Brief Report

Chronic Pain, Functional Status, and Life Satisfaction Are Associated With Patients Living With HIV Discussing Advance Care Planning With Their Family or Friends

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Abstract

Context. In the era of effective antiretroviral therapy, persons living with HIV/AIDS (PLWHA) are living longer, transforming HIV from a universally fatal disease to a serious chronic illness, warranting discussions between patients and their loved ones about advance care planning (ACP). Evidence is needed on factors associated with patients' likelihood to discuss ACP with loved ones.

Objectives. To further characterize factors associated with successful ACP in PLWHAs with their loved ones, we examined associations between patients having ACP discussions with the need for assistance with personal care, chronic pain, life satisfaction, prior family disagreements over health care decisions, sex, age, and interference in daily routines due to memory problems.

Methods. Data were from the Affirm Care study ($N = 370$), which examined social and environmental factors associated with health outcomes among PLWHAs and their informal caregivers.

Results. Slightly more than half of respondents discussed ACP with loved ones (57%). In adjusted analysis, higher levels of chronic pain (odds ratio [OR] = 2.09, $P = 0.045$), needing assistance with personal care (OR = 1.63, $P = 0.023$), greater life satisfaction (OR = 1.02, $P = 0.002$), prior family arguments over health care decisions (OR = 2.80, $P < 0.001$), and female sex (OR = 2.22, $P = 0.001$) were associated with higher odds of discussing ACP with loved ones, whereas age, drug use, education level, depression, and memory problems were nonsignificant.

Conclusion. These results suggest that interventions to increase ACP among PLWHAs and their loved ones should target males. The findings also suggest PLWHAs with chronic pain, the need for assistance with personal care, and those with a history of prior family arguments over health care decisions may be primed for ACP. J Pain Symptom Manage 2019;57:961–965. *© 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

AIDS, advance care planning, African American or black, chronic pain, family or caregiver

Introduction

In the era of effective antiretroviral therapy (ART), persons/patients living with HIV/AIDS (PLWHAs) are living longer, transforming HIV from a universally fatal disease to a serious chronic illness. Patients with serious chronic illnesses benefit from participating in advance care planning (ACP), which has been shown

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to decrease goal-discordant care and the use of unwanted life-sustaining treatment and increase the use of hospice and palliative care.[1–3] Rates of advance directive completion in PLWHAs remain too low; recent data show that up to 92% of PLWHAs admitted to the hospital lack a prior advance directive.[4]

Patients are significantly more likely to discuss ACP with their family than with their physicians.[5] They often rely on previous end-of-life experiences involving other friends and family members to form the basis of their own decisions.[6] In addition, most patients rely on a close family member or friend to be their health care proxy.

There are several perceived benefits to patients discussing ACP with their loved ones. Some patients are motivated to complete ACP for their family's sake, with the hope of reducing family discord.[7,8] Prior advance care planning has been shown to significantly reduce decisional conflict among surrogates for critically ill patients.[9] Patients and families who participate in ACP have lower depression and anxiety during the end-of-life care process[10]; however, some patients feel it is unnecessary to plan for their end of life because family members already know what to do.[11]

The present study sought to identify factors that may affect the likelihood of discussing ACP with family or friends among PLWHAs who were recruited from a large urban HIV clinic in Baltimore, Maryland. We hypothesized that several variables measuring health status (experiencing poorly controlled chronic pain, requiring help with personal care, and having more daily interference from memory problems) along with variables known to be associated with health status (age), would indicate worse health and perhaps a later stage of illness, and be associated with higher rates of ACP discussions with family or friends. In addition, we analyzed whether greater life satisfaction or a family history of disagreement over another family member's health care decisions were associated with greater rates of patients discussing ACP with their loved ones.

Methods

Participants

Data were drawn from 2014 through 2016, of the Affirm Care study, a cross-sectional study that examined social and environmental factors associated with ACP and health outcomes among PLWHAs and their informal caregivers in Baltimore, Maryland. Care recipients were recruited from a Baltimore HIV clinic and several other Baltimore-area community venues. Inclusion criteria included 1) age 18 years or older, 2) documented HIV seropositive, and 3) being either a current or former drug user (e.g., cocaine, heroin, or stimulants). The study was approved by the Johns Hopkins University Bloomberg School of Public Health IRB, and PLWHAs completed consent forms before study participation. Surveys were administered by computer-assisted personal interview, with sensitive information elicited by audio computer-assisted self-interview.

