SUMMARY AND POLICY ISSUES

Estimates of the costs associated with acquired immune deficiency syndrome (AIDS) have varied tremendously. Reports of hospital costs[1] over the lifetime of an AIDS patient have ranged from $24,517 (Belmont, et al., 1985) to $147,000 (Hardy, et al., 1986). The financing as well as the amount of AIDS costs has been subject to differing reports: Medicaid has been said to pay for the care of from 7 percent (Potts, et al., 1986) to 65 percent (Boufford, 1985) of AIDS patients and private insurance to cover from 13 percent (Gamble, 1985; Scitovsky, et al., 1986a) to 65 percent (Seage, et al., 1986; Scitovsky, et al., 1986a) of patients.

The Subcommittee on Health and the Environment of the House Energy and Commerce Committee requested the Office of Technology Assessment to analyze the reasons for these different cost estimates. In response to that request, this Staff Paper identifies specific factors that account for differing cost estimates in 18 studies, discusses problems in predicting costs associated with AIDS, and raises issues related to future. cost estimates.

AIDS is a newly detected disease that has been expensive to treat and that has attacked primarily men in age groups with historically low rates of sickness and death. As a result, AIDS has raised long-standing issues of how to finance catastrophic (very expensive) costs of illness and how much to allocate to prevention and to treatment of human immunodeficiency virus (HIV)[2]

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1 The cost of resources used should be distinguished from the charges to those who pay for the services performed. Most of the studies reviewed here used charges to estimate the direct medical costs borne by patients and other payers, and the amounts derived are costs from the perspective of the payers rather than the providers of services. However, Seage, et al. and Potts, et al. converted hospital charges to costs for inpatient care, and six other studies reported or used the average cost per hospital day (table 1)."

2 Although the virus that causes AIDS has been termed human T-Cell lymphtrophic virus type III (HTLV-III), lymphadenopathy-associated virus (LAV), human immunodeficiency virus (HIV) is now the accepted nomenclature.

infections. AIDS has also raised new issues of how to deal with this specific disease in matters concerning data collection and payment for care.

How to pay for the costs of treating AIDS is but a recent example of the continuing issue of how to pay for illnesses with high treatment costs, high in absolute terms and high as a percentage of income. AIDS patients for the most part have been working-age adults. But it has been estimated that about 17 percent of people in their prime working years have been uninsured for all or part of the year (Farley, 1984) and that about 22 percent of the population under age 65 have been at risk of being unable to afford necessary medical care because they were uninsured, underinsured, or otherwise medically disadvantaged (Bazzzoli, 1986).[3] In such cases, not only the patients and their families, but also the providers who care for them are financially vulnerable in the face of catastrophic expenses.[4]

Although it was beyond the scope of this Staff Paper to examine thoroughly payment of catastrophic costs, on its face the financing of AIDS treatment costs appears similar to that of other very expensive illnesses. With past survival and treatment patterns, AIDS lifetime hospital costs have most likely been under $100,000 (Scitovsky, et al., 1986b), and estimates of annual treatment costs for patients alive at any time during the year[5] have

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3 Farley's data pertain to people 25 to 54 years in 1977. More recent data suggest that the percentage under age 65 that are uninsured has grown during the 1980s (Firshein, 1986; US DDH, Health United States 1986., 1987).

4 Certain Federal and State laws promote the continuation of health insurance coverage for people, such as those with AIDS, who become too sick to continue working, although the actual effect is not known. The Consolidated Omnibus Reconciliation Act of 1985 (P.L. 99-272) requires that employees who are terminated (except for cause) from firms with 20 or more employees be given the opportunity to continue their health insurance coverage under the employer's group policy for 18 months and to convert to individual coverage after that time. In addition, California requires that, for employees who leave work because of a medical disability, health insurers continue group coverage for claims related to that disability for one year at no additional cost'(Bowen, 1987). Some other States may have similar requirements.

been under $40,000 (See tables 1 and 2).[6] Although such expenses maybe devastating and unexpected for the individuals involved, this level of per patient costs is in the same range as treatment costs for other severe medical conditions. Treatment costs have averaged $158,000 over a four-year period for patients with end-stage renal disease who are undergoing dialysis (Eggers, 1984) and about $30,000 (in 1984 prices) in the terminal year for nonelderly people with certain cancers (Long, et al., 1984).

What makes this disease a special case is the increasing prevalence of AIDS and HIV infection and the age groups afflicted. Based on estimates of present infection rates, from 1984 to 1991 AIDS cases are expected to rise from 3.96 to 68.63 per 100,000 U.S. population, and deaths are expected to rise from 1.49 to 25.74 per 100,000 U.S. population (Scitovsky and Rice, 1987).[7] If direct medical costs for AIDS rise, as projected, to about $7,0 billion by 1991, they will account for 1.4 percent of U.S. personal health care expenditures, up from 0.2 percent in 1985.

AIDS has afflicted mostly young men in their prime working years, who are either homosexuals or intravenous (IV) drug abusers. This age-sex group has historically had low mortality rates and low medical expenditures, a pattern on which insurance companies. have relied in calculating health and life insurance premiums. AIDS has disrupted that pattern and added a new

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5 costs per patient alive at any time during the year include costs for some people who did not have expenses for the entire 12-month period, because they died or were diagnosed as having AIDS during the year. By contrast, cost per year for patients alive throughout the year represents the annual cost of caring for a person with AIDS and has been calculated as the cost per patient divided by the number of months each person was in the study times 12 (Seage, et al., 1986).

6 As noted in tables 1 and 2 and in latter sections of this paper, these estimates have generally excluded nursing home and home care and have varied in their inclusion of ambulatory drugs and other services.

7 As advised by the CDC, Scitovsky and Rice increased the CDC estimates by 20 percent.

Table 1.--Differences in Methods Among Studies of AIDS Costs[a]

