
Patterns of Medicaid Expenditures After AIDS Diagnosis

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This article examines average monthly Medicaid expenditures after diagnosis of acquired immunodeficiency syndrome (AIDS) for the diagnosis, mid-illness, and death intervals, as well as Kaplan-Meier estimates of expenditures from AIDS diagnosis to death. A clinical severity measure (the Severity Index for Adults with AIDS [SIAA]) designed to be predictive of patient survival was applied to a population of continuously enrolled New York State Medicaid patients who survived at least 6 months after being diagnosed with AIDS. Our findings suggest that groups of more seriously ill patients who appear to have more intense demand for health care services, especially over the diagnosis and mid-illness intervals, can be identified using the SIAA.

INTRODUCTION

As attempts to contain health care expenditures become a national priority, it is necessary to develop approaches to assess and predict health care costs for populations consuming substantial health care resources. Persons with AIDS present a particular challenge because of the variability of their health care demands, ranging from relatively

low expenditures in stable periods of disease to enormous expenditures for inpatient care of serious complications. Health care expenditures associated with AIDS or infection with human immunodeficiency virus (HIV) have been assessed primarily in three ways. The first approach has focused on evaluating costs of inpatient care episodes (Andrulis et al., 1992, 1987; Fahs et al., 1992; Kelly, Ball, and Turner, 1989; Chupka, Birden, and Andrews, 1992). A second approach includes estimates of the annual costs of care (Bennett et al., 1992; Hellinger, 1991, 1992), while a third method has examined lifetime costs associated with HIV/AIDS care (Hellinger, 1991, 1992, 1993; Hardy et al., 1986; Scitovsky and Rice, 1987; Hay, Osmond, and Jacobson, 1988).

As managed-care approaches assume a stronger foothold in American medicine, analyses of the costs of one particular period, such as an inpatient stay, offer a limited view of health care expenditures for persons with AIDS. Estimates of the costs of care over a year or more are more useful for policymakers and clinicians involved in defining appropriate levels of expenditures for care of this disease. Not only are extended time periods necessary, but expenditure estimates should also account for differences in patient severity of illness. CD4 T-lymphocyte counts have been used to distinguish severity of illness for those who are HIV-infected but have not yet been diagnosed with AIDS (Hellinger, 1993); however, available estimates of annual or lifetime costs of AIDS care do not discriminate among groups of AIDS patients with widely varying clinical courses.

The research presented in this article was supported in part by Grant Number RO1-HS06465 from the Agency for Health Care Policy and Research (AHCPR). Leona E. Markson, Josephine Mauskopf, and Barbara J. Turner are with the Center for Research in Medical Education and Health Care and the Division of General Medicine/ Department of Medicine, Thomas Jefferson University. Linda McKee is with the Department of Information Systems, Thomas Jefferson University. Robert Houchens is with SystemeMetrics, Inc. Thomas R. Fanning is with the New York State Department of Social Services. The opinions expressed in this article are those of the authors and do not necessarily reflect the views or policy positions of the Health Care Financing Administration, AHCPR, Thomas Jefferson University, SystemeMetrics, Inc., or the New York State Department of Social Services.

We studied the association of a clinically based severity measure for persons with AIDS with different expenditure levels incurred within defined intervals after AIDS diagnosis. The SIAA distinguishes four categories of patients with significant differences in survival using data on conditions developed in the first 3 months after AIDS diagnosis (Turner et al., 1991). In this article, we report our application of SIAA categories to examine expenditures in three time intervals after the diagnosis of AIDS for a cohort of New York State Medicaid-enrolled persons with AIDS. Analyses of Medicaid expenditures are of particular policy relevance because Medicaid is the most common payer of health care for persons with AIDS. From 1983 to 1986, Medicaid was estimated to cover costs of care for 50 to 84 percent of all AIDS cases reported in New York State (Fanning et al., 1991). The proportion of AIDS-related hospitalizations in New York financed by Medicaid from 1983-88 increased by 38 percent (Green and Arno, 1990). In a national survey of hospital care for AIDS patients in 1985, Medicaid covered 54 percent of 6,369 AIDS-related admissions studied in 127 non-Federal hospitals (Andrulis et al., 1987).

Total Medicaid expenditures for persons with symptomatic HIV infection in New York were estimated at one billion dollars over a 12-month period from August 1992 to July 1993 (Cosler, 1993). Medicaid payments for AIDS care can be expected to continue to increase because the epidemic has disproportionately affected low-income persons whose only possible source of insurance is Medicaid. Even individuals with greater personal financial resources eventually turn to Medicaid because of the substantial expenditures required for care. Because of the central role of the Medicaid program in paying for AIDS care, approaches to project

anticipated expenditures for AIDS patients are needed by both Federal officials and State Medicaid programs. This article describes an approach used to estimate these expenditures that is sensitive to the clinical diversity of persons with AIDS.

METHODS

Study Population

The patient population for this study was obtained from the New York State Medicaid HIV/AIDS Research Data Base. This data base contains information on inpatient and outpatient service use and expenditures, as well as selected patient demographic characteristics such as age and gender. Information on the patient's clinical course was obtained from diagnostic data coded according to the *International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM)*. Each inpatient record has up to five ICD-9-CM coded diagnoses, and each outpatient record has up to two diagnoses. The claims history for our study population, from AIDS diagnosis to last observed service date, included 38,898 hospital claims, with 67.6 percent of these claims having 4 or 5 recorded diagnoses. The study population was identified by an AIDS case-finding methodology that has been empirically tested (Keyes, Andrews, and Mason, 1991). This methodology searches for conditions in the 1987 AIDS surveillance definition of the Centers for Disease Control and Prevention (1987a), and for use of AIDS-specific services, such as AIDS clinic care or receipt of zidovudine.

The study population was diagnosed with AIDS from October 1983 through April 1990, and was followed until death, the last date of service, or September 1990, whichever occurred first. The sample was restricted to patients 13-60 years of age

(i.e., "adults") at the time of AIDS diagnosis. SIAA was not designed to evaluate clinical severity of pediatric AIDS cases. The Centers for Disease Control and Prevention's (1987b) definition of pediatric AIDS applies to children under 13 years of age at diagnosis, and the SIAA algorithm does not apply to these pediatric patients. We have developed a second severity index for pediatric AIDS populations (Turner et al., 1993a). We analyzed only adult patients who survived at least 6 months after their first AIDS-defining diagnosis. In the total New York State Medicaid HIV/AIDS Research Data Base classified by SIAA during Federal fiscal years (FFYs) 1983-90, 65 percent of the population survived 6 months or more. As a result, the expenditure patterns of short-term survivors, approximately 35 percent of the New York Medicaid AIDS population, are not represented in our analyses. Longer term survivors, as represented by our population, are the ones most likely to be eligible to enter various managed-care programs. The requirement of 6 months of patient history was also necessary in order to obtain sufficient longitudinal information to distinguish expenditure levels associated with the three discrete episodes of care—diagnosis, mid-illness, and death—defined later. These episodes of care are important to evaluate because patient needs and expenditures may vary over the course of advanced HIV infection. Information on variations in expenditure patterns over different episodes of care should be useful for case-management programs, managed-care contracts, or other special programs. The sample was continuously Medicaid-eligible from the date of AIDS diagnosis until last observed service date, to avoid underestimating resource use for patients with intermittent eligibility.