Measures

Background variables included sex, age, race/ethnicity, education level, and monthly income. Current substance use, which was dichotomized as 1 = current substance use vs. 0 = no current substance use, was assessed with items measuring the self-reported use of heroin or cocaine or stimulants in the last six months.[12] Depressive symptoms were assessed using the 10-item version of the Center for Epidemiologic Studies Depression Scale and dichotomized using the cut point of 10 to indicate probable depression.[13]

Pain interference was measured by the item, "During the past 30 days, how much did pain interfere with your normal work or activities, including both work outside the home and housework" with five answer choices, which were collapsed into 0 = none, 1 = a little/moderately, and 2 = quite a bit/extremely.[14] Life satisfaction was measured by 11 items (Cronbach's alpha = .92), such as level of satisfaction with mental and physical health; level of personal achievement; ability to obtain necessities of life such as food and housing; ability to do the things that are important and to live a quality life; feeling safe in their neighborhood; relationships with other people and with God; and overall satisfaction with life.[15] Needing help with personal care was measured by the item, "(In the last year), who has helped you with personal care, which includes eating, bathing, and dressing?" Answer choices were dichotomized into 0 = nobody vs. 1 = friends or family, professionals, or both.[16] Interference due to memory problems was measured by the item, "In the last 30 days, how often did memory problems interfere with your daily activities?" with answer choices from 0 = never to 4 = every day, adapted from the National Health and Aging Trends Study.[17] Previous experiences with family members' ACP was measured by a yes/no item created for this study, "Has your family ever had major disagreements about medical treatment for a family member who was critically ill and not able to tell doctors about what treatment she or he wanted?" Answers were dichotomized into 1 = strongly agree/agree vs. 0 = disagree/strongly disagree.

The outcome variable of ACP was a single yes/no item created for this study that asked, "Have you ever talked with your family or friends about what medical treatments you would want if you were not able to make decisions for yourself?"

Data Analysis

Frequencies and means were run in SPSS v24 for the outcome and independent variables.[18] Next, unadjusted logistic regressions were generated for the variables of interest. Independent variables significant at $P < 0.10$ or lower at the bivariate level and those of theoretical interest were included in an adjusted logistic regression model. The Hosmer-Lemeshow test was used to remove variables from the adjusted analysis with poor model fit.

Results

In this sample ($N = 370$), a fair majority of respondents were African American or black (95.4%), and less than half were female (43.8%, Table 1). Approximately half (52.2%) had at least a high school education, and only one-quarter made at least $1000 per month (25.9%). One-third of respondents scored in the probable depression range of the Center for Epidemiologic Studies Depression Scale (36.8%), and more than one-third currently used heroin, cocaine, or stimulants (40%). Three-fourths of patients (76.3%) reported some degree of chronic pain, which interfered with daily life, with close to one-fourth (24.1%) reporting the highest levels of chronic pain (quite a bit/extremely).

Slightly more than half of respondents in the sample (57.7%) had talked to their family or friends about ACP. In the adjusted analysis, patients who reported the highest levels of chronic pain interfering with their daily life had significantly greater odds of having discussed ACP with family or friends (odds ratio [OR] = 2.27, $P = 0.045$) (Table 2). In addition, patients with greater life satisfaction (OR = 1.02, $P = 0.007$), those who needed help with personal care (OR = 1.54, $P = 0.023$), females (OR = 2.33, $P < 0.001$), and patients who had prior family arguments over health care decisions (OR = 2.97, $P < 0.001$) had significantly greater odds of having discussed ACP with family or friends. Age, education level, drug use, depression, mild/moderate pain, and memory problems were not associated with rates of discussing ACP with family or friends.

Table 1

Demographic and Background Characteristics of Study Participants (Affirm Care Study; $N = 370$)

Background Characteristic	*n* (%) or Mean (SD)	Range
Sex (female)	162 (43.8%)	
Age, mean (SD)	52.4 (6.7)	24–67
Race/ethnicity (African American)	353 (95.4%)	
Education (high school or higher)	193 (52.2%)	
Monthly income ($1000 or more)	96 (25.9%)	
Current drug use (heroin, cocaine, or stimulants)	148 (40.0%)	
Depression (10+ on CES-D)	136 (36.8%)	
Pain interference with activities		
None	88 (23.8%)	
A little/moderately	193 (52.2%)	
Quite a bit/extremely	89 (24.1%)	
Life satisfaction, mean (SD)	83.9 (18.8)	10–110
Need help with personal care (e.g., bathing)	124 (33.5%)	
Limitations to physical functioning, mean (SD)	1.7 (1.3)	0–4
Memory problems	1.2 (1.1)	0–4
Had family arguments over care decisions	109 (29.5)	

SD = standard deviation; CES-D = Center for Epidemiologic Studies Depression Scale.

