End-of-Life Discussions and Preferences Among Persons With HIV

Neil S. Wenger, MD
David E. Kanouse, PhD
Rebecca L. Collins, PhD
Honghu Liu, PhD
Mark A. Schuster, MD, PhD
Allen L. Gifford, MD
Samuel A. Bozzette, MD, PhD
Martin F. Shapiro, MD, PhD

WITH THE DRAMATIC IMPROVEMENT IN TREATMENT MODES THAT ARE AVAILABLE FOR HUMAN IMMUNODEFICIENCY VIRUS (HIV) INFECTION AND THE DECREASE IN MORTALITY AMONG PERSONS WITH HIV, LESS ATTENTION HAS BEEN FOCUSED ON END-OF-LIFE TREATMENT DECISIONS FOR THESE INDIVIDUALS. HOWEVER, HIV REMAINS A PROMINENT CAUSE OF DEATH AMONG US INDIVIDUALS AGED 18 TO 35 YEARS, AND DESPITE THE DROP IN MORTALITY ACROSS THE AGE SPECTRUM, NEW TREATMENT MODES FOR MANY PATIENTS WITH HIV MAY YIELD LONG-TERM SURVIVAL WITH SEVERE DISABILITY OR INCAPACITY. ADDITIONALLY, HIV DEMOGRAPHICS ARE SHIFTING TOWARD NONWHITES AND INTRAVENOUS DRUG USERS, AND LESS EDUCATED INDIVIDUALS NEED ADVANCE CARE PLANNING.

Prior studies demonstrated difficulties in decision making for HIV-infected patients, including lack of identification of surrogate decision makers and decision making with inadequate information. These studies showed that despite the risk of complicated decision making at the end of life, most persons with HIV had not completed advance directives and most had not discussed end-of-life issues with their physicians, even when they desired such discussions. Recent studies have focused on HIV-infected patients’ interest in and some practitioners’ willingness to provide euthanasia. As it becomes a chronic disease, HIV infection will require patients and their health care practitioners to discuss prognosis and make decisions about care goals over an extended time. Yet, few researchers have investigated whether communication about prefer-
ences and decision making has progressed with evolution of therapeutic options. Indeed, increased optimism about HIV treatment may make it easier to avoid planning for future clinical deterioration and death. Furthermore, most studies of advance directives and end-of-life preferences have focused on small convenience samples. To gain an understanding of behaviors and preferences regarding end-of-life care among HIV-infected persons and to identify areas that need improvement, we asked a nationally representative sample of HIV-infected patients about end-of-life discussions with physicians, advance directive use, and willingness to tolerate future adverse health states. Because these questions were included in a broad survey of HIV-infected persons’ characteristics and care, we were able to evaluate in depth the factors associated with end-of-life preferences and behaviors.

**METHODS**

The HIV Cost and Services Utilization Study (HCSUS) cohort is a nationally representative probability sample of HIV-infected adults receiving care in the contiguous United States. The reference population consists of persons aged at least 18 years with known HIV infection who made at least 1 visit for regular or ongoing care to a nonmilitary, nonprison medical care provider other than an emergency department in early 1996. The HCSUS used a multistage design in which geographic areas, health care practitioners, and patients were sampled. Of the 4402 eligible participants sampled, 2864 (71%) completed the interview used in this analysis. The overall coverage rate (the ratio of the population directly represented to the population that would have been directly represented if we had complete responses at all levels) is about 68%. Data were weighted to construct a representative sample.

Most interviews were conducted in person using computer-assisted personal interviewing, with 9% completed by telephone. Interviews began in January 1996 and ended 15 months later. Patients were approached after their health care practitioners obtained their permission. The study protocol was approved by the RAND (Santa Monica, Calif) and local institutional review boards.

**Data Collection**

In addition to gathering data on patients’ demographic characteristics and clinical circumstances (contained in the HCSUS baseline interview), we asked about their preferences and communication about end-of-life issues, their willingness to tolerate future health states, and whether they had completed an advance directive. Communication with one’s practitioner about end-of-life care was addressed by 3 questions: “Did your doctor or nurse ever discuss with you...” “... how you feel about the use of machines and other medical treatments to prolong your life when there is no chance of you getting better?” “... whether you want to be resuscitated if you stopped breathing?” and “... living wills?” These items were collapsed into a dichotomous variable indicating any end-of-life communication between patient and practitioner.

