HIV AS A CHRONIC DISEASE: IMPLICATIONS FOR LONG-TERM CARE AT AN AIDS-DEDICATED SKILLED NURSING FACILITY

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ABSTRACT

Objective. To describe the characteristics and outcomes of the first 3 years of admissions to a dedicated skilled nursing facility for people with acquired immunodeficiency syndrome (AIDS).

Methods. Systematic chart review of consecutive admissions to a 30-bed, AIDS-designated long-term care facility in New Haven, Connecticut, from October 1995 through December 1998.

Results. The facility has remained filled to 90% or more of its bed capacity since opening. Of 180 patients (representing 222 admissions), 69% were male; mean age was 41 years; 57% were injection drug users; 71% were admitted directly from a hospital. Leading reasons for admission were (1) the need for 24-hour nursing/medical supervision, (2) completion of acute medical treatment, and (3) terminal care. On admission, the median Karnofsky score was 40, and median CD4+ cell count was 24/mm³; 48% were diagnosed with serious neurologic disease, 44% with psychiatric illness; patients were receiving a median of 11 medications on admission. Of 202 completed admissions, 44% of patients died, 48% were discharged to the community, 8% were discharged to a hospital. Median length of stay

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was 59 days (range 1 to 1,353). Early (≤ 6 months) mortality was predicted by lower admission CD4+ count, impairments in activities of daily living, and the absence of a psychiatric history; long-term stay (> 6 months) was predicted by total number of admission medications, neurologic disease, and dementia. Comparison of admissions from 1995 to 1996 to those in 1997 to 1998 indicated significantly decreased mortality rates and increased prevalence of psychiatric illness between the two periods ($P < .01$).

Conclusions. A dedicated skilled nursing facility for people with AIDS can fill an important service need for patients with advanced disease, acute convalescence, long-term care, and terminal care. The need for long-term care may continue to grow for patients who do not respond fully to current antiretroviral therapies and/or have significant neuropsychiatric comorbidities. This level of care may be increasingly important not only in reducing lengths of stay in the hospital, but also as a bridge to community-based residential options in the emerging chronic disease phase of the AIDS epidemic.

KEY WORDS AIDS, End-of-Life Care, Health Services, Long-Term Care, Palliative Care, Skilled Nursing Facilities.

INTRODUCTION

Recent advances in the treatment of human immunodeficiency virus (HIV) infection and its complications have led to improved survival for people with acquired immunodeficiency syndrome (AIDS).¹⁻³ While for many patients this has resulted in significant improvement in functioning and a return to productive activity, for others the impact of these therapies has been more limited. In some cases, this may be due to medication nonadherence, toxicity, or inaccessibility; in others, it may be due to late-stage HIV disease, antiretroviral drug resistance, or severe dementia or other neurologic disease. In addition, the coexistence of HIV infection and substance abuse, severe mental illness, homelessness, and other overlapping factors all may converge to create a particularly vulnerable population of HIV-infected patients who are unable to benefit fully from the growing therapeutic advances in AIDS care.⁴⁻⁶

All of these trends have resulted in a need in some areas for the development of long-term care services, including skilled nursing facilities and other institutional settings for the chronic care of people with AIDS. These trends have occurred at the same time as the need for hospice care itself may be decreasing for this population⁷⁻⁹ (D. Hoos, New York State Department of Health, personal communication, December 1999). Moreover, the need for alternative care settings has also increased with the advent of managed-care systems and the incentive to minimize inpatient hospital utilization costs. While a number of long-term care facilities for people with AIDS have been established in recent years, there has been relatively little published on the characteristics of this new level of care and the actual populations that have been served by these AIDS-designated

facilities.⁹⁻¹³ In this report, we describe the characteristics and outcomes of the first 3 years of admissions to a dedicated skilled nursing facility for people with AIDS in New Haven, Connecticut.

STUDY SETTING AND METHODS

New Haven, Connecticut, is a small city (population 130,000) located approximately 90 km northwest of New York City; it has high rates of HIV infection, poverty, and drug use.¹⁴ New Haven was one of the first 12 cities in the US for which AIDS became the leading cause of death for both young adult men and women by the early 1990s.¹⁵ In response to a perceived need for long-term care for people with AIDS, a skilled nursing facility was opened in October 1995.