Category	Belmont, et al.	Berger	Bouf rd	n	Gamble	Hardy, et al.	HIAA/ ACLI	Hull	Kizer[b]	Kizer, et al.	Lennon, 1987	Potts, et al.	Shultz, et al.	Scitovsky et al., 1986b	Scitovsky and Rice, 1987	Seage, et al.
Locale	St. Luke's-Roosevelt Hosp. Center, N.Y.C	Maryland	N.Y.C. municipal hosps.	Calif.	So. Calif.	U.S.	U S.	2 hosps., N. Mex.	Calif.	Calif	Belle Glade, Fla.	3 counties with regional centers, Ala.	Minn.	San Fran.	U.S.	N. Eng. Deaconess Hosp., Boston
Definition of AIDS																
CDC definition	X	-	X	-	-	X	-	-	-	-	-	X	-	X	X[c]	-
Reports to health dept.	-	X	-	-	-	-	-	-	X	X[d]	-	-	X	-	-	-
Specified ICD-9 codes	-	-	-	X[e]	-	-	-	-	-	-	-	X	-	X	-	-
Treatment in AIDS wards	-	-	-	-	-	-	-	-	-	-	-	-	-	X	-	-
Left to respondent	-	-	-	-	-	-	X[f]	-	-	-	-	-	-	-	-	-
Not specified	-	-	-	-	X	-	-		-	-	X	-	-	-	-	-
Patients besides AIDS adults																
Pediatric AIDS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
ARC	-	-	-	-	-	-	M	-	-	-	-	-	-	-	-	-
Year(s) of data	1/1/84-4/30/85	1979-2/85	1985	5/85-6/86	8/85	1984 1985	≤Fall '85	N.S.	7/83-8/85[g]	7/83-8/85[g]	1/1/85 1/31/87	1983-9/86	1984 & 1985	1984	1984	9/1/84-2/28/85
Time period																
Annual	-	-	-	-	-	-	-	-	-	-	-	-	X[h]	X	X	M
Lifetime	-	X	-	X[i]	-	X	-	-	X	X	-	-	-	X[j]	-	
Other	X	-	-	N.S.	X	-	N.S.	N.S.	-	-	N.S.	X	-	-	-	-
Scope of costs																
Direct costs																
Medical costs	-	-	-	X	-	-	X[k]	X[k]	X[l]	X[l]	-	-	X[k,m]	-	-	-
Inpatient hospital	X	X	X[n]	X	X	X	-	-	X	X	X	X	-	X	X	X
Inpatient physician	-	-	-	X	-	X	-	-	X	X	-	-	-	X	X	X
Outpatient, hospital	-	-	-	X	-	-	-	-	X	X	-	-	-	X	X	X
Hospital outpatient, physician	-	-	-	X	-	-	-	-	X	X	-	-	-	X	X	X
Other ambulatory physician	-	-	-	X	-	-	-	-	X	X	-	-	-	-	-	-
Ambulatory drugs	-	-	-	X	-	-	-	-	X	X	-	-	-	-	-	-
Ambulatory ancillaries	-	-	-	X	-	-	-	-	X	X	-	-	-	X[o]	X[o]	-
Home care	-	-	-	X	-	-	-	-	X	X	-	-	-	-	-	-
Nursing home/hospice	-	-	-	P	-	-	-	-	-	-	-	-	-	-	-	-
Counselling	-	-	-	X	-	-	-	-	-	-	-	-	-	-	-	-
Non-personal costs	-	-	-	-	-	-	-	-	-	-	-	-	-	-	X	-
Indirect costs																
Morbidity/disability	-	-	-	-	-	X	-	-	-	-	-	-	X	-	X	-
Mortality	-	-	-	-	-	X	-	-	-	-	-	-	X	-	X	-

Table 1.--Differences in Methods Among Studies of AIDS Costs[a] (Cont'd)

Category	Belmont, et al.	Berger	Boufford	Boven	Gamble	Hardy, et al.	HIAA/ ACLI	Hull	Kizer[b]	Kizer, et al.	Lennon	Potts, et al.	Shultz, et al.	Scitovsky, et al., 1986b	Scitovsky and Rice, 1987	Seage, et al.
Source of cost data	One hosp.	Baltimore	N.Y.C. municipal hosps.	Some Calif. Blue Cross groups[q]	So. Calif. hosps.	One Atlanta hosp.'s charges	352 insurance cos.	National litera-ture	Medi-Cal claims	Medi-Cal claims	One hosp.	One Ala. hosp.	National litera-ture	S.F. Gen. Hosp.	S.F. Gen. Hosp.	[r]
Specific data or assumptions used																
Average admissions[s]	1.8/patient in 16 mos.				2-3/patient in yr.		3/patient (in yr.?)				1.2/patient in 2 yrs.			[t]	1.7/case	1.6/patient 3.3/patient yr.
Average length of stay, days	22	19.5		11.0	17.3	12	23	15.5		14.0	9.9[u]	16.9		11.7	20	21
Los Angeles										17.9						
San Francisco										12.1						
Rest of California										14.2						
Initial hospital stay						31										
Average length of stay, ICU	[v]															1.0
Lifetime hospital days/patient						167.79								35		61.9
Average charge/day						$878 (Atl.)		$815		$606[w]	$697	$962		$773	850	
Average cost/day	$613	$542-550	$800 est.	$1,011	$963 [x]							$540				
Average payment/day																
Average outpatient charge/case							$6,518								$3,000[y]	$2,668
Average home health cost/death							$7,603									
Average survival after diagnosis						392 days (N.Y.)								7.5 mos.		
Discount rate		None	$500 est.			4 X		None	[z]			None	Used rate N.S.			
Changes for projections																

N.S. = Not specified.
X = That category was used by the study noted.
- = Not applicable

Table 1.--Differences in Methods Among Studies of AIDS Costs[a] (Cont'd)

Landesman gave no method for calculating the cost estimates presented.

b Used data from Kizer, et al., 1986.

e Used higher, more recent CDC estimates of AIDS cases than Scitovsky, et al., 1986a.

d Although the report stated that no information had been collected for ARC patients (p. 5), it also defined the onset of AIDS as the first month that symptoms were noticeable, and some of the symptoms included (swollen lymph glands, fever, and diarrhea) are characteristic of ARC but not consistent with the CDC definition of AIDS (p. 13).

e AIDS cases were identified by specified ICD-9 codes plus one hospitalization.

f Many of the respondent companies used ICD-9 codes to identify AIDS claims.

g To estimate costs, used Medicaid claims from 7/84 through 6/85.

h Annual estimates were given, but reference was made to lifetime cost estimates.

i Data for 13 months were used to pull claims for a 16-month period. Data for people who died approximate lifetime costs (Bowen, 1987).

j Unlike annual costs, lifetime costs included only inpatient hospital and physician expenses.

k The scope of medical services was not specified.

l Costs of "vendors'" services covered by Medicaid were included. The extent to which physician, ancillary, drug, home, and long-term care services were covered and hence included in costs was not specified.

m Used cost estimates from the national literature for projections.

n Sixty percent of the AIDS/ARC caseload were drug abusers.

o From hospital outpatient use only.

p Included if in a skilled nursing facility (Bowen, 1987).

q None of the data pertained to individual policies. All patients were employed, at least at the time of diagnosis, for a company that provided health insurance coverage.

r Blue Cross /Blue Shield figures were used for ambulatory costs, and hospital charges were converted to costs for inpatient care.

s Number of admissions per patient is the total number of admissions divided by the number of patients alive at any time during the year (or other time period). Number of admissions per patient year is the total number of admissions divided by the number of months that patients were in the study times 12.

t Admissions per patient ranged from 0.6, for patients who lived all 12 months, to 2.5, for those who died in 1984. Lifetime admissions for those dying in 1984 numbered 3.2 per patient.

u In 1985 Lennon reported an average length of stay of 17 days (Lennon, 1985).

v Fifteen percent of admissions spent time in an intensive care unit.

w Per diem amount that hospitals billed Medicaid, which corresponds to a daily commercial rate of $892.

x Uncollectibles on average were $5,214 per AIDS patient, 3.4 times greater than for an average patient.

y Lower figures were used in higher cost estimates, and higher figures were used in lower cost estimates.

z Although the study did not refer to a discount rate, the study may have used a discount rate of 10 percent and termed the procedure used "inflation adjustment".