The final study cohort included 8,265 persons with AIDS. The mean age at AIDS

diagnosis was 35.5, with a standard deviation of 7.3 years. Twenty-five percent of the population was female. While the entire sample was continuously Medicaid-eligible after AIDS diagnosis, 21.5 percent of the study population was not Medicaid-eligible in the 6 months prior to their AIDS diagnosis date. These patients could have received AIDS care under another insurance program prior to becoming eligible for Medicaid. Almost 56 percent of the population was enrolled in Medicaid for at least 5 months prior to their AIDS-defining diagnosis date, and an additional 22.5 percent were eligible for 1 to 4 months prior to AIDS diagnosis.

We identified 52 percent of the study population as drug users from ICD-9-CM codes for drug dependence and provider codes indicating services for drug abuse, such as methadone maintenance. To assess the accuracy of our definition of drug use, two New York City hospitals participated in a chart abstraction study. From this blinded chart review of 93 Medicaid-enrolled persons noted in charts to be drug users, 81 (87 percent) were correctly identified by our Medicaid drug use algorithm. Because the New York State HIV/AIDS Research Data Base generally had more longitudinal records on patients than it did charts for specific hospitals, some of the non-matching cases may have been due to failure to identify drug abusers in the medical records (Turner et al., 1993b). Chart review data were used to evaluate our data, and not to assign drug use information.

Severity Index for Adults With AIDS

The first AIDS-defining condition and date of this diagnosis for each patient were determined from the SIAA. The SIAA algorithm examines patterns of ICD-9-CM codes in the patient's longitudinal clinical

Table 1
AIDS-Defining Diagnoses and Complications,¹ by Severity Group and Level: Severity Index for Adults With AIDS (SIAA)

Severity Group	AIDS-Defining Diagnosis	Severity Level	Complications ²
1	Kaposi's sarcoma — no organ involvement	0	No complications
	Herpes simplex — mucocutaneous	1	Candida esophagitis
	Disseminated tuberculosis		Bacterial pneumonia
	Candida esophagitis		Pulmonary tuberculosis
	Wasting syndrome		Chronic mucocutaneous herpes simplex
	Salmonella sepsis		Cutaneous Kaposi's sarcoma
2	Pneumocystis carinii pneumonia	2	Visceral Kaposi's sarcoma
3	Disseminated atypical mycobacterial infection	3	Cytomegalovirus retinitis
	Kaposi's sarcoma — organ involvement		Cryptococcal meningitis
	Cryptococcosis		Toxoplasmosis
	Herpes simplex — organ involvement		Disseminated tuberculosis
	Disseminated cytomegalovirus infection		Respiratory failure
	Cryptosporidiosis/isosporiasis	AIDS dementia complex	
	Toxoplasmosis	HIV-related cardiomyopathy	
	Disseminated histoplasmosis	AIDS-associated lymphoma	
	AIDS-associated lymphoma	Cytomegalovirus colitis	
	AIDS dementia complex		
	Disseminated coccidioidomycosis		
	Progressive multifocal leukoencephalopathy		

¹Includes complications assessed within 3 months of AIDS-defining diagnosis.

²Examples taken from a list of 80 types of complications.

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

SOURCE: Center for Research in Medical Education and Health Care, Jefferson Medical College: Information from the SIAA.

records, but can also be applied to clinical information from other sources (Turner et al., 1991). Based on expert judgments, the index classifies 19 AIDS-defining conditions into 3 severity groups and 80 common complications seen in AIDS patients into 4 severity levels (Table 1). The final four SIAA categories integrate information on both the AIDS-defining diagnosis severity group and the level of the most severe complication within 3 months of the first AIDS-related diagnosis. SIAA groups both AIDS-defining diagnoses and complications into categories. This aggregation of clinical conditions is necessary so that there is sufficient power to distinguish significant differences in outcomes.

In SIAA, the least severely ill patients are those in category A, while those in category D are the most severely ill (Table 2). Patients in category A have less severe AIDS-defining conditions (e.g., candida esophagitis, Kaposi's sarcoma), and they

do not experience any of our listed 80 complications within 3 months. Patients classified in category B have *Pneumocystis carinii* pneumonia (PCP) as their AIDS-defining diagnosis and no other complication within 3 months. Category C patients have either a severe defining diagnosis (e.g., toxoplasmosis, AIDS-associated lymphoma) and no complication within 3

Table 2
Severity Index for Adults with AIDS (SIAA), by Category

SIAA Category	AIDS-Defining Diagnosis ¹	Required Complication Level ¹
A	Group 1	0
B	Group 2	0
C	Group 1 or 2	1
C	Group 3	0 or 1
D	Group 1, 2, or 3	2 or 3

¹As defined in Table 1.

NOTES: AIDS is acquired immunodeficiency syndrome. Category A includes the least severely ill patients and category D includes the most severely ill patients.

SOURCE: Center for Research in Medical Education and Health Care, Jefferson Medical College: Information from the SIAA.

months, or they have a less severe defining condition followed by a low or moderately severe complication within 3 months of diagnosis. An example of the latter clinical history is a patient with candida esophagitis as the AIDS-defining condition who develops bacterial pneumonia within 3 months. Finally, regardless of the AIDS-defining condition, all patients with a very severe complication within 3 months are classified in category D. For example, a patient with candida esophagitis who is subsequently diagnosed with cryptococcal meningitis within 3 months is classified into category D. It should be noted that AIDS-defining conditions are included in the complication list. As a result, if a patient had candida esophagitis as the AIDS-defining diagnosis and developed PCP within 3 months after candida esophagitis, PCP would be counted as a complication.

Statistical Analysis

Total Medicaid expenditures after AIDS diagnosis were adjusted to 1990 dollars using the medical component of the Consumer Price Index (CPI) from the U.S. Bureau of Labor Statistics. The medical component of the CPI monitors price movement in the private market through the use of a "market basket" of charges for physician and other health services. Medicaid expenditures are a function of administrative prices, which increase based upon the direction of State policymakers. Therefore, the expenditures that we report are standardized for overall medical inflation in the United States, and not the inflation rate experienced in the payment scale for the New York Medicaid program.

Kaplan-Meier estimates were used to examine cumulative expenditures and hospital days from Medicaid AIDS diagnosis until time of death, as well as to estimate

patient survival times by demographic characteristics and disease severity (Lee, 1980). By using the Kaplan-Meier method to calculate "lifetime" hospital days and Medicaid expenditures after AIDS diagnosis, our resource utilization estimates allow for censored death information and are based on data from the entire study population instead of only those with a known death date. The logrank statistic was used to compare differences in lifetime expenditures after AIDS diagnosis, by patient demographic and disease severity categories. Because some researchers have estimated lifetime costs after AIDS diagnosis using data only on patients with a known death date, we also report cumulative expenditures, hospital days, and survival times for the 4,215 patients (51 percent) with a specific death date in our study population.

