HIV, Aging, and Advance Care Planning: Are We Successfully Planning for the Future?

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Abstract

Introduction: Studies of advance care planning (ACP) completion rates in HIV-infected persons pre-date the “graying” of the HIV epidemic. We sought to examine current ACP completion rates and factors influencing completion among HIV-infected persons.

Methods: HIV-1-seropositive persons aged 45–65 years on effective antiretroviral therapy for a minimum of 6 months were enrolled in a cross-sectional survey. Likelihood of ACP was assessed by demographic and clinical characteristics, tested with odds ratios (OR) and 95% Wald confidence intervals (CI), and adjusted for gender.

Results: Of 238 participants, 112 (47%) completed ACP. Persons ≥ 55 years of age (OR 2.8; CI 1.6,5.0; $p < 0.001$), males (OR 4.1; CI 1.8,9.3; $p = 0.004$), and persons with higher education (OR 2.2; CI 1.3,4.0; $p = 0.007$) were more likely to have completed ACP. Persons with a cardiac event were more likely to have completed ACP (OR 5.5; CI 1.6,25; $p = 0.03$), although this effect was diminished after adjusting for gender (OR 4.5; CI 0.95,21.4; $p = 0.06$). HIV infection diagnosed for greater than 5 years was not associated with ACP completion (OR 1.3; CI 0.7,2.7; $p = 0.4$). Current CD4⁺ cell counts were similar between those completing and not completing documentation (588 cells/ μ L and 604 cells/ μ L, respectively; $p = 0.7$). The likelihood of ACP did not significantly differ with other comorbidities.

Discussion: Less than 50% of middle-aged patients in HIV care had documented ACP. In particular, women and those with lower education were at greatest risk of non-completion and may need interventions to improve ACP.

Introduction

MARKED IMPROVEMENTS in life expectancy over the past two decades have shifted the focus of care for persons with human immunodeficiency virus type 1 (HIV), and the acquired immunodeficiency syndrome (AIDS), from end-of-life planning to optimization of antiretroviral therapy (ART). Enhanced survival of people with HIV infection has led to a 62% increase in the HIV population aged 45 and older.¹ Despite improvements in HIV treatment, life expectancy still lags behind that of HIV-negative individuals.² The combination of HIV infection and older age is associated with development of many age-associated comorbid conditions, and has led to an increasing number of non-AIDS-associated deaths.^{3–6}

Medical care of people aging with HIV infection is complicated by social situations that can adversely affect the lives of HIV-infected persons. HIV-related stigma is prevalent and is intensified by ageism: almost all HIV-infected aging indi-

viduals have experienced HIV-related stigma, and as a result, more than half do not disclose HIV status to family or friends.⁷ Older individuals with HIV often live alone,⁷ are less likely to be involved in a long-term relationship,⁸ frequently have social support networks comprised of HIV-positive partners and friends, and may experience loss of support due to HIV/AIDS-associated deaths.⁹ Without appropriate documentation of a medical power of attorney or state-recognized same-gender marriage, decisions regarding end-of-life or emergent care by a long-term partner are legally deferred to the next-of-kin, possibly an estranged sibling or a family member unaware of an individual's HIV status.

Limited data from previous studies have demonstrated low completion rates of advance care planning (ACP) among HIV-infected individuals (16%–38%),^{10–12} compared with HIV-uninfected populations (36%–97%).^{13–16} However, existing studies pre-date the current “graying” of the HIV epidemic and are comprised of primarily patients younger than

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50 years.^{10–12,17} The aim of the present study was to examine current ACP completion rates and demographic and clinical features influencing documentation of ACP in a cohort of older HIV-infected persons who were receiving care in an HIV specialty clinic.

Methods

Study population

This was a nested cross-sectional study conducted within a larger functional capacity study between February and November 2010. All individuals who received care for HIV infection within 12 months prior to February 2010 in the Infectious Diseases Group Practice (IDGP) Clinic at the University of Colorado Hospital were evaluated for potential participation in a study evaluating functional capacity. Each patient record in the IDGP Clinic has a health care maintenance checklist, including yearly reminders to address advance directives. Patients meeting the following criteria were eligible to participate: (1) aged 45–65 years; (2) able to consent and participate in study procedures; and (3) taking effective combination (two or more) antiretroviral therapy for at least 6 months with one undetectable plasma HIV-1 RNA (<48 copies/mL), and no plasma HIV-1 RNA > 200 copies/mL in the prior 6 months. Eligible individuals were contacted in person, by telephone, or by letter to determine interest. Approval was obtained from the Colorado Multiple Institutional Review Board, and informed consent was obtained from all participants.