The facility, called Leeway, is operated as a freestanding, community-based, not-for-profit corporation. Leeway's operating budget is generated through third-party reimbursement, of which the principal payer is Medicaid. The facility, constructed from renovated space in a former one-story factory building, accommodates 30 residents. Leeway is staffed on a 24-hour basis by a total of 20 nurses (16 registered nurses [RNs], 4 licensed practical nurses [LPNs]) and 10 nurse's aides. The clinical staff also includes a nurse practitioner; two part-time, on-site internists; a consultant psychiatrist; a social worker; a drug treatment counselor; a recreational therapist; and consultants in nutrition and physical therapy. Other on-site services include complementary therapies, including acupuncture, naturopathy, and chiropractic. For other consultative services, including dentistry, and outpatient medical subspecialty visits (e.g., neurology, dermatology, ophthalmology, gastroenterology), patients are transferred to community or hospital outpatient clinics. Intravenous therapy and peritoneal dialysis are provided on site at Leeway. Care is provided on site for episodic illness; conditions with a higher level of acuity than can be managed at the facility result in emergency room evaluation or hospitalization at one of New Haven's two hospitals. Diagnostic radiologic tests and procedures that are more than minimally invasive (e.g., lumbar punctures, central venous catheter insertions) are performed by referral to hospital services.

For this analysis, we conducted a systematic chart review of all patients who had been admitted to Leeway since its opening on October 1, 1995, through December 31, 1998. Chart review was facilitated by the standardized admission form used for all patients, which included a complete history and physical examination, Karnofsky score, Folstein Mini-Mental State Examination,¹⁶ and the Katz Activities of Daily Living (ADL) Scale score,¹⁷ which is routinely determined for all admissions to skilled nursing facilities. Follow-up clinical and outcome

data were obtained through chart notes, as well as facility activity records. Follow-up extended to July 1, 1999.

Descriptive statistics were generated for the entire patient population using the total number of patients as the denominator; for patients with more than one admission during the study period, baseline information was included for only the first admission. Rates of specific outcomes, including transfers, hospitalizations, and deaths, were calculated using total person-days in the facility from all admissions as the denominator. An analysis of discharges was performed for all completed admissions. For the calculation of death rates, deaths were included if they occurred either at the facility or within 2 weeks of discharge or transfer. Length of stay was calculated for all admissions, including those not yet completed, overall, and by different admission subgroups. A secondary analysis was performed to examine discharge outcomes from the facility to attempt to determine variables on admission that might predict such outcomes as death, discharge to the community, or prolonged length of stay at the nursing home. For this analysis, we first compared baseline characteristics of patients who died within 6 months of admission to those of all other patients. Then, excluding those who had died within the first 6 months, we compared those who were discharged to the community within the first 6 months to those who resided at the facility for 6 months or more.

Pearson chi-square tests were used to assess the statistical significance of differences in proportions between groups on categorical variables. Student *t* tests were used for comparisons of continuous variables. The Pearson correlation test was used to test for trend for yearly prevalence of psychiatric illness. The level of significance for all tests was .05. Multivariate analysis was performed using standard stepwise logistic regression methods. All analyses were performed using SAS statistical software, version 6.11 (SAS Institute, Cary, NC, 1995).

RESULTS

The Leeway facility opened to receive patients on October 1, 1995. By 20 weeks of operation, the facility was filled to capacity, and since that time has remained at 90% of capacity or greater. Over 80% of admissions have been referred from New Haven and the nearby surrounding area, with the remaining 20% from elsewhere in Connecticut.

From October 1, 1995, through December 31, 1998, there were a total of 222 admissions to the facility; these admissions represented 180 unique individuals, of whom 142 had one admission, 34 had two admissions, and 4 had three

TABLE 1 Demographic and Admission Characteristics of Residents* at a Skilled Nursing Facility for People with AIDS, October 1995 to December 1999

Characteristics	n (%)
Sex	
Male	124 (69)
Female	56 (31)
Race/ethnicity	
Black	79 (44)
White	73 (41)
Latino/Latina	28 (16)
Health insurance	
Medicaid	167 (93)
Medicare	4 (2)
Private	7 (4)
Primary reason for admission	
24-hour nursing/medical supervision	103 (57)
Completion of acute medical treatment	42 (23)
Terminal care	23 (13)
Respite care	7 (4)
Unsafe home environment	5 (3)
Preadmission residence	
Hospital	128 (71)
Home	22 (12)
Other skilled nursing facility	14 (8)
Hospice	7 (4)
Homeless	3 (2)
Other	6 (3)

