

# **Understanding the Challenge of Capitation: An Analysis of Costs of Care for People with HIV/AIDS at a Community Health Center, 1995-1998**



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**Abstract:** As the number of people with HIV/AIDS in managed care increases, providers, plans, and policymakers must meet the challenges of capitation. Treatment advances have heightened the importance of quickly engaging people with HIV/AIDS in care. Plans, providers, and policymakers must understand the costs of care for people with HIV/AIDS in order to establish payment rates that provide an incentive to outreach to people infected with HIV and develop quality programs.

In this study we analyzed data on service use and cost per person per month, exclusive of pharmacy, for 138 people with HIV and AIDS receiving care at the East Boston Neighborhood Health Center from 1995 through 1998. Costs for people with AIDS dropped dramatically from \$2,474.54 per member month in 1995-1996 to \$887.87 in 1997-1998, while costs for people with HIV rose slightly from \$530.90 to \$623.06. In 1997-1998, two individuals accounted for almost half of the costs of the program. Linear regression demonstrated a modest relationship between clinical variables and total costs per member month ( $r^2 = .126$ ,  $p = .024$ ). Costs for use of mental health and substance use services correlated significantly with total costs per member month. Plans and providers need to receive risk-adjusted payments for people with HIV as well as AIDS, safeguard against risk, and allocate resources in response to the social and behavioral needs that impact health care costs.

**Key words:** Health care costs – AIDS – HIV – managed care programs.

## INTRODUCTION

Increasing numbers of people with HIV and AIDS are receiving care through capitated health care systems (1). Despite initial attempts to adjust payment levels for people with AIDS in some states, little is known about the financial implications of caring for this population under managed care. For providers whose expertise attracts large numbers of people with HIV and AIDS, managed care can pose a serious threat. This threat can only be mitigated if providers limit the extent to which they are at risk for the costs of care and receive a reimbursement rate sufficient to finance the delivery of high quality care.

In this paper, we investigate changes in cost, the distribution of cost, and the impact of clinical and demographic factors and service use on the cost of care for people with HIV/AIDS at the East Boston Neighborhood Health Center (EBNHC) from 1995 through 1998. The experience of EBNHC as a community-based provider highlights key challenges for policymakers and providers in managed care:

- developing capitation rates that provide sufficient resources and the appropriate incentives to outreach to and care for this high-cost and complex population;
- establishing safeguards so that providers with expertise can survive financially while continuing to provide state of the art care; and
- allocating resources and developing linkages to manage the significant social and behavioral needs that can impact medical care usage.

Now that promising new treatments can halt or slow the progression of HIV and dramatically improve the health of those with AIDS, it is essential to engage individuals

with HIV and AIDS in care as early as possible. However, this outreach can bring serious financial hardship to providers that receive “one size fits all” capitation rates. Although the advent of HAART has lowered the cost of care for people with AIDS (2,3), their care remains very expensive. In addition, the cost of care for people with HIV infection that has not progressed to AIDS may be rising. This increase in costs for people with HIV but not AIDS appears to be due to the costs of drug therapy, associated outpatient visits and laboratory tests, and common co-morbid conditions, such as substance dependence or mental health disorders. As costs increase and greater numbers of people with HIV enroll in health plans, the lack of an adjusted rate will increase financial pressure on plans and providers and decrease the incentive to develop quality programs and outreach to and enroll people with HIV.

Only a small number of Medicaid programs offer “risk-adjusted” rates for people with AIDS (1). In these states, health plans are paid a higher rate for people with AIDS than for other enrollees. Even fewer states offer risk adjustment for people with HIV infection that has not progressed to AIDS. Only New York, Colorado, and Oregon have done this, and they just began in 2000. The capitated Johns Hopkins HIV Care Service in Maryland receives risk-adjusted payments for AIDS. They report that while their payments for people with AIDS are adequate, they have experienced losses of approximately \$6,000 per year for people with HIV (4).

In any capitated system, the impact of very high cost “outliers” is important, but it is particularly crucial for the potentially astronomical costs of people with HIV and AIDS. Plans can use a variety of protective mechanisms, such as stop-loss insurance, to guard against the impact of a few individuals who use very high amounts of health care.

