERIOD 1986-1991

Factor	Range of Estimates		
	Low	Intermed.	High
Thousands of cases, cumulative	220	400	750
Percent of cases on Medicaid	30	45	60
Lifetime cost per case ($ thousands)	70	94	150
Percent reimbursed by Medicaid	50	60	70
National costs ($ billions)	15.4	37.6	112.5
Medicaid costs ($ billions)	2.3	10.2	47.3

SOURCES: Secs. II-V and VII, above.

NOTE: See the appendix for a discussion of the considerations that lie behind the low, intermediate and high scenarios for each factor.

by the various patient groups and variations in Medicaid eligibility by group as affected by life insurance coverage. The estimates for the third factor, case costs, differ primarily because of assumptions about the spread of the case management approach which, in turn, will affect the number of hospital days experienced by the typical patient. The low estimate for the fourth factor, reimbursement percentage, reflects the adoption of the case management approach but no change in Medicaid reimbursement policy, whereas the high estimate reflects pressures to cover more services at higher rates. (See the appendix for a more complete discussion of how the three scenarios were projected.) The resulting costs are expressed in dollars of the 1985-1986 period when the lifetime per case cost estimates were produced.

These scenarios assume no change in the definition of AIDS or experimental treatment, the effectiveness of blood donor screening, or the use of Medicaid as an insurer of last resort. Neither are the potential effects of vaccines and therapeutic interventions factored in. However, the development of a vaccine against AIDS would only minimally affect the cost estimates of Table 3 because the vast majority of people who will fall ill in this period have already been infected.

The low and intermediate cumulative national cost figures in Table 3 seem consistent with the estimate presented by MacDonald of the Public Health Service (1986) at Coolfont, which was between $8 billion and $16 billion for AIDS patients' medical care in the year 1991.[2] Scitovsky and Rice (1987) also estimated personal medical care costs for the year 1991. They ranged from $3.5 billion to $9.4 billion in 1984 dollars; the variation in their estimates is primarily due to different assumptions about hospitalization time and average daily hospital charges. Table 3's high-end figure lies well beyond the range of both the PHS and the Scitovsky and Rice estimates.

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[2]Note that Table 3 presents five year cumulative figures, whereas the MacDonald (1986) estimate appears to be for the year 1991. The $8 billion figure was arrived at after inflating the case load numbers by 20 percent for underreporting and underascertainment according to a memo to the author from a HCFA official (see above in sec. II).

The Relative Burden of AIDS Treatment Costs

What is the relative burden for AIDS under the scenarios shown? It appears that the nation will spend about $3,412 billion on health care in the period 1986-1991 and that the states and federal government will spend about $361 billion for Medicaid (Arnett et al., 1986)[3] Thus AIDS can be expected to account for between 0.5 and 3.3 percent of national health care spending over this period, with an intermediate estimate of about 1 percent, and between 0.6 and 13.1 percent of Medicaid expenditures, with an intermediate estimate of about 3 percent.

For comparative purposes, consider the annual cost figures reported by Harris (1986) for several major impairments by the year 1991.[4] They are: AIDS--$8.5 billion; auto accidents--$8.0 billion; digestive cancers--$4.9 billion; lung cancer--$3.9 billion; kidney disease--$3.2 billion; and breast cancer--$3.1 billion.[5] Thus AIDS, if the Harris article figures hold, looks to be among the most expensive of the diseases facing the nation. The comparative costs of AIDS treatment loom even larger if Harris's $8.5 billion comes from the same ballpark as the lower estimate given in Public Health Service (1986). Even the intermediate estimate of Table 3 would result in much higher costs for AIDS as compared to other major impairments.[6]

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[3]Missing years in Arnett et al. (1986) were interpolated or projected on the basis of the cumulative growth rates implied there.

[4]These are reported to be costs in 1991 of "treating patients" based on "the medical inflation index and estimated rates of disease growth." Sources given in the article are Centers for Disease Control and the Health Care Financing Administration.

[5]Scitovsky and Rice (1987, p. 15) on the other hand, estimate that medical expenses for auto accident victims will exceed those for AIDS patients even by 1991. For no other condition--end stage renal disease, digestive system cancers, and cancers of the lung, trachea, bronchus or breast--will the costs exceed 70 percent of treatment costs for AIDS, according to the authors.