*N = 180. Mean age 41 years (range 17–72).

admissions during this time period. Table I presents selected demographic characteristics and the reasons for admission for the group of 180 patients. Almost one-third were female; the mean age was 41 years; and over half were black or Latino. Almost three-quarters were admitted directly from a hospital; the most frequent primary reasons for admission were a need for 24-hour medical or nursing supervision (57%), completion of acute medical treatment (23%), and terminal care (13%). Over 90% of all patients were Medicaid recipients (Table I).

The patient population was comprised predominantly of individuals in the late stages of HIV disease: 88% were classified as stage C3 (AIDS) by the Centers for Disease Control HIV Classification System.¹⁸ The median CD4+ T-lymphocyte count was 24 cells/mm³, and the mean number of prior AIDS-defining illnesses was 3.0. The population also exhibited marked functional impairment: The me-

dian Karnofsky score was 40, the median score on the Folstein Mini-Mental State Examination was 23/30, and only slightly more than half the population was fully ambulatory without assistance; 52% had impairment in at least one domain on the ADL Scale (Table II). The predominant HIV risk behavior in this population was injection drug use (57%), although close to one-quarter had heterosexual contact as a risk factor. Current cocaine or heroin use was reported by 12%, and 12% were on methadone maintenance (Table II).

Of note was the high prevalence of neurologic and psychiatric illness among nursing home residents (Table III): 48% had HIV-related neurologic disease, including 32% with dementia, 19% with peripheral neuropathy, 7% with progressive multifocal leukoencephalopathy, and lower percentages with other HIV-related neurologic conditions. Pre-existing seizure disorders that were not felt to be HIV related were present in 9% of the residents. On admission, 44% of the patients had diagnoses of psychiatric disorders, excluding substance use,

TABLE II Selected Clinical and Risk Factor Data for Residents Admitted to Skilled Nursing Facility for People with AIDS

Clinical Characteristics	N = 180
CDC HIV Stage C3 (AIDS)*	88%
Median CD4+ T-lymphocyte count	24 cells/mm ³ (range 0–1,150)
Mean number of prior AIDS-defining illnesses	3.0
Median Karnofsky score	40 (range 10–90)
Median MMSE† score	23/30
Mobility	
Ambulatory without assistance	55%
Ambulatory with assistance	15%
Wheelchairbound	19%
Bedbound	11%
Impairment in one or more domains of ADL scale‡	52%
HIV risk category§	
Injection drug use	57%
Heterosexual contact	21%
Male same-sex contact	17%
Unknown/other	3%
Substance use history	
History of heroin or cocaine use	65%
Current cocaine or heroin use	12%
Current methadone maintenance	12%

*CDC HIV/AIDS Classification System (see ref. 18).

†Folstein Mini-Mental State Examination (see ref. 16).

‡Katz Activities of Daily Living (ADL) Scale. (see ref. 17).

§Residents may be represented in more than one category.

TABLE III Baseline Neurologic and Psychiatric Illness Among Residents at Skilled Nursing Facility for People with HIV/AIDS* (N = 180)

Type of Illness	Residents with Illness, %
HIV-related neurologic disease*	48
HIV dementia/encephalopathy	32
Peripheral neuropathy	19
Progressive multifocal leukoencephalopathy†	7
Cerebral toxoplasmosis	7
Myelopathy	5
Central nervous system lymphoma	4
Cytomegalovirus encephalitis	4
Cryptococcal meningitis	3
Stroke	3
Epilepsy/seizure disorder‡	9
Any psychiatric illness* §	44
Depression/affective disorder	29
Anxiety disorder	11
Schizophrenia/psychosis	8
Bipolar disorder	4
Mental retardation	3
Post-traumatic stress disorder	2
Other	3

*Includes categories listed in table; percentages reflect percentage of residents with illness or diagnosis on admission. Residents may be represented in one or more categories.

†Presumptive and confirmed.

‡Preexisting; not felt to be HIV related.