Finally, providers need to understand the impact of social factors on cost in order to allocate their resources to provide effective, efficient care. As the incidence of transmission through injection drug use rises, people who are newly infected may have many complicating co-morbid conditions, such as substance abuse and mental health disorders, and social issues, such as homelessness, which may increase costs. We will investigate the impact of these factors in our analysis.

Our study of the impact of clinical and demographic factors and the use of different types of services on cost at EBNHC from 1995 through 1998 is innovative in several ways, allowing us to investigate important issues in managed care for people with HIV and AIDS.

- Our time span permits us to study the effect of treatment advances on cost.
- Our study is unusually comprehensive, incorporating disease stage, CD4 count, viral load, highly active anti-retroviral therapy (HAART), race, gender, age, transmission category, and housing status. While previous research has considered some of these factors, few studies have considered housing status. We are not aware of any studies of the relationship of viral load and cost.
- Our population includes people who are HIV positive but have not developed AIDS.

- While most research in this area investigates the cost of care for hospital-based programs, we focus on people receiving care in a community-based clinic.

Although previous research has investigated some of the factors that drive the cost of care, most of the studies were completed before the advent of HAART. The studies that investigated the impact of disease stage (contrasting people with AIDS to those with HIV infection that has not progressed to AIDS) were completed before HAART. They found that the costs of medical services for people with AIDS ranged from approximately 140 percent to 240 percent of the medical costs for people with HIV without AIDS (5,6,7).

Moore and Chaisson (8) investigated the cost of care for people with different CD4 counts. They divided CD4 counts into four categories: less than 50, 50 to 200, 200 to 500, and greater than 500. The only significant differences in cost were between people with CD4 counts below 50 and those with CD4 counts above 500.

A number of studies have demonstrated that when people with CD4 counts below 200 are placed on HAART, their service use declines enough that the total cost of their care is less than or equal to the cost of care for those who do not take the medications. This occurs despite the high cost of HAART (2,3,9).

The newest measure of disease severity, viral load testing, has had a major impact on the treatment and understanding of HIV. But to our knowledge, no study has examined the relationship between viral load and cost of care.

## **METHODS**

The 138 people in this study included patients enrolled for at least three months between 1995 and 1998 in Project SHINE (Support, Healthcare, Innovation and Education), a multi-disciplinary program at East Boston Neighborhood Health Center that provided and coordinated HIV and AIDS care. East Boston Neighborhood Health Center is a large community health center with over 300,000 visits annually. It serves a poor to working class community.

Data on service use were collected by several methods. We collected data on services provided by EBNHC from the health center's billing system. These services included primary care, a wide range of specialty services, on-site mental health services, labs, x-rays and procedures, urgent care, and physician hospital visits. Data on hospitalizations were gathered from EBNHC's database of inpatient admissions. Nurses, case managers, and social workers completed forms notifying the researchers of other off-site services, including outside medical specialty consultations, tests and procedures, and admissions for detoxification. These forms also notified the researchers of hospitalizations that were not recorded in EBNHC's inpatient database, such as those at psychiatric facilities.

Clinical data, such as CD4 count and viral load, were collected through medical record review. This record review also served as another source of information on off-site

referrals. Periodic review of case management records by the Project SHINE case manager provided demographic and social data, including information on housing status.

Our data did not include home health or pharmacy. Only outpatient mental health and substance abuse treatment that was provided by EBNHC was included in the analysis. Outpatient mental health and substance abuse services from other providers were not analyzed.

Relevant clinical factors, such as treatment, disease stage, and measures of disease severity, change over time. Thus, we created variables consisting of the number of months each patient spent in specific clinical categories. For disease stage, we used the dichotomous categories of “AIDS” and “HIV.” For CD4 count, we created four categories: “CD4 < 50,” “CD4 50 – 200,” “CD4 200 – 500,” and “CD4 > 500.” For viral load, we used four categories: “< 400,” “400 - 10,000,” “10,000 - 100,000,” “> 100,000.” For HAART status, we divided the number of months in which the patient received HAART by the number of months the patient was eligible for HAART using the U.S. Public Health Service Guidelines (10) in order to obtain the proportion of time a patient eligible for HAART actually received HAART.

In order to compare changes over time, we analyzed data from 1995-1996 and 1997-1998 separately.

