The Effect of End-of-Life Discussions on Perceived Quality of Care and Health Status Among Patients With COPD

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Background: Despite strong preferences for discussions about end-of-life care, patients with COPD do not often have these discussions with their providers. Our objective was to determine whether patients who reported having end-of-life discussions also reported higher perceived markers of quality of care and health status.

Methods: A cross-sectional study of data collected at baseline for a trial to improve the occurrence and quality of end-of-life communication in patients with COPD was conducted. The primary exposure was self-reported acknowledgment of having discussions about end-of-life planning with their physicians. The primary outcome measures were patient-reported quality of care and satisfaction with care, which were dichotomized as best imaginable quality of care vs other ratings of quality and highest satisfaction vs other ratings of satisfaction. We adjusted for confounding factors, including patient and provider characteristics, using logistic regression clustered by provider.

Results: Three hundred seventy-six patients were enrolled, of whom 55 (14.6%) reported having end-of-life discussions. Individuals who reported having end-of-life discussions with their physicians were significantly more likely to rate their quality of care as the best imaginable (OR, 2.07; 95% CI, 1.05-4.09) and to be very satisfied with their medical care (OR, 1.98; 95% CI, 1.10-3.55). Discussions were more likely to have occurred among patients with worse health status as measured by St. George Respiratory Questionnaire total and impact scores.

Conclusions: Patients who reported having end-of-life care discussions with their physicians had higher perceived quality of care and satisfaction with their physicians. Discussing end-of-life care with patients who have COPD may improve their perceived overall quality of and satisfaction with care.

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Abbreviations: ATS = American Thoracic Society; SGRQ = St. George Respiratory Questionnaire

With few therapeutic options available to prolong survival, COPD is projected to become the third-leading cause of death by 2020.¹ Despite well-described patient preferences for discussions about care at the end of life, meaningful conversations between

patients and their providers have not yet become part of routine care.^{2,3} As a result, patients with COPD are more likely than those with lung cancer to receive treatment consistent with preservation of life at the end of life, including admission to ICUs and mechanical ventilation.^{4,5} Moreover, palliative care resources often made available to cancer patients are less likely to be offered to patients with COPD.⁶⁻⁸ Attempts by the American Thoracic Society (ATS) to make end-of-life care an integral component of COPD therapy have yet to be translated into real-life practice.⁹

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The reticence of physicians to discuss end-of-life care with their patients has been attributed to a lack of time as well as insecurity about the content of these discussions.^{10,11} However, previous studies have suggested that physicians may have misconceptions about patients' willingness or readiness to have these conversations; they feel that somehow these discussions might break the therapeutic alliance between physician and patient.¹⁰ These perceptions are sometimes held despite consistent evidence that patients would appreciate having discussions about what the dying process should be like. In this context, it may be useful for physicians to know whether the discussion about end-of-life care can reflect on a patient's perceived quality of and satisfaction with care and whether these discussions can lead to perceptions of worse overall health status. The purpose of this study was to identify whether patients who reported having end-of-life care discussions had higher perceived quality of care and satisfaction with care.

MATERIALS AND METHODS

Participants

This study included patients with COPD who had been enrolled in a randomized trial designed to improve the occurrence and quality of communication regarding end-of-life care.¹² Patients who met the GOLD (Global Initiative for Obstructive Lung Disease) criteria for COPD were enrolled between November 2004 and December 2007. The protocol was approved by the institutional review board of the University of Washington and the Veterans Affairs Puget Sound Health Care System (approval number 01378).

Baseline demographic and medical history data for participants were obtained through a self-reported questionnaire. All participants underwent spirometric testing upon enrollment according to the guidelines of the ATS.

