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Conference - 6/98 - Managed Care and HIV Treatment

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FCHR - Managed Care & HIV 6/5/98

c Hellinger - AHPR
Cost of Care/Utilization

East Cost 10% greater hospitalizations
100% greater length of stay
than West coast

Cost = ~~$~~1900 → 2700/month
$109,000 → 133,500 lifetime

Holtgrave & Pinkerton $71,143 → 424,763
discounted dollars + PIs

Denning Study (COC)
- few PWAs recd tx
- more than half not receiving optimum care

? quality of life indicators?
supportive services, drug tx, etc.

o Sara Rosenbaum, CHPR Director

(2)

FCHP - Managed Care

6/5/98

Analysis of C&T -

? - important

- measure? counselling, not necessarily testing

sexual history taking

FCHR/AAHP Meeting on the Role of Managed Health Care in HIV Treatment and Research

June 5, 1998 10:00 am - 3:00 pm

George Washington University Marvin Center
800 21st Street, NW Room 404, Washington, DC

10:00 - 10:15 - Welcome - David Barr - Forum for Collaborative HIV Research
Carmela Bocchino - American Association of Health Plans
Introductions by meeting participants

10:15 - 10:45 - Presentation - Overview of Utilization Research of HIV Care
Fred Hellinger, M.D. - Agency for Health Care Policy and Research

10:45 - 12:15 - Discussion: Providing Cost-effective HIV Care

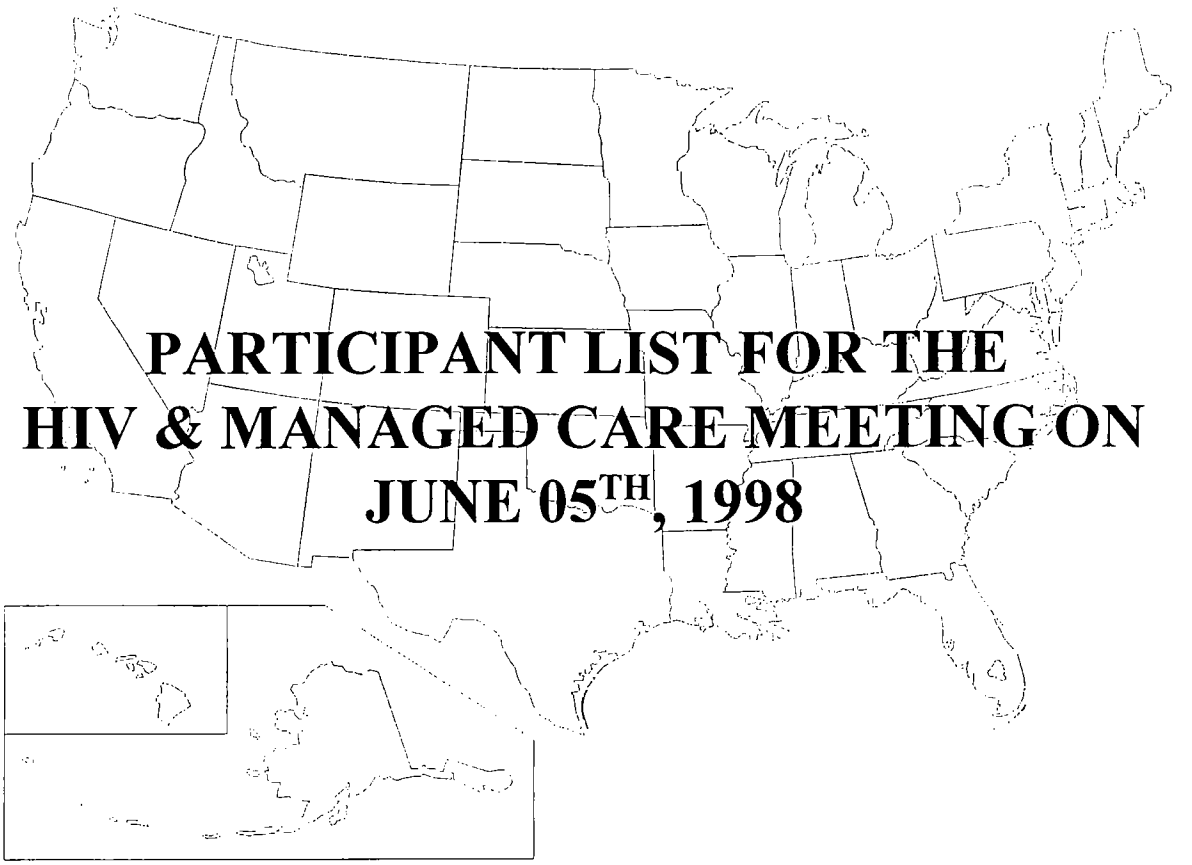
- Developing specifications for HIV care programs -
  Sara Rosenbaum, J.D., Center for Health Care Policy Research
- Providing care management in HIV disease -
  John Ludden, M.D., Harvard Pilgrim Health Care
- Challenges for long-term management of HIV disease -
  Lawrence Deyton, MD, Department of Veterans' Affairs

12:15 - 1:15 - Lunch

1:15 - 2:30 - Discussion: Future research in HIV/AIDS and health care delivery

- Utilization and quality assurance research
- Guidelines dissemination and patient outcomes research
  Sissi Pham, Pharm.D. - Glaxo Wellcome
- Participation in clinical studies
  Michael Saag, M.D. University of Alabama - Birmingham

2:30 - 3:00 - Future opportunities for collaboration between AAHP, the FCHR, health plans and their delivery systems



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Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology
14:223–231 © 1997 Lippincott-Raven Publishers, Philadelphia

Costs to Medicaid of Advancing Immunosuppression in an Urban HIV-Infected Patient Population in Maryland

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Summary: Human immunodeficiency virus (HIV) infection is increasingly an urban disease in the United States, and Medicaid is the principal payer of the health care costs of patients with HIV. We wished to determine the costs to Medicaid of patients in Maryland infected with HIV as immunosuppression progresses, and to determine how costs varied by demographic characteristics of the patient. We analyzed combined economic and clinical data in patients from the Johns Hopkins HIV Service, the provider of primary and specialty care for a majority of HIV-infected patients in the Baltimore metropolitan region. All patients were enrolled in Medicaid and received care longitudinally in Maryland from July 1992 to June 1995. Monthly Medicaid payments were calculated for all inpatient and outpatient services by sex, race, age, use of injecting drugs, $CD4^+$ count (>500, 201–500, 51–200, ≤50 cells/mm^3), several opportunistic diseases, and death. Lifetime costs were also calculated by use of a Markov simulation. During 13,174 person-months of follow-up in 606 patients, a total of $18,223,700 in Medicaid payments was made. Mean monthly payments ranged from $2,436 (SE $171) for patients with $CD4^+$ counts ≤50 cells/mm^3 to $1,015 (SE $177) for patients with $CD4^+$ counts >500 cells/mm^3. Mean monthly inpatient costs ranged from $1,355 (SE $131) for $CD4^+$ counts ≤50 cells/mm^3 and $617 (SE $164) for $CD4^+$ counts >500 cells/mm^3. For those with $CD4^+$ counts ≤50 cells/mm^3, outpatient pharmacy costs averaged $515 (SE $57) monthly, second only to inpatient costs. In bivariate analysis, costs were significantly higher ($p = .013$) in men (mean $1696; SE $126) than in women (mean $1,208; SE $101), though the difference was not significant with multivariate adjustment. Cytomegalovirus retinitis was the most costly opportunistic disease, with mean monthly costs of $7,825 (SE $1,141) within the 6 mo after diagnosis. Within 6 mo of death, mean monthly costs are $4,600 (SE $424). Lifetime costs for treating an HIV-infected patient who presents with a $CD4^+$ count >500 cells/mm^3 are $133,500 over 8.3 years of life. We concluded that in the clinic where the analysis was done, average costs to Medicaid of treating patients increase more than two-fold as the $CD4^+$ count declines from >500 cells/mm^3 to ≤50 cells/mm^3. Interventions that decrease hospitalization, opportunistic disease, and the costs of terminal care may be most likely to decrease overall costs. Demographic patient characteristics do not affect costs significantly when access to care is comparable. **Key Words:** Health care costs—Immunosuppression—Human immunodeficiency virus.

Human immunodeficiency virus (HIV) infection, particularly in its more advanced stages, is associated with frequent opportunistic complications, the use of multiple and often expensive drugs and other therapies, and the relatively frequent need for hospitaliza-

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Manuscript received August 21, 1996; accepted November 27, 1996.

tion (1). Early estimates of the costs of medical care for patients with acquired immune deficiency syndrome (AIDS) ranged from $20,000 to as high as $147,000 per year, much of this care occurring during hospitalization, frequently of long duration (2–9). More recently, the lifetime direct medical care costs for a patient with AIDS have been estimated to be $69,000, with estimated costs of $50,000 from HIV infection until the development of AIDS (10).

As early as 1990, Medicaid was the principal medical insurer of patients hospitalized with AIDS in several U.S. cities (11). In a survey of 11 state and local health departments across the U.S. sponsored by the Centers for Disease Control and Prevention and conducted in 1990–1992, 50% of patients with AIDS were insured by Medicaid (12). In Maryland, Medicaid was insuring 50% of patients with AIDS by 1991, an increase from ~30% 5 years earlier (13). Given the epidemiologic trends in recent years toward HIV infection and the increasing prevalence of HIV infection in young women, racial/ethnic minorities, and injecting drug users (14–16), it is likely that Medicaid will continue to be the major insurer of patients with HIV infection and AIDS. Medicaid costs have risen dramatically in the U.S. in recent years and have become the target of efforts to lower federal and state spending (17). Although a few studies have examined the costs of care to Medicaid recipients using data for the 1980s (18–21), the costs to Medicaid of contemporary HIV care are not well defined. Since reductions in Medicaid costs may be achieved through the use of managed care and capitation of payments (22), it is important to quantify the costs to Medicaid of HIV care and to determine the factors that influence the variability of these costs. Several studies have suggested that the costs of HIV care may vary by certain demographic and behavioral characteristics of the patient. For example, studies of injecting drug users with AIDS from Massachusetts and New York and from the AIDS Cost and Service Utilization Survey (ACSUS) suggested that inpatient costs may be higher than in homosexual men (23–25). A study from Rhode Island suggested that hospital admission in early HIV infection is also more common in injecting drug users, although the reason for admission is typically a complication of drug use and not HIV infection (26). In regard to gender, one study failed to show differences in the cost of AIDS care between men and women (23), although another analysis suggested that women with AIDS receive fewer services, with resultant lower costs than men (25). In a multisite study of HIV-infected patients, whites were less likely than nonwhites to be hospitalized but more likely to utilize outpatient medical care (27).

We wished to determine the cost to Medicaid of the medical care of patients with HIV infection cared for in a large urban practice in Maryland. This practice provides both primary and specialty care for a predominantly poor inner urban population of HIV-infected patients. We have previously presented data indicating that once patients are in our clinic, access to and receipt of HIV care, as well as the clinical outcomes of this care, do not vary significantly by demographic characteristics of these patients (28,29). Medicaid is the predominant insurer of our patients, providing us with an opportunity to quantify how the costs of care change as HIV infection progresses over time and to assess any differences in the cost of HIV care by demographic and clinical characteristics of the patients.

METHODS

Patient Sample

The Johns Hopkins University AIDS Service provides longitudinal primary and subspecialty care for a large proportion of the HIV-infected patients in the Baltimore metropolitan area. To be registered in the clinic, patients must have a previously confirmed HIV infection. Every new patient undergoes an initial comprehensive medical evaluation by a physician or a physician's assistant, a nurse, and a social worker, who use case report forms to collect extensive demographic, clinical, laboratory, pharmaceutical, and psychosocial characteristics. Additional data are collected every 6 months by review of all ambulatory and inpatient medical records supplemented by an automated laboratory database and all available records from facilities other than the Johns Hopkins Hospital. These data are abstracted by trained medical records technicians. Comprehensive HIV clinic medical records are maintained in the HIV clinic separately from the main hospital medical record. Validity checks of the abstracted data are performed on a 10% sample of all collected data; concurrence is >90% on all abstracted fields. Systematic errors result in retraining of abstractors and reabstraction of that field on all records. To ensure a high rate of longitudinal follow-up, medical records from outside institutions are routinely sought on all patients. These include inpatient discharge summaries, outpatient clinic records, laboratory sheets, and home-health records. For patients who have not been seen for at least 12 months, state and national vital statistics are checked.