Respondents were asked about their preferences for aggressiveness of care: “If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means having more pain and discomfort, or would you prefer a plan of care that focuses on relieving pain and discomfort as much as possible, even if it means not living as long?” Response options included “definitely extend life as much as possible,” “probably extend life as much as possible,” “probably relieve pain and discomfort as much as possible, and “definitely relieve pain and discomfort as much as possible.” This item was previously shown to have adequate test-retest reliability. In addition, respondents were queried about willingness to tolerate future adverse health states with 5 items modified from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) that asked whether they “would prefer to live as long as possible in this condition, even if you would not get any better, or if you would prefer to die” than to live permanently (1) in pain, (2) attached to a ventilator, (3) fed through a tube into your stomach, (4) unconscious or in a coma, (5) forgetting or being confused. Patients’ responses to the 5 “willingness-to-tolerate” items were combined into a willingness-to-tolerate index (internal consistency=0.77) ranging from 0 (not willing to tolerate any) to 5 (willing to tolerate all).

Based on prior literature and clinical experience, 4 groups of covariates were hypothesized to be related to these end-of-life variables: demographics, clinical characteristics, psychosocial variables, and practitioner characteristics. Demographics included age (18-35, 36-49, or ≥50 years), sex, race/ethnicity (white, black, Latino, or other), HIV exposure group (men who have sex with men, intravenous drug users, men who have sex with men/intervenous drug users, heterosexual contact, or other), education level (less than high school graduate, high school graduate, completed some college, or college graduate), whether there were children in the household, health insurance status (private, Medicare, Medicaid, or none), region (Northeast, South, Midwest, or West) and employment (employed, unemployed, disabled [and, thus, unable to work], or not working [and not seeking employment]). Clinical variables included lowest CD4 cell count (≥50, 501-200, 201-500, or >500/μL), HIV stage (asymptomatic, symptomatic, or diagnosed as having acquired immunodeficiency syndrome [AIDS]), symptom intensity score (grouped in tertiles), current heavy alcohol use or drug dependence in the past year, scales assessing physical and mental health-related quality of life (grouped in tertiles), and number of hospitalizations in the past 6 months (0, 1, or >1). Psychosocial variables (all measured in tertiles) included scales measuring so-

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special support (3 items; α = .72), positive coping (4 items; α = .57), denial (2 items in which a higher score indicates less denial), emotional well-being (5 items; α = .89), and whether the respondent desired to participate in treatment decisions (2 items; α = .76). Practitioner-related variables included regular practitioner type (physician, nurse, or none), length of the relationship (<1, 1-3, or >3 years), a 2-item scale of respondents’ trust in their practitioner (complete or less than complete), health care practice setting (public, private, small, or other) and teaching or non-teaching site.

For each respondent, an analytic weight was constructed to adjust the sample to represent the entire reference population. Each analytic weight can be interpreted as the number of persons in the underlying population represented by that respondent. Each weight is the product of the sampling probabilities, a multiplicity weight, which adjusts for patients who could have entered the sample through visits to multiple practitioners, and a nonresponse weight, which adjusts for differences in rates of cooperation.15

Analysis
The principal dependent variables in the analysis were communication with practitioner about end-of-life issues, completion of an advance directive, aggressiveness of care preference, and willingness to tolerate future permanent adverse health states. We evaluated the relationship between each of these dependent variables and respondent demographic factors, clinical factors, psychosocial variables, and practitioner variables. The relationships among dependent variables also were explored. Significance testing, with statistical significance at P < .01, was performed by regression and χ² tests for bivariate analyses. All analyses incorporated sample weights to estimate population prevalence parameters.