Study Setting and Design

The setting for the study was the Veterans Affairs Puget Sound Health Care System in Seattle and Tacoma, Washington. We performed a cross-sectional study using baseline information derived from patient self-reported questionnaires reflecting preferences for, and previous occurrence of, end-of-life discussions with providers, ratings of quality of care, and perceptions of health status. These previously validated questionnaires included the Quality of Communication questionnaire,¹³ The Preferences for Dying and Death questionnaire,^{14,15} the St. George Respiratory Questionnaire (SGRQ),¹⁶ the Preferences for Communication About End-of-Life Care and Patient-Specific Barriers and Facilitators to this Communication questionnaire,^{10,17} the Preferences for Life-Sustaining Treatments questionnaire,^{10,17} and the Health Care Communication Questionnaire.^{10,13,18,19}

Our primary exposure was defined as patient acknowledgment of having had an end-of-life discussion with his or her physician. To account for variability in physician practices, patients were clustered by provider. The primary outcome measure was the self-reported assessment of the quality of care and satisfaction with care. Quality of care was rated on an 11-point Likert scale ranging from 0 to 10 (0 = the very worst imaginable to 10 = the

very best imaginable). We categorized patient-reported quality of care into the very best imaginable quality of care vs all lower ratings of quality. Similarly, satisfaction with care was scored with five possible levels of agreement with the statement, "I am very satisfied with the medical care I receive" (1 = strongly disagree to 5 = strongly agree). We categorized patient-reported satisfaction as strongly agreeing with being very satisfied vs all lower endorsements of satisfaction.

Secondary outcome measures included the assessment of provider knowledge and skill, perceptions of breathing problems and treatments for breathing problems, and health status as rated by both patient report and SGRQ scores (e-Table 1). A minimally clinically important difference for the SGRQ scores was considered to be four points.²⁰

Statistical Analysis

Appropriate parametric and nonparametric tests were used to assess bivariate associations. We used logistic regression to quantify the magnitude of association between the occurrence of end-of-life communication with patient-perceived quality and satisfaction with care. All models were adjusted for clustering by physician to accommodate correlated data. First, we examined models that were unadjusted for covariates for each outcome. We then constructed adjusted models by adding the main exposure variable (whether the patient had an end-of-life discussion with his or her physician) and all covariates en bloc. Covariates adjusted for were FEV₁ % predicted, age at baseline, smoking, diabetes, hypertension, depression, and cardiovascular disease. Similarly, SGRQ total, activity, impact, and symptom scores of patients reporting end-of-life discussions and patients not reporting end-of-life discussions were compared in a linear regression model, both unadjusted and adjusted for the same covariates. Analyses were performed using Stata, version 11 (StataCorp).

RESULTS

We enrolled 376 patients, whose baseline characteristics are reported in Table 1. The cohort was consistent with Veterans Affairs populations with COPD and included predominantly older white men with moderate to severe COPD.

Of the 376 patients, 55 (14.6%) reported having had an end-of-life discussion with their physician, although 220 (67.7%) reported a desire to have such conversations. In comparison with those patients who had not had conversations, patients who reported having discussions were more likely to be past smokers and were more likely to be treated with inhaled corticosteroids. Patient who reported previous discussions were also more likely to have concurrent conditions including congestive heart failure, asthma, myocardial infarction, and pneumonia. Increasing severity of COPD as graded by FEV₁ % predicted was not associated with end-of-life discussions. Of the 321 patients who did not have end-of-life discussions, 26 (8.1%) had an FEV₁ % predicted of <30%.

Primary Outcome Measures

The results of the primary outcome measures are presented in Table 2. In unadjusted comparisons with

Table 1—Population Characteristics of Patients Reporting and Not Reporting End-of-Life Discussions