Patients were included in this analysis if they were enrolled in Maryland Medicaid and gave written informed consent to link their clinical data with the state Medicaid claims database maintained by the Policy and Health Statistics Administration of the Maryland Department of Health and Mental Hygiene. Linkage was done using the patients' medical assistance numbers corroborated by their names and dates of birth. Patients were approached to request consent while they were in the clinic prior to seeing their medical care providers. Only 4% of those approached refused to give con-

sent. This was a convenience sample in which the days of the week and clinic session in which patients were approached varied, although there was no systemic pattern in selection of patients; all days of the week and all providers are well represented. A total of 606 patients were included with Medicaid claims extending from July 1, 1992, through June 30, 1995, the most recent date on which adjudicated claims were available from the state. A comparison of our study sample with records of our overall HIV clinic database shows that 86% of patients insured by Medicaid during the time consent was being obtained were enrolled.

Maryland Medicaid

The Maryland Medicaid database maintains all inpatient, outpatient, and pharmacy claims data submitted to the state. We stratified these claims into seven payment categories: (a) inpatient hospitalization (all bundled costs, including professional fees, for acute care hospitals and rehabilitation hospitals), (b) outpatient clinic, (c) emergency room, (d) physician's professional fees (outpatient), (e) outpatient pharmacy, (f) home health care, and (g) special services (includes ambulance, optometrist, durable equipment, physical therapy, and podiatry). We analyzed only payments made by Medicaid, not charges to Medicaid, as the measure of costs to the state and federal governments and ultimately to the taxpayer. All medical claims were analyzed whether for HIV-related care or not. Any care received in the state of Maryland was captured even if not delivered at Johns Hopkins. As far as we know, none of the study patients moved out of state, which is not unusual given that our HIV-infected patients are almost all lifelong residents of the Baltimore, Maryland, area.

Analysis

The Medicaid claims data were divided into 6-month intervals of time corresponding to the 6-month intervals used to ascertain clinical data on the patient. The date of service was used in these analyses. We summed the payments made within each category for each 6-month interval and combined intervals with like demographic or clinical factors. These factors included age groups (≤35 vs. >35 years), sex, race/ethnicity (white vs. nonwhite), injecting drug use as the route of acquisition of HIV, $CD4^+$ lymphocyte count (≤50, 51–200, 201–500, and >500 cells/mm^3), and development of specific opportunistic illness. We also analyzed costs in the 6 months prior to death in those patients who died during follow-up. Payments were inflation-adjusted to 1995 dollars using the total medical care cost component of the Consumer Price Index (30). Monthly payments were calculated by dividing the payments made in each interval by the number of months of enrollment. Incomplete 6-month intervals were due to lapse in Medicaid eligibility, which occurred in only 8% of the total sample. Monthly payments are reported as means with the standard error of the mean, a measure of the precision of the estimate of the mean. Cost distributions are typically skewed toward higher costs, which tends to increase the mean to a value higher than the median, a measure of the middle-most cost when costs are simply ranked. However, insurers such as Medicaid must pay these higher-skewed costs, and the budgetary impact is arguably better represented by the mean rather than the median.

Bivariate statistical comparisons of Medicaid payments between demographic categories were done using the nonparametric Van der Waerden two-sample test (31). A rank statistic was used because it was expected to have more power to detect differences and to be less influenced by extreme values than a t test of the means. The adjusted multivariate association of $CD4^+$ count and the demographic characteristics were assessed using the generalized estimating equation apporoach of Liang and Zeger (32). This method adjusts for the correlation among observations on the same person, although it does not separately model the correlation. We used a Gaussion mean–variance relationship in the model, after a log transformation of payments to achieve a normal distribution appropriate to the model. These analyses were done using SAS (33).

We also constructed a Markov model (34) to calculate lifetime payments to Medicaid for a patient who first presents with a $CD4^+$ count >500 cells/mm^3 and is then followed up until death. In this model, mutually exclusive stages of HIV disease are constructed based on $CD4^+$ strata (>500, 201–500, 51–200, ≤50 cells/mm^3). During each cycle of the model, a patient can either remain in his or her current stage or progress to another stage. Transition pairs (I,j) are defined where "I" is the stage in the cycle preceding the transition and "j" is the stage in the cycle following the transition. The probability of moving from "I" to "j" in any cycle (Pij) is defined as the number of patients moving from "I" to "j," divided by the number starting in stage "I." Cumulative outcomes are assessed by combining these transition cycles in series. By this model, medical payments are calculated for each cycle, based on the patient's stage at the end of the cycle. The cycle duration used for this analysis was 6 months, consistent with our data collection process. Markov analysis was done using Smltree, Version 2.9 (Hollenberg J, Roslyn, NY, U.S.A.). This study was approved by the institutional review boards of the Johns Hopkins Medical Institutions and the Maryland Department of Health and Mental Hygiene.

RESULTS

Patient Sample Characteristics

This analysis is based on data from 606 patients representing 13,174 person-months of follow-up time (Table 1). The patients were predominantly African-American, age ≤35 years, and male, though women were well represented. Injecting and noninjecting drug users were well represented, as were all CD4 strata.

Total and CD4 Stratified Payments

In total, payments to Medicaid were $18,223,700 in these 606 patients (Table 2). Inpatient hospitalization accounted for the majority of these payments, and ambulatory pharmacy payments were the next most expensive category. The mean (standard error of the mean) monthly payments made by Medicaid are shown in Table 3. For the overall patient sample, the mean was $1,508 ($87). With stratification by $CD4^+$ count, mean total monthly payments ranged from a

TABLE 1. *Demographic and clinical characteristics at enrollment of Johns Hopkins patients insured by Medicaid*

	Person-months	Number (%)
Age (yr)		
≤35 (range: 17–35)	7,687	346 (57)
>35 (range: 36–63)	5,487	260 (43)
Sex		
Male	7,883	380 (63)
Female	5,291	226 (37)
Race		
White	1,681	86 (14)
Nonwhite	11,493	520 (86)
HIV transmission		
IDU	8,222	361 (60)
Other	4,952	245 (40)
CD4⁺ count (cells/mm³)		[a]
≤50	3,777	
51–200	2,987	
201–500	4,251	
>500	2,159	
Total	13,174	606 (100)

IDU, intravenous drug use.
[a] Number (%) not given, since each patient may have contributed to more than one CD4⁺ stratum.

TABLE 2. *Total Medicaid payments by service category for 606 patients*

Category	Payments ($)	Percent of total
Total	18,223,700	100
Inpatient	9,428,147	51.7
Outpatient	2,889,281	15.8
Professional fees	591,466	3.2
Pharmacy	3,533,660	19.3
Emergency	294,864	1.6
Home health care	1,164,806	6.4
Special services	321,476	1.8

high of $2,436 ($171), for a CD4⁺ count of ≤50 cells/mm³ to a low payment of $1,015 ($177) for a CD4⁺ count >500 cells/mm³. Payments were consistently higher among service categories associated with a CD4⁺ count of ≤50 cells/mm³ except for outpatient professional fees, which were similar across all CD4⁺ strata. Using the total health care figures, annual costs for the care of a patient with advanced HIV infection (e.g., CD4⁺ count <500 cells/mm³) would be ~$29,000. In contrast, annual costs for the health care of patients with CD4⁺ counts >200 cells/mm³ would be ~$13,000.

Demographic Stratification of Payments

The mean (standard error of the mean) monthly payments made to Medicaid stratified by demographic characteristics of the patients are shown in Table 4. For all patients, no statistically significant differences were found between those who acquired and did not acquire HIV by injecting drugs, whites and nonwhites, or younger and older patients (all $p > 0.05$). However, a significant difference ($p = 0.036$) was found between men and women. Table 4 also shows these payments stratified by CD4⁺ count. When the multivariate analysis was done of monthly payments adjusting simultaneously for CD4⁺ count and the four demographic variables, a CD4⁺ count <50 cells/mm³ was associated with significantly higher mean monthly costs than was a CD4⁺ count >500 cells/mm³ ($p < 0.001$). Monthly payments for CD4⁺ counts of 51–200 cells/mm³ and 201–500 cells/mm³ were not significantly different from payments associated with a CD4⁺ count >500 cells/mm³. Sex was no longer as strongly associated with increased payments ($p = 0.73$), nor was race ($p = 0.56$) or injecting drug use ($p = 0.41$). Age >35 years old was associated with marginally higher payments ($p = 0.06$) in the multivariate adjusted model.

Opportunistic Disease and Death

We assessed the monthly costs of care during the initial 6 months after patients had developed specific

TABLE 3. *Mean (standard error) monthly Medicaid payments by payment category and CD4⁺ lymphocyte count*

	CD4 count (cells/mm³)				
Category	All	≤50	51–200	201–500	>500
Total ($)	1,508 (87)	2,436 (171)	1,201 (112)	1,124 (188)	1,015 (177)
Inpatient	858 (76)	1,355 (131)	660 (96)	674 (183)	617 (164)
Outpatient clinic	228 (17)	287 (17)	209 (13)	209 (12)	186 (15)
Professional fees	45 (5)	39 (7)	54 (14)	45 (10)	39 (16)
Pharmacy	248 (19)	515 (57)	186 (26)	126 (10)	72 (10)
Emergency	24 (2)	30 (3)	20 (3)	21 (3)	23 (4)
Home care	82 (9)	165 (21)	59 (13)	43 (7)	40 (9)
Special services	23 (3)	45 (7)	14 (4)	12 (2)	22 (9)

TABLE 4. *Mean (standard error) monthly Medicaid payments by demographic characteristics and CD4⁺ lymphocyte strata*

Characteristic	CD4 count (cells/mm³)				
	All	≤50	51–200	201–500	>500
Total ($)	1,508 (87)	2,436 (171)	1,201 (112)	1,129 (188)	1,015 (177)
Sex					
Male	1,696 (126)	2,484 (191)	1,246 (142)	1,309 (327)	1,269 (354)
Female	1,208 (101)	2,299 (372)	1,120 (182)	901 (99)	818 (152)
Race					
White	1,418 (171)	2,139 (359)	1,505 (364)	966 (247)	532 (118)
Nonwhite	1,524 (98)	2,492 (192)	1,149 (115)	1,158 (217)	1,081 (200)
Injecting drug use					
Yes	1,374 (83)	2,371 (238)	1,168 (134)	972 (86)	943 (159)
No	1,706 (84)	2,529 (249)	1,188 (187)	1,381 (491)	1,133 (390)
Age (years)					
≤35	1,506 (132)	2,597 (262)	1,170 (155)	1,079 (105)	893 (181)
>35	1,511 (101)	2,318 (227)	1,228 (160)	1,163 (308)	1,104 (277)

opportunistic disease (Table 5). The most expensive opportunistic disease was cytomegalovirus (CMV) retinitis. Toxoplasmosis and AIDS dementia were next most expensive, with *Candida* esophagitis the least expensive of the diseases we analyzed. In contrast, patients with no AIDS-defining opportunistic disease had substantially lower mean monthly costs. We also analyzed monthly costs in the 6 months immediately prior to death. In the 107 patients who died during our follow-up, mean monthly costs were $3,340 ($328) in the 4–6 months prior to death and $6,680 ($652) in the 0–3 months immediately prior to death. On average, mean costs were $4,600 ($424) in the 6 months prior to death.

TABLE 5. *Mean (standard error) monthly Medicaid payments within 6 months after development of opportunistic disease[a] or 6 months prior to death*

	Mean (standard error) ($)	No.
Cytomegalovirus retinitis	7,825 (1,141)	20
Toxoplasmosis	4,615 (1,335)	13
AIDS dementia complex	3,712 (1,091)	31
Mycobacterium avium complex disease	3,602 (761)	36
Pneumocystis carinii pneumonia	3,023 (647)	49
Candida esophagitis	2,563 (491)	58
Death (any cause)		107
4–6 months prior	3,340 (328)	
0–3 months prior	6,680 (652)	
0–6 months prior	4,600 (424)	
No opportunistic disease or death		
CD4⁺ ≤50 cells/mm³	1,838 (150)	250
CD4⁺ = 51–200 cells/mm³	1,080 (100)	245

[a] Diseases for which there were >10 cases.