Multivariable logistic regression models were constructed to evaluate the independent relationship of respondent demographics, clinical factors, psychosocial variables, and practitioner variables with end-of-life communication with one’s practitioner and whether the patient had an advance directive. The advance directive model also included whether the practitioner discussed advance directives with the patient and both models included the willingness-to-tolerate index. Multivariable linear regression was performed on the aggressiveness of care preference score (ranging from 1 [definitely relieve pain] to 4 [definitely extend life]) and the willingness-to-tolerate index. Respondent demographics, clinical factors, psychosocial variables, and practitioner variables served as the predictor variables for these models. Statistical analyses were performed using SAS (Cary, NC) and Stata (College Station, Tex) statistical software.

RESULTS
The HCSUS sample of 2864 patients represents 231400 persons in the United States (95% confidence interval [CI], 162800-300000)16; 98% answered the questions about end-of-life communication and preferences. Most of the population had symptomatic HIV disease; 59% had AIDS and only 10% had asymptomatic disease. Seventy-seven percent of the HCSUS population was male, 89% were younger than 50 years, and 52% had a high school education or less. Forty-nine percent of the population was white, 33% was black, and 15% was Latino. Thirty-seven percent were employed; 46% had an annual household income below $10000; and 32% had private health insurance, 19% had Medicare, and 39% had Medicaid alone.16 Slightly more than half of the physicians caring for these patients were primary care physicians and 40% were infectious disease specialists. Three quarters described themselves as HIV specialists.

End-of-Life Communication With Practitioner
Thirty-five percent of respondents reported that they had discussed use of life-sustaining machines with their practitioner, 32% discussed resuscitation, and 44% discussed living wills. Patients who had one such discussion tended to have others; 26% discussed all 3 topics with their practitioner and 9% discussed 2 topics. Fifty percent discussed none of these topics with their practitioner.

In bivariate analysis, white patients were more likely to discuss end-of-life issues, as were patients with Medicare insurance and disabled patients. Patients with more advanced disease were more likely to have had a discussion with their practitioner. Discussions were more prevalent among patients with more symptoms, more hospitalizations in the last 6 months, and worse health status. A longer relationship with and greater trust in one’s practitioner were associated with more communication (See online appendix at http://jama.ama-assn.org/issues/v285n22/abs/joc02199.html).

In the multivariable analysis predicting any discussion (TABLE 1), physicians communicated less with black (odds ratio [OR], 0.57; 95% CI, 0.39-0.83) and Latino (OR, 0.74; 95% CI, 0.55-0.98) patients about end-of-life issues compared with white patients. Women communicated more with practitioners (OR, 1.39; 95% CI, 1.05-1.84), as did patients who had children in their household (OR, 1.53; 95% CI, 1.12-2.10). Patients whose route of HIV infection was via intravenous drug use (OR, 0.64; 95% CI, 0.45-0.89) and those with less education were less likely to have discussions, but age and employment status were not associated with end-of-life communication.

Patients with an AIDS diagnosis (OR, 1.72; 95% CI, 1.05-2.83) and lowest CD4 cell counts of 50/µL or less were more likely to have discussed end-of-life issues with their practitioner. Patients who were admitted to the hospital more than once in the past 6 months had more than twice the odds of discussion compared with those who had not been hospitalized. However, health-related quality of life and emotional well-being were unrelated to discussions.
Practitioner type and practice setting were not important predictors of discussion; however, patients with more trust in their practitioner were more likely to have had an end-of-life discussion. Compared with patients who had had a relationship with their practitioner for less than 1 year, those whose relationships exceeded 3 years were more likely to have had a discussion (OR, 1.40; 95% CI, 1.00-1.80). Patients who desired a greater role in medical decision making, those who were less willing to tolerate adverse health states, and those who coped more positively were more likely to report end-of-life discussions. Denial and perceived social support were unrelated to discussion.

**Advance Directives**

Thirty-eight percent of respondents reported that they had completed an advance directive. In bivariate analyses, older patients, men, white patients, and those with more education and higher income were more likely to have completed an advance directive. Sicker patients also were more likely to have an advance directive (Online Appendix).

In the multivariable logistic regression model (Table 1), the most important predictor of advance directive completion was respondent report that the practitioner had discussed the topic (OR, 5.82; 95% CI, 4.50-7.52). Black and Latino patients had about half the odds of completing an advance directive, but disabled patients did so more often (OR, 1.38; 95% CI, 1.06-1.80). Education level, health insurance, age, and sex were not significantly associated with having an advance directive. After adjusting for covariates, most clinical variables also were not associated with having an advance directive. Longer patient-practitioner relationships were associated with having an advance directive (Table 1).

