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Use and Predictors of End-of-Life Care Among HIV Patients in a Safety Net Health System

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Abstract

Context—Though highly active anti-retroviral therapy (HAART) has improved survival among many HIV patients, there are still those with advanced illness and limited access to care who may benefit from palliative care and hospice.

Objectives—To examine completion of advance directives, use of palliative care, and enrollment in hospice among HIV patients who receive care at an urban safety net hospital.

Methods—This was a retrospective cohort study of HIV patients in a large, urban safety net hospital in 2010. Physicians abstracted data from the electronic medical record on patient and clinical factors and end-of-life care use. Logistic regression examined predictors of hospice use.

Results—Overall, 367 HIV patients identified electronically by ICD-9 code were hospitalized in 2010. The mean age was 42 years and 57% were African American. Though 28% died, only 6% of the sample received palliative care consultation, and 6% of the sample enrolled in hospice. Those who received hospice had lower albumin levels (adjusted odds ratio (AOR) 4.53, 95% confidence interval (CI) 1.19, 17.34), had received palliative care (AOR 9.73, 95% CI 2.10, 45.09), and completed an advance directive (AOR 16.33, 95% CI 4.23, 61.68). Of those patients who received hospice, the mean time to death after enrollment was 11 days.

Conclusion—Among an urban cohort of HIV patients, the rates of advance directive completion, palliative care use, and hospice use were low. Despite advancements in the treatment of HIV, many patients with advanced illness may benefit from palliative care and hospice services. Advances should be made in identifying those patients earlier in their disease trajectories.

Disclosures

The authors declare no conflicts of interest.

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Keywords

hospice; palliative care; HIV; safety net

Introduction

Human Immunodeficiency Virus (HIV), the retrovirus that causes Acquired Immunodeficiency Syndrome (AIDS), was identified by scientists in the early 1980s.¹ Initially characterized by the diagnosis of opportunistic infections like *Pneumocyctis carinii* pneumonia (PCP) and Kaposi's Sarcoma in otherwise healthy gay men, the demographic characteristics of HIV/AIDS have evolved over time. Additionally, though from 1981 to 1995 there was a rapid increase in AIDS diagnoses, the peak incidence of death of 50,877 was reached in 1996.² It is believed that the rapid decline in deaths in 1996 was secondary to the effectiveness of drug therapy, which became widely available at that time.^{2,3} As of 2012, an estimated 1.2 million persons aged 13 and older were living with HIV infection in the United States.⁴ The estimated number of deaths of persons with HIV infection ever classified as AIDS was 13,712, and the cumulative estimated number of deaths in this population through 2012 was 658,507.⁴

Medical advancement has certainly played a role in increased life expectancy among HIV patients. Highly active antiretroviral therapy (HAART) has evolved from early use of zidovudine (AZT) to include a number of other medications and combination therapies. In fact, research has shown that the life expectancies of among some HIV-positive patients who take antiretroviral therapy may be approaching that of the general population.^{5,6} Despite these advances, there remains a certain segment of the population who do not achieve these increases in life expectancy and progress to the end stages of the disease. For instance, recent data has revealed that in the Southern United States, which are disproportionally affected by HIV, the death rate among persons living with HIV was higher than in any other region of the country.⁷ These states share other characteristics, including high poverty rates and overall poor health of the population.⁸

Early palliative care has been shown to improve quality of life and in some instances, even survival for patients with certain disease states,^{9–11} and despite advancements in treatment, there still may be a need for palliative care for patients with HIV/AIDS as well.¹² Though initiation of early palliative care may be hampered by difficulties with prognostication that exist,¹³ previous research suggests that palliative care may be able to help with pain and symptom management, discussions about goals of care, and initiation of hospice if appropriate.^{14–16} Despite the progress made in the care of patients with HIV, some patients progress to advanced AIDS. This is particularly true in areas where there are higher levels of poverty and patients lack adequate insurance coverage.^{8,17} Palliative care and hospice providers have much to offer to treat pain and relieve symptoms that these patients may experience. The goal of this study is to examine the rates of advance directive completion, palliative care, and hospice use among patients hospitalized with HIV and AIDS in a large, urban population-based safety net health system, which provides care to the county's low-income, uninsured, and vulnerable population

Methods

Study Population

We conducted a retrospective cohort study of all consecutive patients admitted in 2010 with HIV or AIDS to the Parkland Hospital, a large, urban teaching public hospital in Dallas, Texas. Parkland is the sole safety net hospital in all of Dallas County. Low income patients who are Dallas County residents (regardless of citizenship) are eligible for county-based health insurance which provides low cost access to outpatient and inpatient services (and medications) in the safety net integrated delivery system. All inpatient and outpatient data, orders, medications, and care are captured in its comprehensive Epic electronic medical record (EMR).¹⁸ The study was approved by the UT Southwestern Medical Center Institutional Review Board, and all research personnel completed Human Subjects Protection, Health Insurance Portability and Accountability Act (HIPAA) research, and Conflicts of Interest training.