Approximately 18 percent of our study population overlap with the study population originally used to develop the SIAA algorithm. Although the purpose of this article is not to validate the SIAA algorithm, we report Kaplan-Meier survival estimates by SIAA for FFYs 1984-86 (part of the SIAA development population) and FFYs 1987-90 (not part of the SIAA development population) to provide additional information on how SIAA distinguishes severity categories since our original report of the index (Turner et al., 1991). We also report variations in the proportions of our study population assigned to SIAA categories A-D, based on the number of months of eligibility for Medicaid before AIDS diagnosis, to determine whether those with fewer months of eligibility have more severe diagnoses as a result of already having AIDS before enrollment on Medicaid. It is expected that this problem has been minimized in our study population, because all patients in our analysis lived at least 6 months after their first

Medicaid-recorded diagnosis of AIDS. Patients who "spend down" to Medicaid many months after the diagnosis of AIDS are more likely to be severely ill at the time of enrollment and would probably be at high risk of death within the 6-month period after Medicaid enrollment. As a result of these caveats in our data, the reported findings represent expected expenditures after AIDS diagnosis that are covered by Medicaid, and not necessarily the total costs of care from AIDS diagnosis until death.

Average monthly Medicaid expenditures for specified disease intervals were analyzed by patient demographic characteristics and disease-severity category. Three intervals in each patient's service utilization history were defined. The diagnosis interval was defined as the 3 months following the patient's first AIDS-defining diagnosis. The mid-illness interval was defined as the months after the diagnosis interval until the last 2 months of life or the last month of observation. The death interval was comprised of the last 2 months of life for patients with a known death date. Differences in average monthly expenditures, by selected patient demographic and clinical characteristics in each of the three disease intervals, were determined using the Wilcoxon Rank Sum statistic. We

analyzed average monthly expenditures by SIAA severity category, gender, drug use, age at AIDS diagnosis, and year of diagnosis. The New York Medicaid program operates on a FFY starting October 1 and ending September 30. We report our analyses for FFYs 1984-86, 1987-88, and 1989-90, because patient outcomes were relatively comparable within these FFY groups. Because expenditures for methadone maintenance can be substantial and affect the level of expenditures for the drug user group, we reanalyzed expenditures after AIDS diagnosis and average monthly expenditures after excluding methadone maintenance expenditures.

RESULTS

Information on median Medicaid expenditures, hospital days, and months of survival after AIDS diagnosis is displayed in Table 3, stratified by SIAA severity category. The largest proportions of the study population were in the two highest severity categories: 46 percent in category C and 35 percent in category D. As shown, the median survival in months declined with increasing severity category. In our study population, the median survival of patients in category A, unadjusted for other factors, was nearly twice that of patients in category D.

Table 3
Median Months of Survival, Hospital Days, and Medicaid Expenditures After AIDS Diagnosis, by SIAA Category: 1984-90

SIAA Category	n	Survival in Months ¹	Hospital Days ²	Medicaid Expenditures in 1990 Dollars ²
Total	8,265	17	111	89,999
A	514	27	99	70,524
B	1,048	20	92	78,227
C	3,797	17	106	86,224
D	2,906	15	123	92,141

¹ $p < .0001$ from a Logrank statistic.

² $p < .001$ from a Logrank statistic.

NOTES: AIDS is acquired immunodeficiency syndrome. SIAA is the Severity Index for Adults with AIDS. Category A includes the least severely ill patients and category D includes the most severely ill patients.

SOURCE: Center for Research in Medical Education and Health Care, Jefferson Medical College: Data from the New York State Medicaid HIV/AIDS Research Data Base, Federal fiscal years 1984-90.

As previously noted, patients diagnosed in FFYs 1987-90, approximately 82 percent of the study population, were not included in the original SIAA development population. The median survival times for those not previously studied was 30, 24, 18, and 16 months for categories A-D, respectively. We previously reported median survival estimates of 33, 21, 17, and 12 months for categories A-D for a New York Medicaid population diagnosed between 1983 and 1986 (Turner et al., 1991). In both populations, SIAA distinguishes groups of patients by severity of illness. Except for category A, improvements in survival were observed in the more recent time period.

While the number of months of eligibility for Medicaid prior to AIDS diagnosis was significantly associated with the SIAA category ($p < .001$), the differences among the groups were modest. For example, among patients who were not eligible in the 6 months prior to AIDS diagnosis, 36 percent had the most severe SIAA category, compared with 36 percent among patients who had 1 to 4 months of eligibility and 35 percent among patients who had 5 or more months of eligibility. Overall, 6.2 percent of the study population were classified in category A (the least severe), while only 3.5 percent of those who were not eligible for Medicaid before AIDS diagnosis were in the least severe category. As a result, the influence of left censoring or having AIDS before Medicaid eligibility appears to be relatively small in the study population, although this is an indirect way of assessing left censoring.

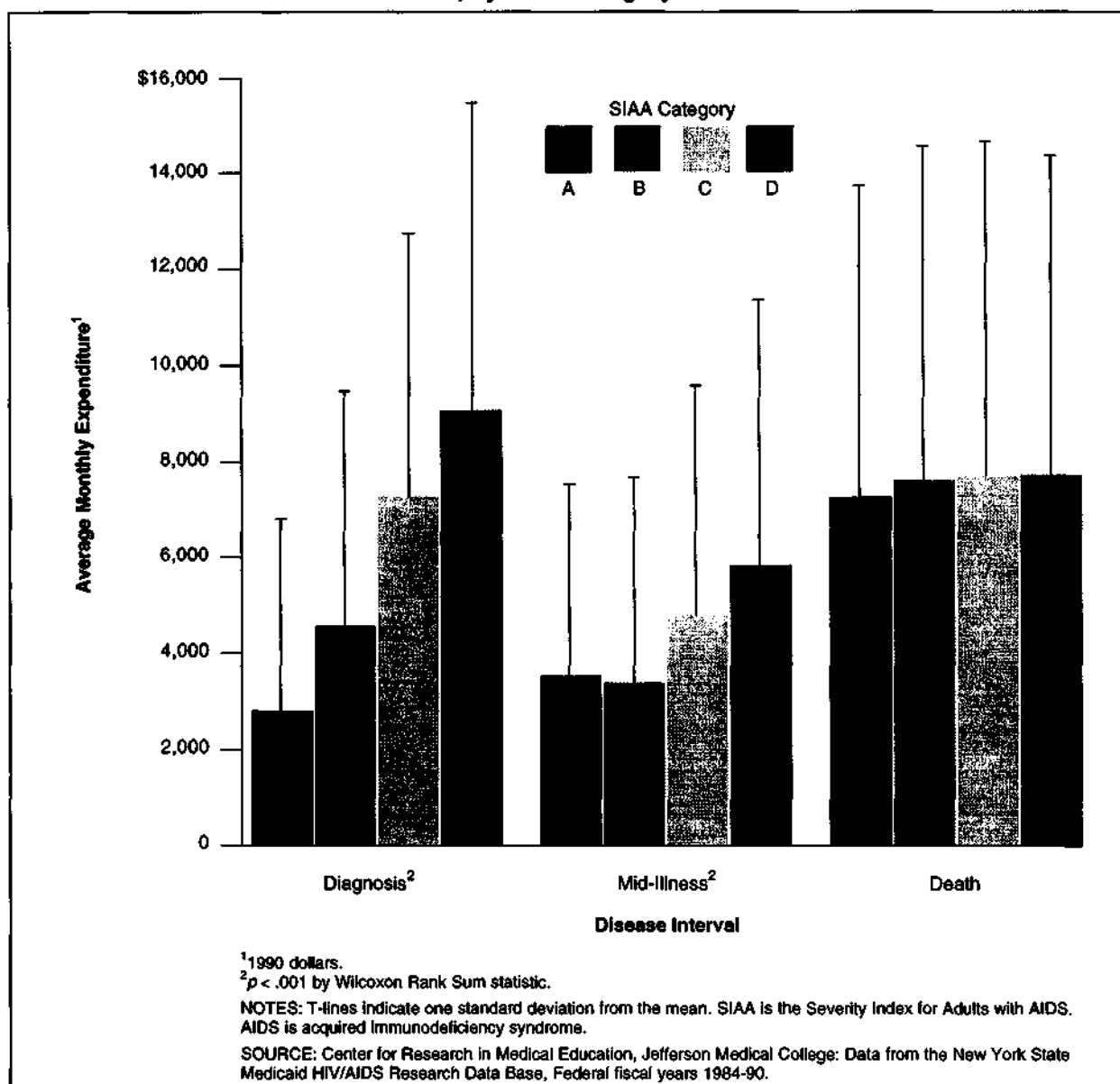
Median number of hospital days and expenditures after AIDS diagnosis rose steadily with increasing severity of illness, even though patients in category A had a median survival time that was 1 year longer than those in category D. While the median survival time of the study population was 17