Table 2. -- Per Unit Costs of AIDS[a]

Category	Belmont, (N.Y.C.)	Berger (Md.)	Bowen (Calif.)	Gamble (So. Calif.)	Hardy, et al. (U.S.)	HIAA/ACLI (U.S.)	Hull (N. Mex.)	Kiser, et al. (Calif.)	Landesman	Lennon, 1987 (Belle Glade,) Fla.)	Potts, et al. (Ala.)	Shultz, et al. (Minn.)	Scitovsky, et al., 1986b (San. Fran.)	Scitovsky and Rice, 1987 (U.S.)	Seage, et al., (Boston)
Cost per AIDS hospital admission															
Mean			$11,121	$16,652						$6,887	$10,588		$ 9,024	$17,000	$14,189
Median													6,248		
KS													5,695		14,874
PCP													14,120		13,520
KS and PCP															10,499
Other infectious diseases													10,682		
Other neoplasms													9,665		
Diseases of blood													2,440		20,633
All other													6,125		
Regular room use only													7,331		
At least one ICU day													23,360		
Private Insurance											10,292				
Indigent											11,982				
California Medicaid								$ 8,500[b]							
Los Angeles								12,300							
San Francisco								6,700							
Rest of California								8,500							
California commercial								12,500							
Hospital cost															
Per AIDS patient							$14,200 - 19,1000		$42,000[d]	$ 7,939	23,295			28,900	22,097
Blue Cross/Blue Shield															30,350
Private insurance															9,832
Medicaid															21,911
No insurance coverage															12,357
Per AIDS patient year[e]															42,517
Outpatient AIDS cost															
Per patient								9% med. costs[f]						3,000	2,668
Per patient year															3,988
Lifetime costs per AIDS patient															
Direct medical costs			68,565												
Medicaid, Calif.								$59,000							
Los Angeles								70,000							
San Francisco								52,000							
Rest of California								65,000							
Non-Medicaid, Calif.								91,000							
Los Angeles								109,000							
San Francisco								74,000							
Rest of California								110,000							
Hospital costs	$24,517[g]	$27,500			$147,000[h]								27,571[i]		

Table 2. -- Per Unit Costs of AIDS[a] (Cont'd)

Category	Belmont, (N.Y.C.)	Berger (Md.)	Bowen (Calif.)	Gamble (So. Calif.)	Hardy, et al. (U.S.)	HIAA/ACLI (U.S.)	Hull (N. Mex.)	Kiser, et al. (Calif.)	Landesman	Lennon, 1987 (Belle (Glade,) Fla.)	Potts, et al. (Ala.)	Shultz, et al. (Minn.)	Scitovsky, et al., 1986[b] (San. Fran.)	Scitovsky and Rice, 1987 (U.S.)	Seage, et al., (Boston)
Personal medical cost per case															
AIDS															
Mean			$35,533[j]			$36,158[k]					$1,000[l]			$35,592[m]	24,764[n]
Lived all year													7,026		
Died during year													23,425		
Diagnosed, not died, during year													12,040		
Los Angeles			46,671												
San Francisco			33,909												
Bay Area			37,953												
Hospital deaths			68,565												
ARC						$33,332									

[a] See table 1 for the methods used by each study. Because of the differences in methods, results may not be comparable across studies.

[b] Costs per person were higher near onset of AIDS and near death. Billed charges were used to estimate non-Medicaid costs. Hospital inpatient charges were broken down by major service categories.

[c] Data pertain to 21 admissions of 15 patients, most of whom remained alive. Some patients had additional care outside the State. Dates were not given.

[d] Citation was from J. Bienstock, with no details given on composition of costs. The cost of inpatient care for newly diagnosed patients (at least 8,000) was estimated as $336 million for 1985 and the annual cost to society was estimated at more than half a billion dollars.

[e] Hospital cost per patient is the cost divided by the number of patients alive at any time during the year (or other time period). Hospital cost per patient year is the cost divided by the number of months that patients were in the study time 12.

[f] Services not provided to inpatients accounted for 9 percent of all Medicaid medical costs and included more than hospital outpatient services (see table 2). Assuming a life expectancy of 8 months, the study estimated average total Medicaid costs at $59,000, the commercial equivalent of $91,000.

[g] Excludes professional services. Relates to costs over 16 months of the study period.

[h] Includes inpatient hospital and physician costs.

[i] Figure refers to inpatient hospital and professional costs. The authors also estimated that lifetime hospital costs per AIDS patient across the United States ranged from $60,000 to $75,000, but it was not clear whether the U.S. figure included inpatient professional costs.

[j] Study also reported cost per case by certain diagnostic codes.

[k] Excludes reinsurance claims.

[l] Average of cost estimates taken from the national literature.

[m] For 1986.

[n] Cost per patient alive during the year. Cost per patient year was $46,505.

layer of medical expenses that was totally unexpected only a few years ago. To the extent that HIV continues to be transmitted, increasing rates of AIDS and HIV infection will fuel even higher medical expenses.[8]

The 'reported sources of payment have varied widely. It has been estimated that Medicaid has paid for the care of from 12 to 65 percent of patients (depending on the type of hospital); Medicare has covered 1 to 3 percent of patients; private insurance, including Blue' Cross/Blue Shield and commercial policies, has covered 13 to 65 percent of patients; and those with no insurance, including indigent people, have ranged from 2 to 40 percent of patients (table 3). Researchers at the Health Care Financing Administration (HCFA) have estimated that, combining Federal and State costs, Medicaid has paid about 23 percent of AIDS medical costs and that by 1991 direct medical costs of AIDS will consume 2.5 percent of Federal Medicaid payments (US HCFA, 1986). These estimates assume that Medicaid covers 40 percent of AIDS patients. Like the cost studies from which they are drawn, the reports cited in table 3 generally include inpatient care, but vary in the scope of other services included. All estimates seem to exclude long-term care and (except for one) home care, types of care that may well not be covered by insurance (HIAA, n.d.; Farley, 1986), and some exclude physician services and ambulatory drugs as well (See table 1). Moreover, the data known to have been compiled fail to indicate the cost burden on various payers--including patients and their families, private insurers, and government programs--because the data relate to a moment in time, not payment for AIDS treatment over the course of the disease.