Data Collection

Eligible inpatients were identified electronically by ICD-9 code (042) in the EMR. Physician abstractors, who were blinded to the purpose of the study, were trained in how to review the inpatient and outpatient charts to collect data on completion of an advance directive (living will or medical power of attorney), receipt of palliative care consultation in the inpatient or outpatient setting, and enrollment in hospice. Other independent variables obtained during chart review, included sociodemographic information (age, gender, race, ethnicity, marital status, insurance status), laboratory values (most recent albumin, viral load, and CD4 count), and clinical variables (documentation of ever being prescribed HAART or ever being seen either in the primary HIV Clinic or one of the community based HIV Clinics affiliated with the hospital). The physician abstractors used a standardized paper abstraction form to collect data. Documentation of certain opportunistic infections or AIDS-defining illnesses was also electronically identified by ICD-9 code including: primary CNS lymphoma (200.5), progressive multifocal leukoencepahlopathy (046.3), toxoplasmosis (130 - 130.9), Kaposi's sarcoma (176), disseminated mycobacterium avium complex (MAC) or MAC bacteremia (0.31.2), cryptosporidium infection (007.4), and AIDS dementia complex (294.1). These specific conditions were chosen based on published guidelines that are used to determine hospice eligibility.^{19,20} The identified patients' charts were reviewed from January 1, 2009 to July 31, 2014.

Statistical Analysis

Descriptive statistics were used to characterize the baseline sociodemographic characteristics of the overall sample and to compare baseline characteristics of patients who enrolled in hospice versus those who did not. The statistical tests used included the chi-square test, Fisher's exact test, t-test, and Wilcoxon rank-sum tests as appropriate. Patient and clinical characteristics associated with hospice referral in the univariate analyses at the p <.20 level were entered into a stepwise multivariable logistic regression to identify independent predictors of hospice referral. We present unadjusted and adjusted odds of receiving hospice services after controlling for age, male gender, Black vs. White race, Hispanic ethnicity, advance directive status, marital status, palliative care consult, evidence

of being prescribed HAART, CD4 count, albumin level, insurance status, history of certain opportunistic infections, and viral load. We used Stata 12.1 (College Station, TX) software and significance levels of p < 0.05 for all statistical comparisons.

Results

Sociodemographic Characteristics

A total of 367 unique HIV patients were electronically identified by ICD-9 code as having been admitted to the hospital during the study period. For the total sample, the mean age was 42 years, 76.0% were male, 57.0% were black, and 24.0% were Hispanic. The majority (80.7%) of patients were single. With regard to insurance status, 37.1% had Medicaid, 36.2% participated in the county health assistance program, 15.5% had Medicare, and 7.9% were self-pay. Only 3.3% had commercial insurance. This county assistance program helps county residents pay for health care services received specifically within the county hospital and its affiliated clinics. This program does not fund home health or hospice care.

Clinical Characteristics

The mean CD4 count was 197 cells/ μ l and mean viral load 376,136 copies/ml for the total sample. The vast majority of patients (92.4%) had been to one of the affiliated HIV Clinics at least once, 91.3% had ever been prescribed HAART, and 60.8% had a CD4 count less than 200 cells/ μ l at some point during the study period. For those patients whose date of death was documented (N = 79), the median time to death from admission was 7.5 months.

Use of Advance Care Planning, Palliative Care, and Hospice

Only 8.7% of the total sample had some documentation of an advance directive in the EMR. Of those who did have documentation of an advance directive, most had a living will (90.3%), while only 9.7% had a medical power of attorney. Only 6.3% of the total sample received palliative care consultation, either during an inpatient hospitalization or in the outpatient setting. Of those who received palliative care consultation, 54.6% enrolled in hospice. While 27.5% of patients died, only 5.9% of the total sample were documented to have enrolled in hospice. Of those who enrolled in hospice, the median time to death after enrollment was 3 days and the mean time to death after enrollment was 11 days (range 1 - 55 days).