All participants completed a single study visit that included a medical record review, a standardized interview, quality of life questionnaire (SF-36® Health Survey), and an assessment for functional capacity through frailty or disability evaluations. The question “Do you have an advanced directive, living will, or durable power of attorney for health care decisions?” was incorporated into the standard interview after 35% of subjects had already completed the visit. A positive response to any of these questions was collapsed into a dichotomous variable indicating any completion of ACP.

Definitions

Co-morbid conditions were determined by medical record review and included prior diagnosis of any of the following: stroke or transient ischemic attack, dementia (any cause), psychiatric disease (depression, anxiety, bipolar disorder, schizophrenia, or psychiatric disease not otherwise specified), diabetes, kidney disease (calculated creatinine clearance <30 mL/min by Cockcroft-Gault), malignancy (excluding non-melanoma skin cancer), lung disease (chronic obstructive pulmonary disease, asthma, pulmonary hypertension, or interstitial lung disease), cardiac event (myocardial infarction, angioplasty, or coronary artery bypass grafting), and hepatitis B or C. Laboratory values were the most recent values available in the medical record.

Frailty was defined by Fried’s criteria for weight loss, weakness, exhaustion, and slowness, as previously described.¹⁸ Low activity was defined as self-report of being “limited a lot” in vigorous physical activities such as running, lifting heavy objects, or participating in strenuous sports.^{19–21} One point was given for each abnormality, with “frailty” requiring three or more points.

Disability was determined through the Short Physical Performance Battery (SPPB). The SPPB assessed tandem stand, walking speed, and sit-stand test time, with zero points indicating inability to complete a task, and four points indicating performance at the expected speed. Of a possible 12 points, a score of less than 9 was considered “disabled” for the present study.²²

Statistical analysis

Study data were collected and managed using Research Electronic Data Capture (REDCap) tools hosted at the University of Colorado.²³ Demographic and clinical characteristics were reported as *n* (%) by ACP status, and odds of ACP for each characteristic or diagnosis were expressed as odds ratios (OR). To summarize and test differences in the likelihood of ACP, 95% Wald confidence intervals (CI) and chi-square *p*-values, or exact chi-square for small cell counts, are reported. Demographic characteristics were adjusted for differences by gender in predicting ACP using logistic regression. SF-36 Health Survey scores were normalized to a general population mean of 50 and compared by ACP using two-sample *t*-tests. Analyses were performed with SAS V9.2.

Results

Between February and November 2010, 806 HIV-infected patients aged 45–65 years were evaluated for study eligibility. Of these, 542 patients met eligibility requirements, 369 entered the study, and 359 subjects completed the study visit. ACP completion was ascertained on 238 (66%) of the study participants. Responses were available for all 238 subjects, of which 112 (47%) reported completion of ACP. Men were more likely (52%) to have ACP completion than women (21%; Table 1).

Univariate analyses indicated that persons over age 55, those who contracted HIV through sex with a same-sex male partner, and those with higher income and education, were more likely to have completed ACP. Other demographic characteristics associated with ACP completion among the study population are shown in Table 1. Of 38 females and 200 males, 8 (21%) females and 35 (18%) males were Hispanic, 11 (29%) females and 28 (14%) males were black, 5 (13%) females and 62 (31%) males completed a college education or higher, 8 (21%) females and 28 (14%) males had previously used intravenous drugs, and 7 (18%) females compared to 62 (31%) males were current users of an illicit substance (primarily marijuana). In logistic regression analyses, no gender interaction was observed in the odds of ACP for race, ethnicity, education, income, or living situation. Lower ACP completion among those with income less than \$50,000 per year, non-Caucasians, and persons without a college education was, however, confounded by female gender. When controlled for gender, persons living with a partner/spouse, children, or a roommate, were more likely to have completed ACP (adjusted OR 1.9; CI 1.1,3.2) than those living alone (*p*=0.03).

Persons with a current or prior history of AIDS trended toward increased odds of ACP completion (OR 1.7; CI 1.0,3.0; *p*=0.06). Current CD4 count was similar between those completing and not completing documentation (geometric mean 501 [CI 446,564] cells/ μ L and 513 [CI 457,575] cells/ μ L, respectively; *p*=0.70).