[6]Cimmons (1986) reports figures from the Center for Health Statistics, CDC, and the Public Health Service suggesting that by 1991 AIDS will have become the seventh leading cause of death in the United States, exceeded only by heart disease, cancer, stroke, accidents, chronic lung disease, and pneumonia. It will by this time have surpassed diabetes, suicide, liver disease, and arteriosclerosis, according to the article.

As public institutions become the "hospitals of last resort" for AIDS patients, some may face threats to their financial viability. Even with partial reimbursement from Medicaid programs, hospitals in high-impact communities could suffer calamitous AIDS cost burdens. So could the state health budgets that support about half the Medicaid costs and the local agencies supplying nonhospital services to AIDS victims. The "generous" state (and municipalities) that cover a wide variety of services and reimburse at high percentages may begin to tighten up on Medicaid coverage and benefits.

Caveats

In concluding this cost summary, several caveats merit emphasis. The cost estimates developed above are based on the means of some critical variables. Yet the likelihood that the costs for an AIDS patient will be assumed by Medicaid depends on the variance around the means of, for example, per patient costs, life expectancy, and patient assets. The larger the dispersion around these means, the more patients Medicaid will become responsible for. Data on the current size of such variances are unavailable but it seems intuitively likely that the variances for patient costs and life expectancy will be falling in the future as treatment models for AIDS patients become more standardized.

The costs for AIDS treatment will not cease in 1991. If the medium estimate of annual personal treatment costs calculated by Scitovsky and Rice (1987, p. 11) come to pass, costs will have grown at a compound growth rate of more than 40 percent between 1986 and 1991. Such a figure gives some indication of how costs might mount in the years following 1991.

Finally, treatment costs represent only a portion of the losses AIDS will impose on the United States. The nation will also lose the output that would have been produced by the hundreds of thousands of victims, most in the prime of their working lives. These economic costs and other issues needing study are the subject of the final section.

IX. ANSWERING THE REMAINING QUESTIONS

The review of existing knowledge that gave rise to the estimates contained in this Note does not form a sound enough basis for planning and policy. Longitudinal studies of cohorts of AIDS patients appear to be necessary for developing definitive answers about the costs of AIDS over the coming years.[1]

Such studies should rely on retrospective and prospective tracking of AIDS victims under a variety of circumstances. Selecting study cohorts from states that vary in case load, patient group shares (and thus pathologies), Medicaid eligibility rules, and health insurance access laws would provide a broad base of relevant experience.[2] The analyses should begin soon and should track patients for several years so that the effects of medical interventions and possible changes in co-factors and risk exposure behavior could be observed.

Information is needed on expenses incurred and the forms of reimbursement by patient group, type of facility, and location. Such data would make possible forecasts for specific time periods and would facilitate the tracking of time trends in AIDS costs and payer shares.

The data collected will help answer a host of important questions.[3] How will the costs of treating AIDS be shared between the private and public sectors? In the private sector, how will treatment costs be distributed among individuals, prepaid plans, and private insurance carriers? Can hospitals and other health facilities recoup their expenses? How will access to proper care vary with the socioeconomic

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[1]The need to work under strict confidentiality rules will complicate any studies attempted and will, inevitably, add to study costs.

[2]It may be possible to "piggy-back" on some of the state level studies now under way or planned, depending on the feasibility of standardizing data definitions and collection procedures.

[3]Primary data collected from AIDS will permit derivation of variances as well as the means for important variables. These will yield more precise projections of the cost burdens for various payers.

status and location of the AIDS victim? Do health insurance companies and HMOs face financial disaster?

On the public side, how much will be paid by the federal government through Medicaid and Medicare? The Veterans Administration? How much by the states under Medicaid programs and support for public hospitals? How much by local government in uncompensated public hospital expenses and locally financed social services to victims?[4]

Lost productivity--the sacrifice of national product--threatens to become an enormous cost.[5] Careful observation of the morbidity and mortality experience of patients in the study cohorts will permit calculations of the economic output lost as young and middle-aged workers fall victim to the disease, become disabled, and die.

Policies governing access, eligibility, appropriate treatment, reimbursement, and other such issues must be grounded on accurate and comprehensive knowledge of the ramifications of the AIDS epidemic. The nation faces a devastating and costly killer. "Know thine enemy" remains the best advice.

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[4]Intergovernmental Health Policy Project (1985) details actions taken by state and local governments in the earlier days of the epidemic.

[5]For the current patient groups, however, the *social* cost of the lost output will be smaller than for the general population to the extent that homosexuals and drug users have fewer dependents than others their age. That is, a large part of the lost output would have been consumed by the patients themselves.