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8 One would expect health insurance premiums of Private insurers to rise to the extent that AIDS cause medical expenditures to rise for age groups that have historically had low expenses.

Table 3. -- Estimated Sources of Payment for Personal Medical Costs of AIDS[a]

Study	Medicaid	Medicare	Private Insurance			None/ self pay	Indigent	Other
			Total	Blue Cross/ Blue Shield	Commercial			
Belmont, et. al.[b]	20% patients	10%		46%	7%	24%		
Berger[c]	19.7% adms. 14% hosp. cost							
Bouff rd	65% patients	1%		13%			21	
Gamble[d]	23.4% hosp. charges	3.4%		13.3%				59.9%
HIAA/ACLI					100%			
Hull[e]	58% hosp. cost		25%			17%[f]		
Kizer	12% patients		43.4%					
Kizer, et. al.	8% costs							
Lenon, 1987[g]	16.7% patients	12.5%			19.4%		40.3%	11.1%
Potts, et. al.	6.8% adms. 9.6% hosp. cost 1.4% hosp. payments[h]	6.8% adms. 2.8% hosp. cost 3.7% hosp. payments	63.6% adms. 61.8% hosp. cost 94.9% hosp. payments			22.7% adms. 26.0% hosp. costs 0 hosp. payment		
Scitovsky, et al., 1986a[i]	18-65% patients	1-3% patients	13-65% patients					2-35% patients
Scitovsky in Luehrs	30.5% cases	2.6%	43.3%					23.6%
Seage, et al.	18% patients			47%	18%	18%		

[a] Boven; Hardy, et al.; Landesman; Lennon; Shultz, et al. and Scitovsky, et al., 1986b reported no information on payment sources.

[b] Nine percent of patients had changes in insurance coverage from initial admission, mostly from Blue Cross or self pay to Medicaid. Not noted in the table is that an additional 2 percent of patients were covered by 1199 Union.

[c] About 19 percent of the study population had Medicaid coverage, and Medicaid paid 9 percent of all (not only AIDS) hospital costs in fiscal year 1984.

[d] The rate of uncollectibles for AIDS charges has been 3.4 times the average for other diagnoses (Gamble, 1985 Starr, 1987).

[e] For the University of New Mexico hospital. All AIDS patients who had private insurance on their first admission were on Medicaid for subsequent admissions.

[f] Specified as self pay/indigent.

[g] For Jan. 1, 1985 to Jan. 31, 1987. The entry in "Other" refers to cases paid by county welfare.

[h] Percentage of total hospital costs paid by third parties for the 20 AIDS cases studied.

[i] Based on figures from several other studies reviewed by the authors.

Also noteworthy is the different distribution of payment for AIDS expenditures compared with payment for total U.S. hospital and physician services (US, DHHS, 1986). In 1985, private insurance paid 36 percent of all hospital care and 45 percent of all physician services, in the same range as estimates for AIDS payments. But Medicaid seems to pay a much higher percentage and Medicare clearly pays a lower percentage for AIDS than for overall health care. In 1985, Medicaid paid 9 percent of general hospital care and 4 percent of general physician services, compared with estimates of 12 to 65 percent for AIDS, and Medicare paid 29 percent of general hospital care and 21 percent of general physician services, compared to estimates of 1 to 3 percent for AIDS. Medicare's lower share reflects the younger age groups that have contracted AIDS and their short surival time, which has made it unlikely that AIDS patients live long enough to qualify for benefits as disabled persons. Medicare's share will rise to the extent that AIDS patients survive longer and qualify for coverage.

Another longstanding policy issue is how much to allot to a particular disease and, within that total, how to allocate resources between prevention and treatment, in this case, between preventing the transmission of HIV infection and treating people who are already infected or who have symptoms of disease. Prevention entails not only medical research to develop vaccines or dregs, but also epidemiological research to describe and predict the spread of the disease and educational efforts to interrupt viral transmission. During 1986 an estimated $ 542 million was spent on activities that relate mostly to prevention; research received 43 percent of that amount, blood screening 51 percent, and education 6 percent. More than twice as much, $1 billion, was spent in 1986 to treat AIDS (Scitovsky and Rice, 1987). In considering the appropriate amount to allocate for prevention and the appropriate mix of preventive activities, one should note that there is no indication that

transmission of HIV infection has peaked.

To the extent that intensified preventive activities could reduce HIV transmission and future AIDS cases, the allocation of expenditures has implications not only for future medical costs and their sources of payment, but also for who bears the burden of the disease. Screening of donated blood for HIV infection is intended to arrest HIV transmission through the blood supply, the route by which hemophiliac AIDS patients and other transfusion-associated cases have contracted the disease. Continuation of the present pattern of disease would entail a substantial burden for employers of people who become ill from HIV infection, since so much of the total AIDS costs stems from illness and premature death among people in their working years. Certain groups, such as homosexual and bisexual men and IV drug abusers, have been identified as being at high risk of AIDS. In addition, a disproportionate percentage of AIDS patients have been black and Hispanic, 39 percent of AIDS patients vs. only 18 percent of the general U.S. population, and blacks and Hispanics have accounted for an enormous share of female and pediatric AIDS patients, 73 percent and 80 percent respectively (US HHS, MMWR, 10/24/86).

Some countries, such as Switzerland "and Britain, have undertaken more widespread and more intensive educational efforts to prevent HIV infection than the United States. But recently the Surgeon General of the Public Health Service, Members of Congress, and the Institute of Medicine have called for expanded efforts to prevent the spread of the virus in the United States (KOOP, 1986; IOM, 1986; S.63) .

Issues more specific to AIDS concern data collection and hospital payment for AIDS cases. Estimating the costs of AIDS and the impact of HIV infection has been greatly hampered by the difficulty of identifying AIDS cases in claims files and hospital records. In July 1986, new codes for AIDS and other HIV infections were added to the International Classification of

Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) (Federal Register, 1986). As medical providers and insurers begin to use the new codes, researchers and policymakers will find it easier to identify and track treatment of the disease. ICD-9-CM codes form the basis of Medicare's diagnosis-related groups (DRGs), which in turn determine Medicare's payment for hospital operating expenses. Although the new ICD-9-CM codes became effective October 1, 1986, HCFA stated in the Federal Register notice that it did not expect their use to change the classification of cases in the DRG system.