The methods we used to assign costs were based on Medicaid fee-for-service payments. We used this fee structure for two reasons. First, Medicaid is the single largest payer for people with HIV and AIDS at EBNHC and nationally. Second, Medicaid is the only payer to offer health plans risk-adjusted capitation rates for enrollees with HIV and AIDS. The adjusted capitation rates are based on Medicaid’s historic fee-for-service costs for this population.

We calculated total cost per person by summing costs for primary care, specialty care, laboratory, radiology, procedures, on-site mental health, urgent care, emergency room care, inpatient medical and mental health costs, and the cost of admissions for detoxification. We divided this cost by the number of months the individual was enrolled in order to calculate cost per “member” per month.

### **Analyses**

We examined the correlation between the total cost per member month and the cost per individual for use of a particular type of service, the correlation of clinical factors with total cost per member month, and the correlation of age with total cost per member month. We also performed a t-test on the relationship of gender to cost, and used ANOVA to test the relationship of ethnicity, housing status, and transmission factor to cost. To predict cost, we performed linear regressions using clinical and demographic factors.

## RESULTS

### Patient Sample

The 138 people served by Project Shine for at least three months from 1995 through 1998 were a demographically heterogeneous group (see Table 1 for details). All risk factors were represented, with the most common being injection drug use. A small group of patients were homeless during their enrollment, while almost half experienced unstable housing situations. “Unstable” refers to situations in which a person is not able to stay in his/her own home although he/she is not on the street or in a shelter. For example, the individual might “double-up” with relatives.

**Table 1**  
**Demographics**  
**N=138**

<b>Ethnicity</b>	<b>Number</b>	<b>Percent</b>
White	66	48%
Latino/a	36	26%
African-American	19	14%
Other	17	12%
<b>Gender</b>		
Female	54	39%
Male	84	61%
<b>Risk Factor</b>		
Injection drug use	59	43%
Heterosexual sex	42	30%
Men who have sex with men	36	26%
Blood transfusion	1	1%
<b>Housing</b>		
Homeless	11	8%
Unstable	64	46%
Stable	58	42%
Unknown	5	4%
<b>Age Range</b>	21 – 57 years	

In 1995-1996, 93 people were enrolled in the program. The average number of months enrolled in Project SHINE was 13.8. In 1997-1998, 107 people were served for an average of 16.5 months.

The distribution of CD4 count, viral load, disease stage, and HAART use in the 1995-1996 and 1997-1998 populations are described in Tables 2 and 3.

**Table 2**  
**1995-1996 Clinical Variables**  
**N=93**

<b>Clinical Variables</b>	<b>N (non-zero cases)</b>	<b>Percent of population who spent any time in category (not mutually exclusive)</b>	<b>Average proportion of months spent in category</b>
<b>CD4 Count</b>			
<50	13	14%	81%
50-200	27	29%	57%
200-500	56	60%	70%
>500	34	37%	67%
<b>Disease Stage</b>			
AIDS	42	45%	92%
HIV	58	62%	93%

**Table 3**  
**1997-1998 Clinical Variables**  
**N=107**

<b>Clinical Variables</b>	<b>N (non-zero cases)</b>	<b>Percent of population who spent time in any clinical category (not mutually exclusive)</b>	<b>Average proportion of months spent in category</b>
<b>CD4 Count</b>			
<50	12	11%	53%
50-200	31	29%	57%
200-500	72	67%	70%
>500	45	42%	67%
<b>Disease Stage</b>			
AIDS	56	52%	92%
HIV	64	60%	93%
<b>Viral Load</b>			
<400	27	25%	26%
400-10,000	77	72%	30%
10,000-100,000	65	61%	35%
>100,000	36	34%	38%
<b>HAART</b>			
eligible patients	103	96%	32%
recipients/eligible	63*	61%**	34%