§Lifetime prevalence.

||Excludes substance abuse, personality disorders, dementia.

dementia, and personality disorders; 29% of the total group had depression or other affective disorders; 11% had anxiety disorders; 8% had schizophrenia or other psychoses; and lower percentages had been diagnosed with other psychiatric disorders.

Patients were admitted to the skilled nursing facility on a median of 11 medications, including more than 80% on antiretroviral therapy and/or on prophylaxis against *Pneumocystis carinii* pneumonia and over 60% on antifungal and/or antimycobacterial prophylaxis or suppression (Table IV). Two-thirds of all residents were on analgesic medication, close to two-thirds were on psychiatric medication, and more than half were on antiemetics, antidiarrheals, or other medications to manage gastrointestinal symptoms. Approximately one-third of

the patients were on medications for respiratory symptoms, cytokines, and/or appetite stimulants or anabolic agents. Lower percentages were on cardiac/circulatory medications, anticonvulsants, and corticosteroids.

Concerning on-site consultations at the facility, 68% of the patients underwent psychiatric consultation, 47% received physical therapy, 35% received podiatry services, 15% were seen by a chiropractor, and 9% received acupuncture and/or naturopathic treatments. Concerning transfers of residents for acute care and outpatient services or procedures, 23% underwent emergency room evaluation (8.3 visits per 100 person-months), and 39% were hospitalized one or more times during their stays at the facility (13.7 per 100 person-months) (Table V). The

TABLE IV Admission Medications* Among Residents at Skilled Nursing Facility for People with HIV/AIDS (N = 180)

Type of Medication	Residents on Medication, %
Antiretroviral therapy	87
<i>Pneumocystis carinii</i> pneumonia prophylaxis	86
Antifungals	68
Antivirals	31
Antimycobacterials	
≥1 agent	67
≥2 agents	42
Other antibiotics	68
Analgesics†	67
Narcotics	48
Non-narcotics	36
Psychiatric medication†	64
Benzodiazepines	32
Antidepressants	22
Sedatives/hypnotics	23
Neuroleptics	12
Gastrointestinal (e.g., antiemetics, antidiarrheals, H ₂ blockers, prokinetic agents, other)	55
Respiratory agents (e.g., antihistamines, decongestants, bronchodilators, other)	30
Cytokines (e.g., erythropoietin, granulocyte colony-stimulating factor)	30
Appetite stimulants/anabolic agents	26
Cardiac/circulatory agents	12
Anticonvulsants	12
Corticosteroids	10

*Median number of medications = 11 (range 0–31).

†Residents may be on more than one type of analgesic or psychiatric medication.

TABLE V Transfers of Residents from HIV/AIDS Skilled Nursing Facility for Acute Care/Outpatient Services*

Type of Transfer	No. of Transfers	% of Admissions†	Rate per 100 person-months
Emergency room evaluations	91	23	8.3
Hospital admissions	153	39	13.7
Outpatient clinics	353	57	29.7
Procedures/tests	159	36	14.2

*Leading reasons for transfers were as follows: Emergency room: chest pain/dyspnea, altered mental status, injury/fall, gastrointestinal bleeding/distress, pneumonia. Hospital: chest pain/dyspnea, bacterial pneumonia, bacteremia/sepsis, gastrointestinal bleeding/distress, focal neurologic deficit. Outpatient: dental, ophthalmology, dermatology, neurology, otorhinolaryngology consults. Procedures: diagnostic radiology, transfusions, central line placement/removal, aerosol pentamidine, radiation therapy.

†Percentage of admissions in which ≥ 1 transfer took place.

primary reasons for these transfers for acute care included chest pain, dyspnea, altered mental status, pneumonia, bacteremia, gastrointestinal bleeding or distress, and focal neurologic deficits. Of the patients, 57% were sent out for outpatient subspecialty clinic visits (29.7 per 100 person-months) and 36% for diagnostic procedures or tests (14.2 per 100 person-months).

Of all residents, 25% developed new or recurrent infections during follow-up after admission to the facility, including (not mutually exclusive) 12% with bacterial pneumonia, 9% with oroesophageal candidiasis, 8% with bacteremia, 7% with herpes zoster, and 4% each with cytomegalovirus disease, cryptosporidiosis, and deep fungal infection (cryptococcosis or aspergillosis).