Some studies of hospital costs have found that payments for AIDS cases have fallen far short of the costs incurred for their care, primarily for inpatient services. For example, daily care for an AIDS inpatient in New York City municipal hospitals cost $800, but the hospitals received only $500 in payment (Boufford, 1985). For certain Alabama hospitals, Potts, et al. reported that Medicaid revenue fell far below hospital costs, while Medicare's payments exceeded hospital costs (table 3). It is not clear what underlies this shortfall--low payment rates of certain payers, nonpayment of charges by patients (bad debts), inefficient management of patient care, or hospital accounting methods, although Medicaid's low payment rates are well known. This situation, then, raise policy issues concerning adequate compensation of hospitals providing care to poor people.

Better data on costs and payment rates could improve public and private policymaking. The amount and method of payment provide incentives regarding how and where AIDS cases are treated, such as intensive care units, outpatient clinics, hospices, or homes, and these decisions in turn may well influence the total costs associated with the disease and the quality of life of the people affected. Distributive justice and rational policymaking also require adequate compensation of medical providers that care for a disproportionate

share of AIDS patients who cannot afford to pay for their own care.

By far the most comprehensive and rigorous study of national costs was performed by Anne Scitovsky, Dorothy Rice, and their colleagues for the Centers for Disease Control (CDC) (Scitovsky, et al., 1986a; Scitovsky and Rice, 1987). According to Scitovsky, et al.'s estimates, in 1986 the average cost of the personal medical expenses of an AIDS patient alive at any time during the year was $35,592, and lifetime hospital costs in 1984 prices ranged from $60,000 to $75,000 (Scitovsky, et al., 1986b; Scitovsky, et al., 1987). Scitovsky and her colleagues also estimated that in 1986 total costs associated with AIDS, including direct and indirect costs (See table 4), were $8.7 billion and will reach $66.5 billion in 1991 (Scitovsky and Rice, 1987). In these calculations, indirect costs (productivity losses) of sickness and death dwarf direct medical costs, a pattern that reflects primarily the premature deaths of working-age adults. The great increase in total costs by 1991 stems from projected increases in the prevalence of AIDS cases, 172,800 in 1991 compared with 31,440 in 1986.

The studies reviewed give far from a complete picture of costs. Primarily because of data limitations, many studies have excluded the cost of most services used outside the hospital, such as. drugs, long-term care, hospice or home care, ambulatory physician visits, ambulatory ancillary services, counseling, and community support services. These nonhospital services will account for a larger part of direct medical costs if hospitalizations are avoided or shortened and if medical developments extend the lives of AIDS patients. Furthermore, estimating the cost of nonhospital services is necessary to calculate the total medical cost of different approaches to managing AIDS and to analyze fully the cost implications of relying less on hospitalization and more on community support services, as exemplified by the San Francisco model.

Table 4. -- AIDS Costs and Projections[a]

Category	Berger (Md.)	Hull[b] (N. Mex.)	Kizer[c] (Calif.)	Potts, et al. (Ala.)	Shults, et al.[d] (Minn.)	Scitovsky and Rice, 1987[e] (U.S.)
1985						
Total						$4,836 mil.
Direct						949
Medical	$4. mil.		$64.1 mil.			630
Medicaid			5.0			
Private Sector			59.1			
Nonpersonal						319
Indirect						3,887
Mortality						3,626
Morbidity						261
1986						
Total					$38.0 mil.	8,674
Direct						1,662
Medical			135.0 mil.		5.8	1,119
Inhospital		$0.6-2.86 mil				
Medicaid			10.6			
Private Sector			124.4			
Nonpersonal						542
Indirect					32.2	7,012
Mortality					31.0	6,556
Morbidity					1.2	456
987						
Total					76.8	
Direct						
Medical			236.4 mil		11.6	
Inhospital		1.2-5 72 mil.				
Medicaid			18.6			
Private Sector			217.8			
Nonpersonal						
Indirect					65.2	
Mortality					62.8	
Morbidity					2.4	
988						
Total					137.3	
Direct						
Medical			371.3 mil.		20.8	
Inhospital		2.4-11.44 mil.				
Medicaid			29.1			
Private Sector			342.2			
Nonpersonal						
Indirect					116.5	
Mortality					112.2	
Morbidity					4.3	

Table 4. -- AIDS Costs and Projections[a] (Cont'd

Category	Berger Md	Hull[b] N M	Kizer[c]	Potts, et al. A	Shultz, et al.[d] Minn	Scitovsky and Rice, 1987[e] U S
1989						
Total					229.4	
Direct						
Medical			571.9 mil.		34.7	
Medicaid			44.9			
Private Sector			527.0			
Nonpersonal						
Indirect					194.7	
Mortality					187.5	
Morbidity					7.2	
					364.4	
990						
Total						
Direct						
Medical			853.7 mil.		55.0	
Medicaid			67.0			
Private Sector			786.7			
Nonpersonal						
Indirect					309.4	
Mortality					297.9	
Morbidity					11.5	
991						
Total						66,464
Direct			1,225.9 mil.			10,869
Medical						8,544
Inhospital				$8,526.1 mil.[f]		
Medicaid			96.3			
Private Sector			1,129.6			
Nonpersonal						2,325
Indirect						55,595
Mortality						52,280
Morbidity						3,315
1986-1990						
Total					846.0	
Direct					128.0	
Indirect					718.0	
Mortality					691.5	
Morbidity					26.5	

[a] See table 1 for the me hod used by each study. Because of the differences in methods, the results are not strictly comparable across studies.

These estimates assume AIDS cases double every 12 months. I≤ cases double every 6 months, inhospital costs were estimated as $1.8-$8.58 mil. in 1986 $7 2-$34 32 mil. in 1987, and $28.8-$137.28 mil. in 1988.

[c] Estimates are for California during fiscal year July 1, 1984 through June 30, 1985.

These estimates are from a model that predicts a gradual increase in the time during which cases double--8, 10, 12, 14, and 16 months per doubling. This model was a good predictor of cases from Jan.-Aug. 1986. For "direct health care costs," an estimate of $91,000 per case is used as the middle range of $30,000-$147,000 per case lifetime costs cited in the literature. These costs thus seem limited to hospital costs, but refer to lifetime costs even though the estimate made here is an annual one.

[e] Medium estimate from the 1987 study, which is based on the CDC's h gher, revised projections of AIDS cases (18,720 n 1985, 31,440 in 1986, and 172,000 n 1991).

[f] After adjustment for inflation (Potts, 1987).