Table 2

Adjusted Odds Ratios of Independent Variables Associated With Talking to Family or Friends About Advance Care Planning ($N = 368$)

Variables	Adjusted Odds Ratios	Confidence Interval	*P*-value
Sex (female)	2.22	1.40, 3.54	0.001
Age	0.98	0.94, 1.01	0.214
Race/ethnicity (African American)	0.99	0.34, 2.95	0.995
Education level (high school or greater)	1.41	0.88, 2.26	0.152
Drug use	0.97	0.60, 1.55	0.894
Depression (CES-D ≥ 10)	1.35	0.78, 2.33	0.290
Pain interference with activities			
None (reference)	1.00		
A little/moderately	1.60	0.89, 2.87	0.119
Quite a bit/extremely	2.09	1.02, 4.28	0.045
Life satisfaction	1.02	1.01, 1.04	0.002
Need help with personal care (e.g., bathing)	1.63	1.07, 2.49	0.023
Memory problems	0.88	0.69, 1.11	0.270
Previous family arguments over care decisions	2.80	1.67, 4.71	<0.001

CES-D = Center for Epidemiologic Studies Depression Scale.

Discussion

The present study sought to assess the effect of health status variables (chronic pain, personal care, memory problems, depression), demographic variables (sex, age, education level, drug use), life satisfaction, and prior family disagreements over health care decisions on the likelihood of patients discussing ACP with their family or friends, among a sample of PLWHAs who currently or formerly used drugs, the majority of whom were socioeconomically disadvantaged African Americans. Only slightly more than half of the respondents had talked to their close loved ones about ACP, despite guidelines recommending PLWHAs discuss ACP with their family particularly if they are older or have significant comorbidities.[19]

Patients with greater chronic pain were more likely to discuss ACP with their loved ones; prior results from the Affirm Care study have shown that patients with chronic pain are also more likely to discuss ACP with their physicians.[20] One explanation is that PLWHAs with the most severe chronic pain are in the later stages of their illness or have significant comorbidities, prompting discussions of ACP with their loved ones.

In a similar light, PLWHAs who required assistance with personal care in the previous year, such as eating or bathing, had greater odds of having discussed advance care planning with their friends or family. These PLWHAs may be in a more advanced stage of illness or more aware of their mortality, making ACP more salient for them.

Although our results showed an association between greater life satisfaction and greater odds of having had ACP discussions with family or friends that was statistically significant, with an OR of 1.02, it is unclear that this is a clinically meaningful finding.

Previous studies have shown that African American patients are more inclined to favor family-centered rather than individual-centered ACP, particularly with a "trusted" loved one.[17,21] Our study revealed that patients with families who experienced prior disagreements about health care decisions were more likely to be proactive about discussing their own ACP with their families, consistent with previous studies.[7,8]

Furthermore, females were more likely to discuss ACP with their family or friends. Several possible explanations have been proposed; women may have closer, more open relationships with others, especially those in their social network. These close relationships may provide more opportunities for discussion of issues that are typically difficult to approach, such as ACP. Interestingly, these conversations may not always lead to completion of advance directives, as rates of advance directive completion have been shown to be equivalent between African American females and males.[17]

Prior studies have indicated that interventions to discuss ACP with PLWHAs leads to improved ACP completion and documentation.[22] Data from the SPIRIT trial, an ACP intervention in dialysis patients, suggest that the ACP intervention led to increased goal-concordant decision-making, surrogate decision-making confidence, and reduced decisional conflict. In addition, the intervention led to reduced surrogate bereavement depressive symptoms for African American patients (but not whites).[23,24] Further research is needed to investigate whether ACP interventions in PLWHAs translates into differences in actual end-of-life care delivered.

In terms of limitations, this study uses cross-sectional baseline data, which precludes making causal claims or establishing temporality among the variables. In addition, advance care planning is a multifaceted construct that could mean different things to different people (writing an advance directive versus talking to friends or family informally); future research could formally measure the complete informal and formal advance care planning of patients with their families. Patients in this population are at high risk for social isolation and poor caregiver support; although 90% of our patients reported support from a family member/caregiver, it is possible that for the remaining patients, they did not report receiving help with personal care because there was no one available to provide such support. Finally, generalizability is a limitation, given that this sample of PLWHAs was recruited primarily from a population that is actively engaged in treatment at an academic hospital.

In summary, these results suggest that timely ACP for PLWHAs still occurs too infrequently. Patients with higher levels of chronic pain, or those who require assistance with personal care, both of which may be a surrogate for more advanced disease, are more likely to discuss ACP with loved ones. Patients with prior family history of disagreements over other family members' health care decisions were more proactive in discussing their own ACP with family. Finally, females were more likely to discuss ACP with family. Interventions to improve end-of-life care planning should take into account factors that may influence a patient's likelihood to discuss ACP, including chronic pain, challenges encountered with personal care, prior family disagreements over health care decisions, and life satisfaction.

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The authors declare no conflicts of interest.

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