<table>
<thead>
<tr>
<th>Table 1. Multivariable Analysis of Factors Associated With End-of-Life Communication and Having an Advance Directive*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Odds Ratio (95% Confidence Interval)</strong></td>
</tr>
<tr>
<td><strong>Communicated About End of Life</strong></td>
</tr>
<tr>
<td><strong>Completed an Advance Directive</strong></td>
</tr>
<tr>
<td><strong>Age, y</strong></td>
</tr>
<tr>
<td>18-34 Referent Referent</td>
</tr>
<tr>
<td>35-49 1.09 (0.89-1.33) 1.25 (0.93-1.67)</td>
</tr>
<tr>
<td>≥50 1.16 (0.77-1.75) 1.29 (0.87-1.91)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
</tr>
<tr>
<td>Male Referent Referent</td>
</tr>
<tr>
<td>Female 1.39 (1.05-1.84) 1.16 (0.90-1.67)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
</tr>
<tr>
<td>White Referent Referent</td>
</tr>
<tr>
<td>Black 0.57 (0.39-0.83) 0.53 (0.43-0.65)</td>
</tr>
<tr>
<td>Latino 0.74 (0.55-0.98) 0.43 (0.30-0.62)</td>
</tr>
<tr>
<td>Other 0.84 (0.53-1.33) 0.88 (0.50-1.55)</td>
</tr>
<tr>
<td><strong>HIV exposure group</strong></td>
</tr>
<tr>
<td>MSM Referent Referent</td>
</tr>
<tr>
<td>IVD 0.64 (0.45-0.89) 0.64 (0.41-0.91)</td>
</tr>
<tr>
<td>MSM/IVD 1.42 (0.99-2.01) 0.62 (0.41-1.01)</td>
</tr>
<tr>
<td>Heterosexual contact 0.90 (0.62-1.31) 0.70 (0.47-1.06)</td>
</tr>
<tr>
<td>Other 0.79 (0.50-1.25) 0.71 (0.43-1.17)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>Less than high school graduate Referent Referent</td>
</tr>
<tr>
<td>High school graduate 1.07 (0.80-1.41) 0.99 (0.68-1.48)</td>
</tr>
<tr>
<td>Some college 1.44 (1.05-1.97) 1.02 (0.60-1.74)</td>
</tr>
<tr>
<td>College graduate 1.37 (1.02-1.85) 1.58 (0.96-2.60)</td>
</tr>
<tr>
<td><strong>Children in household</strong></td>
</tr>
<tr>
<td>No Referent Referent</td>
</tr>
<tr>
<td>Yes 1.53 (1.12-2.10) 1.00 (0.69-1.43)</td>
</tr>
<tr>
<td><strong>Health insurance</strong></td>
</tr>
<tr>
<td>None 0.95 (0.66-1.35) 0.85 (0.51-1.43)</td>
</tr>
<tr>
<td>Medicaid 1.31 (0.83-2.07) 0.94 (0.57-1.58)</td>
</tr>
<tr>
<td>Private 1.32 (0.97-1.80) 1.00 (0.61-1.68)</td>
</tr>
<tr>
<td>Medicare 2.09 (1.30-3.37) 1.12 (0.55-2.27)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
</tr>
<tr>
<td>Employed Referent Referent</td>
</tr>
<tr>
<td>Disabled 1.07 (0.74-1.55) 1.38 (1.06-1.80)</td>
</tr>
<tr>
<td>Unemployed 1.06 (0.67-1.68) 1.12 (0.73-1.71)</td>
</tr>
<tr>
<td>Not working 0.76 (0.56-1.02) 1.10 (0.73-1.66)</td>
</tr>
<tr>
<td><strong>HIV stage</strong></td>
</tr>
<tr>
<td>Asymptomatic Referent Referent</td>
</tr>
<tr>
<td>Symptomatic 0.99 (0.62-1.59) 1.26 (0.75-2.11)</td>
</tr>
<tr>
<td>AIDS 1.72 (1.05-2.83) 1.66 (0.86-3.22)</td>
</tr>
<tr>
<td><strong>Lowest CD4 cell count, µL</strong></td>
</tr>
<tr>
<td>&lt;50 1.80 (1.23-2.63) 1.07 (0.63-1.83)</td>
</tr>
<tr>
<td>50-200 1.28 (0.93-1.77) 0.94 (0.55-1.62)</td>
</tr>
<tr>
<td>201-500 1.15 (0.82-1.60) 1.01 (0.58-1.75)</td>
</tr>
<tr>
<td>&gt;500 Referent Referent</td>
</tr>
<tr>
<td><strong>Hospitalizations in previous 6 mo</strong></td>
</tr>
<tr>
<td>0 Referent Referent</td>
</tr>
<tr>
<td>1 1.07 (0.79-1.43) 1.03 (0.82-1.29)</td>
</tr>
<tr>
<td>&gt;1 2.26 (1.55-3.29) 1.15 (0.77-1.70)</td>
</tr>
<tr>
<td><strong>Physical health</strong></td>
</tr>
<tr>
<td>Lowest tertile 1.17 (0.76-1.82) 1.50 (1.07-2.11)</td>
</tr>
<tr>
<td>Middle tertile 1.17 (0.94-1.46) 1.44 (1.08-1.92)</td>
</tr>
<tr>
<td>Highest tertile Referent Referent</td>
</tr>
</tbody>
</table>