Characteristic	Patients Reporting End-of-Life Discussions (n = 55)	Patients Not Reporting End-of-Life Discussions (n = 321)	P Value
Male sex	52 (94.6)	313 (97.5)	.228
Age, y	70.9	69.1	.214
White race	44 (80.0)	247 (76.9)	.968
Education: college or higher	33 (60.0)	169 (52.6)	.347
Married	29 (52.7)	134 (41.7)	.154
Yearly income			.860
< \$19,999	21 (38.1)	115 (35.8)	
\$20,000-\$39,999	14 (25.5)	94 (29.3)	
≥ 40,000	11 (20.0)	65 (20.2)	
Smoking status			.002
Past	46 (83.6)	203 (63.2)	
Current	5 (9.1)	88 (27.4)	
FEV ₁			.887
< 30%	4 (7.3)	26 (8.1)	
30% to < 50%	24 (43.6)	129 (40.2)	
50% to < 80%	16 (29.1)	109 (34.0)	
≥ 80%	11 (20.0)	57 (17.8)	
Hospitalization outside the Veterans Affairs Hospital for breathing problems	5 (9.1)	25 (7.7)	.795
ED or urgent care visits for breathing problems	7 (12.7)	51 (15.9)	.486
Treatment			
With prednisone	22 (40.0)	92 (28.7)	.141
With antibiotics	16 (29.1)	81 (25.2)	.650
With long-acting β agonist	32 (58.1)	167 (52.0)	.398
With short-acting β agonist	49 (89.1)	292 (91.0)	.658
With inhaled corticosteroid	42 (76.4)	180 (56.1)	.005
Comorbidities			
Asthma	32 (58.2)	113 (35.2)	.001
Cancer	12 (21.8)	60 (18.7)	.621
Congestive heart failure	14 (25.4)	38 (11.8)	.008
Coronary artery disease	12 (21.8)	53 (16.5)	.360
Depression	16 (29.1)	113 (35.2)	.327
Diabetes	18 (32.7)	71 (22.1)	.096
Drug abuse	3 (5.5)	16 (5.0)	.903
Myocardial infarction	16 (29.1)	51 (15.9)	.020
Hypertension	34 (61.8)	181 (56.4)	.505
Pneumonia	29 (52.7)	122 (38.0)	.043
Posttraumatic stress disorder	9 (16.4)	68 (21.2)	.379
Stroke	6 (10.9)	31 (9.7)	.801

Data are presented as No. (%) unless indicated otherwise.

patients who did not have end-of-life discussions, patients who had end-of-life discussions were twice as likely to report having received the best possible care (OR, 2.01; 95% CI, 1.06-3.81). These results were consistent after adjusting for FEV₁ % predicted; age

at baseline; and presence of smoking, diabetes, hypertension, depression, and cardiovascular disease (OR, 2.07; 95% CI 1.05-4.09). Similarly, in unadjusted and adjusted comparisons, patients who had end-of-life discussions were also twice as likely to agree that they were very satisfied with their medical care (unadjusted OR, 2.02 [95% CI, 1.16-3.50]; adjusted OR, 1.98 [95% CI, 1.10-3.55]).

Table 2—Unadjusted and Adjusted ORs of Primary Outcome Measures Controlled for Clustering by Provider

Outcome Measure	Unadjusted		Adjusted	
	OR (95% CI)	P Value	OR (95% CI)	P Value
I have the best imaginable quality of care.	2.01 (1.06-3.81)	.032	2.07 (1.05-4.09)	.036
I am very satisfied with the medical care I receive.	2.02 (1.16-3.50)	.012	1.98 (1.10-3.55)	.022

Secondary Outcome Measures

Unadjusted and adjusted ORs for secondary outcomes measures are provided in Table 3. In both unadjusted and adjusted models, patients who had ever had an end-of-life discussion were more likely to acknowledge that their provider probably or definitely knew the treatments they wanted (unadjusted

Table 3—Unadjusted and Adjusted ORs of Secondary Outcome Measures Controlled for Clustering by Provider

Outcome Measure	Unadjusted OR (95% CI)	P Value	Adjusted OR (95% CI)	P Value
My doctor is very or extremely knowledgeable.	1.87 (0.99-3.50)	.053	1.73 (0.87-3.43)	.120
My doctor probably or definitely knows the treatments I want.	9.33 (3.62-24.06)	.000	7.69 (2.83-20.94)	<.001
My doctor provides a very good or excellent explanation of my breathing problems.	3.98 (1.95-8.12)	.000	4.48 (1.85-10.81)	.001
My doctor provides very good or excellent treatments for my breathing problems.	2.08 (1.06-4.05)	.032	1.98 (0.90-4.39)	.091
I feel confident most to all of the time dealing with my breathing problems.	2.05 (0.99-4.21)	.052	1.84 (0.82-4.14)	.141
My perception of my health is good to excellent.	0.79 (0.40-1.54)	.483	0.64 (0.32-1.27)	.203