\* number of eligible patients who received HAART

\*\* percent of eligible patients who received HAART



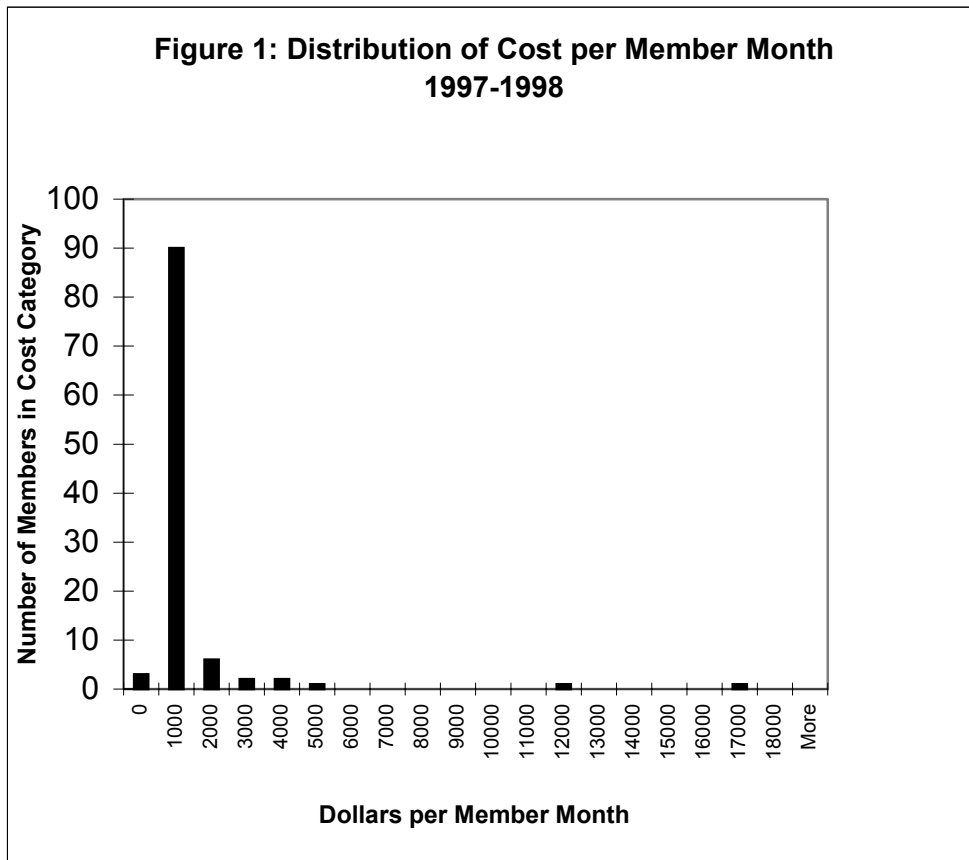
### Distribution of Costs

The central tendency and standard deviations of total cost per member month in 1995-1996 and 1997-1998 are presented in Table 4.

**Table 4**  
**Cost per Member Month**

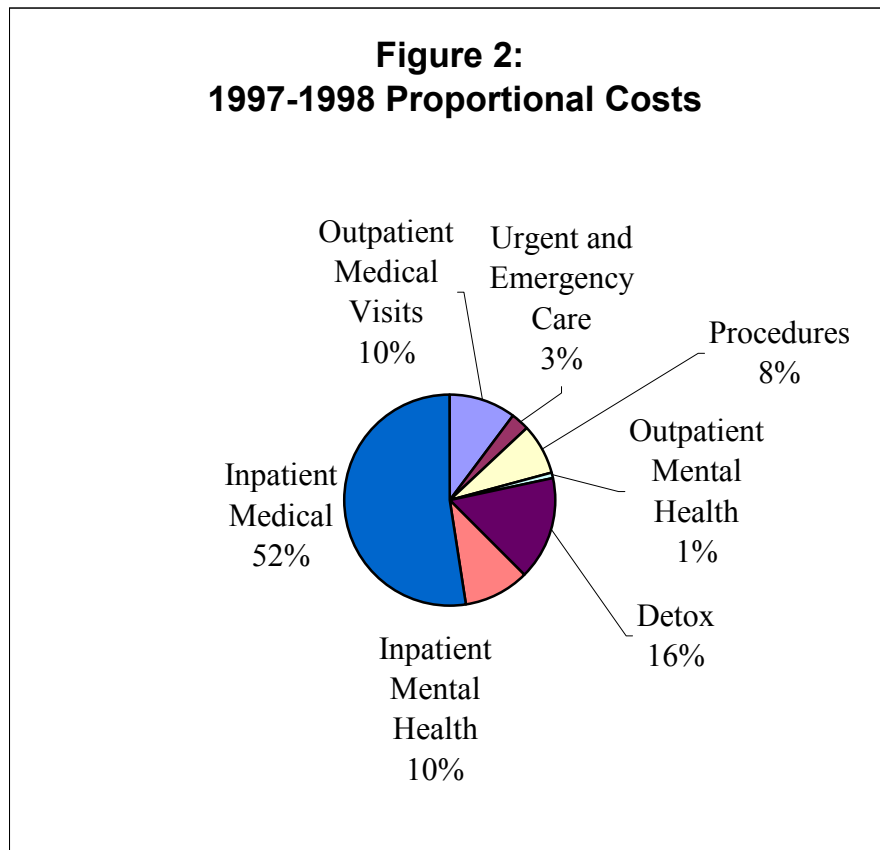
	1995-1996	1997-1998
<b>Mean</b>	\$1,316.08	\$735.22
<b>Median</b>	\$184.05	\$214.27
<b>Standard Deviation</b>	\$4,334.69	\$2,126.05