Lifetime Costs

Our Markov analysis of cumulative Medicaid payments for a patient enrolled into our clinic with a CD4⁺ count >500 cells/mm³ (median CD4⁺: 697 cells/mm³; range 502–1,728) and followed up until death was based on the transition probabilities shown in Table 6. By use of these probabilities and the annualized payments for each CD4⁺ count—defined clinical stages for Table 3, the cumulative lifetime payments would be $133,500 over a life span of 8.3 years from enrollment.

DISCUSSION

Analysis of trends in the epidemiology of HIV disease in the U.S. indicates that during the 1990s, HIV infection has become increasingly a disease of urban minority populations (14,15). Furthermore, Medicaid has become the predominant payer of the medical costs for the HIV-infected population (11). Our data indicate that on average, Medicaid payments increase 2.4-fold as the CD4 count declines from >500 cells/mm³ or less. Mean monthly costs increase progressively as patients approach death, which is consistent with the severe immunosuppression and debility that commonly accompany very late-stage HIV infection. Another multisite study of predominantly white homosexual/bisexual men receiving care from 1990 to 1991 showed that a decline in CD4⁺ count from >500 to <50 cells/mm³ or AIDS was associated with a three-fold increase in utilization of outpatient services and an eight-fold increase in hospitalization. Costs, however, were not available in this study (35).

TABLE 6. *Semiannual transition probabilities used in Markov analysis based on the Johns Hopkins cohort*

Enrolment CD4⁺	Probability of transition to				
	CD4⁺ >500	CD4⁺ = 201–500	CD4⁺ = 51–200	CD4⁺ ≤50	Death
>500	0.85	0.11	0.02	0.01	0.01
201–500	—	0.85	0.10	0.03	0.02
51–200	—	—	0.74	0.17	0.08
≤50	—	—	—	0.80	0.20

Our estimate of $133,500 in payments by Medicaid over a lifetime of 8.3 years is higher than the $119,000 estimate of costs over a lifetime of 12 years based on 1991 ACSUS data (10). However, it is notable that in ACSUS, patients spent an average of 68 months (almost half of the entire follow-up time) with a CD4⁺ count >500 cells/mm³, incurring costs at a rate of only $248 per month, and costs were also based on 1992 dollars. In our study, the median CD4⁺ at enrollment was 697 cells/mm³, and a median of only almost 24 months would be spent in our lowest cost stratum. Other recent modeled estimates of lifetime health care costs directly related to HIV infection were $94,726 (36) and $87,800 (36). Our higher empirical costs of care in comparison with ACSUS and the modeled estimates suggests that in our patients, hospitalization and other use of health care is occurring for reasons other than HIV-related complications, particularly when the CD4 count is ≥500 cells/mm³. For example, injecting drug users may be more likely to develop complications such as endocarditis or sepsis that require expensive inpatient treatment (37). Chronic illness such as depression, asthma, and hypertension and surgical interventions for trauma are also occurring in many of these inner-city Medicaid-insured patients.

In our patients, opportunistic illness seldom occurs until the CD4⁺ count has declined below 100 cells/mm³ and is most common when the CD4 count has fallen below 50 cells/mm³ (38). Our analysis suggests that the cost of managing opportunistic disease contributes to the increasing costs associated with a declining CD4⁺ count. Cytomegalovirus retinitis was the most expensive of these complications and *Pneumocystis carinii* pneumonia the least expensive, possibly reflecting the outpatient management of this disease common in current practice. Of interest, our costs for CMV retinitis were quite similar to the annual cost of $100,300 estimated in a recently published study that modeled resource utilization in the management of opportunistic disease (39). Our costs for the other opportunistic illnesses were higher, on average, than these modeled estimates. One caveat to the interpretation of our analyses of the costs of opportunistic disease is that the sample sizes are small for some of these diseases, thereby decreasing the precision of the estimates of monthly costs.

In comparison with estimates from more than 5 years ago, the use of inpatient care has substantially declined from as high as 80% of overall costs (40). The percentage is also lower than that found more recently in New York State, where 69% of expenditures for persons with HIV infection were for inpatient hospitalization (41). An earlier analysis of hospitalization rates of AIDS patients in Maryland demonstrated a progressive decline from 1988 through 1992 (37). Another factor with the potential to decrease inpatient costs is the improved ambulatory management of HIV-infected patients, including the use of prophylaxis for *Pneumocystis carinii* pneumonia, an opportunistic complication of HIV infection associated previously with high inpatient costs (42,43). Although the total payments for hospitalization increase about two-fold for a CD4⁺ >500 cells/mm³ to a CD4⁺ <50 cells/mm³, the proportion of total costs attributable to inpatient costs is relatively stable across the four CD4⁺ strata: ~50%.

Ambulatory pharmacy costs were the second most expensive service category and were proportionately highest when the CD4⁺ count was ≤50 cells/mm³, which is consistent with both the prophylactic and therapeutic use of drugs in advanced disease. Pharmacy accounted for only 11% of mean monthly costs when the CD4⁺ count was between 201 and 500 cells/mm³, a time when antiretroviral drugs are used in our patients, but drugs for prophylaxis of opportunistic disease are less commonly used, and treatment of complications is also less common. The use of antiretroviral therapy has improved survival in late-stage HIV infection (44) and increased the time to development of expensive late-stage complications of HIV infection in earlier-stage disease (45). These changes

in the natural history of treated infection, however, may not have decreased overall costs but shifted them to later in the disease process (46). Our data encompassed a time when reverse-transcriptase inhibiting antiretroviral monotherapy was most commonly used with one of three available nucleoside-analog drugs, although dual reverse-transcriptase antiretroviral therapy was being used in some patients. We have recently entered an era of combination antiretroviral therapy, which may include protease inhibitors that may alter the natural history of HIV disease even further. Although our cost data are as contemporary as possible for Medicaid claims data in our state, whether they will reflect very recent changes in therapy is unknown. We believe, however, that these data can serve as a comparative benchmark for the future costs of HIV medical care in this new era.

Home health care accounted for 7% of mean monthly costs in late-stage disease. This reflects an increasing emphasis on providing care in the home, usually a less costly mode than utilization of either outpatient or inpatient medical care facilities. Emergency room use constituted just over 1% of overall costs, a proportion that was relatively stable across all $CD4^+$ strata. Particularly in an inner-city population, the emergency room can be an expensive and commonly used setting for provision of medical care (47). The relatively low proportion of emergency room costs in our patients may reflect the availability to our patients of a comprehensive care clinic available for both urgent and routine visits and may not generalize to settings in which such a facility is not available.

The higher payment that we found in men compared with women in our bivariate analysis is consistent with results from the ACSUS and the New York State study, both of which indicated that women had lower hospital costs than men (25,41). Our multivariate analysis, however, suggested that the difference in costs between men and women is not significant after other factors are adjusted for. If the costs of HIV care in women are less than for men in our clinic, it is not reflected in differences in progression to AIDS or survival (29,48). A previous study showed higher costs in injecting drug users in early HIV infection but found similar costs to noninjecting drug users in advanced disease (26). Lower costs in our injecting drug users in all stages of immunosuppression may be related to noncompliance with care, although we would note that these possible differences in costs are not reflected in differences in progression to AIDS or survival between those who use and those who do not use drugs (29). With regard to race, another recently published study of AIDS patients has suggested that nonwhites may incur higher costs than whites (49). Our study did not corroborate this result. It is possible that enrollment in Medicaid tends to minimize differences in receipt of care between racial groups.

Typical of those insured by Medicaid, our patient sample was likely to be female, young, and nonwhite. Such a patient sample is likely to be representative of the demography of the HIV-infected population as it has evolved in the U.S. in recent years (14,15). Our results may not generalize to patients with the financial resources to have private insurance or to medically indigent patients with no insurer. We also do not know whether our results would necessarily generalize to Medicaid-insured HIV-infected patients in other states. In Maryland there is an all-payer rate setting system in which Medicaid payment rates to hospitals are about equal to private insurer rates. Additionally, the actual cost of care for inpatient services is tied more closely to payments than in most states (50). Therefore, our inpatient data probably provide a good representation of the actual costs of care. Although we believe this to be an advantage of our data, it probably results in inpatient Medicaid payments being higher in Maryland than in other states. Payments of outpatient care are not regulated in Maryland and are likely to be less than the actual costs.

In summary, our study was not designed to quantify the costs of HIV care across the U.S. but instead to determine the relative costs that a Medicaid program will likely incur in providing payment for an HIV-infected patient population. For this purpose, we believe that we comprehensively captured the medical care received by these patients. We also wished to determine whether the costs of contemporary care differ according to demographic characteristics of the patients in a setting in which we knew that receipt of care, progression to AIDS, and survival do not differ by sex, race, or injecting drug use (28,29). For such subgroup cost comparisons, we believe this provides an advantage over analyses where receipt or quality of care might vary among different providers in different settings. Interventions that decrease hospitalization, opportunistic disease, and the cost of terminal care are most likely to lower overall costs. These data should provide a useful comparative benchmark of the cost of health care for Medicaid-insured HIV-infected patients as we enter a new era of treatment using combination antiretroviral therapies.

Acknowledgment: Supported by the Agency for Health Care Policy and Research (RO1 HS07809). We wish to thank Mary Stuart, Sc.D., Director of the Policy and Health Statistics Administration of the Maryland Department of Health and Mental Hygiene, for her assistance, and we also acknowledge the technical computer programming support of Laura Yu and Joel Gibson.

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Transitions in Insurance and Employment Among People with HIV Infection

This article examines the extent to which people with HIV infection change their insurance and employment status over time and investigates the correlates of such changes. Data come from the AIDS Cost and Services Utilization Survey, which followed 1,949 HIV-infected adults over an 18-month period that began March 1, 1991. In the first interview, overall, 33% of respondents had private insurance; 40% had public coverage (i.e., Medicaid, Medicare, CHAMPUS); and 27% had no insurance. Among the subgroup with AIDS, corresponding figures were 32%, 54%, and 14%. Overall, 65% were unemployed; among those with AIDS, 82% were unemployed. Over the 18-month period, 23% of respondents reported a change in insurance status and 27% reported a change in employment status. Among those who began the study with private insurance, only 15% reported losing this coverage. Transitions from no insurance to public coverage occurred most frequently. Compared to those who began the study with AIDS, those who progressed to AIDS during the study period were more likely to experience a change in insurance (18% vs. 32%). Consistent with prior studies, public insurance plays a major role in financing care for people with HIV infection. Transitions from public coverage to no insurance may disrupt access to care.

Treatment of human immunodeficiency virus (HIV) infection involves periodic medical visits to monitor the patient's condition, prolonged use of an array of antiretroviral and prophylactic medications, and possible inpatient care to combat severe opportunistic infections or other debilitating conditions. Recent advances in the development of therapeutic agents, such as protease inhibitors, offer promise of successfully managing HIV disease, but at an increased cost. Treatment regimens consisting of combinations of protease inhibitors and other antiretroviral medications are estimated to cost more than $10,000 per person per year (Pear 1997a), and the cost may rise for those who develop side effects from the medication. Prior estimates of the lifetime costs of treating HIV infection, such as Hellinger's (1993) estimate of $119,000, are likely to be too low in the current treatment environment. Progress in treatment of HIV infection may result in increased life expectancy, as well as increased lifetime and aggregate costs of care.

In this context, issues of financing care and treatment for people with HIV infection become salient. Prior studies suggest that public programs support a large proportion of HIV-related medical care. Fleishman and Mor (1993) found that 47% of their sample of 937 adults with AIDS had public health insurance (i.e., Medicaid, Medicare or VA). Based on data from 11 communities, Diaz et al. (1994) reported that 55% of people with acquired immune

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Inquiry 35: 36–48 (Spring 1998).

0046-9580/98/3501-0036$1.25

examines only the 1,949 respondents over the age of 13. Berk, Maffeo, and Schur (1993) provide further information concerning the sampling design.