(Continued on next page)
tive compared with those who had had relationships of less than 1 year.

Aggressiveness of Care and Willingness to Tolerate

When asked whether they would prefer life-extending care or care focused on comfort, HCSUS respondents expressed widely divergent opinions. Thirty percent of respondents stated that they would definitely desire to extend life and 14% probably would want to extend life, even if it meant having more discomfort. Thirty-two percent said they would definitely desire to relieve pain, even if it meant having more discomfort. Thirty-two percent said they would definitely desire to relieve pain, even if it meant having more discomfort.

Concerning whether they would want to remain alive in adverse health states, 91% of respondents reported that they would prefer to die than to live permanently in a coma. Eighty-seven percent said they would definitely desire to relieve pain, even if it meant having more comfort. In adverse health states, 91% of respondents reported that they would prefer to die than to live permanently in a coma. Eighty-seven percent said they would definitely desire to relieve pain, even if it meant having more comfort.

In bivariate analyses, respondents' aggressiveness of care preference was related to willingness to live permanently in future adverse health states. The willingness-to-tolerate index demonstrated a gradient from a mean of 1.69 tolerable states among patients who definitely desired to extend life to a mean of 0.74 tolerable states among patients who definitely desired to relieve pain (Table 2). Patients who desired to relieve pain reported more communication about end-of-life issues with their practitioners and were more likely to have completed an advance directive; 54% of respondents who definitely desired to relieve pain reported having an end-of-life discussion, whereas a discussion occurred with 44% of those who definitely desired to extend life. Patients with a less aggressive care preference were more likely to have completed an advance directive (Table 2).

The multivariable models of factors associated with patients' aggressiveness of care preference and willingness-to-tolerate index score are presented in Table 3. Demographic factors were independently associated with these preferences, whereas clinical variables, psychosocial variables, and descriptors of the patient-practitioner relationship tended to be unrelated.

Older patients were less willing to tolerate future adverse health states; however, age was not significantly related to aggressiveness of care preference. Women were less likely to desire life extension and were less willing to tolerate future adverse health states. Black patients were willing to tolerate more adverse health states, but race/ethnicity was not related to aggressiveness of care preference. Human immunodeficiency vi...
The data in this study reveal that there has been little improvement in the proportion of HIV-infected individuals who complete advance directives compared with earlier studies of more limited populations in the late 1980s and early 1990s.\(^2,3\) Haas et al\(^5\) showed that among those who had not discussed end-of-life care with their practitioners, 72% desired to do so. Demographic characteristics were not associated with desire for discussion in that study\(^5\) or in studies conducted in non–HIV-positive samples.\(^21,22\) As demonstrated in a recent smaller study,\(^23\) the prevalence of discussion among individuals with HIV infection has not increased, suggesting a persistent unmet need for patient-practitioner communication about end-of-life issues. Black and Latino race/ethnicity and low education level are associated with lack of communication and not completing an advance directive. Consistent with prior studies,\(^22,24\) clinical need was associated with end-of-life discussions and completing advance directives. The strongest facilitator of end-of-life discussions was having 2 or more hospital admissions in the past 6 months. This may be simply an indicator of recent illness that stimulates discussion about end-of-life issues. In contrast, hospitalization may present a point in illness conducive to discussion of prognosis and end-of-life care.