months, more than one-half of the population spent 3.5 months or more of this time in the hospital (Table 3). The median number of hospital days after AIDS diagnosis for patients in category A was 35 days fewer than the number for patients in category D. Similarly, patients in category A had median expenditures after AIDS diagnosis that were \$21,600 less than those found for patients classified in category D. These patterns indicate that patients with severe complications occurring within 3 months of diagnosis had substantially more intense use of health care resources within a shorter interval of time than patients with less severe conditions.

Average monthly expenditures for the four severity categories in each of the disease intervals are shown in Figure 1. In the diagnosis interval, average monthly expenditures rose progressively with increasing severity. Patients in the most severe category had average monthly expenditures of \$9,132 in the diagnosis interval, an average three times higher than that of patients in the least severe category. For patients in categories A-D, the median number of months of care in the mid-illness episode, based on Kaplan-Meier estimates, were 22, 15, 12, and 10 months, respectively. In the mid-illness interval, average monthly expenditures were comparable for patients in categories A and B, while higher monthly expenditures were observed for patients in categories C and D. The population in categories A and B had no complications within the first 3 months after AIDS diagnosis and appeared to continue to have relatively low expenses for care in the following months. Patients in category D had average monthly expenditures of \$5,881 during the mid-illness interval, an average 1.6 times greater than the average monthly mid-illness expenditures for patients in category A. In addition, the higher average

Figure 1

Average Monthly Expenditures and Standard Deviations for the Diagnosis, Mid-Illness, and Death Intervals, by SIAA Category: 1984-90



monthly expenditures for patients in category D during the mid-illness episode were accumulated over a shorter period of time than patients in less severe categories. In the last 2 months of life, average monthly Medicaid expenditures were approximately equal across all severity categories.

Figure 1 also suggests that average monthly expenditures for category A

increased over the disease intervals, with expenditures lowest in the diagnosis interval, increasing in the mid-illness interval, and highest during the death interval. In contrast, categories B, C, and D had average monthly expenditure patterns in the mid-illness interval that were lower than the diagnosis interval. The expenditure patterns over the disease intervals

Table 4

Median Months of Survival, Hospital Days, and Medicaid Expenditures After AIDS Diagnosis, by Gender and Drug Use: 1984-90

Gender and Drug Use	<i>n</i>	Survival in Months ¹	Hospital Days ¹	Medicaid Expenditures in 1990 Dollars ¹
Female Drug User	1,219	17	116	100,077
Female Non-Drug User	855	16	100	84,384
Male Drug User	3,052	18	116	94,460
Male Non-Drug User	3,138	16	93	76,454

¹*p* < .0001 from a Logrank statistic.

NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCE: Center for Research in Medical Education and Health Care, Jefferson Medical College: Data from the New York State Medicaid HIV/AIDS Research Data Base, Federal fiscal years 1984-90.

tended to be "U" shaped for category B, C, and D patients. The standard deviations for average monthly expenditures were large for all SIAA categories, indicating substantial variation, even after adjusting for disease severity and disease interval.

Median expenditures, hospital days, and months of survival after AIDS diagnosis also varied by gender and drug use (Table 4). Higher resource use was observed for drug users compared with non-drug users, with female drug users having the highest resource use of all. However, male and female drug users appear to survive slightly longer than non-drug users of the same gender. The observed median number of days hospitalized after AIDS diagnosis was 16 days greater for female drug users compared with female non-drug users. Similarly, drug-using males had a median of 23 inpatient days more than non-drug-using males. Median expenditures after AIDS diagnosis for drug-using females were more than \$15,000 higher than for females without evidence of drug use. Male drug users had median expenditures after AIDS diagnosis that were \$18,000 higher than non-drug-using males. The higher expenditure patterns among drug users do not appear to be due to drug treatment costs. Excluding expenditures for methadone maintenance reduced median Medicaid expenditures after AIDS