Respondent Interviews

Respondents were interviewed in person approximately every three months over the 18-month observation period. Sixty-nine percent of the original sample completed all six interviews. Twenty-three percent of respondents died during the study, and another 8% were lost to follow-up, primarily because they could not be located.

Independent variables. The variables of race/ethnicity, gender, and HIV transmission group were measured by the screening questionnaire. Respondents indicated whether they were white (non-Hispanic), black (non-Hispanic), Hispanic, Asian or Pacific Islander, American Indian or Alaskan Native. The small number of nonwhite respondents who were neither black nor Hispanic (n = 36) were combined with whites in the analysis. HIV transmission category was coded as IDU or non-IDU; respondents who noted multiple transmission behaviors were coded as IDU if any injection drug use was indicated. Level of education was dichotomized as high school graduate or less versus at least some college in order to focus on a relatively highly educated group.

Each interview obtained data on insurance coverage. The reference period for each interview was the 3-month period since the previous interview (or since March 1, 1991 for the first interview). Respondents were asked whether they had been covered by "any private health insurance plan . . . that pays for any part of hospital bills, doctor bills, or surgeon bills."[1] Additional questions asked whether the respondent had been covered during the reference period by: 1) Medicaid, 2) Medicare, 3) CHAMPUS or CHAMPVA, and 4) "any other public assistance program (besides Medicaid or Medicare) that pays for medical care."

In each interview, respondents indicated whether they were currently working full time, working part time, or not working. Those people who became unemployed or changed from full- to part-time work were asked whether this change had happened because of HIV infection.

Respondents reported total pretax income from all sources in the month prior to the interview. Respondents were instructed to include any income from a spouse or partner.[2] In view of the predominance of low-income individuals in the sample, income was dichotomized at $500 per month or less, versus more than $500 per month. Respondents also indicated if they received Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) payments.

Medical Record Data

To determine each respondent's illness stage, inpatient and outpatient medical record data from the usual source of care for each respondent were reviewed. Up to 10 discharge diagnoses were recorded for each inpatient admission. For each outpatient encounter, any mention of one of 73 HIV-related conditions or symptoms was recorded and dated. Based on the first mention of an AIDS-defining condition in the records (using the 1987 definition), the date of AIDS diagnosis was determined. Similarly, for respondents who began the observation period asymptomatic, the first mention of HIV-related symptoms was used to define the start of the symptomatic non-AIDS period. This information was used to assign each respondent to one of three categories of illness stage in each interview period: asymptomatic, symptomatic non-AIDS, and AIDS.[3] If a respondent advanced from one stage to another during an interview period, that person was assigned to the more serious stage. For each period, two dummy variables were derived to represent AIDS and symptomatic non-AIDS, respectively.[4] In addition, a dummy variable was derived to indicate the first interview period in which the respondent had received a diagnosis of AIDS.

The date on which a respondent first tested positive for HIV was recorded from medical records. If the records did not contain this information, the self-reported date of first HIV-positive notification was used. These data were used to calculate the length of time a person had been aware of HIV infection prior to the start of the study period on March 1, 1991.

Analysis

Of the initial sample of 1,949 HIV-infected adults, 26 were either ineligible for part of the study period (by being incarcerated or out of the country) or missed one or more interviews and then had subsequent interviews. Due to the erratic nature of their participation in the study, these respondents were removed from the analysis, leaving an analytic sample of 1,923 respondents.

Analyses of employment were conducted in addition to analyses of insurance because employment

aid, Medicare, and "other public" coverage at baseline. Overall, 33% had private coverage, 41% had Medicaid, 5% reported Medicare coverage, and 22% noted "other public" coverage. A total of 1,324 respondents (69%) indicated only one source of insurance, and 259 (13%) reported no insurance.

For purposes of analysis, a smaller number of categories of insurance coverage was necessary. Any respondent who had private insurance was classified in the "private insurance" category, regardless of other coverage. Given the small number of respondents with Medicare but no Medicaid, a general "public insurance" category was derived, which included anyone with either Medicare or Medicaid (but no private insurance). Finally, the 245 respondents with only "other public" coverage were asked to specify the nature of this coverage; their responses were examined in detail. Most of the responses referred to county-run programs for the indigent. Consequently, these people were assumed to have no formal health insurance and were placed in the same category as the 259 respondents who indicated no insurance. These procedures resulted in 33% of the sample being classified as having private insurance, 39.8% as having public coverage, and 27.2% as having no insurance.[7]

In the first interview, the 1,293 respondents without private insurance were asked if they had ever had private health insurance, and, if so, the last month and year of private coverage. Forty-seven percent of this group did have private insurance at some time prior to the interview. However, when the last date of private coverage was compared to the reported date of the first HIV-positive test, 61% of these respondents (365 of 602) lost private insurance at least six months *before* the date of their first positive HIV test. Thus, the predominant pattern in this group was *not* one of losing private coverage subsequent to becoming ill with HIV infection.

Among respondents with private insurance, 21% reported that their plan was a health maintenance organization (HMO). Forty-six percent of those with private insurance had a private physician as their usual source of care, while 49% reported an outpatient clinic as their usual care source. Ten percent reported that they were covered under a family plan, and the remainder had an individual plan.

Correlates of Employment and Insurance Status

Among respondents with AIDS at baseline, 82% were unemployed, while 14.1% were employed full time and 3.9% had part-time employment. For symptomatic respondents, 58.6% were unemployed, 32.1% had full-time work, and 9.3% were employed part time. Corresponding figures for asymptomatic respondents were 53.2%, 37.7%, and 9.1%.

The pattern of insurance coverage for respondents with AIDS also differed from that for symptomatic or asymptomatic respondents. The three groups were similar in terms of the proportion with private insurance (31.9%, 32.7%, and 34.9%, for AIDS, symptomatic, and asymptomatic, respectively). People with AIDS were most likely to have public insurance (54% compared to 36% for symptomatic and 29% for asymptomatic), and they were least likely to have no insurance (15% vs. 32% for symptomatic and 36% for asymptomatic).

As expected, insurance status was strongly related to employment status. Among respondents with full-time employment, 76.7% had private coverage, 2.8% had public coverage, and 20.5% had no health insurance. Among those who were unemployed, 58.1% had public coverage, 26.6% had no insurance, and only 15.4% had some form of private insurance. Fifty-eight percent of those with part-time employment had no insurance, while 23% had private insurance and only 18% had public coverage.

Multivariate analyses. Table 2 reports results of separate multinominal logistic regressions of employment status (columns 2 and 3) and of insurance status (columns 4 and 5), for interviews 1 through 6.[8] Unemployment was the reference category for analyses of employment status. Being female, having an IDU history, being black or Hispanic, and having relatively low education each significantly lowered the odds of full-time employment (compared to being unemployed). The pattern of effects was generally similar for part-time employment (compared to being unemployed). The coefficient for interview number indicates a linear trend of lower odds of full-time employment over time. Having an AIDS diagnosis reduced the odds of being employed, both full and part time; the effect of being symptomatic (non-AIDS) was in the same direction, although weaker.

In analyses of insurance status, private insurance served as the reference category. Each variable had significant effects, controlling for the others. Female gender, IDU history, black race, Hispanic ethnicity, low education, and low income each increased the odds of having public coverage and (with two exceptions) the odds of having no coverage. The odds of having public coverage rose over time, as indicated by the coefficient for interview number. People with

Table 4. Transitions in employment status

Previous status	Current status		
	Full time	Part time	Unemployed
Full time	1,993	71	234
Part time	89	304	165
Unemployed	100	136	4,923

Note: Entries on the diagonal represent the number of pairs of interviews in which no change occurred.

employment transitions were in the direction of becoming unemployed or losing full-time employment. However, transitions into employment were not uncommon. (Among respondents who completed all six interviews, almost half [47%] of transitions were shifts into unemployment, while nearly a third [32%] were shifts out of unemployment.) A sequence of moving from employment through a temporary spell of unemployment and then back to being employed (either full or part time) is possible. Such a pattern would involve at least two changes; however, only 3% of respondents had two or more employment changes during the study period.

The number of people who said they stopped working full time in each interview period was small, ranging from 88 in the first interview to 60 in the sixth interview. Among these people, from 64% (interview 4) to 52% (interview 5) cited HIV as the reason for stopping full-time work. Although the small numbers imply that these percentages should be interpreted with caution, these results do suggest that there is a baseline level of fluctuation in employment status that may not be related directly to HIV infection, since 36% to 48% of such changes were not attributed to HIV-related causes.

The transition matrix for insurance status reveals that relatively few transitions involved private insurance. Only 19% of transitions involved a loss of private insurance. Moving from public or no coverage to having private insurance was also relatively rare. In contrast, nearly 50% of all transitions were shifts from no insurance to public coverage. Another 19% of transitions involved shifts from public to no coverage.

The likelihood of any change in employment was related to employment status in the first interview. Only 12% of those who were unemployed at baseline reported any subsequent employment change, compared to 44% of those with full-time work and 88% of those with part-time work. Similarly, baseline insurance status was related to experiencing any subsequent change. Fifteen percent of respondents with private insurance in the first interview had some change in insurance, compared to 10% of those with public insurance and 52% of those with no insurance.

Longitudinal Analyses of Any Change

Factors associated with having any change in employment and in insurance coverage were examined using GEE logistic regression. The dependent variable was whether any transition occurred in the period between a pair of interviews. The analyses used data from interviews 2 through 6; ninety-seven respondents who completed only the first interview were excluded from these analyses. To reflect the dynamic aspects of respondents' experiences, three variables were derived. One dichotomous variable, new AIDS diagnosis, took on the value of 1 in the particular interview period in which a respondent received his or her first AIDS diagnosis; otherwise it was 0. This variable was intended to reflect the possibility that circumstances surrounding a person's initial AIDS diagnosis may be particularly associated with change in employment or in insurance. Two other dichotomous variables reflected changes in employment status. A *positive* employment change was any transition from part-time to full-time employment or from unemployment to either full- or part-time work. A *negative* employment change reflected any transition into unemployment, as well as a shift from full- to part-time work.

Change in employment status. Results of the GEE logistic regression analysis of any change in employment appear in Table 6. Notably, receiving an *initial* AIDS diagnosis significantly increased the odds of any change in employment. However, having an AIDS diagnosis per se (i.e., including both the period of initial diagnosis and subsequent periods) significantly lowered the odds of a change in employment status. The episode leading to an initial AIDS diagnosis may involve leaving full-time employment; after this episode, people may remain

Table 5. Transitions in insurance status

Previous status	Current status		
	Private	Public	None
Private	2,537	49	52
Public	14	3,295	102
None	55	263	1,557

Note: Entries on the diagonal represent the number of pairs of interviews in which no change occurred.

have private insurance. This study's figure of 33% of people with AIDS who have private insurance is very close to Fife and McAnaney's (1993) estimate of 32.5%, which was based on data from Philadelphia from 1988 to 1991, and to Fleishman and Mor's (1993) figure of 30%, which was based on data from nine communities during the period 1989–90. (The 1996 MEPS data yield an estimate of 70.9% of the general population aged 18–64 who have private coverage.)

Estimates of insurance coverage will be affected by a study's sampling design. For example, Diaz et al. (1994) found that 20% of people with AIDS had private coverage; however, the proportion with private coverage ranged from 11% for respondents recruited from public hospitals to 40% for a population-based sample. Weissman et al. (1994) reported that 17% of people with AIDS had fee-for-service coverage, and 33% were enrolled in an HMO; however, that study used an HMO as one of three sampling sites. (The same project found that 36% of people with AIDS were employed, compared to 18% in the present study [Massagli et al. 1994]. Again, differences in the composition of the sample may in part explain these results.) Most research suggests that the proportion of persons with AIDS having private coverage is in the 20% to 40% range, but more precise estimates must await a rigorously designed national probability sample.

Medicare played a relatively small role in financing care for ACSUS respondents. The proportion of respondents reporting Medicare coverage rose slightly over time, from 5% at Time 1 (n = 100) to 10% at Time 6 (n = 157), but much of this increase was due to a reduction in the number of respondents in each interview wave as a result of attrition. In addition, one must be cautious in interpreting self-reports of Medicare coverage, since respondents may be unclear concerning the distinction between Medicare and Medicaid. (Among respondents who reported Medicare coverage, between 13% and 18% also reported that they did *not* receive SSDI payments.)

