The Value of Disease Severity in Predicting Patient Readiness to Address End-of-Life Issues

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Background: Although patient-physician discussion is the most important tool for end-of-life planning, less than 30% of seriously ill patients have held these discussions. While physicians use objective disease severity and recent clinical events to trigger end-of-life discussions, it is not known if such findings predict patient readiness. We evaluated the ability of disease severity measures and recent clinical events to predict patient readiness for end-of-life discussions in patients with chronic lung disease.

Methods: The desire for discussion about end-of-life care was evaluated in 100 outpatients with a diagnosis of chronic lung disease presenting for pulmonary function testing. Objective disease severity was indicated by the percentage of the predicted forced expiratory volume, use of oral corticosteroids, a functional status score, frequency of recent hospitalizations, and required use of mechanical ventilation.

Results: In multivariate analysis, patient desire for an end-of-life discussion with the physician was not associated with percentage of predicted forced expiratory volume in 1 second (odds ratio [OR], 0.99; 95% confidence interval [CI], 0.96-1.03), oral corticosteroid use (OR, 1.34; 95% CI, 0.40-4.54), functional status score (OR, 1.37; 95% CI, 0.34-5.56), hospitalizations in the past year (OR, 0.33; 95% CI, 0.09-1.20), or previous mechanical ventilation (OR, 1.37; 95% CI, 0.34-5.56).

Conclusions: Patients appear no more or less interested in end-of-life discussions at later stages of chronic lung disease. Physicians cannot use disease severity measures or recent clinical events to accurately predict when patients desire end-of-life discussions. Focusing on physician skill in using specific communication strategies for patients at all stages of illness may be the most promising approach to increasing end-of-life discussions.

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METHODS TO address and plan end-of-life care and the use of life-sustaining treatments fall generally into 3 categories: written advance directives; surrogate decisions by physicians, families, or friends; and direct discussions between patients and their physicians.

After initial optimism, advance directives such as living wills have proven disappointing. Only 10% to 20% of patients complete advance directives and, when completed, they are limited in their effect on future health care.1-8 Surrogate decisions by physicians and families are commonly used but poorly match patients’ own desires and values,9-11 and often leave surrogates uncomfortable and favoring intense life support even in the face of medical futility and knowledge that such care may not be the patient’s wish.12,28-33

Direct patient-physician discussion is thus the most important tool for end-of-life care planning. Although the vast majority of patients desire such discussions, generally less than 30% of even seriously ill patients have held them with their physicians.1,13-17

Most patients and physicians agree that physicians should initiate discussions about end-of-life care.13,14,18,19 Studies have disclosed a number of physician-related barriers to initiating discussions, including deciding the timing of such discussions and concerns about patient receptiveness.20,21 These barriers are often derived from physician perception that the illness is not yet advanced enough for patients to want or accept these discussions.21-24

If clinical clues, such as disease severity or major clinical events or findings, could signify patient receptiveness to end-of-life discussions, physicians could approach the subject with more certainty. While it is known that physicians use clinical events to trigger these discussions,12,24 it is not known whether disease severity or major clinical events predict patients’ desire or receptiveness.
In this study, we evaluated the ability of disease severity and major clinical events to assist physicians in predicting when patients might be ready to address end-of-life decisions. We chose chronic lung disease as a model because it presents a progressive chronic illness with established objective severity measures and a high probability of requiring future intensive care and life support.

**METHODS**

This study was a cross-sectional analysis of 100 consecutive patients, 18 years and older, who were completing scheduled outpatient pulmonary function testing ordered by their physician. Study entry criteria consisted of a clinical diagnosis of chronic lung disease by either the patient’s physician or American Thoracic Society standards, including the excessive production of sputum or phlegm for 3 months in each of 2 consecutive years.26 All consecutive patients were enrolled to obtain an unbiased cohort for intragroup comparison with various levels of objective chronic lung disease severity. Patients were modestly reimbursed for their time spent completing a 30-minute interview immediately after their pulmonary testing. Exclusion criteria included an active nondermatologic malignancy, impaired communication (visual, auditory, or speech), poor-quality pulmonary function tests, organic brain disease or psychiatric illness that impaired the ability to answer questions, and the use of pulmonary function testing solely for disability purposes. Only 1 eligible patient approached for enrollment refused participation. The institution’s Human Studies Committee approved the study, and all patients completed informed consent. Enrollment continued until 100 patients completed the study.