The cost distribution was heavily right skewed in both time periods, but particularly in 1997-1998. Of the two individuals whose costs were greater than two standard deviations above the mean in that time period, one was five standard deviations above the mean with a cost per month of \$12,829.46, and the other was seven standard deviations above the mean with a cost of \$17,126.36 per month. These data are represented in Figure 1. The total cost of the program for 1997-1998 with these individuals included was \$1,474,490.34. When they were excluded from the data, the total program cost dropped by almost half to \$756,748.51.



These two individuals differed in important ways. While one reported injection drug use as the primary risk factor, the other reported heterosexual contact. They were from two different ethnic groups, of two different genders, and at different stages of disease. While one individual never developed AIDS, the other individual had AIDS during most of the enrollment period. They also shared certain characteristics. Both had mental health issues, periods of homelessness, CD4 counts between 200 and 500 during most of their enrollment, and substance dependence disorders that resulted in their being the two most expensive users of inpatient detoxification services in 1995-1998. Analyses on the 1997-1998 data were performed with and without these two patients.

The average cost per member month in 1995-1996 was almost twice the average cost per member month in 1997-1998, including all patients (see Table 4 above). In 1995-1996, inpatient costs accounted for 67 percent of total costs. In 1997-1998, inpatient costs accounted for 62 percent of total costs. See Figure 2 for the distribution of all 1997-1998 costs.



We compared average costs per month for people with AIDS for more than 75 percent of the study period. In 1995-1996 the average cost per month for individuals who had AIDS was \$2,474.54, whereas for people who had HIV it was \$530.90. The mean cost for people with AIDS fell dramatically in 1997-1998 to \$887.87. For people with HIV it rose slightly to \$623.06.

## Relationship Between Costs and Demographic and Clinical Variables

First, we analyzed bivariate relationships between total cost per member month and demographic variables, clinical variables, and the cost of particular services.

We found significant positive relationships with medical inpatient costs (see Table 5), as these costs accounted for a large proportion of total costs. The costs of urgent and emergency care, inpatient mental health, and detoxification also correlated with total cost, although primary and specialty care costs did not.

**Table 5**  
**Relationship between Cost per Service and Total Cost per Member Month**

Service	1995-1996	1997-1998 <sup>1</sup>
Primary Care	-.08	.12
Specialty Care	-.08	.13
Emergency Room	.15	.62**
Urgent Care	.92**	.24*
Medical Inpatient	.99**	.89**
MH Inpatient	.15	.63**
Inpatient Detox.	.26*	.54**

<sup>1</sup>without two highest cost users

\* p < .05, two-tailed

\*\* p < .01, two-tailed

Bivariate analyses on demographic variables revealed no significant relationship between age and cost. We also found no significant differences in cost between groups for gender, race, and transmission category. When the two highest cost individuals in the 1997-1998 population were included in the analyses, there was a significant difference in cost by housing status ( $F = 22.309$ ,  $p < .00$ ). This is not surprising as these two individuals had both been homeless. When they were removed from the analysis, the difference was no longer significant, although costs decreased as housing status improved. The average cost per month for individuals who had been homeless was \$818.75, for those with unstable housing, \$463.22, and for those with a history of stable housing, \$422.13.