The proportion of people with HIV infection who are members of minority or disadvantaged groups has grown over time. These epidemiological trends imply that the role of Medicaid in financing HIV care will continue to grow. It is likely that the proportion of HIV-infected people with Medicaid has increased since the ACSUS data were collected, while the proportion with private coverage has probably decreased.

Transitions. Analyses of change in employment and insurance produced some noteworthy results. Over the 18-month study period, 70% of respondents experienced no change in employment or in insurance status. This picture of stability is echoed in another study, which found that two-thirds of people with AIDS who were working at the time of their AIDS diagnosis had a job approximately 16 months later (Massagli et al. 1994), and that 64% had no change in insurance status since AIDS diagnosis (Weissman et al. 1994).

Anecdotal reports have suggested that, over time, people with HIV infection who are employed *eventually* will stop working and will lose employer-provided health insurance. However, only 15% of those who began the study with private insurance lost that coverage. Several factors may explain the observed stability in private health insurance. Right censoring provides one explanation: the 18-month observation period may not have been sufficiently long to observe transitions in insurance status (and in employment status as well); transitions that may have occurred after the observation period was completed would not be reflected in the data (i.e., they would be censored). The relative stability of insurance suggests that prospective studies will need an observation period longer than 18 months to reduce the amount of right censoring.

A second possible explanation for stability in private coverage relates to the sampling design. A large proportion of ACSUS respondents were recruited from public hospitals. Some patients at public hospitals already may have lost private coverage, which forced them to seek care at public institutions. According to this explanation, stability in insurance status was observed because many transitions had occurred prior to the study period. However, other data do not conform to this explanation: over 60% of those who had lost private coverage before the first interview reported losing that coverage at least six months *before* being notified of HIV infection. For some of these individuals, HIV testing may have occurred late in the disease course, and loss of private health insurance may have been due to the undiagnosed effects of HIV infection. For others, however, factors other than HIV infection may have resulted in loss of private insurance. The substantial proportion who lost private coverage before their first positive HIV test suggests that this explanation can be at best partial.

Finally, some respondents may have extended private insurance under provisions of the Consolidated

infection who are covered by some form of managed care arrangement has increased since 1992. The capability of managed care plans to provide adequate services to people with chronic diseases such as HIV is a current policy issue.

Another major development since ACSUS is the recent advances in treatment of HIV infection, especially the use of combination drug therapy including protease inhibitors. A key issue in the current treatment environment is the extent to which people with HIV infection have access to the newly available pharmaceuticals. Those who have private health insurance still may have difficulty in obtaining access to medications (Pear 1997a) due to formulary restrictions, yearly expenditure caps, or other limitations. State AIDS drug assistance programs also are experiencing intense budget pressures, as shown by restrictions on the number of enrollees or on the number of covered pharmaceuticals (Pear 1997a). Recent recommendations to begin combination therapy as early as possible in the disease course only will heighten the demand. In this context, the key issue may not be whether a person has public or private coverage, but rather the extent to which the plan has generous pharmaceutical benefits.

If these therapies live up to their initial promise, they may prolong the time between HIV infection and development of AIDS, as well as the period of survival after initial AIDS diagnosis. This may, in turn, have several other effects. One outcome may be an increased role for Medicare as a payer for HIV care: a higher proportion of people with AIDS now may be surviving for the 29-month period required before becoming eligible for Medicare. A second outcome may be a decrease in the rate of employment changes, and hence insurance changes, if the new therapies delay the onset of debilitating symptoms or conditions and thereby enable HIV-infected people to remain at work longer. A related issue derives from the possibility that the health status of people with HIV infection actually may improve if new therapeutic regimens succeed in restoring functioning. In the future, transitions from unemployment to employment may become even more common. If formerly disabled people seek to return to work, their Medicaid coverage may be threatened, thereby impairing access to the very drugs that made their recovery possible in the first place. (On the other hand, improvement in health status and reentry into the labor force may enable people to obtain employer-sponsored health insurance. But the extent of such opportunities is unknown.) This possibility, in conjunction with Medicaid's dominant role in financing HIV-related care and the current findings on transitions out of public insurance, points to the importance of scrutinizing the extent of periods of ineligibility for Medicaid, assessing the impact of these periods on access to and quality of care, and considering policies to minimize the adverse impact of such periods.

Notes

Portions of this paper were presented at the 1997 annual meeting of the Association for Health Services Research. I thank Liliana Pezzin and Philip Cooper for helpful comments on previous versions of the manuscript. No official endorsement of the views in this paper by the Agency for Health Care Policy and Research or the Department of Health and Human Services is intended or should be inferred.

1 Respondents with private insurance also indicated whether the plan was a health maintenance organization; whether the plan was individual or family coverage; and whether they received insurance through an employer, a union or some other group, or directly from an insurance company.

2 Respondents chose one of 14 income ranges, from a minimum of $0 to $200 to a maximum of $4,001 or greater.

3 A diagnosis of AIDS requires a diagnosis of specific indicator conditions, such as certain cancers, opportunistic infections, or low levels of CD4 cells (a measure of immune system functioning). People can have HIV-related symptoms, such as night sweats or diarrhea, without having an AIDS diagnosis.

4 If medical record data were insufficient to determine disease stage for a specific interview period, a value was imputed using the nearest preceding nonmissing disease stage. Self-reported screener data were used if medical record data were unavailable. By assuming stability in disease stage over time, this procedure will result in conservative tests of the effects of disease stage.

5 These analyses were conducted using SUDAAN 7.0 software (Shah, Barnwell, and Bieler 1996). GEE analyses used an exchangeable correlation structure, which assumes that the correlation between any pair of interviews is constant; GEE estimates are asymptotically robust to misspecification of the correlation structure. GEE is an extension of generalized linear models (McCullagh and Nelder 1989) to deal with correlated observations. A "working" correlation matrix, representing the pattern of relationships among observations from the same person, is incorporated into the fitting function used to derive the estimates of regression coefficients. Standard errors are adjusted to account for nonindependence of observations. GEE is a "marginal," or "population averaged" approach, in which the within-cluster dependency is modeled separately from the regression of interest. For nonlinear models, GEE

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Havens PL, Cuene BE, Holtgrave DR. **Lifetime cost of care for children with human immunodeficiency virus infection.** Pediatric Infectious Disease Journal. 1997, 16(6):607-610.

Katz MH, Chang SW, Buchbinder SP, Hessol NA, O'Malley, Doll LS. **Health Insurance and use of medical services by men infected with HIV.** Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 1995, 8(1):58-63.

Mauskopf JA, Paul JE, Wichman DS, White AD, Tilson HH. **Economic impact of treatment of HIV-positive pregnant women and their newborns with zidovudine-Implications for HIV screening.** Journal of the American Medical Association. 1996, 276(2):132-8.

Owens DK, Nease RF Jr. **A normative analytic framework for development of practice guidelines for specific clinical populations.** Medical Decision Making. 1997, 17(4):409-426.

Wilson IB, Sullivan LM, Weissman, JS. **Costs and outcomes of AIDS care; Comparing a health maintenance organization with fee-for-service systems in the Boston health study.** Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 1998, 17(5):424-432.

Abstracts

Bennett CL, Curtis JR, Achenbach C, Arno P, Bennett R, Fahs MC, Horner RD, Shaw-Taylor Y, Andrulis D. **U.S. hospital care for HIV-infected persons and the role of public, private, and veterans administration hospitals.** Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 1996, 13(5):416-421.

Summary: Hospitals are a major provider of medical care for human immunodeficiency virus HIV-infected persons. Although utilization and patterns of care profiles in public and private hospitals have been evaluated for acquired immunodeficiency syndrome IDS-related Pneumocystis carinii pneumonia (PCP), one of the most costly and common severe complications of AIDS, information from Veterans Administration (VA) hospitals has not been reported previously. This article reports on inpatient care for PCP patients by obtaining data from VA, private, and public; hospitals. Cost and resource utilization data from VA, private, and public hospitals. Cost and resource utilization data were obtained from reviews of medical records, claims, and provider bills from 26 non-VA hospitals and 18 VA hospitals in 10 cities in the United States. Data on severity of illness, patterns of care, and outcomes for PCP were obtained from medical record reviews from 2,174 PCP cases treated in 82 non-VA and 14 VA hospitals in five U.S. cities. Estimates were made of the average costs and the rates of use of diagnostic tests, anti-PCP medications, and intensive care units for samples of public hospital, private hospital, and VA patients with PCP. With mean charges for a single PCP episode of $14,500 to $16,060, PCP remains one of the most costly complications of AIDS. Although the severity of PCP illness at admission was greatest at public hospitals, the intensity of care was lowest: for frequency of cytologic diagnosis (48% at public, 62% at VA, and 66% at private hospitals), bronchoscopy (45% at public, 60% at VA, and 66% at private hospitals), and intensive care unity use (11% at public, 22% at VA, and 19% at private hospitals). In-hospital mortality rates for PCP also differed in the three types of hospitals (20% at public, 24% at VA, and 18% at private hospitals). Patterns of PCP care differ among VA, public, and private hospitals. Future studies on the HIC epidemic should include data collected from uniform data sources from VA hospitals, in addition to public and private hospitals, to provide insight on the processes of care and outcomes for HIV-infected persons.

Havens PL, Cuene BE, Holtgrave DR. **Lifetime cost of care for children with human immunodeficiency virus infection.** Pediatric Infectious Disease Journal. 1997, 16(6):607-610.

Background: Knowledge of the cost of care for children with HIV infection is necessary to analyze the economic impact of recommendations for universal counseling and voluntary HIV testing of pregnant women. *Objectives:* To estimate the total cost of care for children with HIV infection. *Methods:* We performed a retrospective cohort study of all 88 children with (n=29) or at risk for (n=59) perinatally acquired HIV infection cared for at Children's Hospital of Wisconsin between February 2, 1987, and June 1, 1995. Review of medical records for all 29 children with perinatally acquired HIV infection or AIDS identified: date of HIV diagnosis; date of classification into Category N,A, B or C; date of AIDS diagnosis; and date of death or transfer of care. The time each subject remained in each CDC category was calculated and the Kaplan-Meier product-limit method was used to calculate survival time for all patients in each CDC category. Hospital-based inpatient and outpatient charges were estimated as the sum of the charges for each category. From that, total charges were calculated assuming that hospital-based charges were 83% of total charges. *Results:* Based on a median survival time of 120 months, the mean lifetime charges for hospital-based care for children with HIV infection was $408,307 (estimates raged from $172,217 to $498,539). If hospital-based care represents 83% of the total charges for care of children with HIV infection, then mean total lifetime charges for care of children with HIV infection were $491,936 ($207,490 to $600,649). *Conclusions:* The care of children with HIV infection is expensive. This information may be useful in planning for care programs and for analyzing the economic impact of recommendations for universal counseling and voluntary HIV testing of pregnant women.

Katz MH, Chang SW, Buchbinder SP, Hessol NA, O'Malley, Doll LS. **Health Insurance and use of medical services by men infected with HIV**. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 1995, 8(1):58-63.

Summary: Among 178 HIV-infected men from the San Francisco City Clinic Cohort (SFCCC), we examined the association between health insurance and use of outpatient services and treatment. For men with private insurance, we also assessed the frequency of avoiding the use of health insurance. Men without private insurance reported fewer outpatient visits than men with fee-for-service or managed care plans. Use of zidovudine for eligible men was similar for those with fee-for-service plans (74%), managed care plans (77%), or no insurance (61%). Use of Pneumocystis carinii pneumonia prophylaxis was similar for those with fee-for-service (93%) and managed care plans (83%) but lower for those with no insurance (63%). Of 149 men with private insurance, 31 (21%) reported that they had avoided using their health insurance for medical expenses in the previous year. In multivariate analysis, the independent predictors of avoiding the use of insurance were working for a small company and living outside the San Francisco Bay Area. Having private insurance resulted in higher use of outpatient services, but the type of private insurance did not appear to affect the use of service or treatment. Fears of loss of coverage and confidentiality may negate some benefits of health insurance for HIV-infected persons.