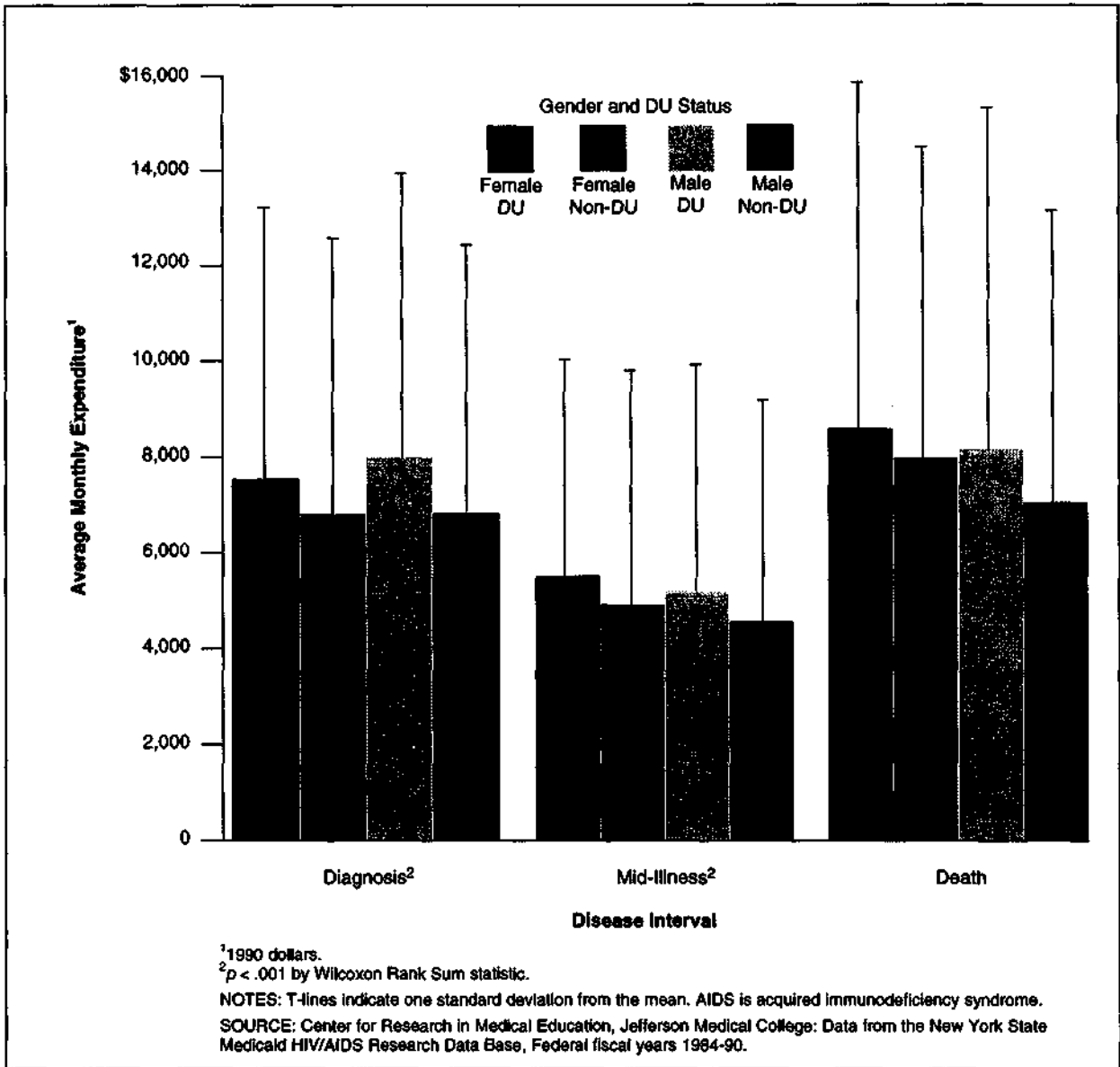
diagnosis for drug users (\$97,312 versus \$98,569), but median expenditures after AIDS diagnosis were still significantly higher for drug users compared with non-drug users after this exclusion (\$97,312 versus \$81,030, *p* < .001).

Figure 2 displays average monthly expenditures in the diagnosis, mid-illness, and death intervals by gender and drug use. For both females and males, drug users had higher average monthly Medicaid expenditures in every interval, compared with patients not having evidence of drug use. For females, the difference in expenditures by drug use was approximately 10 percent in each interval, and for males it was slightly greater—approximately 13 percent. After exclusion of methadone maintenance costs, both male and female drug users still had higher expenditures in each interval compared with non-drug users.

Females and drug users were more likely to be eligible for Medicaid for 5 or more months prior to AIDS diagnosis. In the 6 months prior to AIDS diagnosis, 74 percent of females had Medicaid eligibility for 5 or more months, compared with 50 percent of males. Five or more months of eligibility in the 6 months before AIDS diagnosis was observed for 65 percent of drug users, compared with only 47 percent of non-drug users. Despite these differences in Medicaid

Figure 2

Average Monthly Expenditures and Standard Deviations for the Diagnosis, Mid-Illness, and Death Intervals, by Gender and Drug Use (DU) Status: 1984-90



eligibility before AIDS diagnosis, only modest differences were observed in the SIAA classification by gender and drug use. Among female drug users, the proportion of patients in category D was 32 percent, compared with 34 percent for female non-drug users; among males, the proportion was 36 percent for drug users and 37 percent for non-drug users. At the time of the first AIDS diagnosis,

meaningful differences in severity of illness by gender and drug use were not observed for our study population, all of whom survived at least 6 months after AIDS diagnosis.

Table 5 shows that median survival, hospital days, and Medicaid expenditures after AIDS diagnosis increased by patient year of diagnosis. Median survival increased 77 percent from FFYs 1984-86 to FFYs

Table 5

Median Months of Survival, Hospital Days, and Medicaid Expenditures After AIDS Diagnosis, by Year of Diagnosis: 1984-90

Federal Fiscal Year of Diagnosis	<i>n</i>	Survival in Months ¹	Hospital Days ²	Medicaid Expenditures in 1990 Dollars ²
1984-86	1,486	13	88	65,340
1987-88	2,958	16	106	91,739
1989-90	3,821	23	142	106,154

¹*p* < .0001 from a Logrank statistic.

²*p* < .001 from a Logrank statistic.

NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCE: Center for Research in Medical Education and Health Care, Jefferson Medical College: Data from the New York State Medicaid HIV/AIDS Research Data Base, Federal fiscal years 1984-90.

1989-90. Median expenditures and hospital days after AIDS diagnosis increased more than 60 percent during the same time period. Figure 3 shows average monthly expenditures for each interval, by year of diagnosis. Expenditures in the death interval increased steadily over time, with average monthly expenditures for patients diagnosed in FFYs 1989-90 about 20 percent higher than for those diagnosed in FFYs 1984-86. When we analyzed average monthly expenditures in the last 2 months of life by year of death, a similar pattern appeared. The average monthly cost in the death interval averaged \$6,671 for deaths in FFYs 1984-86, compared with \$8,064 for deaths in FFYs 1989-90. There was not a consistent trend in average monthly expenditures in the diagnosis and mid-illness intervals by year of diagnosis.