Of the clinical variables, the proportion of enrollment spent with a CD4 count less than 50 correlated significantly with total cost per member month in both time periods when the two highest cost individuals were excluded. The proportion of time an individual had AIDS as opposed to HIV correlated significantly with cost in 1995-1996 but not in 1997-1998.

The results of the regression of demographic and/or clinical factors on total cost per member month varied depending on the time period and whether the highest cost

individuals were included (see Table 6). In 1995-1996, CD4 count and disease stage combined explained a significant 19 percent of the variance in cost. With the addition of demographic variables the explanatory power of the equation increased to a significant 25 percent of the variance.

**Table 6**  
**Multiple Regression of Clinical and Demographic Variables on**  
**Cost per Member Month**

Independent Variables	1995-96		1997-98 with all		1997-98 without top two	
	r <sup>2</sup>	p	r <sup>2</sup>	p	r <sup>2</sup>	p
All Clinical Variables	NA	NA	.063	NS	.150	NS
CD4 alone	.186	.001**	.221	NS	.102	.028*
CD4 and Disease Stage	.186	.003**	.021	NS	.126	.024*
Demographics	.066	Not sig.	.356	.000**	.080	NS
Demographics and CD4 and DS	.254	.039*	.373	.000**	.204	.08

In 1997-1998, when the highest cost individuals were included, the only regressions that were significant were those that used homelessness as an independent variable. Without these two individuals, CD4 count combined with disease stage predicted 13 percent of the variance in costs.

## DISCUSSION

Major findings that emerged from the study were changes over time in costs for HIV and AIDS, the difficulty of predicting costs, the impact of a few very high-cost individuals on program costs, and the importance of non-medical factors.

The major differences between costs in 1995-1996 and in 1997-1998 appear to result from treatment advances. Costs for AIDS dropped dramatically, mainly due to decreases in hospital costs for people with AIDS. Costs rose slightly for HIV despite the exclusion of pharmacy. While disease stage correlated with cost per member month in 1995-1996, there was no such correlation in 1997-1998. This appears to be due to the role of HAART in 1) reducing the severity of the disease and thus the need for inpatient stays and emergency room visits for people with AIDS and 2) increasing the treatment possibilities (and associated costs) for people with HIV. The gap between costs for people with HIV and people with AIDS has narrowed, although it is still large enough to impact providers and payers.

These findings underscore the importance of establishing risk-adjusted rates for people with HIV as well as for people with AIDS. New York, Colorado, and Oregon risk-adjust for HIV. Providers cannot accept risk or provide quality care for large numbers of people with HIV if they are systematically underpaid. Capitation rates for people with HIV may safely be lower than those for AIDS, but they should exceed the rate paid for other Medicaid populations, such as low income women and children or most people with disabilities (11).

Using clinical and demographic information, we were able to predict only a modest amount of variance in cost. In 1995-1996 we were able to predict a significant 25 percent of the variation in cost using CD4 count, disease stage, and demographics. However, in 1997-1998, the only statistically significant model used CD4 count and disease stage to predict 13 percent of the variance in costs. The failure of our other models to reach statistical significance may be attributable to our small sample size. However, these results are consistent with those found in the literature that attempts to predict (non-HIV) health care costs by using health status indicators and demographics.

Newhouse (12) states that among researchers who have tried to predict health care costs for a variety of populations using a wide range of indicators, “the consensus is that 15-20 percent of the variance in costs is the most that could be explained...” (p.30-31). Our findings and Newhouse’s “consensus” statement suggest that health care plans and providers are unlikely to be able to predict costs precisely. From these findings, it appears that the determinants of the cost of care for a person with HIV or AIDS are complex and multidimensional, and that variation in health care use may be influenced by factors we cannot yet measure or cannot measure well.

The impact of the highest cost individuals is quite striking. The two highest cost individuals in 1997-1998 were responsible for half of the program’s total costs: approximately \$700,000 out of \$1,400,000 over two years. Although the impact of outliers is related to program size, these findings indicate that all programs must protect themselves against the potential impact of a few individuals whose care is extremely expensive. Our findings on the impact of outliers, the modest amount of variation we were able to predict, and Newhouse’s “consensus” statement underscore the difficulty of predicting costs and the consequent importance of protective insurance mechanisms.