Predictors of Hospice Use

In univariate analysis, patients who received palliative care consultation (OR: 21.28, 95% CI: 7.79, 58.18) or had an advance directive (OR: 24.78, 95% CI: 9.42, 65.22), were more likely to enroll in hospice. Furthermore, patients who had CD4 counts less than 25 cells/µl (OR: 2.76, 95% CI: 1.15, 6.63) and albumin less than 2.5 g/dl (OR: 5.27, 95% CI: 2.18, 12.73) were also more likely to enroll in hospice. In multivariable analysis, hospice use was more likely among patients who were 55 years of age and older (AOR: 6.13, 95% CI: 1.17, 32.07), had an albumin of < 2.5 g/dl (AOR: 4.53, 95% CI: 1.19, 17.34), had an advanced directive documented in the EMR (AOR: 16.33, 95% CI: 4.32, 61.68), and palliative care consultation (AOR: 9.73 95% CI: 2.10, 45.09) CD4 count was no longer statistically

significant. (Table 2). Of note, there were no statistically significant differences in hospice enrollment based on race, ethnicity, marital status, or insurance status in this sample.

Discussion

Our study examined completion of advance directives, use of palliative care, and hospice enrollment among HIV/AIDS patients admitted to a local safety net hospital. Our findings suggest that there continues to be a place for palliative consultation in this population. For instance, on both univariate and multivariate analysis, patients who received palliative care consultation and completed an advance directive were more likely to enroll in hospice. Palliative care consultation may have influenced completion of advance directives, as addressing goals of care is a mainstay of this specialty. Despite these findings, there is still work to be done. For instance, while at least 28% of the study sample died, only 6% received palliative care consultation, and almost 6% enrolled in hospice. Furthermore, of those who enrolled in hospice, the mean time to death was 11 days, which suggests that these patients were referred to hospice late in their disease trajectories. This was true though 25% of patients had a CD4 count less than 25 cells/µl during the study period.

There are factors associated with the disease trajectory of HIV/AIDS that may explain these findings. The disease trajectory of HIV/AIDS is more often that of a chronic illness than in the early years of the epidemic. This makes prognostication more challenging, and this challenge may certainly have some bearing on hospice enrollment. For instance, cancer, which has a more steady progression to the terminal phase,²¹ remains the most common primary hospice diagnosis (36.9% in 2012), while of the non-cancer hospice diagnoses, HIV/AIDS is the least common (0.2% in 2012).²² Furthermore, in some cases, the life expectancies of patients with HIV/AIDS are approaching those of the general population, and some research suggests that the proportion of deaths among those with HIV/AIDS that are attributable to non-AIDS diseases such as hepatic, cardiovascular, and pulmonary diseases is increasing.²³ Despite these findings, there is a subset of HIV/AIDS patients that may have pain, depression, anxiety, and other symptoms related to their illness,²⁴ and palliative care has been shown to improve patient outcomes in those and other domains.¹⁶

There are some limitations that should be taken into account. This study was limited to patients seen in one healthcare system, which may influence the study's generalizability to other settings; however, this healthcare system provides care for most HIV patients in the county,²⁵ and may be comparable to care provided to HIV patients in other settings. Some of the patients in the sample were lost to follow-up, and may have received additional care at other hospitals and health care systems. Additional work should be done in multiple settings and with a larger sample of patients that may further enhance the external validity of these findings. Despite these limitations, this study contributes to a body of literature that demonstrates a continued need for palliative care for HIV patients. These services are needed particularly among those with advanced illness, limited access to care, and among underrepresented minority groups who have been found to underutilize these services traditionally.

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The clinical characteristics that were associated with hospice use should also be noted. In this sample, race, ethnicity, and insurance status were not associated with hospice use. This has been shown previously in palliative care patients who received their care at this specific healthcare system with varying diagnoses,²⁶ and is contrary to existing literature that cites race/ethnicity and socioeconomic status as barriers to hospice enrollment.^{27,28} On multivariable analysis, those who had lower albumin levels were more likely to enroll in hospice. Prognostication in those with low albumin levels may be less difficult to determine, as low levels suggest a limited prognosis, and albumin levels of 2.5 g/dl are often used to as supporting evidence for hospice eligibility.^{19,20} Patients who were 55 years and older were also more likely to enroll in hospice. These findings are similar to previous research in this population that has shown that age >40 years and CD4 < 132 cells/ μ l were among other multivariate predictors of death for HIV patients within 30-days of hospital discharge.²⁵ As advances in the treatment of HIV continue to progress, its disease trajectory will continue to be transformed to that of a chronic disease model. Interventions have been developed to address advance care planning among HIV-positive adolescents and their surrogates that have been feasible and acceptable to patients and their families, and initiated discussion about end-of-life issues when these patients were medically stable.^{29,30} Similar approaches should be investigated in other patient populations as well. Future research should also examine which clinical predictors are most useful in determining prognosis in this population, and for those with advanced illness, pain, and other symptoms related to their condition, palliative care consultation should be considered.