The patient-physician relationship plays a large role in end-of-life communication, as described in a qualitative analysis of patients with HIV.\(^25\) In this study, patients with longer relationships with their physician and those with more trust were more likely to have had end-of-life discussions. Patients who desired a greater role in decision making also reported more discussions. Ongoing relationships infused with trust may be an important promoter of end-of-life discussion. Of course, direction regarding trust cannot be discerned from these data; increased trust in practitioners might be a product of end-of-life discussions and similar communication.\(^26\)

It should be noted that even after adjusting for trust, willingness to tolerate adverse health states, and characteristics of the patient-practitioner relationship, race/ethnicity remained a strong predictor of end-of-life discussion. These findings suggest that attention to trust and the patient-practitioner relationship alone will not overcome barriers to end-of-life discussion and decisions among ethnically diverse groups. Re-

<table>
<thead>
<tr>
<th>Table 2. Relationship of Aggressiveness of Care Preference With End-of-Life Discussions With Practitioner, Advance Directive Completion, and Willingness to Live in an Adverse Health State*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggressiveness of Care Preference</td>
</tr>
<tr>
<td>Discussed with practitioner Machines</td>
</tr>
<tr>
<td>Resuscitation</td>
</tr>
<tr>
<td>Advance directives</td>
</tr>
<tr>
<td>Any end-of-life issue</td>
</tr>
<tr>
<td>Completed advance directive</td>
</tr>
<tr>
<td>Willing to live permanently In coma</td>
</tr>
<tr>
<td>In pain</td>
</tr>
<tr>
<td>Attached to ventilator</td>
</tr>
<tr>
<td>Tube fed</td>
</tr>
<tr>
<td>Confused</td>
</tr>
<tr>
<td>Willingness-to-tolerate index, mean</td>
</tr>
</tbody>
</table>

*Data are percentage of respondents except for willingness-to-tolerate index. For all factors, \(P<.001\) for difference across levels of aggressiveness of care preference.
Table 3. Multivariable Analysis of Factors Associated With Aggressiveness of Care Preference and Willingness to Tolerate Adverse Health States