OR, 9.33 [95% CI, 3.62-24.06]; adjusted OR, 7.69 [95% CI, 2.83-20.94]) and that their doctor provided a very good or excellent explanation of their breathing problems (unadjusted OR, 3.98 [95% CI, 1.95-8.12]; adjusted OR, 4.48 [95% CI, 1.85-10.81]). However, in adjusted models, patients' confidence in their physicians to provide treatments for their COPD was not associated with having had an end-of-life discussion (OR, 1.98; 95% CI, 0.90-4.39). Moreover, in both unadjusted and adjusted models, those who had end-of-life discussions were not more likely to state that their health was good to excellent (unadjusted OR, 0.79 [95% CI, 0.40-1.54]; adjusted OR, 0.64 [95% CI, 0.32-1.27]). Although there was a trend in both unadjusted and adjusted models, there was no statistically significant association between end-of-life discussions and the confidence that patients had in dealing with their breathing problems.

Patients who reported having had end-of-life discussions had higher overall SGRQ scores indicating worse overall health status, as shown in Table 4. In an unadjusted linear regression model, total SGRQ scores were 7.17 points higher (95% CI, 1.14-13.21) among patients who reported having had end-of-life discussions. This association did not significantly change after adjustment (interval difference, 6.09; 95% CI, 1.18-10.99). SGRQ impact scores were also significantly higher in patients with end-of-life discussions in both unadjusted and adjusted models (unadjusted interval difference, 7.57 [95% CI, 1.39-13.75]; adjusted interval difference, 6.54 [95% CI, 1.56-11.52]). SGRQ activity scores were 7.32 points higher in patients with

end-of-life discussions in the unadjusted model (95% CI, 0.86-13.78), but this finding was statistically nonsignificant in the adjusted model (interval difference, 5.13; 95% CI, -0.78 to 11.05). Finally, SGRQ symptom scores were not significantly different between the two groups (unadjusted interval difference, 3.19 [95% CI, -5.29 to 11.61]; adjusted interval difference, 3.90 [95% CI, -3.93 to 11.72]).

DISCUSSION

Despite demonstrating that two-thirds of the patients with COPD desired end-of-life care discussions, we found that patients rarely had such conversations with their physicians. When such conversations took place, however, patients were significantly more likely to report having had the best perceived care. These results suggest that physicians should not be reticent to have end-of-life discussions and that having such discussions is associated with patient perceptions of high quality of and satisfaction with care. Patient-reported measures of quality of and satisfaction with care are important instruments that are becoming increasingly integrated into performance and quality assessment within health systems.

Even though ATS recommendations suggest having such discussions when the disease course becomes severe, we found no association by severity as assessed by FEV₁ % predicted. A considerable proportion of patients who did not have end-of-life discussions had an FEV₁ < 30% predicted. We found, though, that health status as assessed by the SGRQ total and

Table 4—Adjusted and Unadjusted Differences in SGRQ Scores Between Patients Reporting End-of-Life Discussions and Patients Not Reporting End-of-Life Discussions Controlled for Clustering by Provider

SGRQ Score	Mean Scores for Patients Not Reporting End-of-Life Discussions	Interval Difference in Scores Between Patients Reporting End-of-Life Discussions and Patients Not Reporting End-of-Life Discussions			
		Unadjusted Interval (95% CI)	P Value	Adjusted Interval (95% CI)	P Value
Total score	48.8	7.17 (1.14-13.21)	.020	6.09 (1.18-10.99)	.015
Activity score	65.2	7.32 (0.86-13.78)	.026	5.13 (-0.78 to 11.05)	.089
Impact score	37.2	7.57 (1.39-13.75)	.016	6.54 (1.56-11.52)	.010
Symptom score	52.6	3.19 (-5.29 to 11.61)	.458	3.90 (-3.93 to 11.72)	.329

SGRQ = St. George Respiratory Questionnaire.

impact scores was highly associated with having had end-of-life discussions, suggesting that these discussions may have been based more on overall health status and the impact of COPD than on the severity of airflow limitation. Although the ATS recommendations may focus on end-of-life care specifically for those with severe COPD, this cohort clearly demonstrates a spectrum of disease severity complicated by age and comorbid conditions that may make discussions about preferences for end-of-life care appropriate regardless of the markers of COPD severity.