The mechanism that most directly addresses this issue is stop-loss insurance, which insures that the provider or plan will not be at risk once costs for any particular individual rise over a certain amount, e.g., \$100,000. The establishment of “risk corridors” -- a type of risk sharing -- can also protect against unexpectedly high costs due to individuals with very high health care use or costly treatment innovations.

Finally, our findings highlight the impact of non-medical factors on cost of care for individuals with HIV and AIDS. High costs were not necessarily associated with illness severity. For example, one of the two highest cost individuals in 1997-1998 did not progress to AIDS during the study period, despite incurring startlingly high costs.

Use of urgent and emergency care, use of detoxification programs, and mental health admissions were all correlated with total overall costs. High use of urgent and emergency care may represent a level of social instability that interferes with engagement in primary and preventive care. Illnesses that could have been addressed at an early stage in ambulatory care instead progress to the point of requiring hospitalization by the time the individual presents for care.

Substance abuse is a second factor that although unrelated to the severity of HIV/AIDS may play a major role in health care costs. Active substance abuse is a sign of social instability and may also lead directly to numerous co-morbid conditions that can require hospitalization. Costs for inpatient detoxification correlated significantly with total costs. In contrast, our analyses based on injection drug use as a risk factor did not find significant relationships with cost, and previous research using transmission factor as a marker for active substance abuse has reached inconclusive results (7, 13,14). Perhaps costs for inpatient detoxification are a more sensitive indicator of which individuals are actively using drugs.

Inpatient mental health costs also correlated significantly with total costs. Costs for mental health treatment can be expensive, and mental health disorders may complicate an individual's medical care.

Homelessness, another measure of social instability, may also affect cost. Homelessness may increase the likelihood that a clinician will choose to treat an individual as an inpatient rather than an outpatient, and it may delay discharge from a hospital. Previous research has reported conflicting results on the effect of homelessness on cost. Weissman (13) found that people who were ever homeless were significantly more likely to be hospitalized, while Seage (14) reported that homelessness was not a significant predictor of increased hospitalizations. In our study, the significant relationship of homelessness to cost of care disappeared when the two highest cost individuals, both of whom were homeless, were removed from the data. Nevertheless, it is worth noting that even when these individuals were excluded, the mean cost for homeless individuals was almost twice that of those with stable or unstable housing.

Although health insurance does not cover non-medical needs, such as housing, capitated providers may find themselves paying for housing problems and other social needs either in higher health care costs or by allocating resources to help individuals access concrete services such as housing support. Plans must take this into account when allocating resources in areas such as case management. Policymakers need to understand this to establish relevant linkages, such as links between housing organizations and medical providers.

The New York Medicaid program, which is implementing a new system of risk-adjusted managed care for people with HIV and AIDS, has specifically addressed the issue of non-medical needs. The state has asked providers and health plans to form Special Needs Plans for people with HIV and AIDS. New York requires that these plans establish

explicit and detailed linkage agreements with a wide range of community-based organizations, such as providers of supportive services for the homeless.

One of the weaknesses of our study is the absence of data on pharmacy costs. We do not know what effect pharmacy costs would have had on our findings. Another weakness, common to most research that attempts to analyze the relationship of social factors to costs, is the difficulty of accurately measuring factors such as housing instability and active drug use. While we could differentiate those who were ever homeless from those who had never been homeless, anecdotal experience from our clinic suggests that the risk of hospitalization rises during the period in which an individual is homeless and decreases once that individual finds stable housing. We did not have sufficiently detailed data to confirm these reports. Nor did we have the data to directly measure which individuals were actively abusing substances during the period of analysis. Our calculations were based on transmission factor.

## CONCLUSION

The results of our investigation of the factors that impacted the cost of care for people with HIV and AIDS at EBNHC from 1995 through 1998 highlight key issues in managed care for people with HIV and AIDS:

- the extent to which costs are not predictable and the resulting importance of protective insurance mechanisms, particularly for small providers;
- the recent changes in costs of HIV and AIDS care, indicating the need to risk-adjust for people with HIV who have not developed AIDS; and
- the importance of non-medical factors in health care use and cost. Strong support for mental health and substance abuse treatment and other social support services is necessary, both within health plans and through links to outside agencies.

Health plans, providers, and policymakers must respond to these challenges if people with HIV and AIDS are to receive appropriate care in capitated health care systems.

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