<table>
<thead>
<tr>
<th>β Coefficient (95% Confidence Interval)</th>
<th>Aggressiveness of Care Preference</th>
<th>Willingness to Tolerate Adverse Health States</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–34</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>35–49</td>
<td>–0.05 (–0.18 to 0.07)</td>
<td>–0.19 (–0.25 to 0.05)</td>
</tr>
<tr>
<td>≥50</td>
<td>–0.15 (–0.40 to 0.10)</td>
<td>–0.43 (–0.67 to –0.18)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Female</td>
<td>–0.38 (–0.62 to –0.15)</td>
<td>–0.46 (–0.74 to –0.18)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Black</td>
<td>0.14 (–0.07 to 0.34)</td>
<td>0.47 (0.30 to 0.64)</td>
</tr>
<tr>
<td>Latino</td>
<td>0.14 (–0.06 to 0.34)</td>
<td>0 (–0.19 to 0.19)</td>
</tr>
<tr>
<td>Other</td>
<td>0.13 (–0.23 to 0.26)</td>
<td>0.04 (–0.28 to 0.36)</td>
</tr>
<tr>
<td>HIV exposure group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>IVD</td>
<td>0.31 (0.10 to 0.52)</td>
<td>0.33 (0.02 to 0.64)</td>
</tr>
<tr>
<td>MSM/IVD</td>
<td>–0.17 (–0.32 to –0.01)</td>
<td>0.06 (–0.14 to 0.25)</td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>0.54 (0.31 to 0.78)</td>
<td>0.40 (0.14 to 0.67)</td>
</tr>
<tr>
<td>Other</td>
<td>0.25 (0.06 to 0.43)</td>
<td>0.32 (0.48 to 0.59)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school graduate</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>High school graduate</td>
<td>–0.01 (–0.12 to 0.09)</td>
<td>–0.13 (–0.26 to 0)</td>
</tr>
<tr>
<td>Some college</td>
<td>–0.05 (–0.19 to 0.09)</td>
<td>0.09 (–0.10 to 0.27)</td>
</tr>
<tr>
<td>College graduate</td>
<td>0 (–0.20 to 0.20)</td>
<td>0.15 (–0.03 to 0.33)</td>
</tr>
<tr>
<td>Children in household</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Yes</td>
<td>0.23 (0.05 to 0.42)</td>
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*HIV indicates human immunodeficiency virus; MSM, men who have sex with men; and IVD, intravenous drug user. Models include the following additional variables: employment, region of country, lowest CD4 cell count, HIV stage, hospitalizations, physical and mental health, symptom intensity score, emotional well-being, social support, coping, denial, length of relationship with practitioner, teaching hospital practice setting, and trust in practitioner. None of these independent variables was significantly associated with the dependent variable in either model. The dependent variable in the aggressiveness of care preference model ranges from 1 (definitely prefers to relieve pain) to 4 (definitely prefers to extend life). The dependent variable in the willingness-to-tolerate model is the mean number of tolerable adverse health states ranging from 0 to 5. For the aggressiveness of care model, F35,2 = 201.2 (P = .005) and for the willingness-to-tolerate model, F35,2 = 23.1 (P = .04).
life issues with one’s practitioner. Thus, a default posture not to provide aggressive care in these clinical situations would override the preferences of many of the patients least likely to communicate their wishes. As an alternative, this study shows that information about care preferences can be elicited prospectively. The data presented here not only emphasize the groups who are at risk of poor communication about these issues but also suggest that clinicians can play a role in improving communication with these individuals.

This study has several limitations. Decision making toward the end of life is often most problematic for the patient newly entering into the health care system; the HCSUS sample includes only persons in care for HIV infection. In addition, the findings that we present are from a cross-sectional data collection. As such, the relationships between variables, such as that of patient-practitioner communication with advance directive completion, must be considered associations rather than causal. Interventions are needed to evaluate whether practitioner communication can increase advance directive completion and ultimately improve end-of-life care. The focus of this study is on communication and preferences in guiding end-of-life care. These cover only 2 of the domains of quality end-of-life care.29,30

As HIV care enters its third decade, attention is focused on novel therapeutic approaches and new treatment modes. Providers of HIV care should not forget that despite the renaissance in therapeutics, many patients will die of HIV. Health care practitioners have an important opportunity to encourage discussions about end-of-life care preferences and surrogate decision making. This is particularly important for the marginalized groups that make up an increasing proportion of the HIV-infected population and who are least likely to have engaged in advance care planning.


Funding/Support: The HCSUS was conducted under a cooperative agreement U19HS058578 to Drs Bozette and Shapiro between RAND and the Agency for Healthcare Quality and Research. Dr Wenger was a Soros Foundation Project on Death in America Faculty Scholar during this project.

Acknowledgment: We acknowledge Victor Gonzalez for his technical assistance in the preparation of the manuscript.

REFERENCES

# Online Appendix. Bivariate Relationship of Demographic, Clinical, Psychosocial, and Practitioner Factors With End-of-Life Discussions and Completion of an Advance Directive

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(Continued)
Online Appendix. Bivariate Relationship of Demographic, Clinical, Psychosocial, and Practitioner Factors With End-of-Life Discussions and Completion of an Advance Directive (cont)*