Of the 222 total admissions to the facility during the study period, there were 202 completed discharges (91%) by the end of the follow-up period on July 1, 1999 (Table VI). Of these, 44% of the patients died, 39% were discharged to the community, 9% left the facility against medical advice, and 8% were discharged to a hospital. The median overall length of stay at the facility was 59 days; by patient subgroup, the median length of stay was 50 days for those who were discharged home, 66 days for those who died, 114 days for those admitted for long-term nursing care, 37 days for those admitted for completion of acute medical treatment, 28 days for those admitted for respite care, and 15 days for those admitted for terminal care. The overall death rate for patients in the facility was 8 deaths per 100 person-months.

In the examination of predictors of early mortality (≤ 6 months after admission), significant baseline variables included Karnofsky score, Mini-Mental State Examination score, CD4+ count, any impairment in activities of daily living, inability

to ambulate, and psychiatric history (lower prevalence of psychiatric illness in the early mortality group) (Table VII).

The analysis of short-term versus long-term stay (those staying less than 6 months compared to those staying 6 months or more), excluding the group that died within the first 6 months, revealed that long-term stay was associated with non-white race, male gender, a baseline neurologic diagnosis, and/or dementia (Table VIII).

On multivariate analysis of predictors of mortality, stepwise logistic regression indicated that early mortality (≤ 6 months after admission) was predicted by low admission CD4 count (adjusted odds ratio 1.002, 95% confidence interval [CI] 1.00–1.004 per CD4 cell decrease) and the presence of impairment in one or more domain of activities of daily living (adjusted odds ratio 2.99, 95% CI 1.46–6.13). On multivariate analysis of predictors of long-term stay, stepwise logistic regression indicated that long-term stay (> 6 months) at the facility was predicted by the total number of admission medications (adjusted odds ratio 1.072, 95% CI 1.005–1.114 per medication) and the presence of dementia (adjusted odds ratio 2.35, 95% CI 1.16–4.78).

TABLE VI Dispositions and Discharges for Residents Admitted to HIV/AIDS Skilled Nursing Facility

Total number of patients	180
Total number of admissions	222
Total number of discharges	202 (91%)
Died	44%*
Discharged to community	39%
Left against medical advice	9%
Discharged to hospital	8%
Death rate at the facility	8 deaths/100 person-months
Median length of stay at the facility	
Overall	59 dayst
By patient subgroup	
Discharged to home	50 days
Died	66 days
Still residing at facility	384 days
By primary reason for admission	
24-hour nursing/medical supervision	114 days
Completion of acute medical treatment	37 days
Respite care	28 days
Terminal care	15 days

*Percentages reflect percentages of all discharges. Overall, 49% of all patients died.

†Range 1 to 1,353 days. Overall mean length of stay = 152 days.

TABLE VII Predictors of Early Mortality (≤ 6 Months) by Baseline Characteristics of Residents of HIV/AIDS Skilled Nursing Facility

Based Characteristics	Died ≤ 6 months (N = 74)	All Others (N = 106)	Odds Ratio	95% Confidence Interval	P
Mean Karnofsky score	38	46	—		<.01
Median MMSE*	21/30	24/30	—		<.01
Median CD4+ T lymphocytes/mm ³	14	30	—		<.01
Total medications (mean number)	11	12	—		<.01
Impairment in ADL†	75%	42%	4.1	2.1–7.9	<.14
Not ambulatory‡	49%	17%	4.6	2.4–8.9	<.01
Psychiatric history	35%	51%	0.5	0.3–0.9	<.04

*MMSE = Mini-Mental State Examination (see ref 16).

†Impairment in 1 or more of 13 domains of Katz Activities of Daily Living Scale recorded on standard intake screen (see ref. 17).

‡Includes wheelchairbound or bedbound patients.

DISCUSSION

This report describes the initial experience of a dedicated skilled nursing facility for people with AIDS and suggests that this level of care will meet an important service need for long-term care as the AIDS epidemic matures and AIDS increasingly becomes a chronic disease. Although earlier reports have described the provision of hospice services to people with AIDS^{19–22} and the experience of nursing units within hospitals or geriatric nursing homes,^{9,10} this is one of the first studies to examine the experience of a freestanding, AIDS-designated long-term care facility in the era of highly active antiretroviral therapy (HAART). This facility, established in a small urban community with a high rate of AIDS cases, has remained filled to capacity since opening and has become an integral part of the continuum of care in the local AIDS service environment.