In addition, these studies do not give a complete accounting of the costs of infection with HIV, the organism that causes AIDS, and the spectrum of symptoms that it causes. For example, with one exception, the studies reviewed here pertain only to AIDS, and none included pediatric cases. In part, this incomplete accounting has resulted from reliance on incomplete records of public health departments, hospitals, and insurance companies. The situation also reflects the fact that AIDS, HIV, and the manifestations of HIV infection have been detected so recently that classification and recording systems are still evolving as knowledge of the disease grows.[9] Another reported factor is the reluctance of people with HIV infection or symptoms to participate in studies, mainly because they strongly guard confidentiality.

Existing studies also do not indicate how costs and sources of payment change over the course of AIDS or other symptoms of HIV infection. It has been theorized that costs peak around the time when AIDS is first diagnosed and again when the patient is close to death and that as the disease progresses, patients without insurance spend their own assets and may come to rely on Medicaid and other government programs. However, the total cost burden on different payers--private insurers, government programs, patients, their families and friends--and how it changes over the course of the disease are not known.

Several studies projected the costs that would be associated with AIDS in future years on the assumption that present patterns of costs will continue. As some of the authors noted, great uncertainty surrounds these estimates because conditions are constantly changing. Knowledge and management of the disease are changing rapidly in ways that will almost certainly affect incidence and transmission of HIV infection, prevention of

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9 Seage and his colleages are analyzing the costs of ARC patients at a Massachusetts facility (Seage, 1987).

infection, treatment of symptoms, and "survival of patients.

Although all of these factors in turn have implications for costs, the direction of change is unclear. Preliminary results of a 2-year study in Massachusetts support the general impression that the cost of treating AIDS patients has declined. This study of 75 percent of the living AIDS patients treated in Massachusetts found that the cost of treating AIDS decreased at all five hospitals (Seage, 1987). Other factors, though, may increase treatment costs. Neurological symptoms such as dementia, which may require long-term institutional care, have only recently been identified in AIDS patients. The drug azidothymidine (AZT) has only recently been found to improve the condition and prolong survival of AIDS patients with certain symptoms. Other drugs are being tested in the hopes that they will arrest the progression of ARC to AIDS. How these developments on balance will affect treatment, the course of the disease, and the costs of AIDS is not yet clear. Expenditures associated with AIDS and HIV infection will clearly rise as viral transmission continues largely unabated. Expenditures may also rise if drugs that prolong survival must be continued throughout life.

REVIEW OF COST ESTIMATES~

The great variation in methods used by the studies reviewed make comparisons of cost estimates difficult and often impossible. The studies varied in their definition of AIDS, scope and definition of costs, time period, and geographic area. Furthermore, projections of the costs of AIDS and HIV infection in future years are handicapped by the continuing spread of the virus and the dynamic nature of treatment regiments.

Definition of the Health Problem

The costs to be included in an analysis depend on the definition of the health problem under study and the perspective taken. For national reporting purposes, the CDC has restricted the definition of AIDS to people who have antibodies to HIV, a deficiency of T helper cells, and certain opportunistic infections, presumably because HIV had impaired their immune systems (IOM, 1986; Kizer, et al., 1986).[10] Under this definition, people who are infected with HIV and have symptoms attributed to the virus are not considered AIDS patients unless they have had one of these specific infections. People with AIDS-related complex (ARC), for example, have symptoms that range from swollen lymph glands, recurrent fevers, and unintentional weight loss to dementia and fulminant disease that leads to death (IOM, 1986). In addition to people with AIDS and ARC, many people have been infected with the virus but have no symptoms of disease. Although it is not clear what percentage of infected people are likely to develop AIDS or ARC, the Public Health Service has estimated that 20 to 30 percent of the 1 to 1.5 million people in the United States thought to be infected in mid 1986 will develop AIDS within 5 years (Coolfont Report, 1986), Estimates of the percentage of people with HIV infection who are likely to develop AIDS have risen as infected cohorts have been followed over time, and the percentage may well increase as people are followed for longer periods. Based on such observations, some researchers have estimated that over 50 percent of the people infected with HIV will

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10 In 1986, the CDC supplemented its definition for nationalreportingwith one based on clinical expression of disease and intended for public health purposes. The 1986 classification system consists of 4 groups that range from acute and asumptomatic infection to persistent generalized lymphadenopathy and other disease, including overt AIDS (CDC Classification System, Morbidity and Mortality Weekly Report, 1986). In addition, the CDC is considering revisions of its national reporting (surveillance) definition, such as adding a *category* for presumptive AIDS and expanding the diseases considered indicators of AIDS (CDC Revising, AIDS Record, 1986).

eventually develop AIDS (Volberding, 1987), and a researcher in Germany has predicted 75 percent will develop active AIDS within 7 years (German Researchers, Dec. 15, 1986).

All of the studies reviewed in this Staff Paper documented costs associated with AIDS, but only the survey by the Health Insurance Association of America and the American Council of Life Insurance collected information on ARC (see table 1). The results of that survey give only a partial picture of ARC costs since the data pertain only to claims paid by the insurance companies surveyed and exclude costs paid by other payers, such as patients and government programs. These same limitations apply to the survey's estimates of AIDS costs. The survey's estimates of direct medical costs for AIDS were similar to those for ARC, $36,159 compared with $33,332 per case (see table 2). However, disability claims for ARC patients fell substantially below those for AIDS ($8,293 vs. $29,566). These figures should not be considered definitive. The survey left the definitions of AIDS and ARC to the respondent companies and asked for information from fall 1985 and before instead of for a specific time period. Nor was information available on benefits and lengths of coverage, factors that could have accounted for the different levels of disability claims.

None of the studies cited attempted to document the costs of people who are infected with HIV but have not developed AIDS or ARC. These people are likely to obtain initial counseling and over time may seek and receive more medical care in order to rule out serious disease (IOM, 1986). Only the study by Scitovsky and her colleagues included costs related to general HIV infection. Their estimates included the costs of screening blood for HIV, research on HIV, and general education to prevent the spread of the infection, but not costs for the personal medical costs of individuals infected with HIV (Scitovsky, et al., 1986; Scitovsky and Rice, 1987).

Scope of Costs Included

A comprehensive study of AIDS costs would include all of the costs associated with the use of resources for the disease, regardless of where they occurred or who paid for them. Costs directly attributable to the disease consist of direct medical costs, which are incurred for the care of specific patients, and direct nonpersonal costs such as research, education, and screening of donated blood, which are targeted more generally to the disease or to groups in the population. Indirect costs, which are intended to calculate 'the effects of sickness and death, are often measured by the losses in worker productivity that result from illness, disability, and premature death.[11] Although it is well recognized that the burden of illness also includes the suffering of patients, their families, and their friends, no appropriate method has been developed to calculate these costs, and they are usually left out of quantitative estimates.[12]

The perspective of the analysis affects the costs to be included. The perspective of society is the broadest and encompasses total resource costs, whether they are paid by patients, insurance companies, employers, government programs, or others. The costs to a government program, such as Medicaid, or an insurance company would be more limited than society's to the extent that

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11 An alternative method of placing a value on health and life is to measure the amount that people are willing to pay to avoid sickness, disability, or death. The 'human capital" approach using worker productivity has been more extensively used to calculate the costs of different diseases and is the only one known to have been applied to the costs of AIDS. Both approaches have drawbacks that are related to distributional issues. Since the human capital method values people's health and lives according to their earning levels, it values groups with higher average incomes (men, whites, working age, wealthy) more highly than people with lower average incomes (women, blacks, children, elderly, poor). Similarly, people with higher incomes are more able and hence more willing to pay larger amounts to forego illness and death.