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<th>Metropolitan Statistical Area size</th>
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<th>Discussed Advance Directive</th>
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| Clinical                          |                    |                          |                            |               |                     |
| HIV stage                         |                    |                          |                            |               |                     |
| Asymptomatic                      | 19                 | 18                       | 28                         | 33            | 24                  |
| Symptomatic                       | 28                 | 25                       | 36                         | 41            | 30                  |
| AIDS                              | 49                 | 47                       | 60                         | 67            | 52                  |
| Lowest CD4 cell count, /µL        |                    |                          |                            |               |                     |
| <50                               | 51                 | 49                       | 62                         | 69            | 52                  |
| 51-200                            | 37                 | 33                       | 45                         | 51            | 39                  |
| 201-500                           | 28                 | 25                       | 36                         | 40            | 32                  |
| >500                              | 17                 | 17                       | 33                         | 37            | 26                  |
| Symptom intensity index           |                    |                          |                            |               |                     |
| Lowest tertile                    | 28                 | 25                       | 37                         | 42            | 32                  |
| Middle tertile                    | 35                 | 33                       | 45                         | 50            | 40                  |
| Highest tertile                   | 44                 | 41                       | 54                         | 60            | 44                  |
| Hospitalizations in previous 6 mo |                    |                          |                            |               |                     |
| 0                                 | 32                 | 29                       | 41                         | 46            | 36                  |
| 1                                 | 42                 | 41                       | 54                         | 60            | 44                  |
| >1                                | 59                 | 58                       | 68                         | 76            | 54                  |
| Physical health                   |                    |                          |                            |               |                     |
| Lowest tertile                    | 43                 | 40                       | 54                         | 60            | 43                  |
| Middle tertile                    | 38                 | 36                       | 46                         | 52            | 40                  |
| Highest tertile                   | 25                 | 23                       | 35                         | 40            | 32                  |
| Mental health                     |                    |                          |                            |               |                     |
| Lowest tertile                    | 37                 | 34                       | 46                         | 52            | 37                  |
| Middle tertile                    | 37                 | 34                       | 48                         | 53            | 39                  |
| Highest tertile                   | 32                 | 29                       | 40                         | 45            | 38                  |
| Drug or heavy alcohol use         |                    |                          |                            |               |                     |
| Yes                               | 36                 | 35                       | 47                         | 53            | 33                  |
| No                                | 35                 | 32                       | 44                         | 49            | 39                  |

| Psychosocial                      |                    |                          |                            |               |                     |
| Positive coping                   |                    |                          |                            |               |                     |
| Lowest tertile                    | 29                 | 27                       | 39                         | 43            | 32                  |
| Middle tertile                    | 33                 | 30                       | 42                         | 48            | 37                  |
| Highest tertile                   | 42                 | 40                       | 52                         | 58            | 44                  |
| Denial                            |                    |                          |                            |               |                     |
| Lowest tertile                    | 35                 | 32                       | 44                         | 50            | 32                  |
| Middle tertile                    | 38                 | 34                       | 47                         | 53            | 39                  |
| Highest tertile                   | 33                 | 32                       | 44                         | 48            | 43                  |
| Emotional well-being              |                    |                          |                            |               |                     |
| Lowest tertile                    | 36                 | 34                       | 45                         | 52            | 38                  |
| Middle tertile                    | 37                 | 34                       | 47                         | 52            | 37                  |
| Highest tertile                   | 32                 | 30                       | 41                         | 46            | 40                  |
| Total perceived support           |                    |                          |                            |               |                     |
| Lowest tertile                    | 33                 | 30                       | 41                         | 47            | 33                  |
| Middle tertile                    | 34                 | 31                       | 45                         | 50            | 37                  |
| Highest tertile                   | 38                 | 36                       | 48                         | 53            | 44                  |
| Decision-making desire            |                    |                          |                            |               |                     |
| Lowest tertile                    | 33                 | 29                       | 40                         | 46            | 30                  |
| Middle tertile                    | 34                 | 33                       | 45                         | 50            | 38                  |
| Highest tertile                   | 39                 | 35                       | 50                         | 54            | 46                  |

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Online Appendix. Bivariate Relationship of Demographic, Clinical, Psychosocial, and Practitioner Factors With End-of-Life Discussions and Completion of and Advance Directive (cont)*

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*HIV indicates human immunodeficiency virus; MSM, men who have sex with men; IVD, intravenous drug user; and AIDS, acquired immunodeficiency syndrome. Data in bold and data in bold and italic indicate P <.01 and P <.001, respectively, for comparison between all levels of independent variable and dichotomous dependent variable.