These results are in general agreement with findings established in other studies. Janssen et al² found that in a group of 101 patients with COPD, only 20 (19.8%) had ever discussed cardiopulmonary resuscitation or mechanical ventilation with their physician. Even fewer had discussed the process of dying (14.9%) or palliative care (10.9%). Similarly, Heffner et al,²¹ in looking at patients with chronic lung disease, found that only 19.0% of patients had discussed advanced directives with their physicians and only 15.2% of patients had discussed life support. Accordingly, only 14.3% of patients felt that their physicians understood their end-of-life wishes. Even the highest rates of end-of-life communication reported still only show that one-third of patients with oxygen-dependent COPD have discussed the types of treatment they would want at the end of life.¹⁰ Not until patients reach very advanced stages of disease may physicians feel compelled to initiate end-of-life care. Indeed, in our study, we found that patients who reported having had end-of-life discussions were, on the whole, more ill, as reflected by their higher SGRQ scores. Similarly, 75% of Canadian respirologists surveyed in one study admitted that they often waited until FEV₁ reached <30% predicted before discussing mechanical ventilation.²² For these patients, discussions may occur only after an acute deterioration in symptoms, when patients and family are already under significant emotional and functional stress and where careful reflection about preferences cannot be considered fully.

In this study, we show that the act of initiating an end-of-life conversation was highly associated with how patients perceived the quality of and their satisfaction with medical care. Whether these discussions are interpreted by patients as signs of a caring, holistic physician or whether they simply reflect a satisfaction that comes with having their questions addressed is not known. Nonetheless, patients who had had end-of-life discussions were more likely to rate their medical care as the best imaginable and to strongly agree that they were very satisfied with the medical care they received. Furthermore, they were more likely to acknowledge that their provider knew the kinds of treatments they wanted and that their provider offered very good or excellent explanations for their

breathing problems. This perception was true despite the fact that these patients appeared to have a greater disease burden. This suggests that higher ratings of quality and satisfaction were independent of a physician's ability to provide symptomatic relief.

The idea that patients with COPD may, in fact, desire end-of-life discussions is not new; however, exploring the relationship between having had end-of-life care discussions and the patient's overall perception of quality and satisfaction with care is novel. In a survey eliciting views on cardiopulmonary resuscitation and in-hospital ventilation from 100 patients with COPD, 98% felt that these issues should be discussed with all patients.³ Although not all patients may welcome such conversations, a significant proportion has been shown to seek out information on their prognosis.^{23,24} Even in the absence of a physician-directed discussion, patients often have established opinions on life support, symptom relief, and continuity of care.⁷ Unearthing these opinions early in the disease process rather than at times of extremis offers a strong opportunity to have patients fully consider their overall values and discuss these with potential surrogates and providers. These discussions are the means to increase the likelihood that the care they receive at the end of life is concordant with their desires and values.

This study had a number of important strengths, including a relatively large number of patients with COPD who were well characterized from a socio-demographic, burden of comorbid illnesses, physiologic, and health status perspective. Moreover, we had the ability to tie patients to their individual provider and to directly attribute patients' perceptions of their quality of and satisfaction with care to that provider. Our study is based on patient-reported discussions and does not rely on proxy measures as assessed through chart, provider, or surrogate assessments.

This study had some potential limitations. We could not examine the content of those discussions that had already occurred. Although attempts were made to control a number of other confounders, including severity of disease, comorbidities, and sociodemographics, residual confounding factors are a possibility. Relatively few women participated in this study, making generalizability to women as well as nonveteran populations difficult. Because of our observational study design, no cause and effect statements between end-of-life discussions and our outcome measures can be made.

CONCLUSIONS

This study demonstrated that having end-of-life discussions is associated with higher ratings of patient satisfaction with and quality of medical care. The paucity

of these conversations at even the most advanced stages of disease, however, suggests that significant additional effort will be needed to facilitate these discussions. In the context of our performance ratings of physicians based on patients' report of satisfaction and quality, having end-of-life care discussions may present an opportunity for physicians to improve their overall ratings. More importantly, these results suggest that patients perceive high-quality care as care that includes discussions about the end of life and that physicians should not be reticent to have discussions about end-of-life care. These discussions offer the best opportunity to ensure that care at the end of life is concordant with patients' wishes and values.

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Additional information: The e-Table can be found in the "Supplemental Materials" area of the online article.

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