12 What people are willing to pay to avoid a medical problem would theoretically include the effect of pain and suffering.

their coverage excludes certain services and settings (long-term or home care), restricts the number or cost of services (hospital days or mental health services), or requires patient cost sharing.

None of the studies reviewed included the full scope of costs associated with AIDS (table 1). There was a great deal of variation in what was and was not included. All seemed to include inpatient hospital costs, either explicitly or implicitly, by stating that they included direct medical costs. In general, inpatient hospital services are the most likely medical care to be covered by insurance (Farley, 1985), but cost estimates based on claims submitted to private insurers and public programs may include only part of inpatient expenses, depending on patient cost sharing and benefit limitations. It is not clear whether some of the estimates from specific hospitals included inpatient physician charges. A minority of the studies included ambulatory physician and ancillary services. Only Kizer, et al. reported expenses for ambulatory drugs, home health, and long-term care, and the extent of coverage for these service categories was not clear (Kizer, et al., 1986).

Only the national estimates of AIDS costs by Hardy and Scitovsky and Shultz' estimate of AIDS costs in Minnesota added indirect costs connected with sickness, disability, and premature death (Hardy, et al., 1986; Shultz, 1986; Scitovsky and Rice, 1987) (table 4). As Scitovsky and her colleagues stressed, these indirect costs have dwarfed direct ones. For 1986, indirect costs were estimated at $7.0 billion for the entire United States and $32.2 million for Minnesota, compared with direct costs of $1.7 billion for the United States and $5.8 million for Minnesota (Scitovsky, et al., 1987; Shultz, 1986). More than 90 percent of these indirect costs stemmed from premature death rather than illness or disability, a reflection of the fact that deaths

from AIDS have been concentrated among people, primarily men, at the beginning and middle of their working lives.

The estimate of U.S. costs by Scitovsky and Rice was the only study to calculate the nonpersonal direct medical costs of general activities to further knowledge or prevent infection (Scitovsky and Rice, 1987). This is an important omission from other studies, since Scitovsky and Rice estimated that such costs in 1986 amounted to $542 million, almost 1/3 of all direct medical costs. These estimates by Scitovsky and Rice represent by far the most comprehensive and most rigorous calculation of national AIDS costs (Scitovsky, et al., 1986; Scitovsky, et al., 1987).

Although Scitovsky and Rice and Shultz, et al. took the perspective of the total society in their cost estimates, other studies were more limited. Most enumerated costs to specific hospitals or inpatient hospital charges to payers, especially third-party payers, such as Medicaid: Although Bowen did not include indirect costs, he calculated total charges billed, regardless of who paid for them.

Time Periods Used

The studies also varied in the time periods considered (table 1). Three studies, (the two by Scitovsky and others and one by Seage, et al.) calculated annual costs, that is, the costs associated with AIDS during a 12-month period. Five studies, including one by Scitovsky, et al. and one by Hardy, et al., estimated the "lifetime" costs of AIDS patients from diagnosis to death. The lifetime estimates by Scitovsky and Hardy were limited to hospital and physician inpatient services, but the ones by Bowen and Kizer included a range of ambulatory services as well. In general, the other studies reported data for more than one year, often according to what was

available in the data set being used.

Geographical Differences

Many different geographical areas were used for the cost estimates. As one would expect because of their high incidence of AIDS, New York City and California (San Francisco, Los Angeles, and the State) were the most frequently studied. These areas along with others were also the sources of data for Hardy's and Scitovsky's national estimates. Taken together, the cost studies provide information from areas of high (New York City, California, Florida), medium (Boston, Maryland, Minnesota), and low (Alabama, New Mexico) numbers of reported cases (US DHHS, MMWR, 12/12/86).

AIDS patients in San Francisco have had the shortest average lengths of hospital stay, even for patients on Medicaid (Kizer, et al., 1986; Scitovsky, et al., 1986b). It also appears that San Francisco patients have the lowest lifetime hospital costs. This experience has been widely attributed to the support services and the different patient mix in the San Francisco community. It has been suggested that since 97 percent of San Francisco AIDS patients are homosexual or bisexual men, they are more likely to have social support to enable earlier discharge from hospital than AIDS. patients in New York, for example, where 30 percent of AIDS patients have been intravenous (IV) drug users. However, no significant differences have been found in lengths of stay or hospital costs between IV drug users and other AIDS patients in New York (Anderman in Scitovsky, et al., 1986b). There is more support for the possibility that Kaposi's sarcoma, which is more common among male homosexual AIDS patients, is less likely to require hospitalization than other opportunistic infections and that community services to shorten or avoid hospitalization are more available in San Francisco.

Average lengths of stay reported in New Mexico; Alabama; Belle Glade, Florida; and Los Angeles were also below Scitovsky's national estimate of 20 days (Gamble, 1985; Hull, 1986; Kizer, et al., 1986; Lennon, 1985; Potts, et al. 1986). The information presented in these studies is insufficient to draw further conclusions about the relative cost of hospital or other medical services. It is clear that the average length of stay of 31 days and the average lifetime hospital costs of $147,000 reported by Hardy, et al. for the first 10,000 AIDS were much higher than subsequent reports (Hardy, et al.) Scitovsky and her colleagues estimated that lifetime hospital costs in 1984 prices most likely ranged between $60,000 and $75,000 (Scitovsky, et al., 1986b). Perhaps, as has been suggested, it took longer to diagnose and determine the treatment of the early AIDS patients that provided the basis for Hardy's estimates. And as the hi@ fatality rate of the disease became widely known, people in the terminal phase of AIDS may have been treated less intensively and hence less expensively.[13]

PROJECTIONS OF AIDS COSTS

Five of the studies reviewed made projections of the costs that would be associated with AIDS in future years (tables 1 and4). Only those by Scitovsky and her colleagues related to the United States as a whole; Hull projected costs for New Mexico, Kizer for California, and Shultz for Minnesota. Since the 1987 Scitovsky study incorporated more recent CDC predictions of AIDS but used the same methods as her 1986 study, only the latter estimates will be discussed here.