Appendix

CONSIDERATIONS UNDERLYING CUMULATIVE COST SCENARIOS IN TABLE 3

CUMULATIVE COSTS, NATIONAL AND FOR MEDICAID

$NC_n = K_n \times Z_n$

$MC_n = K_n \times M_n \times Z_n \times R_n$

where

NC_n = national cumulative costs, 1986-1991, for scenario n[1]

K_n = number of cumulative cases, 1986-1991, for n

Z_n = lifetime treatment cost per case, for n

MC_n = Medicaid cumulative costs, 1986-1991, for n

M_n = Percentage of cases on Medicaid, averaged over 1986-1991, for n

R_n = Percentage of per-case treatment cost reimbursed by Medicaid, averaged over 1986-1991, for n

FACTOR K. NUMBER OF CUMULATIVE CASES, 1986-1991

K_1 OR LOW SCENARIO[2]

The following formula was used to calculate the cumulative number of cases for the period 1986-1991, weighted to account for treatment that took place or will take place outside this time span.

$$K_1 = {}^*C_{86\text{-}91} = C_{0\text{-}91} - D_{0\text{-}85} - [(L\text{-}AD_{86})/L]D_{86} - [(L\text{-}AP_{86})/L]P_{86} - [(L\text{-}AC_{91})/L]C_{91}$$

where

${}^*C_{86\text{-}91}$ = cumulative weighted case load, 1986-1991

$C_{0\text{-}91}$ = cumulative total case load, 1986-1991[3]

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[1]Scenarios: 1=low, 2=intermediate, 3=high.

[2]For convenience, all patients are assumed to be diagnosed or to die at mid-year.

[3]270,000, according to Institute of Medicine (1986, p. 8).

D_{0-85} = deaths through 1985[4]

L = life expectancy for typical patient for period 1986-1991[5]

AD_{86} = average months ill in 1986 for patients dying in in 1986

D_{86} = deaths in 1986[6]

AP_{86} = average months ill in 1986 for patients diagnosed before 1986

P_{86} = cases in 1986 that were diagnosed before 1986[7]

AC_{91} = average months ill in 1991 for patients diagnosed in 1991

C_{91} = new cases diagnosed in 1991[8]

So that

$$K_1 = 270,000 - 10,000 - .5(11,000) - .5(3,000) - .5(33,000) = 220,000$$

K_2 OR INTERMEDIATE SCENARIO

Because the low scenario is based on figures from the most widely cited case load projection and because the high scenario (see below) is based on more speculative considerations, the intermediate scenario used a cumulative case number one-third of the way from the low to the high scenarios. The estimate for K_2 is thus 400,000.

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[4]10,000 (rounded to nearest one thousand) according to Morgan and Curran (1986, p. 461).

[5]Assumed to be 12 months (which accords with figures used in Scitovsky et al. 1986, p. 3105) Although diagnostic and treatment procedures are bound to improve over this period, which lengthens life expectancy, the share of patients with pulmonary infections, who survive fewer months than those with soft tissue cancers, appears to be growing. Thus it was assumed that 12 month's average survival would continue.

[6]11,000 (rounded to nearest one thousand) according to Scitovsky and Rice (1987, p. 6).

[7]3,000 (rounded to nearest one thousand) according to Scitovsky and Rice (1987, p. 6).

[8]66,000 (rounded to nearest one thousand) according to Scitovsky and Rice (1987, p. 6).

K_3 OR HIGH SCENARIO

According to the Institute of Medicine (1986, p. 91), a high estimate of the number of seropositives alive in the United States in 1986 was 1.5 million. This estimate includes people at all symptomatic stages, from none to full-scale AIDS. The high estimate of the number of seropositives (equivalently defined) who will convert to frank AIDS symptoms within five years is 50 percent (from Johnstone, 1986, p. 199). The cumulative case load is the product of these two numbers. These data do not offer sufficient detail to adjust for treatment expenses falling outside the time period (except for those who died before 1986), as was done for the low scenario above. The estimate for K_3 is thus 750,000.