Mauskopf JA, Paul JE, Wichman DS, White AD, Tilson HH. **Economic impact of treatment of HIV-positive pregnant women and their newborns with zidovudine-Implications for HIV screening.** Journal of the American Medical Association. 1996, 276(2):132-8.

Objectives: To estimate the economic impact of (1) treating pregnant women who are HIV-positive with zidovudine and (2) voluntary screening programs for pregnant women for HIV infection and offering treatment with zidovudine to those found to be HIV-positive. *Main outcome Measures:* Number of cases of pediatric HIV infection and costs of screening, zidovudine treatment, and pediatric HIV infection treatment. *Design:* Healthcare costs associated with treatment of HIV-positive pregnant women and their newborns are estimated as the costs of zidovudine and its administration and the reduction in costs of treating pediatric HIV infection. The lifetime costs of pediatric HIV infection are derived from the published literature. Estimates of the reduction in maternal-to-fetal transmission rates are taken from the AIDS Clinical Trials Group (ACTG) Protocol 076. Costs of a voluntary screening program include costs of screening tests and counseling. Sensitivity and threshold analyses are performed to determine the impact of changes in input parameter values including zidovudine treatment costs, efficacy of treatment, costs of pediatric HIV infection, prevalence of HIV infection in pregnant women, screening test sensitivity and specificity, and pregnancy termination rates on the results. *Results:* Assuming transmission rates are reduced from 25.5% to 8.3% as found in the ACTG 076 trial, treatment costs of $104,502 for 100 HIV-positive pregnant women and their newborns are offset by the reduction of $1,701,333 associated with fewer cases of pediatric HIV infection for a net savings of $1,596,831. The sensitivity and threshold analyses show that overall cost savings from treatment of HIV-positive pregnant women and their newborns are achieved for a wide range of possible maternal treatment costs, efficacy rates, and lifetime pediatric HIV treatment costs. In the base-case analysis for the voluntary screening program, overall cost savings are seen when the HIV prevalence rate among pregnant women is greater than 4.6 per 1,000. However, this threshold prevalence rate is sensitive to changes in parameter values—especially pediatric HIV treatment costs, counseling costs, efficacy of treatment, and years of additional HIV treatment for the pregnant women. *Conclusions:* Offering zidovudine treatment to pregnant women known to be HIV-positive will decrease the number of cases of pediatric HIV infection and reduce health care costs. Voluntary screening programs for pregnant women will further decrease the number of cases of pediatric HIV infection. The effect f a screening program on health care costs varies according to HIV prevalence and the costs associated with the screening program.

Owens DK, Nease RF Jr. **A normative analytic framework for development of practice guidelines for specific clinical populations.** Medical Decision Making. 1997, 17(4):409-426.

Background: A central problem in practice guideline development is ho to develop guidelines that appropriately account for variations in clinical populations and practice settings. Despite recognition of this problem, there is no formal mechanism for assessing what the need is for flexibility in guidelines, or for deciding how to incorporate such flexibility into recommendations. *Objective:* This research sought to provide a formal basis to determine when clinical circumstances vary sufficiently that guideline recommendations should differ, how recommendations should be tailored for a specific clinical setting, and whether the benefit associated with such site-specific guidelines justifies the expense of their development. *Results:* The authors describe an approach for estimating the maximum health benefit that developers can obtain by eliminating uncertainty about differences in the patient populations and practice settings in which a guideline will be used. This estimate, the expected value of customization, provides a mechanism to evaluate the cost-effectiveness of the development of site-specific guidelines that account explicitly for variation in clinical circumstances. Application of this method to the development of screening guidelines for human immunodeficiency virus (HIV) infection indicates that the development of site-specific guidelines potentially is cost-effective. Site-specific guidelines either improve, or leave unchanged, the efficiency of HIV screening; whether they increase or decrease total expenditures and health benefits depends on the choice of a cost-effectiveness threshold, and the clinical problem. *Conclusions:* Development of guideline recommendations based on decision models provides a normative approach to evaluating the need for and the cost-effectiveness of site-specific guidelines that have been tailored to specific practice settings. Such site-specific guidelines can improve substantially the expected health benefit and the economic efficiency of practice guidelines.

Wilson IB, Sullivan LM, Weissman, JS. **Costs and outcomes of AIDS care; Comparing a health maintenance organization with fee-for-service systems in the Boston health study.** Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 1998, 17(5):424-432.

Objective: a 4-month observational cohort study was performed to compare the performance of one health maintenance organization (HMO) with tow fee-for-service (FFS) systems in Boston, Massachusetts in treating 255 patients with AIDS. *Main Outcome Measures:* Total 4-month costs; cost subcomponents, including inpatient, outpatient, home care, and zidovudine costs; functional status (difficulties with activities of daily living); and satisfaction with care. *Results:* Compared with FFS patients, HMO patients were better educated, more often white, less often on Medicaid and more often reported homosexual or bisexual behaviors as HIV risk factors (all factors, p=.001). Both groups had similar duration of AIDS, baseline hemoglobin levels, and leukocyte counts. Total 4-month costs at the HMO were significantly lower than those in the FFS settings ($4,799 U.S. versus $8,540 U.S.: p=.013), as were outpatient costs ($1,131 U.S. versus $1,614 U.S.: p=.001), after adjustment for sociodemographic factors, baseline functioning, main HIV risk factor, and other clinical variables. Adjusted physical functioning (p=.32) and patient satisfaction (p=.82) were similar between systems. *Conclusions:* The HMO had significantly lower total costs without any observable decrement in functional outcomes or patient satisfaction. The largest component of these cost savings came from reduced spending on inpatient care, but the HMO also spent less on outpatient and home care. Better coordination of care at the HMO may have been responsible for these lower costs.

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THE HENRY J. KAISER FAMILY FOUNDATION

Using Payment to Promote Better Medicaid Managed Care for People with AIDS

Prepared by

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Carol Tobias
Medicaid Working Group

NATIONAL ACADEMY *for* STATE HEALTH POLICY

JULY 1997

The George Washington University
WASHINGTON DC
MEDICAL CENTER

FORUM FOR COLLABORATIVE HIV RESEARCH

May 26, 1998

Dear Colleague:

On behalf of the Forum for Collaborative HIV Research and the American Association of Health Plans, I want to thank you for agreeing to participate in the upcoming meeting on the role of managed care in HIV treatment and research. Here are the logistical details for the meeting. The meeting agenda and a current list of participants is attached.

Time: **June 5th - 10:00 a.m. - 3:00 p.m.**

Location: **Marvin Center of the George Washington University**
800 21st St, NW (between H & G Streets)
Room 404

If you have questions or comments about the meeting, please call me at 202-530-2307. If you need assistance with travel or accomodations, please call William Gist at 202-530-2334. I look forward to seeing you on June 5th.

Yours truly,

David Barr
Director
Forum for Collaborative HIV Research

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FCHR/AAHP Meeting on the Role of Managed Health Care in HIV Treatment and Research

10:00 - 10:15 - Welcome - David Barr, Carmela Bocchino
Introductions by meeting participants

10:15 - 10:45 - Presentation - Overview of Cost and Utilization Research of HIV Care
Fred Hellinger, M.D. - Agency for Health Care Policy and Research

10:45 - 12:15 - Discussion: Providing Cost-effective HIV Care

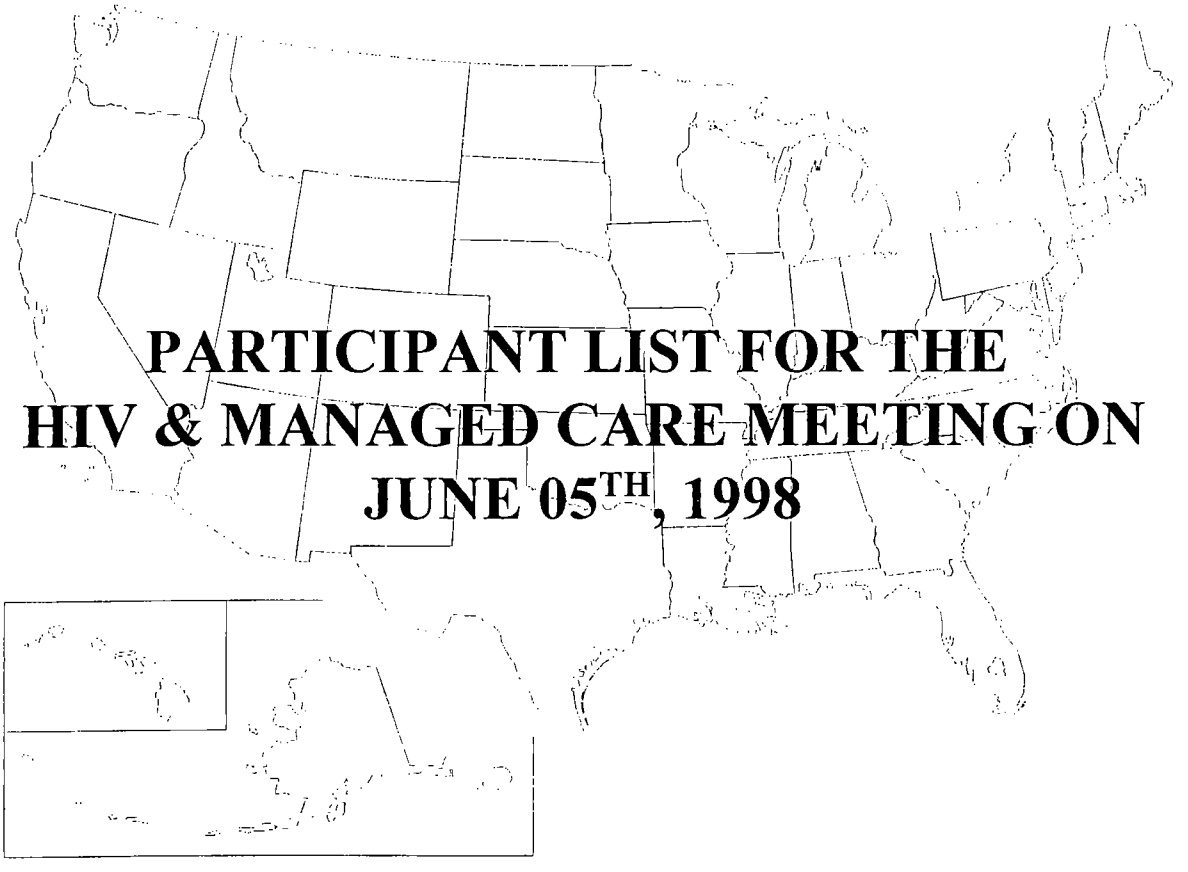
- Developing specifications for HIV care programs -
  Sara Rosenbaum, J.D., Center for Health Care Policy Research
- Providing care management in HIV disease -
  John Ludden, M.D., Harvard Pilgrim Health Care
- Challenges for long-term management of HIV disease -
  Lawrence Deyton, MD, Department of Veterans' Affairs

12:15 - 1:15 - Lunch

1:15 - 2:30 - Discussion: Future research in HIV/AIDS and health care delivery

- Utilization and quality assurance research
- Guidelines dissemination and patient outcomes research
- Participation in clinical studies

2:30 - 3:00 - Future opportunities for collaboration between AAHP, the FCHR, health plans and their delivery systems



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DRAFT - JANUARY 8, 1998

KEY APPROACHES TO THE USE OF MANAGED CARE SYSTEMS FOR PERSONS WITH SPECIAL HEALTH CARE NEEDS

Guidance for States Considering the Development of Managed Care Programs for Persons With Special Health Care Needs

JANUARY 1998

This guidance was jointly developed by the Health Care Financing Administration, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Indian Health Service, the Substance Abuse and Mental Health Services Administration, the Office of Disease Prevention and Health Promotion, and was reviewed and commented on by the Managed Care Technical Advisory Group.