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13 It has also been suggested that Hardy's estimates were high because much of their data on average length of stay came from New York City, which may have had higher than average stays (Hardy, 1987) and that there was a selection bias toward sicker (terminally ill) patients from looking at people in hospitals over a short time period (Seage, 1987).

Scitovsky and Rice predicted that by 1991 the annual total costs associated with the 172,000 AIDS patients estimated for that year would reach $66.5 billion, up from $4.8 billion in 1985 for 18,720 patients and $8.7 billion in 1986 for 31,440 patients (Scitovsky and Rice, 1987). Like their estimates of current costs, these estimates included direct (medical and nonpersonal) costs and indirect (mortality and morbidity) costs. In each year, indirect costs accounted for about 80 percent of the total, mostly because of premature mortality.

Shultz counted direct and indirect costs, but not nonpersonal direct costs in his estimate that from 1986 through 1990 Minnesota's AIDS costs would total $846 million (Shultz, et al., 1986). Hull estimated that annual inhospital costs for New Mexico AIDS patients would range from $2.4 to $11.44 million in 1988 if cases doubled every 12 months (Hull, 1986), close to their current national rate. Both of these studies used Scitovsky's and Hardy's estimates of per case costs rather than the costs observed within the respective States. Hull used Scitovsky's figures for the low end and Hardy's for the upper end of his estimated range, and Shultz used an average of *Scitovsky's* and Hardy's figures.

Kizer limited his projections to direct medical costs and used Medi-Cal (California Medicaid) claims as the basis for estimates of Medicaid and private sector costs. Assuming that Medicaid pays and would continue to pay about 8 percent of direct medical costs, he estimated that their total would rise from $135 million in fiscal year 1985-86 to $1,225.9 million in fiscal year 1990-91 (Kizer, 1986).

Although these studies differed in the estimated number of future AIDS cases, per case medical costs, and the types of costs included, they all based their projections on the assumption that present patterns of costs would

continue. Scitovsky and her colleagues in particular realized the drawbacks of this approach, but also recognized that they had no basis on which to predict changes in the direction of future costs (Scitovsky, et al., 1986).

Because knowledge about AIDS, its prevention, and treatment is evolving at a rapid rate, many factors that affect the incidence, symptoms, and management of the disease may change dramatically over the next five years in ways that would affect costs. As noted above, areas of uncertainty with important implications for costs are the number of infected people who will develop AIDS or other symptoms and the rate of viral transmission and spread of the disease. Conversion to AIDS seems to increase 5 to 7 years after infection (Volberding, 1987). Since AIDS was first identified in the United States in the early 1980s, information is still unfolding on the natural course of HIV infection and the probability that an infected person will develop AIDS."

In the long run, the rate of transmission of the virus may change, either by increasing or decreasing, with implications for the number of infections-and the incidence of disease. The rate of transmission could be slowed by screening donated blood for HIV and hence reducing transfusions of infected blood and by changes in sexual practices of high-risk people. On the other hand, HIV could become more prevalent among current low-risk populations, such as heterosexuals and children. And there are reports of infection with a variant of HIV termed HIV-II (Clavel, et al., 1986). Since tests currently used to screen donated blood do not detect infection from this slightly different virus, development and use of an additional screening test, and additional costs, may be needed to ensure a safe blood supply.

Because complications of AIDS seem to differ among high-risk groups, changes in incidence patterns could influence the manifestations and hence the

cost of the disease. For example, treatment for Kaposi's sarcoma, which has been more likely to afflict AIDS patients who are male homosexuals, has been. less expensive than treatment for pneumocystis carinii pneumonia, which is more common among IV drug abusers with AIDS. A lower incidence of AIDS among male homosexuals and a higher incidence among IV drug abusers could therefore result in higher average costs of treatment. Higher incidence among infants may also raise average and total costs. In general, these infants have become infected in utero (Selwyn, 1986), so more pediatric cases would be expected as HIV infection spreads among heterosexuals. The medical care of infants with AIDS may be especially costly if they are institutionalized for long periods because their mothers are incapacitated with AIDS. .

The management of AIDS cases appears to have changed and will continue to change over time. However, the direction of the change in costs is unpredictable. Some developments lower inpatient use and probably total costs. There are reports that AIDS patients are less likely to be admitted to intensive care units than they were when less was known about the course of the disease and that the average length of hospital stay has declined (Scitovsky, et al., 1986a). Seage's preliminary data for Massachusetts, mentioned above, suggests such a decline in hospital treatment costs. In addition, some services, such as blood transfusions for anemia, that formerly justified hospital admission are now provided on an ambulatory basis. Spurred by the example of community services in San Francisco, other localities are attempting to promote more supportive; less expensive alternatives to inpatient treatment, such as home and hospice care.

Other developments may make management of AIDS and HIV infection more costly. Neurological symptoms, such-as dementia, are increasingly being detected in AIDS patients. Patients with such symptoms may require more

intensive care than can be provided through home care services or hospices. The drug azidothyddine (AZT), which FDA recently approved for AIDS patients with certain symtoms, is expensive ($10,000 - $12,000 per year (Volberding, 1987)) and often requires blood transfusions for resulting anemia, a service that is also costly. There is also the possibility that drugs will be developed to prevent or delay disease in infected people or to retard the progression of the disease inpatients with symptoms. Any of these or other developments that change the length of the disease or the survival rate may also affect the total costs of treatment. Increased knowledge of HIV infection may also lead to higher costs. Based on the possibility that tuberculosis may be predictive of AIDS, the CDC in mid 1986 recommended that people with HIV infection be tested for tuberculosis and that tuberculosis patients in certain instances be tested for HIV infection (US, MMWR, 7/18/86). As noted above, new tests to screen the blood supply for variants of HIV would also add to the costs associated with AIDS. Treatment costs may also rise if people are diagnoses as having AIDS earlier in the course of the disease.

An additional area of uncertainty in cost projections concerns the representativeness of the data that have formed the basis of existing cost estimates and their generalizability to other sites of care and areas of the country. Data have been drawn from a range of hospitals (municipal, private, and teaching hospitals), payers (government and private insurers), and geographical regions. However, in most cases, the categories of costs and disease severity have not been sufficiently standardized to permit comparisons. Furthermore, almost all the data on medical costs have centered on acute-care hospitals. With the exception of data on California Medicaid patients (Kizer, et al., 1986), no information has been available on the costs of long-term care and of ambulatory care separate from hospital outpatient

clinics or on changes in costs over the course of the disease. And none of the studies reviewed included patients' out-of-pocket expenses. Thus, the generalizability and comprehensiveness of existing information have not been established.