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Table 1

Baseline Characteristics of the Study Population (N = 367)

Characteristics	Total Sample	Enrolled in Hospice	Enrolled in Hospice	p-value
	N = 367 (%)	N = 22 (%)	N = 22 (%)	
Mean Age (years)	42	45.7	41.8	0.06
Age 55 and older	34 (9.3)	3 (13.6)	31 (9.0)	0.44
Male Gender	279 (76.0)	16 (72.7)	263 (76.2)	0.71
Race*				
Non-Hispanic Black	209 (75.2)	10 (62.5)	199 (76)	
Non-Hispanic White	69 (24.8)	6 (37.5)	63 (24.1)	0.22
Hispanic	88 (24.0)	6 (27.3)	83 (23.8)	0.71
Marital Status				
Divorced/Legally Separated	28 (7.63)	4 (18.2)	24 (7.0)	
Married	31 (8.5)	1 (4.6)	30 (8.7)	
Single	296 (80.7)	16 (72.7)	280 (81.2)	
Other	12 (3.3)	1 (4.6)	11 (3.2)	0.25
Insurance				
Charity	133 (36.2)	10 (45.5)	123 (35.7)	
Commercial	12 (3.3)	0	12 (3.5)	
Medicaid	136 (37.1)	6 (27.3)	130 (37.7)	
Medicare	57 (15.5)	5 (22.7)	52 (15.0)	
Self-pay	29 (7.9)	1 (4.6)	28 (8.1)	0.66
Opportunistic Infection or AIDS-defining Illness [*]				
Yes	51 (13.9)	6 (27.3)	45 (13.0)	
No	316 (86.1)	16 (72.7)	300 (87.0)	0.06
 CD4 Count <25 cells/µL				
Yes	90 (24.5)	10 (45.5)	80 (23.2)	
No	277 (75.5)	12 (54.5)	265 (76.8)	0.02
Yes	103 (28.1)	9 (40.9)	94 (27.3)	
No	264 (71.9)	13 (59.1)	251 (72.8)	0.17
Mean CD4 Count cells/µL (Range)	249 (1 – 1321)	79.8	205.1	0.0001
Mean Albumin, g/dl (Range)	3.3 (0.4 - 5.2)	2.5	3.3	0.0001
Mean Viral Load, copies/ml (Range)	376084 (0 - 10,000,000)	713406	354312	0.29

Characteristics	Total Sample	Enrolled in Hospice	Enrolled in Hospice	p-value
	N = 367 (%)	N = 22 (%)	N = 22 (%)	
Seen in HIV Clinic at Least Once				
Yes	339 (92.4)	22 (100)	317 (91.9)	
No	28 (7.6)	0	28 (8.1)	0.40
Ever Prescribed HAART				
Yes	335 (91.3)	20 (90.9)	315 (91.3)	
No	32 (8.7)	2 (9.1)	30 (8.7)	0.59
Received Palliative Care Consultation				
Yes	23 (6.3)	10 (45.5)	13 (3.8)	
No	344 (93.7)	12 (54.6)	332 (96.2)	< 0.001
Documentation of an Advance Directive/Code Status				
Yes	32 (8.7)	13 (59.1)	19 (5.5)	
No	335 (91.3)	8 (40.9)	326 (94.5)	< 0.001
Advance Directive Type				
Living Will	28 (90.3)	12 (92.3)	16 (84.2)	
Medical Power of Attorney	3 (9.7)	1 (7.7)	3 (15.8)	0.27
Deceased				
Yes	101 (27.5)	22 (100)	79 (22.9)	
No	266 (72.5)	0	266 (77.1)	< 0.001

* Only non-Hispanic Blacks and non-Hispanic Whites were included in this analysis

** CNS Lymphoma, Progressive Multifocal Leukoencephalopathy, Toxoplasmosis, Kaposi's Sarcoma, Disseminated Mycobaterium Avium Complex (MAC) or MAC Bacteremia, Cryptosporidium Infection, and AIDS Dementia Complex

Table 2

Predictors of Hospice Use. Logistic Regression Analysis

Characteristic	OR (95% CI)	AOR (95% CI)**
Age 55	1.60 (0.45, 5.71)	6.13 (1.17, 32.07)
Albumin < 2.5 g/dl	5.27 (2.18, 12.73)	4.53 (1.19, 17.34)
Viral load >100,000 copies/ml	1.85 (0.76, 4.47)	3.36 (0.88, 12.89)
Had an Advance Directive	24.78 (9.42, 65.22)	16.33 (4.32, 61.68)
Received Palliative Care Consultation	21.28 (7.79, 58.18)	9.73 (2.10, 45.09)

** Adjustment for age, gender, Black vs. White race, Hispanic ethnicity, advance directive status, marital status, palliative care consult, prescribed HAART, CD4 count, albumin level, insurance status, history of opportunistic infection, and viral load