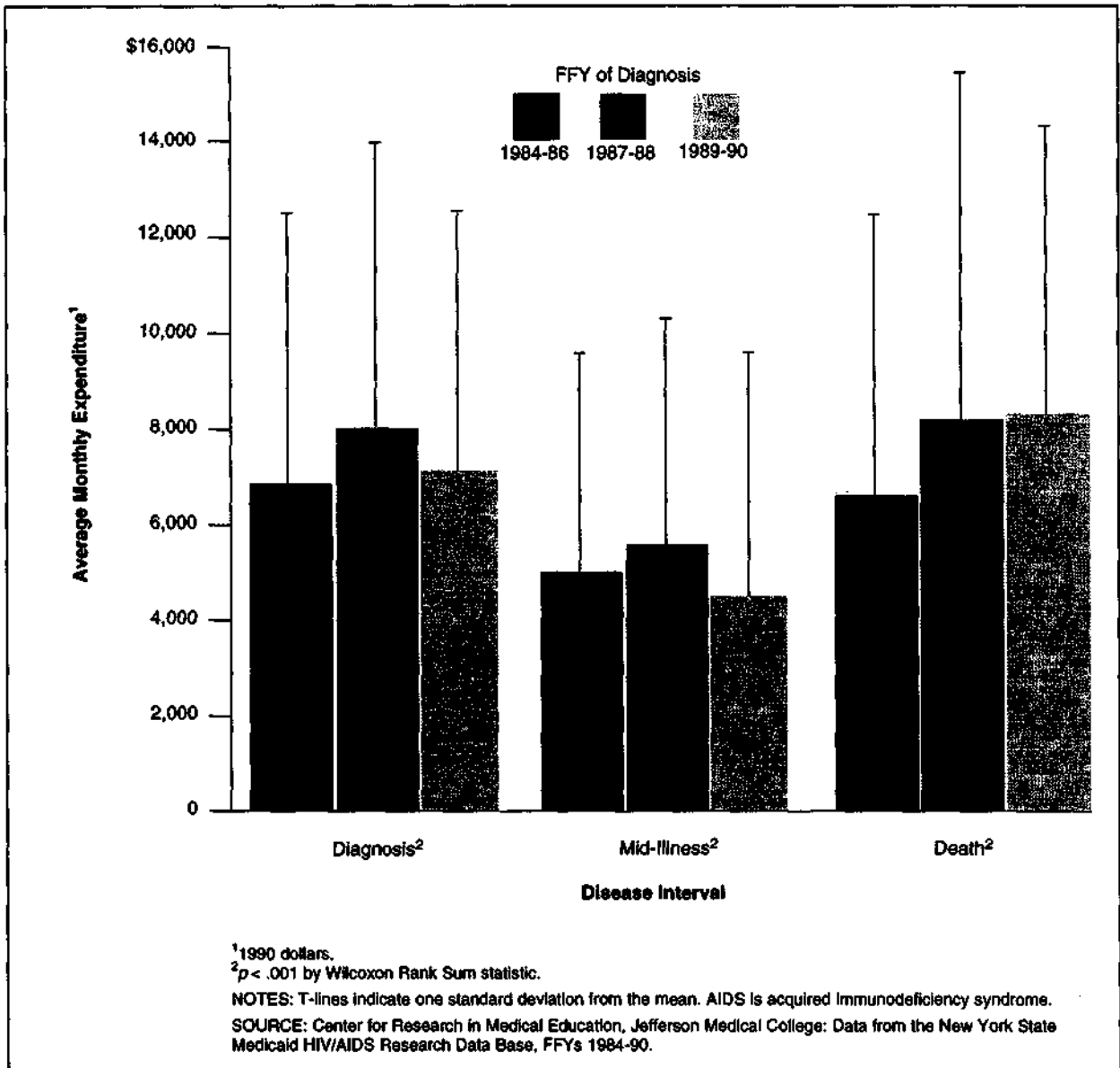
When monthly expenditure patterns were analyzed by age at diagnosis, grouped by decade (i.e., 13-29, 30-39, 40-49, and 50-60 years), no consistent pattern was observed. In addition, while median expenditures after AIDS diagnosis were highest for those 30 to 39 years of age at AIDS diagnosis (\$91,516), this amount was not significantly different from the observed expenditures for the other groups (*p* = .06). The median number of hospital days and survival after AIDS diagnosis also did not vary

significantly by age at AIDS diagnosis. We were concerned that older patients might be disproportionately represented within the group surviving fewer than 6 months after AIDS diagnosis and potentially excluded from our analyses. As a result, we examined average age at AIDS diagnosis in the population surviving more than 6 months compared with the population surviving fewer than 6 months, but we did not observe meaningful differences. Average age at AIDS diagnosis was 36 years for patients surviving fewer than 6 months, and 35 years for those surviving more than 6 months after diagnosis.

When we compared survival and resource use for the subset of our study population with a known death date (*n* = 4,215) with that of the total study population (*n* = 8,265), significant differences were found. The median survival after AIDS diagnosis was estimated at only 11 months for those with a known death date, compared with 17 months for the entire study population. The median number of hospital days after AIDS diagnosis was also lower in the sample of persons with a known death date compared with the entire study group (86 versus 111 days), as were median expenditures after AIDS diagnosis (\$68,882 versus \$89,999). These data suggest that analyses based on a

Figure 3

Average Monthly Expenditures and Standard Deviations for the Diagnosis, Mid-Illness, and Death Intervals, by Federal Fiscal Year (FFY) of Diagnosis: 1984-90



sample of patients with known death times may substantially underestimate survival and resource utilization after AIDS diagnosis. Kaplan-Meier estimates of total expenditures after AIDS diagnosis provide a way to analyze expenditures when the total survival time is not known for the entire sample.

DISCUSSION

State Medicaid programs are faced with the dual challenge of rising health care costs and public demands to control spending. In our study population, the observed per patient median Medicaid expenditures after AIDS diagnosis rose by more than 60

percent from FFY 1984 to FFY 1990 for patients who survived at least 6 months after AIDS diagnosis. This increase in expenditures may reflect an improved survival for persons with AIDS. We observed a 9-month increase in the median survival after AIDS diagnosis. However, our analyses do not take into account the growth in the number of new AIDS cases that, coupled with increasing per case expenditures, have produced an enormous financial strain on State Medicaid programs.

Cost estimates for AIDS patients have been typically estimated for an entire study population without accounting for differences in severity of illness. In this study, we show that SIAA categories allow for further discrimination in projecting expenditure patterns for persons with AIDS. SIAA incorporates information regarding the first AIDS-defining diagnosis, as well as secondary complications occurring within 3 months of diagnosis. This approach recognizes the diversity and multiplicity of clinical complications typical of disease progression in persons with AIDS. Based on information from this relatively brief interval of 3 months, it is possible to distinguish groups of patients differing significantly in duration of survival, number of hospital days, and total expenditures. Monitoring expenditures in this manner can help State policymakers evaluate State Medicaid initiatives, such as comprehensive Medicaid case management targeted to persons with AIDS, the addition of new drugs to State formularies, home and community-based waiver services, and hospice care.

Almost one-third of our study population was in category D, with a severe AIDS-defining diagnosis or a serious complication within 3 months. This group had intense demands for health care resources over a relatively short period of time. They had higher average monthly Medicaid

expenditures, compared with patients with less severe conditions, in both the diagnosis and mid-illness intervals after AIDS diagnosis. If managed-care programs are to assume care for these patients, allocation of resources for their care must be appropriately increased to avoid financially penalizing their providers. SIAA offers a potential tool for policymakers and clinicians to allocate more equitably resources for patients with significant demands for care. SIAA can also facilitate the targeting of programs designed to manage care, by specifying case-management programs tailored to the initial severity of illness of the patient population.