**DATA COLLECTION AND STUDY INSTRUMENT**

Pulmonary function tests were interpreted by means of American Thoracic Society criteria.26 The percentage of the predicted forced expiratory volume in 1 second (FEV1) is a common estimate of lung impairment, often categorized as normal (>80%), mild (65%-80%), moderate (50%-65%), and severe to very severe (<50%). We used these categories to classify our patients’ respiratory impairment. To compare results with our earlier end-of-life work in patients without chronic lung disease in the same setting,16 the Karnofsky Performance Scale was used to measure functional status.

The survey instrument was designed on the basis of previous studies in qualitative and quantitative end-of-life research.18,19 The structured, standardized survey was administered by a trained research associate, blinded to the patient’s other data, in a confidential, private setting. The 53 items in the survey included questions about patients’ end-of-life beliefs, desires, opinions, and attitudes, as well as information on the intensity of their previous health care. Life-sustaining treatments were defined for the patients in this study as possibly including “mouth-to-mouth breathing, pumping on your chest (CPR), feeding tubes, and ventilators (breathing machines).”

**STATISTICAL ANALYSIS**

Power calculations, based on patient responses in an earlier study, determined an a priori minimum sample size of 81 patients to detect a 10% effect in patient end-of-life preferences with 95% confidence. The SPSS-PC software (SPSS Inc, Chicago, Ill) was used for all analyses. Univariate analysis included χ2 testing for categorical variables and t test for continuous variables. For Likert scale questions (5 possible responses) there were no significant differences in continuous and categorical analysis; therefore, dichotomous results are reported for simplicity and clarity.

A logistic regression model was developed to assess the effect of patient variables on the dependent variable: the patients’ desires to have end-of-life discussions. Variables in the disease severity domain included percentage of predicted FEV1, oral corticosteroid use for lung disease, and functional status by the Karnofsky Performance Scale. Measures of intensity of recent care included previous mechanical ventilation for respiratory failure and the number of hospitalizations in the past year. Variables remained in the model if the P values were equal to or less than .05. Results are reported as odds ratios with confidence intervals.

**RESULTS**

Demographic characteristics of the patients are shown in Table 1.

Objective measures of disease showed the expected broad range of severity. Patients were distributed among severity categories of percentage of predicted FEV1 as follows: normal, 17; mild, 34; moderate, 21; and severe, 28. Of the 83 patients with abnormal results of pulmonary function tests, 47 had obstructive disease, 20 restrictive, and 16 mixed obstructive and restrictive disease. Their mean and median percentage of predicted FEV1 were 64% and 66%, respectively. Eleven patients were receiving home oxygen therapy and 57 required oral corticosteroids for their chronic lung disease either currently or at some time in the past. The patients’ mean and median Karnofsky Performance Scale scores were 73.5 and 70.0, respectively, representing functional status at the minimal level of self-care, unable to carry on normal activity or work.

Intensity of care characteristics of the patients showed that 59% had been hospitalized in the past year, with 15%...
having had 3 or more hospitalizations. Twenty-two of the 100 patients had received mechanical ventilation for their chronic lung disease previously.

Multivariate analysis results are shown in Table 2. Objective measures of chronic lung disease severity and intensity of recent health care did not predict the patients’ wish to discuss end-of-life care with their physicians. The mean percentage of predicted FEV\(_1\) was similar in patients wanting and not wanting discussions (64% vs 65%, respectively; \(P = .87\)). Of 57 patients requiring oral corticosteroids, 48 (84%) desired discussions, compared with 37 (86%) of 43 who had not required corticosteroids (\(P = .80\)). In univariate analysis, functional performance was lower in patients wanting discussions, with a mean Karnofsky Performance Scale score of 72 vs 80 in those not wanting discussions (\(P = .03\)). However, functional status did not predict readiness for discussions when adjusted for other variables in the multivariate model. Recent hospitalizations also did not correlate with the desire for discussions. Of 59 patients hospitalized in the past year, 48 (81%) desired discussions vs 37 (90%) of 41 not hospitalized (\(P = .22\)).

Eighty-five patients were interested in end-of-life discussions with their physician and 18 (21%) reported having held such discussions.

### COMMENT

Most patients and physicians expect physicians to initiate end-of-life discussions.\(^{13,14,18,19}\) Timing these discussions remains difficult for physicians, who must balance candor, hope, and individual patient characteristics.\(^{19,22}\)

It is consistent with other areas of medical practice that physicians use available clinical clues to initiate action on their part. Just as 30 lb of involuntary weight loss prompts appropriate diagnostic tests, so might a prolonged and uncomfortable period of mechanical ventilation in a patient with chronic lung disease lead a physician to judge future mechanical ventilation as potentially undesirable to the patient, and consider initiating an end-of-life discussion.