Health Care Financing Administration January 1998

KEY APPROACHES TO THE USE OF MANAGED CARE SYSTEMS FOR PERSONS WITH SPECIAL HEALTH CARE NEEDS

Introduction

This guide is provided to States for review and consideration during the planning stages of Medicaid managed care programs (Section 1115 and 1915(b) waivers, voluntary programs, and new State option programs) for persons with special health care needs. The medical, social and financial needs of persons with special health care needs are often complex and unique to each individual. We envision that the application of these key approaches will assist States in identifying and resolving potential problems associated with providing adequate access to quality medical services, assuring an adequate provider network for these populations, and addressing their social and support needs. This guide (while not mandatory), in addition to serving as a resource to States, also serves as a broad statement of HCFA's goals for care delivery systems intended to serve persons with special health care needs. As a result, we hope this guide will help facilitate actions at the State and community level as these programs are initially conceived and developed in order that the issues raised in this guide are addressed by a State before their program is submitted to HCFA for review and consideration.

Before presenting these approaches, it is important for States to develop a comprehensive profile of the health of the specific population and service needs. The development of this profile should be epidemiologically-oriented and based on the following processes: (1) assessing the incidence and prevalence of medical conditions within a community as well as specific social and demographic features associated with Medicaid eligibility and service use; (2) assessing health-related service (as well as social and other support services) needs necessary for improving the population's health; and (3) identifying and coordinating existing public and private resources to create a system to meet the needs of Medicaid beneficiaries in the new health delivery system.

Based on the above process, States will be able to quantify the population's need, identify social or demographic characteristics related to the access and use of primary and specialty services, and tailor purchasing specifications and delivery systems (considering existing funds or structures) to create cost-effective systems of care for adults and children with special needs. This information may also contribute to identifying population-based variations in expenditure patterns for purposes of rate setting and risk adjustment. Data that are commonly available to State Medicaid agencies include: vital statistics; reportable events (tuberculosis, HIV/AIDS); and statewide surveys such as the National Immunization Survey and the Behavioral Risk Factor Surveillance System.

The following framework covers five broad areas related to the planning and development of the new delivery network -- the environment, access and quality, benefits and the delivery system, finance, and evaluation and reporting. Each area includes a series of statements and questions

which reflect those items we believe a State should take into consideration when including persons with special health care needs in managed care systems.

Finally, you will note that the framework contained in this guidance is not targeted at specific special needs populations such as children with special health care needs, or individuals with developmental disabilities. While such a framework was considered, it was decided that a more productive use of this guidance would be to identify those core elements that are shared by most special needs populations and to translate those core elements into the guidance that follows. We believe this guidance, while not targeted, does address many of the issues shared by all special needs populations and we recognize that there are unique needs among these groups that this document does not address. We also recognize that the entire area of managed care for persons with special health care needs is very new and that this guidance will evolve as the knowledge base in the field continues to evolve. To this end, we hope this document serves as a catalyst for dialogue and discussion among States, health plans, providers, consumers, advocacy groups, and any other organizations that could shed new light on this matter. Our shared goal is to improve systems of care for persons with special health care needs and we anticipate that this guidance is a starting point in that effort and we welcome any comments that will improve this guidance in the future.

KEY APPROACHES TO THE USE OF MANAGED CARE SYSTEMS FOR PERSONS WITH SPECIAL HEALTH CARE NEEDS

I. THE ENVIRONMENT

Critical to the success of any State managed care initiative is the building of understanding and support from the grassroots level (which includes relevant State and local public agencies, advocacy groups, consumers, providers, and managed care organizations (MCOs)) for the programs being considered and developed by the State. Such an approach is needed in order to receive feedback on the feasibility of a State's proposal and the degree of knowledge and support of the provider community, the beneficiary community (or the advocates who represent them), as well as the MCO community. Such efforts can be formally built into a program in the form of advisory councils, ombudsman programs, and routine public forums to name a few possible options.

Engagement of key stakeholders with interest in the planning, development, implementation and monitoring of managed care programs for persons with special health care needs. (1)

States should consider:

- Developing processes to ensure adequate input from key stakeholders such as other public agencies (e.g., mental health and substance abuse agencies), beneficiaries and families, MCOs, providers, consumer advocacy groups, and professional associations.

- Establishing a key stakeholders advisory committee that provides direct, documented input in the development and implementation of the waiver. Examples of the types of responsibilities and functions the committee could have include monitoring of service utilization, establishment of health care outcome measures, and assessing quality of care for special needs populations. The committee should also have regular meetings and a formalized structure.

- Defining key terms related to the use of managed care services for persons with special health care needs, such as: populations considered to have special needs, case management, case worker, utilization review management, supports, practice guidelines, performance measures, types of gatekeepers, medical necessity.

- Monitoring access and satisfaction measures for persons with special health care needs, such as ongoing meetings between Medicaid staff and MCO management, medical directors, beneficiaries and family members, providers, and advocacy groups.

II. ACCESS

Of fundamental importance to any managed care service delivery system is the ability of enrollees to access appropriate services in a timely manner. Issues that impact upon access include: efforts by a State to market the program to beneficiaries; outreach and education efforts to increase the rate at which beneficiaries choose and access their MCO or provider; the availability of written materials in threshold languages along with staff capable of communicating in those threshold languages; assuring that the provider network is experienced and has the expertise needed to care for persons with special health needs; and, whether and how the State's auto-assignment process takes into account time sensitive and continuity of care issues for persons with special health needs. Together, the issues identified below should be given due consideration in order to assure access to services for persons with special health needs.

Enrollment and marketing practices for persons with special health care needs. (2)

States should consider:

- Assessing the types of assistance or information that will be targeted to persons with special health care needs (beyond the standard material given to all enrollees) to assist their understanding of the capacity of various MCOs in meeting their special health needs.

  - Enrollment materials should be made available for persons with sight or hearing impairments or for people who do not speak English. Also, the establishment of thresholds for these materials should be considered by the State. These individuals need to be identified by the State prior to initiating the enrollment process.
  - Multi-language materials (written and audiovisual) should be made available at an appropriate comprehension level (based on community standards).
  - Assurances should be provided that services (to aid in enrollment) are available for persons with cognitive impairments (or their guardians) during the MCO selection process.
  - Plans should be developed to reach homeless beneficiaries and others without a phone/mailbox.
  - Outreach materials and intake services should be made available at locations that are especially convenient to persons with special health care needs.

- Advising persons with special health care needs of how they can continue to obtain care from their current system or provider under the new program or transition to

a new system/provider. States should further consider programs that allow persons with special health care needs to use their current providers if those providers are not participating with any of the contracted MCOs (i.e., use out-of-network providers). And, States should consider conducting an assessment of the health care risks for special needs beneficiaries if critical patient-provider relationships are severed.

- Developing plans to use a "health needs assessment" process or other process (such as review of past Medicaid claims data) to identify existing or undiagnosed medical conditions. This process could be used to assist beneficiaries in selecting appropriate MCOs and providers based on identified medical and social needs. This process could include trained enrollment counselors or community-based organizations offering face-to-face, confidential enrollment information to assist persons with special health care needs during the enrollment process.

- Developing beneficiary enrollment materials that include information regarding each MCO's network of services and providers available to special needs populations. These materials should clearly describe enrollment options, including: options for MCO/provider selection and the selection of specialty providers as gatekeepers; pre-authorization and referral guidelines, covered specialty services and listing of available specialists; availability of any special services, expertise, and experience offered by providers and MCOs; exemption options; disenrollment provisions; lock-in periods and rules for changing MCOs/providers; excluded services.

- Offering a beneficiary enrollment hotline. If the State chooses to do so, it should assure that beneficiary enrollment hotline operators are knowledgeable of enrollment options and MCO service and provider capabilities for persons with special health care needs. Further, the State should consider ways to assure that the hotline is able to address the language needs of non-English speaking persons with special health care needs.

- Ways to demonstrate that patient confidentiality is assured throughout the enrollment, disenrollment, default assignment, and care delivery processes and what penalties are associated with breaches of privacy or confidentiality. Communications with MCO enrollees must be consistent with the Americans with Disabilities Act prohibition on unnecessary inquiries into the existence of a disability.

- Providing assurances that persons with special health care needs are assigned to MCOs capable of serving their particular needs (if the State permits auto-

assignment for persons with special health care needs). States should further consider what unique variables are most appropriate in the auto-assignment algorithm that address the needs of persons with special health care needs. And, States should consider developing a process to investigate those instances where there are a significant number of persons with special health care needs being auto-assigned and a process to take corrective action to reduce that number.

- Developing an auto-assignment process that assigns persons with special health care needs first to the MCO that includes their traditional provider of care. States should determine how to obtain, identify and account for this variable. States should further consider that if the current provider is not part of any MCO or not available and a default assignment is made, that there be a transitional period included in which the person with special health care needs could be offered special arrangements (e.g., time-limited exemption for out-of-network care) to assure continuity of care.

- Incorporating into their default assignment processes providers who have demonstrated experience and expertise in the provision of care for people with special health care needs. [Note: the State should describe any standards/process for designating providers as "experienced" or "expert" in providing care for persons with special health care needs.]

- Providing assurances that once default has occurred that notification to the beneficiary of their MCO assignment occurs within the shortest possible time. States should also consider ways to provide assurances that life-sustaining, ongoing treatment needs are provided for during transition periods and that financial responsibility for care provided during this period is clearly articulated.

- Developing policy(ies) on voluntary disenrollment for persons with special health care needs and permitting involuntary disenrollment for such persons but should define the circumstances under which it can occur.

- Developing plans to take advantage of the data they currently have access to regarding individuals enrolled in Medicaid but who will be transitioning to managed care versus individuals newly eligible for Medicaid. Specifically, how will this available information be used by a State or a designated organization such as an enrollment broker regarding current patient-provider relationships, the type(s) of special needs of enrollees, etc?

III. BENEFITS AND THE DELIVERY SYSTEM

The system of care for persons with special health care needs must be capable of responding to both the routine and unique medical and social needs of these enrollees. This includes assuring the availability of adequate numbers of providers to care for the target population, assessing provider experience and expertise against the population to be enrolled, assuring linkages with non-Medicaid services needed to care for the target population, and any special accommodations needed in order to care for persons with special health care needs.

An essential component of providing successful care and services to individuals with special health care needs is the effective provision and coordination of needed supports. The generic term "supports" means material and personal assistance that is directly related to the individual's ability to experience the best possible outcomes from the medical care provided. For example, the provision of consumer-directed personal assistance services has been shown to be a major variable in both avoiding institutionalization and in improving physical health and quality of life for persons with special health care needs. The State needs to demonstrate how its network of inter-related health services and supports operates to achieve the best possible outcomes for the consumer, including improved consumer satisfaction, quality of life and physical health. This and other important benefits and delivery system issues are identified below and should be taken into consideration in the State's design.

Tailoring services and benefits coverage to meet the diverse medical and social needs of persons with special health care needs. (3)

States should consider:

- Assessing the adequacy of an MCO's primary and specialty care provider capacity to meet the needs of special populations. Specifically:

  - Assessing whether there are and will be appropriate numbers of experienced health care professionals available to care for the special needs populations.
  - Determining whether managed care plans with experience in providing care to this population expressed interest in participating in the new program.
  - Developing criteria to use in assessing whether a plan's provider base has an appropriate range and level of experience/expertise in providing care to special needs populations.
  - Assessing the experience of these MCOs in delivering services in urban and rural areas.
  - Developing plans to recruit additional, experienced care providers able to accept new patients if MCO capacity is deemed inadequate.
  - The State and MCOs (and providers) should develop plans to keep abreast of the rapidly changing science base (e.g., in HIV care).

- Including providers that possess the technical expertise and experience needed to care for special needs populations (e.g., community mental health clinics, FQHCs, Ryan White CARE Act programs, public health clinics) into the provider network for delivering services.

- Defining the benefits package for special needs populations and describing the range of services (and any limits on those services) provided for the physical and mental health needs of beneficiaries. For example, if substance abuse treatment is covered, is it available in a continuum of services settings based on the most appropriate and cost-effective methods?

- Developing policies and procedures for assuring that special needs beneficiaries enrolled in managed care will be referred by the MCO to fee-for-service Medicaid-covered benefits covered as State Plan services carved out of the capitated rate (e.g., pharmaceuticals, dental care, mental health services, substance abuse treatment) or under 1915(c) programs.

- Providing adequate assurances on the extent to which new pharmaceuticals (e.g, multiple drug therapies for HIV care) and related tests will be accessible in the managed care environment. States should consider problems experienced by special needs populations in accessing drug treatment "good cause" for expedited beneficiary complaint resolution or disenrollment.