TABLE VIII Predictors of Long-Term (≥ 6 Months) Stay by Baseline Characteristics in Residents of HIV Skilled Nursing Facility*

Baseline Characteristics	Long-Term (≥ 6 months), % (N = 55)	Short-Term (<6 months), % (N = 51)	Odds Ratio	95% Confidence Interval	P
Non-white, %	69	53	2.0	0.9–4.4	<.09
Male, %	75	59	2.0	0.9–4.7	<.09
Neurologic diagnosis	53	26	3.3	1.4–7.3	<.01
Dementia	47	22	3.3	1.4–7.5	<.01

*Analysis excludes patients who died within 6 months after first admission to the facility (n = 74).

Although it may be counterintuitive at first consideration, with the increasing effectiveness of antiretroviral therapy and other medical interventions that can prolong life in HIV-infected individuals, it is likely that the need for this level of long-term care will expand. While some patients are able to return to more autonomous levels of functioning as a result of the benefits of the new therapies, for others with late-stage disease or accompanying psychiatric or neurologic disease, their disease course may become one of more prolonged impairment—the conversion of death, in effect, to long-term disability. This may be expected to generate an ongoing need for long-term care options, including skilled nursing facilities such as the one described here. In addition, however, as part of an extending continuum of care, it may become equally important to develop community-based residential alternatives for the growing population of patients that may, with improvements in HIV therapy, be able to be discharged from inpatient facilities.

The population at Leeway has been a heterogeneous one, including patients admitted for short-term convalescence and long-term care, suggesting that such a facility must also be prepared to deal with acute medical issues in addition to the more chronic level of care customary in many nursing homes. In addition, although close to 50% of patients admitted to the facility ultimately died within the observation period, over 30% were discharged home to the community, indicating that there is an important role for rehabilitative services in such institutional settings. In addition, the finding that over 20% of the patient population was admitted for completion of acute medical treatment suggests that this type of facility can play an important and cost-effective role in the management of the complications of HIV disease. From these data alone, at an average daily bed rate of approximately \$300 at the skilled nursing facility compared with over \$1000 at the facility's major referral hospital, the cost-saving implications for hospitals are evident. Such potential savings will become even more attractive as managed-care plans proliferate, with the important priority of reducing inpatient hospital lengths of stay.

One of the more striking findings in our study was the high prevalence of psychiatric and neurologic disease in our patient population. Close to half of the patients in our study had a significant neurologic and/or psychiatric diagnosis. This may reflect the anticipated increasing incidence of HIV-related neurologic disease among patients with AIDS, who live longer with ongoing immunosuppression as a result of more effective therapies in the HAART era.²³ It may also reflect the fact that people with serious neurologic impairment from HIV disease may be in particular need of skilled nursing care due to decreased ability to care

for themselves. Further, patients with significant psychiatric comorbidity may be less likely as a group to benefit from the impact of the new therapies—and their demanding daily dosing schedules—outside a structured environment with both medical and psychiatric supervision. They may also be more likely to be admitted to a skilled nursing facility earlier in the course of their HIV disease, reflecting a need for more intensive supportive care services than would be available routinely in a noninstitutional setting. Finally, the high prevalence of substance use in our patients—those dually and triply diagnosed, with HIV disease, neuropsychiatric illness, and drug use disorders—converges with the other diagnoses to create a unique range of needs.^{24–26}

All of these factors suggest the critical importance of a combination of medical, mental health, drug treatment, and rehabilitative services in long-term care settings in which this vulnerable patient population is likely to become increasingly concentrated.^{12,27} Further, it is important to recognize that skilled nursing facilities such as this one in fact may be selecting patients with multiple comorbidities since those able to function at higher levels would tend to be removed progressively from the potential patient pool, leaving only those with no other alternatives to constitute the group eligible and appropriate for long-term care. In addition, in our study, the absence of psychiatric illness was a predictor of survival on multivariate analysis, and neurologic disease and dementia were predictors of long-term stay, suggesting that there may be other selection effects following admission by which patients with neuropsychiatric illness would tend to make up an increasing proportion of the patient population over time.