There is evidence that physicians do, in fact, use disease severity and intensity of recent care to begin end-of-life discussions in chronic lung disease. Sullivan et al\(^{21}\) found that physicians use objective measures such as FEV\(_1\) and deteriorating nutritional status as prompts for end-of-life discussions. McNeely et al\(^{23}\) found that physicians use FEV\(_1\) and recent hospitalization to initiate end-of-life care discussions. For a variety of chronic diseases, including chronic lung disease, McGrew\(^{24}\) suggested “trigger points,” defined as objective clinical findings or events that indicate appropriate times for physicians to initiate end-of-life discussions.

Our study shows that, for chronic lung disease, objective disease severity and intensity of recent care are not associated with patient desire or readiness for end-of-life discussions. Distinctive values and characteristics of individual patients appear to eliminate any benefit that objective clinical clues might offer physicians in this regard. Although physicians might still wish to use worsening objective data or significant clinical events as helpful reminders to initiate end-of-life discussions, previous studies caution that awaiting such disease progression will delay discussions past the period most patients desire them.\(^{13,14,19}\) Further concern about this practice is provided by McNeely et al,\(^{23}\) who found that 68% of pulmonary physicians discussed end-of-life care with less than half of their patients with chronic lung disease before mechanical ventilation was required, and Heffner et al,\(^{14}\) who found that only 14% of patients in a pulmonary rehabilitation program believed their physicians understood their end-of-life wishes.

Our study suggests that patients are no more or less interested in discussing end-of-life care at advanced disease severity than at earlier disease stages. Yet, in the face of this uncertainty about individual patient responsiveness, physicians must still proceed with discussions. Several strategies have emerged from a growing body of work in health communication to assist physicians in addressing end-of-life care in all patients.\(^{19,27-31}\) A common goal of the strategies is to approach the subject without stimulating common, and often incorrect, patient assumptions about their physician’s view of disease status, hopefulness, future physician effort, or even imminent death. To accomplish this, it has been suggested that end-of-life plans be discussed routinely as part of patient intake histories, during preoperative visits, or during first posthospitalization follow-up visits.\(^{17,19}\) In addition, specific measures have been suggested to help in difficult discussions. These include the use of open-ended questions, neutral topic introductions, specific phrasing and prompts, focused listening, soliciting patient goals and values, clarifying strategies, and minimizing the discussion of treatment details.\(^{19,27-31}\) An example initiation using these methods might be: “Some of my patients with your illness have thought about how they want their medical care at the end of life. How would you like us to deal with this?”

This study is the first, to our knowledge, to show the dissociation of chronic lung disease severity and patient receptiveness for end-of-life discussions. Little other work has been reported in this area. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) study\(^{17}\) evaluated seriously ill hospitalized patients and found no association between disease severity or functional capacity and having held an end-of-life discussion. The study was limited in its use of specific objective disease severity measures because of a patient population with a variety of diagnoses.

### Table 2. Multivariate Analysis of Disease Severity and Intensity Association With Patients’ Desire to Discuss End-of-Life Care With Their Physician

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEV(_1), % predicted</td>
<td>0.99</td>
<td>0.96-1.03</td>
</tr>
<tr>
<td>Receiving oral corticosteroids</td>
<td>1.34</td>
<td>0.40-4.54</td>
</tr>
<tr>
<td>Previous mechanical ventilation</td>
<td>1.37</td>
<td>0.34-5.56</td>
</tr>
<tr>
<td>Functional status (KPS)</td>
<td>0.50</td>
<td>0.16-1.55</td>
</tr>
<tr>
<td>Hospitalizations in past year</td>
<td>0.33</td>
<td>0.09-1.20</td>
</tr>
</tbody>
</table>

Abbreviations: CI, confidence interval; FEV\(_1\), forced expiratory volume in 1 second; KPS, Karnofsky Performance Scale score.
The current study has strengths and weaknesses. It enrolled actual patients with chronic lung disease rather than using hypothetical health scenarios. In addition, the patient population showed a heterogeneous mix of disease severity, typical in medical practice, and the study addressed these issues in the ambulatory setting as suggested by the SUPPORT study. The findings of this study may have limited applicability to other populations with higher socioeconomic or educational status, and the study is limited by a one-time, cross-sectional patient analysis.

With more than 100,000 patients in the United States dying of chronic lung disease each year, physicians will frequently encounter end-of-life issues in these patients. Aware of the failures of advance directives and the inaccuracies and difficulties of surrogate decision making, physicians cannot use objective disease progression to predict which patients are most receptive to end-of-life discussions. Focusing on physician skill in using specific communication strategies in all patients appears to be the most promising approach to make direct discussion of end-of-life issues a more customary and comfortable part of chronic lung disease management.

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REFERENCES