As shown in Table 2, cardiac event was the only comorbid condition that was significantly associated with completing

TABLE 1. UNIVARIATE AND GENDER-ADJUSTED ANALYSIS OF DEMOGRAPHIC CHARACTERISTICS ASSOCIATED WITH COMPLETION OF ADVANCE CARE PLANNING (ACP)

Characteristic and value	Overall cohort n=238 (%)	Advance care documented		Odds ratio for completing ACP (95% CI ^a)	p Value	Adjusted odds ^b (95% CI ^a)	Adjusted p value ^b
		Yes n=112 (%)	No n=126 (%)				
Age > 55 years	71 (30)	46 (41)	25 (20)	2.8 (1.6,5.0)	<0.001	3.8 (2.0,7.3)	<0.001
Male gender	200 (84)	104 (93)	96 (76)	4.1 (1.8,9.3)	<0.001		
Caucasian	182 (76)	92 (82)	90 (71)	1.8 (1.0,3.4)	0.05	1.7 (0.9,3.2)	0.11
Hispanic or Latino	43 (18)	19 (17)	24 (19)	0.9 (0.6,2.2)	0.70	1.1 (0.6,2.2)	0.78
College education or higher	67 (28)	41 (37)	26 (21)	2.2 (1.3,4.0)	0.007	2.0 (1.1,3.7)	0.02
Retired, part-time or unemployed	166 (70)	88 (79)	78 (62)	2.3 (1.3,4.0)	0.006	2.4 (1.4,4.4)	0.003
Household income ≥\$50,000/year	37 (16)	23 (21)	14 (11)	2.1 (1.0,4.3)	0.05	1.9 (0.9,3.9)	0.09
Live with partner, roommate, or other (versus living alone)	146 (61)	78 (70)	68 (54)	1.9 (1.1,3.3)	0.02	1.8 (1.1,3.2)	0.03
Hospitalized in prior year	48 (20)	28 (25)	20 (16)	1.8 (0.9,3.4)	0.08	1.7 (0.9,3.3)	0.11
MSM ^c	154 (65)	80 (71)	74 (59)	1.8 (1.0,3.0)	0.04		
Heterosexual	65 (27)	21 (19)	44 (35)	0.4 (0.2,0.8)	0.006	1.5 (0.7,2.9)	0.30
HIV-1 diagnosed ≥5 years prior	199 (84)	96 (86)	103 (82)	1.3 (0.7,2.7)	0.41	1.4 (0.7,2.8)	0.38

^aConfidence interval.^bAdjusted for gender.^cMen who have sex with men.

ACP (OR 5.5; CI 1.2,25.9; $p=0.03$). Gender was a confounding factor with cardiac event, dementia, frailty, disability, stroke, and hepatitis C. In the adjusted model including gender, no comorbid disease was associated with an increased odds of ACP completion (all $p>0.05$). Although lung disease was not associated with an increased odds of ACP completion, the five enrolled subjects on home oxygen had all completed ACP ($p=0.02$). Completion of ACP was significantly more likely if a participant reported poorer health-related quality of life in the physical domains of the SF-36 Health Survey, but not in mental health domains ($p<0.001$ versus $p=0.9$; Fig. 1).

Discussion

The ACP completion rate in our population of middle-aged HIV-infected persons was higher than that reported a decade earlier in both younger HIV-infected and older HIV-

uninfected populations. However, by including only persons on effective antiretroviral therapy, our rate of 47% may reflect a more compliant patient population that is engaged in regular HIV care, and may overestimate completion rates among all middle-aged HIV-infected adults. The similar rate of ACP completion among those diagnosed with HIV infection more recently and those diagnosed prior to implementation of more effective ART suggests that ACP completion in this aging population is not merely a result of prior end-of-life AIDS discussions in the earlier years of the HIV epidemic.

ACP completion among men mirrors completion rates in those acquiring HIV-1 through men who have sex with men (MSM), and reflects an increasing awareness of advance care planning among this population. The trend toward lower ACP completion among minorities and Hispanics, and the significantly lower ACP completion rate among those with less income and education, are consistent with findings of other

TABLE 2. UNIVARIATE AND GENDER-ADJUSTED ANALYSIS OF CLINICAL CHARACTERISTICS ASSOCIATED WITH COMPLETION OF ADVANCE CARE PLANNING (ACP)