For patients in our study population diagnosed with AIDS in FFYs 1989-90, median Medicaid expenditures after AIDS diagnosis were \$106,154. In a 1992 article, Hellinger estimated the lifetime costs of treating a person with AIDS to be \$102,000. More recent estimates by Hellinger (1993) suggest that the costs after AIDS diagnosis may have declined by 1992 as a result of decreased use of hospital care. Other studies have indicated that more than 80 percent of Medicaid expenditures for AIDS are for inpatient care (Andrews, Keyes, and Fanning, 1991). By analyzing AIDS expenditures within fixed time intervals after the date of diagnosis, clinicians and planners can obtain more specific information on particular phases after AIDS diagnosis to determine when resource use is especially intense. Of particular note, our study population evidenced very high expenditures in the last 2 months of life (i.e., the death interval), which is relatively uniform across the SIAA categories. For our study population, monthly expenditures in the death interval averaged \$7,500 (1990 dollars). This estimate is similar to the \$8,000 estimated cost (1984 dollars) of care in the last month of life for a population

of AIDS patients receiving services through the Michigan Medicaid program from 1984 to 1987 (Solomon et al., 1989). This pattern of high expenditures in the last months of life parallels that in the general population (Long et al., 1984; Clark, 1992) and reflects the importance of advance directives (Murphy and Finucane, 1993) and other approaches to more realistically deliver quality care to terminally ill persons.

In our study population, drug users appeared to have somewhat longer survival and higher observed Medicaid expenditures. In other analyses, we have reported that survival patterns in our study population reflect a complex set of factors, including differences in the clinical course of the disease, access to drug therapies such as zidovudine, and Medicaid eligibility patterns (Turner et al., 1994). Because State planners need information about expenditure patterns for all Medicaid AIDS patients, we did not require a year of eligibility before AIDS diagnosis for persons included in this study. In contrast, continuous eligibility was required after AIDS diagnosis, to estimate the anticipated expenses among a population that relied on Medicaid for their AIDS care. In our study population, the lowest observed Medicaid expenditure patterns after AIDS diagnosis were among male non-drug users. Consistent with these findings, expenditure levels in the Medi-Cal program have been reported to be lowest among gay or bisexual males (Hay and Kizer, 1993). While sexual orientation could not be determined in our study population, we presume that a high proportion of the male non-drug users in the New York State Medicaid HIV/AIDS Research Data Base are gay or bisexual, because HIV infection through heterosexual contact was relatively low among males during the timeframe of our study.

Some of the limitations of our analyses should be noted. The total costs of AIDS

care are likely to be greater than we reported, because some services might not have been covered by the Medicaid program. In addition, the expenditure data reported in this article also reflect a payment structure that has been set between the New York State Medicaid program and providers of care for services covered by the Medicaid program, and this payment might underestimate "true" costs. However, because the Medicaid program covers a broad range of services, we would expect that Medicaid expenditures are highly correlated with the total costs of care.

Our study population differs from the entire AIDS population nationwide. In our cohort, females comprised one-fourth of the population, compared with 11 percent of AIDS cases reported nationally (Centers for Disease Control and Prevention, 1992). In addition, more than 50 percent of our study population were identified as drug users, which is nearly twice that of reported cases nationally (Centers for Disease Control and Prevention, 1992). Because drug users and females consumed greater resources, this population may have had higher expenditures for care and more hospital days than other populations with more non-drug users and males.

Our expenditure estimates include all Medicaid expenditures from the point of the patient's first AIDS-defining diagnosis. We did not attempt to distinguish expenditures for conditions that were not AIDS-related, such as injuries, or other preexisting conditions, such as hypertension. Research conducted by Solomon and Hogan (1992) suggests that 12.5 percent of the total amount of health care received by HIV-infected patients from 1985-89 in the Michigan Medicaid program was unrelated to HIV infection. These expenditures are included in our "AIDS care" expenditures. We analyzed expenditures for care among

a population who survived at least 6 months because these longer term survivors would most likely be the group that health care providers would have an opportunity to enroll in specialized case-management programs or other managed-care programs. When calculating total costs to the New York Medicaid program, information on patients surviving less than 6 months should also be considered. SIAA also categorizes AIDS-defining diagnoses into severity groups which could be used to classify short-term survivors by severity of illness (Turner et al., 1991).

It is difficult for us to fully assess the effect of coded diagnoses on our results. While a number of researchers have expressed concerns about the quality of the information derived from ICD-9-CM coded diagnoses contained in administrative data bases (Steinberg, Whittle, and Anderson, 1990), many of the validation projects conducted on these data sources provide encouraging results about the relative accuracy of the clinical information. A reabstraction study of Medicare data showed that the ICD-9-CM diagnoses for serious conditions such as cancer and heart disease were accurate in more than 85 percent of the chart abstract cases (Fisher et al., 1992). Rosenblum et al. (1993) recently reported that the predictive value of a coded diagnosis of HIV in Medicaid records was 91 percent or higher, although there was undercoding of this diagnosis. While these validation projects show the relative strength of administrative data bases, miscoding is known to occur, and it is unclear how potential miscoding in the New York State Medicaid HIV/AIDS Research Data Base may have influenced our results.

In the diagnosis interval, we measured both AIDS severity and resource use during the same period of time, with both of

these measures dependent upon utilization information. While these types of associations can become circular, we believe that we measured severity relatively independently of resource use. The SIAA identifies the defining diagnosis and most severe complication within 3 months of diagnosis based on ICD-9-CM codes recorded from visits with providers. Patients are unlikely to ignore most conditions considered in the index. The index is independent of utilization, in that frequency of visits does not determine the patient's severity level. The SIAA considers the severity of the patient's diagnoses, not the total number of visits or ICD-9-CM codes. We recognize that if patients fail to seek care for their medical conditions, we could not assess severity of these conditions, but costs are probably lower if the patient does not seek care. There is no potential circularity of the associations between the SIAA in the mid-illness and death intervals, because all of the severity information is obtained in the diagnosis interval.

Although SIAA was designed to predict AIDS survival using clinical information observed in the first 3 months after AIDS diagnosis, our analyses showed that it is also predictive of different expenditure levels for Medicaid AIDS patients. By classifying patients by the severity of their clinical complications, cases could be prospectively followed in order to monitor expenditures, and to retrospectively analyze patient histories to facilitate the development of patient-management strategies. As suggested by Scitovsky (1989), the cost of HIV-related illness is a "moving target," and cost measurement requires tools that can be sensitive to the dynamic features of this disease. Since SIAA was first developed, the Centers for Disease Control and Prevention (1992) has revised the AIDS case definition to incorporate information

on CD4 T-lymphocyte counts and several additional clinical conditions. Additional clinical conditions may need to be added to the SIAA model, and CD4 T-lymphocyte count, when available, should be considered as a potential covariate in analyses of more recently diagnosed populations.

The development of severity measures that can be applied to longitudinal data bases is a relatively new field of investigation. Our data indicate the value of a severity measure using readily available clinical data on the early course of disease after AIDS diagnosis to assess expenditures and resource use of an AIDS patient population. When studying complex diseases such as AIDS, severity measures are necessary to account for significant differences in health care delivery, by patients with differing disease-related complications. The combination of SIAA severity categories and analysis of expenses within fixed intervals after disease onset should be helpful when assessing the impact of various patient management programs and in developing capitation or other prospective payment mechanisms.

ACKNOWLEDGMENTS

The authors thank Karen Jordan for her assistance with manuscript preparation and Jim Cocroft for his assistance with data processing.