This trend is substantiated by the increasing serial cross-sectional prevalence of psychiatric illness in the population over time at this facility, from just over 40% in 1995 to close to 60% in 1998 ($P < .01$) (Figure). These findings are corroborated by other studies in which psychiatric illness and/or dementia were predictive of increased length of stay or intensity of care among patients with AIDS in hospital or geriatric nursing home settings.^{8,27,28} This likely will exert pressure on such facilities to keep beds available for more acute, short-term admissions and result in a growing need for other community-based residential alternatives for people with chronic disability from AIDS and these other associated conditions. Moreover, the overall decline in mortality due to more effective antiretroviral therapy will only intensify these changes: Within our population, there was a significant decrease in mortality of those admitted from 1997 to 1998 compared to those from 1995 to 1996 ($P < .01$). Indeed, at Leeway, all of these trends have resulted in a need for the construction of an additional on-site 10-bed unit, now under way, which will accommodate the growing size of the patient population

FIGURE Prevalence of psychiatric illness in residents of HIV/AIDS skilled nursing facility, 1995–1998. *Test for trend (Pearson correlation), $P < .01$, 1995 through 1998.

and be designed especially—both in physical layout and staffing patterns—to care for patients with AIDS and serious mental illness.

As has been described in earlier reports examining the delivery of care to patients with AIDS in geriatric nursing home settings,^{9,13} our patient population required a high level of medical and nursing intensity and had a higher acuity of illness than would be expected in many other nursing home settings. The high median number of medications (11 in this sample, likely to increase as our therapeutic options advance) and the frequent need for referral to the hospital for acute care interventions, procedures, and outpatient subspecialty consultations all indicate that the care needs for such patients cannot be extrapolated simply from what would be expected in a geriatric nursing home. Although our facility has negotiated a separate daily bed reimbursement rate with our state regulatory agency, intended to reflect the higher acuity level of our population, this may become increasingly problematic over time, especially with capitated payment systems, Medicare, and private insurers, due to the growing complexity and cost of antiretroviral agents and other HIV-specific therapies.

Aside from the clinical and health services aspects of our experience, it is important to note the unique nature and dynamics in the care continuum of a skilled nursing facility for people with AIDS. The relatively small size of the institution, the communitylike nature of the facility—with a common eating area and many group activities—and the long stays compared to an inpatient hospital all contribute to important social and emotional bonds that arise among patients and between patients and staff. For patients and their families, this AIDS-dedi-

cated facility may be the first place in which they have been able to speak about and receive support for being affected by AIDS without fear of ostracism or adverse consequences.

For some patients, there is the prospect that they may recover enough to be discharged home; indeed, the remarkable recoveries of some patients at the nursing home—the “Lazarus syndrome” increasingly seen in HIV care—are a testament to the benefits of intensive nursing and rehabilitative care along with HAART. However, for many other patients, it is evident that they either will soon die or will be unlikely ever to leave the facility. This duality both reinforces hopefulness and, whenever a patient dwindles or dies, serves as a reminder of the frailty and uncertainty that still characterize HIV disease even in the HAART era.²⁹ Thus, the facility serves not only as a refuge from an outside world in which AIDS still carries a heavy stigma, but also as a place of last resort when all other options have failed and AIDS continues to take a heavy toll. These subtle and conflicting themes may pose particular challenges for emotional and psychosocial care for patients, families, and staff at such facilities over time. These and other special concerns—such as how to address drug use, sexual risk taking, and certain infection control issues in a group environment that seeks to have a noninstitutional ambience—have continued to require close and thoughtful attention as our clinical experience in this facility evolves.

In conclusion, this study suggests that a dedicated skilled nursing facility for people with AIDS can occupy an important and increasingly strategic role in the continuum of care services as AIDS becomes more of a chronic disease. In addition to those admitted for short-term convalescence and the small percentage of patients admitted for respite or terminal care, the largest proportion of patients in such facilities will be those requiring long-term care of indefinite duration. The success of HAART and other HIV-related therapies carries with it the new challenge of caring for a patient population that survives longer but is not able to respond sufficiently to our new therapeutics—for medical, social, behavioral, or other reasons—to return to autonomous functioning in the community. Skilled nursing facilities such as this one should be integrated into the extending continuum of HIV care services, together with noninstitutional, community-based options for those patients with chronic care needs who may no longer require inpatient nursing care.

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dedicated to the residents and staff of Leeway and to the memory of Catherine Kennedy, without whose vision, commitment, and quiet tenacity Leeway would never exist.

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