- Ways of making the delivery system accessible to beneficiaries with mental and physical disabilities in accordance with the ADA. Further, the State should describe the mechanisms it has identified to respond to situations in which services are not accessible or persons with disabilities experience discrimination in attempting to access services.

- In conjunction with MCOs, ways of permitting specialists to act as gatekeepers for persons with special health care needs. Further, States/MCOs should consider establishing procedures to permit persons with special health care needs to obtain standing referrals to a specialist (including out-of-network specialists, if the MCO does not have a provider with appropriate training and experience). And, States should consider ways of determining appropriate training and experience.

- Assessing how they plan to define medical necessity and whether and how this definition differs from what is contained in their State Plan.

- Whether there are additional services that would be of particular benefit to persons with special health care needs, not contained in the State Plan, that the State could

include in its contracts with managed care plans that go beyond the standard benefit package (e.g., habilitative care).

- Assessing the role of gatekeepers and/or specialists in determining authorization for services. Further, States should consider ways to assess the role of the case manager and patient in the use of specialty providers and services.

- Establishing linkages with social programs such as special education, criminal justice, welfare, transportation, housing, and other public assistance programs. And, States should assess the extent to which efforts are being made (by the State and through the State's contracts with MCOs) to coordinate non-Medicaid health care services and wrap-around services.

- Developing a plan to assess and provide access to specialized adaptive equipment and medication.

Case Management - Coordination of services and supports for individuals with special health care needs. **(4)**

The need for case management and care coordination for persons with special health care needs in a managed care delivery system is important to assure identification of service needs, timely receipt of services, the sharing of information within the care system, and efficient use of resources. The integration and coordination of services (and information related to those services) is of particular importance to individuals with special health care needs who often receive services from multiple providers in multiple locations. In addition, as some special health needs populations receive some of their care in a managed care setting and the remainder outside the managed care plan, the need for case management and coordination is even more critical to assure appropriate receipt of services, quality monitoring, and reimbursement.

States should consider:

- Assessing the availability of case management services to coordinate services and gauge the types of training case managers receive. Further, States should consider efforts to develop and utilize individual care plan or health needs assessment tools to assist in management decisions based on expected goals along with ways to assess how effective case managers are in procuring needed services for persons with special health care needs. And, States should consider developing qualifications (e.g., degree, license, experience) that case managers need to participate under the State's managed care program.

- Ensuring that services are coordinated between acute care and long term care

needs, where appropriate, to assure integration, coordination, and nonduplication of services and payments.

- Identifying the most appropriate ways patients with complex medical conditions are managed -- e.g., designated advocates (with specific training in needs of patient), "exceptional needs coordinators", general case manager, or others.

- Enabling persons with special health care needs and their families/care givers to participate in the development of care plans and to have informed choice of providers.

IV. FINANCE

The manner in which States decide to reimburse MCOs and providers for the delivery of services plays a major factor in how those systems of care operate and how enrollees access services. The methodologies used by State's to reimburse MCOs and providers continue to evolve, particularly as State's contemplate serving persons with special health care needs. The issues States face when providing services to special needs populations include a recognition that resource use is more frequent and intense and that MCOs and providers expert and experienced in the delivery of care to special needs populations may cost more and therefore reimbursement methodologies should not place MCOs and providers at undue risk for caring for these groups.

States should consider:

- Methods to develop rates of payment to MCOs and provider that assure adequate payments that enable them to serve persons with special health care needs.

- Reimbursement methodologies (e.g, diagnosis-based risk adjusted capitation rates, risk sharing, risk corridors, stop-loss protection, reinsurance coverage) that address concerns related to the possibility of adverse selection (e.g., protections against undue financial risk or MCOs de-marketing their services to avoid financial risk resulting from enrollment of persons with special health care needs).

- Whether new pharmaceuticals (e.g., for HIV care) are to be provided within a capitation rate and what adjustments will be made to account for these costly drugs and related tests.

V. QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT

MCOs and providers must be held accountable based on systematic and objective evaluations of their performance under managed care programs, particularly ones that serve persons with special health care needs. Such efforts need to take into consideration the human and financial resources needed to commit to such an undertaking, the target population(s) to be served, what outcome measures are most meaningful for those groups, the systems needed to collect, process, and validate the data being collected, and how the findings from these efforts are translated into improved systems of care and improved health outcomes.

Developing workable databases. (5)

States should consider:

- Developing a plan to collect encounter, or other patient-level data, from MCOs for persons with special health care needs. Such a plan should account for current resources (financial and personnel) available and what additional resources are planned to accomplish this task. Also, such a plan should describe the State's time frames for developing and validating a data collection methodology and what specific strategies the State plans to employ to collect information on special needs populations.

- Conducting studies using person-level encounter data among persons with special health care needs, such as patterns of service use, identifying providers servicing special needs groups, tracking movement of high cost patients between MCOs, patterns of under utilization of health services, and analyzing enrollment and disenrollment data to identify patterns of adverse selection by selected diagnosis.

- Developing specific outcome measures (and what those measure are) for special needs populations (in addition to any utilization review activities). Such measures if developed should describe how these outcome measures will be used to assess MCO and provider performance, whether such measures will be tied to financial incentives, and how the results of these efforts are linked to improving the health status of Medicaid beneficiaries.

- Conducting an assessment to determine any differences in access and use of services based on racial or ethnic factors or other access priorities based on review and analysis of prior utilization patterns.

- Undertaking medical record reviews, consumer surveys, case studies (e.g., Facct and QARI), or other types of studies to assess the quality of care within managed care plans for persons with special health care needs.

Quality management and monitoring MCOs for compliance with contractual requirements. (6)

The delivery of quality care and the ability to monitor MCO performance are vital functions that a State must be able to perform (directly or through its contractors). Quality assurance activities (including the development and deployment of tools to enhance data collection to support quality improvement efforts) has increased in scope and importance as Medicaid managed care enrollment has become more common. However, the use of data generated from these efforts needs to be more systematically incorporated into monitoring efforts in order to hold plans and providers accountable for their performance under that system.

States should consider:

- Developing a plan describing how it intends to monitor MCO compliance with HCFA regulations. Specifically, how the State will monitor whether:
  - MCOs allow enrollees, to the extent possible, to choose their health practitioner, maintain a program that allows enrollees to voice complaints, and provides for timely resolution of grievances;
  - performance measures have been developed to determine compliance with appropriate access standards;
  - health services are comparable to those available for fee-for-service beneficiaries in the same locale;
  - MCOs are not discriminating against enrollees on the basis of health status or need of health services;
  - MCOs have not terminated enrollment based on an adverse change in an enrollees's health status;
  - it has provided annual external reviews conducted by an independent reviewer for its MCO program; and,
  - MCOs have maintained an internal quality assurance program that addresses special need populations.

- Developing plans that assure that the complaint and grievance processes are expedited for people with life-threatening conditions such as AIDS, and that such plans provide minimum expected time-frames for resolution of complaints and grievances for such individuals.

- Requiring HEDIS performance measures for its MCO's quality assurance programs and assess the need for and utility of performance measures specific to special needs populations.

- Conducting consumer satisfaction surveys of persons with special health care

needs. Such an effort should address the need for over-sampling in the general survey population to assure fair and adequate representation.

- Developing a strategy for assessing specific aspects of quality care for persons with special health care needs enrolled in managed care plans for purposes of early identification of potential problem areas and for long-term assessment. States should further consider the need to conduct targeted quality of care studies or investigations by external consultants to assess quality of care for persons with special health care needs.

- Developing continuous quality improvement (CQI) goals to incorporate as part of contractual agreements with MCOs for purposes of building MCO capacity and meeting the needs of persons with special health care needs.

- Ways in which to evaluate patterns of referrals to specialists and subspecialists.

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FORUM FOR COLLABORATIVE HIV RESEARCH

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Date: May 18, 1998

RE: HIV & Managed Care Meeting

Number of pages including cover sheet: 5

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FORUM FOR COLLABORATIVE HIV RESEARCH

May 18, 1998

Dear Colleague:

A few weeks ago you should have received an invitation to a meeting entitled the Role of Managed Care in HIV Treatment and Research. The meeting will take place on June 5th in Washington, DC from 10:00 a.m. through 3:00 p.m. The meeting is co-sponsored by the Forum for Collaborative HIV Research and the American Association of Health Plans. As we have not yet heard as to whether you or a representative will be able to attend the meeting, I am sending the invitation again.

I hope you will be able to attend. A meeting agenda and logistical information will arrive later this week.

Yours truly,

David Barr
Director

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April 12, 1998

Dear Colleague:

We are writing on behalf of the Forum for Collaborative HIV Research (FCHR) and the American Association of Health Plans (AAHP) to invite you to a meeting to discuss the expanding role of health care plans in HIV care and research, new standards of care for the treatment of HIV disease, and future directions in HIV clinical research. The meeting will be held on June 5th from 10:00 a.m. to 3:00 p.m. in Washington, DC.

In the past year we have seen dramatic changes in the treatment of HIV disease. New drugs and diagnostic tools have brought us closer than ever to turning HIV into a chronic, manageable illness. Already the results are remarkable, with rates of death, hospitalization and new AIDS diagnoses all decreasing for the first time since the start of the epidemic. The new treatments present us with a new era in the care of patients with HIV. HIV care is increasingly complex with a standard of care that is evolving rapidly. The treatments are complicated to use, expensive and must be taken for the life of the patient. The success of the new treatment strategy will depend entirely upon the ability of physicians to apply the strategy correctly and work closely with patients to adhere to the regimen. Without these elements in place, patients are at risk for developing resistance to the new drugs, which then lose efficacy. The development of drug-resistant HIV can not only pose a threat to the patient, but to the public health as well, as drug-resistant strains of HIV may be transmissible to others.

Due to the growing use of managed care organizations by Medicaid programs, many health care plans can expect to see a steady rise in HIV-infected patients. The Centers for Disease Control and Prevention estimate that between 650,000 and 900,000 Americans are infected with HIV. Of these, approximately 500,000 know their HIV status. The new treatment strategies will bring more people into care at an earlier point in the course of the disease and will keep people in care longer. According to the HIV Cost and Services Utilization Study (HCSUS), funded by the Agency for Health Care Policy and Research, 30% of people with HIV/AIDS have private insurance, about 30% are on Medicaid, 19% are on Medicare and 21% have no health insurance. Estimates regarding the annual cost of HIV care vary for many reasons, including the stage of disease of the patient. However, the use of new pharmaceutical products is recommended for patients in early stages of illness and these drugs cost, on average, $9,000 to $13,000 a year. The drugs are taken indefinitely. While these costs are high, if the drugs are able to prevent the onset of AIDS, then the extremely high costs of late-stage illness can be avoided.

The FCHR/AAHP meeting will bring together health care providers and representatives from the pharmaceutical industry, federal and state government agencies,

HIV research, patient advocates, and employers. The meeting will provide participants with background information about: (1) where HIV patients receive care today, (2) the costs associated with HIV treatment, (3) the growing trends of patients with HIV in managed care, and (4) the new clinical practice guidelines and current dissemination efforts. We will discuss the growing needs of MCO/HMOs as they provide more care to a population that requires on-going medical attention from a physician with HIV expertise, and which requires a number of specialists and ancillary services.

The meeting will also provide an opportunity for participants to discuss the need for continued clinical, behavioral and economic research in HIV care and the role that managed care organizations and other health care providers can play in assuring that such research is directed at achieving optimal, cost-effective outcomes. We will discuss research efforts that can involve collaboration with health care providers, including randomized, controlled trials to compare treatment regimens, studies in patient outcomes and utilization of resources, and behavioral interventions regarding treatment adherence and primary prevention.

We hope that you will be able to join us to learn and exchange information. Attached you will find background information about the sponsoring organizations and a logistics form with which to make arrangements for your attendance.

Thank you in advance for your cooperation and we look forward to seeing you on June 5th. Attached is a form for you to fax back indicating whether or not you or your representative will attend the meeting. Please fax the form ASAP to William Gist at 202-296-0025. Details about the location, exact times and an agenda will arrive shortly.

Yours truly,

David Barr
Executive Director
FCHR

Carmella Bocchino
Vice-President, Medical Affairs
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