FACTOR M. PERCENTAGE OF CASES ON MEDICAID

The following formula[9] was used to calculate the estimated percentage of patients who would qualify for Medicaid reimbursement, by patient group:

$$M_n = g_n G_n + u_n U_n + s_n S_n$$

where, for each scenario n

g_n = the percentage of homosexual/bisexual males on Medicaid

G_n = the share of all patients infected through homosexual contact

u_n = the percentage of drug-user patients on Medicaid

U_n = the share of all patients infected through IV drug use

s_n = the percentage of other patients on Medicaid

S_n = the share of all patients infected through other means

[9]For convenience, the formula is assumed to yield the average M over the time span 1986-1991. Moreover, no account is taken of patients who become eligible for Medicaid during the course of their illnesses, i.e., for each patient, Medicaid eligibility is assumed to be binary.

M_1 OR LOW SCENARIO

$M_1 = 90(20) + 10(70) + 50(10) = 30$

where G, U, and S are derived from Public Health Service (1986). Almost all drug users (U) are assumed to be on Medicaid. Only 10 percent of gays (G) are assumed to be on Medicaid because of COBRA protections. Half the remaining patients (S) are assumed to be on Medicaid because a substantial share are low-income mothers and their children.

M_2 OR INTERMEDIATE SCENARIO

M_2 = midpoint between low and high scenarios = 45

M_3 OR HIGH SCENARIO

$M_3 = 90(30) + 40(60) + 90(10) = 60$

where the patient group shares show an increase for U along the lines argued by A. R. Moss (see reference in Sec. II above.) S is assumed to be made up almost exclusively of low-income women and their children who qualify for Medicaid under AFDC, if not through medical indigence or disability. Four in ten gay patients (G) are assumed to be on Medicaid as a result of health insurance gaps (e.g., for young workers, individual and small group health plan members and those discriminated against in insurance and employment).

FACTOR Z. LIFETIME TREATMENT COST PER CASE

The range in treatment costs results from uncertainty about the extension of the case management approach to AIDS treatment. Section V presents arguments both for the spread of that model and for its lack of long-term viability.

For each scenario, $3,000/case for outpatient services was added to the estimate referenced, reflecting the "medium" estimate in Scitovsky and Rice (1987, p. 10).

Z_1 OR LOW SCENARIO

Z_1 = $70,000

from Scitovsky et al. (1986, p. 3106), "...we estimate that lifetime hospital costs for AIDS...are most likely around $60,000 to $75,000 [i.e., $67,500]."

Z_2 OR INTERMEDIATE SCENARIO

Z_2 = $94,000

from Kizer et al. (1986, p. i), $91,000 for hospital costs.

Z_3 OR HIGH SCENARIO

Z_3 = $150,000

from Hardy et al. (1986, p. 210), $147,000 for hospital costs.

FACTOR R. PERCENTAGE OF PER-CASE TREATMENT COST REIMBURSED BY MEDICAID

The following formula[10] was used to calculate the estimated percentage of charges that are reimbursable under Medicaid, by type of service.

$$R_n = i_n I_n + o_n O_n + h_n H_n$$

where, for each scenario

i_n = the reimbursement rate for inpatient services

I_n = the share of total patient charges in inpatient services

o_n = the reimbursement rate for outpatient services

O_n = the share of total patient charges in outpatient services[11]

h_n = the reimbursement rate for all other services[12]

H_n = the share of total patient charges in other services

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[10]For convenience, the formula is assumed to yield the average R over the time span 1986-1991.

[11]E.g., skilled nursing facilities and visits to physicians.

[12]E.g., home care and social services.

R_1 OR LOW SCENARIO

$R_1 = 60(70) + 60(15) + 0(15) \simeq 50$

based on the assumption that the case management approach will have become increasingly common. (Shares of costs for service types I, O, and H adapted from Scitovsky et al., 1986, p. 3105, and Scitovsky and Rice, 1987, pp. 10-11; H cost assumed to equal O costs.) But it was also assumed that H services will continue to be nonreimbursable. (See Kizer et al., 1986, pp. 13 ff; also, personal communication from Jeannie Martin, Director, Hospice of San Francisco.)

R_2 OR INTERMEDIATE SCENARIO

$R_2 = 60$

which is the midpoint between low and high scenarios; roughly equal to current reimbursement rate in California as shown in Kizer et al. (1986, p. 12).

R_3 OR HIGH SCENARIO

$R_3 = 70(90) + 70(05) + 70(05) = 70$

based on continuation of heavy hospitalization (i.e., I service) model (Kizer et al., 1986, pp. 12ff.) and successful pressure to raise reimbursement rates on I, O, and H services. (The reimbursement percentage already appears to be at 75 percent of hospital costs at Bellevue in New York City, according to Graham and Ricklefs, 1987.)

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