Comorbid disease or event	ACP completion among persons with disease or event (%)	Odds ratio for completing ACP (95% CI ^a)	Adjusted odds ^b (95% CI ^a)
Cardiac event	9/11 (82)	5.5 (1.2,25.9)	4.5 (1.0,21.4)
Dementia	4/6 (67)	2.3 (0.4,12.8)	1.9 (0.3,10.5)
Frailty	13/20 (65)	2.2 (0.9,5.8)	2.5 (0.9,6.9)
Malignancy	17/30 (57)	1.6 (0.7,3.4)	1.4 (0.6,3.1)
Disability	8/14 (57)	1.5 (0.5,5)	2.6 (0.8,8.6)
Chronic kidney disease	9/16 (56)	1.5 (0.5,4.1)	1.4 (0.5,4.1)
Hepatitis B	11/21 (52)	1.2 (0.5,3.1)	1.1 (0.5,2.8)
Psychiatric disease	68/140 (49)	1.2 (0.7,2.0)	1.2 (0.7,2.1)
Diabetes	11/23 (48)	1.0 (0.4,2.4)	1.1 (0.5,2.7)
Hepatitis C	18/44 (41)	0.7 (0.4,1.4)	0.8 (0.4,1.5)
Stroke	3/8 (38)	0.7 (0.2,2.9)	0.9 (0.2,4.1)
Lung disease	11/31 (35)	0.6 (0.3,1.3)	0.6 (0.3,1.4)

^aConfidence interval.^bAdjusted for gender.

FIG. 1. SF-36[®] Health Survey is normalized to a population mean of 50, with a scale ranging from 0–100. The shaded bars represent mean scores and error bars represent 95% confidence intervals. * $p < 0.01$; † $p < 0.05$; ‡ $p < 0.001$.

studies.^{10,11,24–26} Interestingly, in our population these effects were all reversed in women, and were not merely due to confounding by socioeconomic factors. ACP completion among women was surprisingly low, in sharp contrast with prior studies in both HIV-infected and uninfected populations in whom gender differences were negligible or favored completion in women.^{10,11,16,17,24} This gender discrepancy among HIV-infected women may reflect increased awareness for ACP completion among the MSM population, low awareness of ACP among middle-aged women compared to studies of older women, low perceived need for ACP among married women, or differences between women and men in HIV disclosure status to family.

Although there was a strong association between poor self-reported physical health and completion of ACP, few specific comorbid conditions increased the odds of ACP. Comorbidities such as dementia, malignancy, and emphysema, portend poor prognoses, and may be expected to provide a greater impetus for an individual to address ACP.¹⁵ Although we were unable to demonstrate that such conditions increased completion rates, the infrequent occurrence of many comorbid diseases limits our ability to detect differences if they existed. The increased ACP completion rate among persons with cardiovascular events, while based on a small event number, is consistent with findings in both HIV-infected and uninfected populations, and may reflect patient perceptions about the prognosis of specific diseases.¹⁶

Despite federal regulatory requirements and a yearly reminder to providers in this clinic to address advance directives, less than half of our established population had completed ACP. With clinic time constraints and acceptance of HIV as a chronic rather than terminal disease, ACP may be deferred with an assumption that a future acute illness or serious event will promote these discussions. Unfortunately,

despite the Joint Commission on Accreditation of Healthcare Organization quality indicator and federal regulations requiring hospital admissions to receive information on advance directives, just over half of participants hospitalized in the past year in our study had completed ACP at any time. Improved ACP completion rates will require further intervention in both the inpatient and outpatient settings.

Our inclusion criteria provide a closer look at ACP among middle-aged persons adherent to antiretroviral therapy. Although our study sample is reflective of the majority of persons engaged in HIV care,^{27,28} our results may not be applicable to all HIV-infected populations. Furthermore, we expect that HIV-infected persons not engaged in regular care, lacking an established provider-patient relationship, or who are less compliant with antiretroviral therapy, are less likely to have addressed ACP. Future studies should explore ACP completion rates among these populations who are not engaged in regular care and receiving effective antiretroviral therapy, and are thus at greater risk of HIV-related complications and mortality. While we provide an assessment of demographic and clinical influences on ACP, we did not examine specific rates of provider education about ACP, or the barriers to completion in persons who have been provided education about ACP. Individual religious or cultural beliefs on health care decision making may play a role in the completion of ACP, but these factors were not assessed in this study. Our study population included only persons currently on antiretroviral therapy, was primarily Caucasian, non-Hispanic, and had a very low rate of current injection drug use (<1%). Accordingly, our results may not be generalizable to other HIV care settings.

Although there has been progress over the past decade in promoting ACP in aging HIV patients, less than half of established clinic patients have documented ACP. If patient and provider reluctance to address ACP is due to time constraints,

this will likely be a continued barrier despite increasing age and medical complexity. Primary care settings have improved ACP completion through various methods, including physician education, computer prompts for physicians, pre- and post-visit patient reminder cards, mailed advance directives, waiting room educational material, and a combination of interventions.^{29–31} ACP should be addressed on a regular basis, barriers to completion of documentation should be explored, methods to improve completion should be tested, and a concerted effort should be made to encourage ACP in women and those of lower socioeconomic status.

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Author Disclosure Statement

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