REFERENCES

- Andrews, R., Keyes, M.A., and Fanning, T.: Lifetime Medicaid Service Utilization and Expenditures for AIDS in New York and California. *Journal of Acquired Immune Deficiency Syndromes* 4:1046-1058, 1991.
- Andrulis, D.P., Weslowski, V.B., Hintz, E., and Spolarich, A.W.: Comparisons of Hospital Care for Patients With AIDS and Other HIV-Related Conditions. *Journal of the American Medical Association* 267(18):2482-2486, 1992.
- Andrulis, D.P., Beers, V.S., Bentley, J.D., and Gage, L.S.: The Provision and Financing of Medical Care for AIDS Patients in US Public and Private Teaching Hospitals. *Journal of the American Medical Association* 258:1343-1346, 1987.
- Bennett, C.L., Pascal, A., Cvitanic, M., et al.: Medical Care Costs of Intravenous Drug Users With AIDS in Brooklyn. *Journal of Acquired Immune Deficiency Syndromes* 5(1):1-6, 1992.
- Centers for Disease Control and Prevention: Classification System for Human Immunodeficiency Virus (HIV) Infection in Children Under 13 Years of Age. *Morbidity & Mortality Weekly Report* 36:25-35, 1987b.
- Centers for Disease Control and Prevention: *HIV/AIDS Surveillance Report, Second Quarter Edition*. Atlanta, July 1992.
- Centers for Disease Control and Prevention: Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome. *Morbidity & Mortality Weekly Report* 36:1s-5s, 1987a.
- Chupka, L.A., Birden, H.H., and Andrews, L.: Financial Aspects of the Provision of Care to AIDS Patients at Hartford Hospital. *Connecticut Medicine* 56(9):467-468, 1992.
- Clark, N.: The High Costs of Dying. *The Wall Street Journal*, February 26, 1992.
- Cosler, L.: New York State Medicaid Program. Personal communication, September 1993.
- Fahs, M.C., Fulop, G., Strain, J., et al.: The Inpatient AIDS Unit: A Preliminary Empirical Investigation of Access, Economic, and Outcome Issues. *American Journal of Public Health* 82(4):576-578, 1992.
- Fanning, T.R., Cosler, L.E., Gallagher, et al.: The Epidemiology of AIDS in the New York and California Medicaid Programs. *Journal of Acquired Immune Deficiency Syndromes* 4:1025-1035, 1991.
- Fisher, E.S., Whaley, F.S., Krushat, W.M., et al.: The Accuracy of Medicare's Claims Data: Progress Has Been Made But Problems Remain. *American Journal of Public Health* 82(2):243-248, 1992.
- Green, J., and Arno, P.S.: The Medicaidization of AIDS: Trends in the Financing of HIV-Related Medical Care. *Journal of the American Medical Association* 264(10):1261-1266, 1990.
- Hardy, A.M., Rauch, K., Echenber, D., et al.: The Economic Impact of the First 10,000 Cases of Acquired Immunodeficiency Syndrome in the United States. *Journal of the American Medical Association* 255(2):209-211, 1986.

- Hay, J., and Kizer, K.W.: Medi-Cal Expenditures for Persons With AIDS. *AIDS & Public Policy* 8(2):91-102, 1993.
- Hay, J., Osmond, D., and Jacobson, M.: Projecting the Medical Care Costs of AIDS and ARC in the United States. *Journal of Acquired Immune Deficiency Syndromes* 1:466-485, 1988.
- Hellinger, F.J.: Forecasting the Medical Care Costs of the HIV Epidemic: 1991-1994. *Inquiry* 28(3):213-225, 1991.
- Hellinger, F.J.: Forecasts of the Costs of Medical Care for Persons With HIV: 1992-1995. *Inquiry* 29(3):356-365, 1992.
- Hellinger, F.J.: The Lifetime Cost of Treating a Person With HIV. *Journal of the American Medical Association* 270(4):474-478, 1993.
- Kelly, J.V., Ball, J.K., and Turner, B.J.: Duration and Costs of AIDS Hospitalizations in New York, Variations by Patient Severity of Illness and Hospital Type. *Medical Care* 27(12): 1085-1098, 1989.
- Keyes, M., Andrews, R., and Mason, M.: A Methodology for Classifying AIDS Cases Using Medicaid Claims Data. *Journal of Acquired Immune Deficiency Syndromes* 4:1015-1024, 1991.
- Lee, E.T.: *Statistical Methods for Survival Data Analysis*. Belmont, CA. Lifetime Learning Publications, 1980.
- Long, S.H., Gibbs, J.O., Crozier, J.P., et al.: Medical Expenditures of Terminal Cancer Patients During the Last Year of Life. *Inquiry* 21:315-327, Winter 1984.
- Murphy, D.J., and Finucane, T.E.: New Do-Not-Resuscitate Policies: A First Step in Cost Control. *Archives of Internal Medicine* 153:1641-1647, 1993.
- Rosenblum, L., Buehler, J.W., Morgan, M.W., et al.: HIV Infection in Hospitalized Patients and Medicaid Enrollees: The Accuracy of Medical Record Coding. *American Journal of Public Health* 83(10):1457-1459, 1993.
- Scitovsky, A.A.: Studying the Cost of HIV-Related Illnesses: Reflections on the Moving Target. *Milbank Quarterly* 67(2):318-343, 1989.
- Scitovsky, A.A., and Rice, D.P.: Estimates of the Direct and Indirect Costs of the Acquired Immunodeficiency Syndrome in the United States, 1985, 1986, and 1991. *Public Health Reports* 102:5-17, 1987.
- Solomon, D.J., Hogan, A.J., Bouknight, R.R., and Solomon, C.T.: Analysis of the Michigan Medicaid Costs to Treat HIV Infection. *Public Health Reports* 104(5):416-424, 1989.
- Solomon, D.J., and Hogan, A.J.: HIV Infection Treatment Costs Under Medicaid in Michigan. *Public Health Reports* 107(4):461-468, 1992.
- Steinberg, E.P., Whittle, J., and Anderson, G.F.: Impact of Claims Research on Clinical Practice. *International Journal of Technology Assessment in Health Care* 6(2):282-287, 1990.
- Turner, B.J., Denison, M., Eppes, S.C., et al.: Survival Experience of 789 Children With the Acquired Immunodeficiency Syndrome. *Pediatric Infectious Disease Journal* 12:310-320, 1993a.
- Turner, B.J., Markson, L.E., McKee, L.J., et al.: *Consequences of Patterns of Provider Care for AIDS: Final Report*. Prepared for the Agency for Health Care Policy and Research under Grant Number HS06465. Rockville, MD., August 1993b.
- Turner, B.J., Markson, L.E., McKee, L.J., et al.: Health Care Delivery, Zidovudine Use, and Survival of Women and Men with AIDS. *Journal of Acquired Immune Deficiency Syndromes* forthcoming 1994.
- Turner, B.J., Markson, L.E., McKee, L., et al.: The AIDS-Defining Diagnosis and Subsequent Complications: A Survival-Based Severity Index. *Journal of Acquired Immune Deficiency Syndromes* 4:1059-1071, 1991.

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