

Deciding about mechanical ventilation in end-stage chronic obstructive pulmonary disease: how respirologists perceive their role

P. Daniel McNeely,* Paul C. Hébert,*† MD, MHSc(Epid);
Robert E. Dales,* MD, MSc; Annette M. O'Connor,†‡ RN, PhD;
George Wells,*† PhD; Doug McKim,* MD; Karen E. Sullivan*

Abstract

Objective: To determine when respirologists approach patients with end-stage chronic obstructive pulmonary disease (COPD) to decide about the use of mechanical ventilation, what information they provide to patients and how they provide it.

Design: Self-administered national survey.

Participants: All Canadian specialists in respiratory medicine; of 401 eligible respirologists, 279 (69.6%) returned a completed questionnaire.

Outcome measures: Timing and content of doctor-patient discussions regarding mechanical ventilation; physicians' perception of their level of involvement in the decision-making process; and patient and physician characteristics that may influence decisions.

Results: Discussions were reported to occur most often at advanced stages of COPD: when the patient's dyspnea was severe (reported by 235 [84.2%] of the respondents) or when the patient's forced expiratory volume in the first second was 30% or less than predicted value (reported by 210 [75.3%]). A total of 120 respondents (43.0%) stated that they discuss mechanical ventilation with 40% or less of their COPD patients before an exacerbation necessitates ventilatory support. Most (154 [55.2%]) described the decision-making process as a collaboration between patient and physician; 83 (29.7%) reported that the patient decides after he or she has considered the physician's opinion. Over half (148 [53.0%]) of the respondents indicated that they occasionally, often or always modify the information provided to patients in order to influence their decision about mechanical ventilation.

Conclusions: Discussions with COPD patients concerning end-of-life decisions about mechanical ventilation are reported to occur in advanced stages of the disease or not at all, with patients' input where possible. Information presented to patients is often modified in order to influence the decision. Future studies should explore ways to involve patients further in the decision-making process and to improve the process for both patients and physicians.

Résumé

Objectif : Déterminer, lorsque les respirologues abordent des patients atteints de bronchopneumopathie chronique obstructive (BPCO) au stade ultime pour prendre une décision sur l'utilisation de la ventilation mécanique, les renseignements qu'ils fournissent aux patients et comment ils les fournissent.

Conception : Sondage national à remplir soi-même.

Participants : Tous les spécialistes en médecine respiratoire au Canada. Sur 401 respirologues admissibles, 279 (69,6 %) ont renvoyé un questionnaire rempli.

Mesures des résultats : Moment et teneur des discussions médecin-patient au sujet de la ventilation mécanique; perception des médecins quant à l'importance de leur intervention dans la prise de décision; caractéristiques des patients et des médecins qui peuvent avoir une incidence sur les décisions.



Evidence

Études

From *the Department of Medicine, †the Clinical Epidemiology Unit and ‡the School of Nursing, University of Ottawa, Ottawa, Ont.

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Résultats : On a signalé que les discussions se déroulaient le plus souvent aux stades avancés de la BPCO : lorsque la dyspnée du patient est grave (mentionné par 235 [84,2 %] des répondants) ou lorsque le volume expiratoire maximal dans la première seconde s'établit à 30 % ou moins de la valeur prévue (mentionné par 210 [75,3 %] des répondants). Au total, 120 répondants (43,0 %) ont déclaré qu'ils discutent de la ventilation mécanique avec 40 % ou moins de leurs patients atteints de BPCO avant qu'une aggravation nécessite une assistance ventilatoire. La plupart (154 [55,2 %]) ont décrit le processus décisionnel comme une collaboration entre le patient et le médecin; 83 (29,7 %) ont signalé que le patient prend une décision après avoir tenu compte de l'avis du médecin. Plus de la moitié (148 [53,0 %]) des répondants ont indiqué qu'ils modifiaient à l'occasion, souvent ou toujours les renseignements fournis aux patients afin d'orienter leur décision au sujet de la ventilation mécanique.

Conclusion : Selon les répondants, les discussions avec des patients atteints de BPCO qui portent sur des décisions en fin de vie au sujet de la ventilation mécanique ont lieu aux stades avancés de la maladie, avec l'apport des patients lorsque c'est possible, ou n'ont pas lieu du tout. On modifie souvent les renseignements présentés aux patients afin d'influencer la décision. Des études à venir devraient porter sur des façons de faire participer davantage les patients à la prise de décision et d'améliorer le processus à la fois pour les patients et pour les médecins.

End-stage chronic obstructive pulmonary disease (COPD) is often extremely disabling and may force patients to lead a bed-to-chair existence. In severe cases, exacerbations are common and may result in acute respiratory failure, necessitating endotracheal intubation and mechanical ventilation.¹

Deciding to discuss end-of-life issues with COPD patients and to recommend such interventions as mechanical ventilation is complex. First, physicians must try to evaluate the patient's prognosis, the overall benefits and risks of various outcomes following such an intervention and the patient's readiness to discuss end-of-life issues as well as understand the patient's expectations and values.^{2,3} Patient characteristics such as age and health status (e.g., presence of comorbid conditions such as severe dementia^{4,5}) may affect how physicians approach the topic. Similarly, physician characteristics such as number of years in practice, practice setting, discipline, and socio-cultural and psychological characteristics may affect how or whether physicians decide to engage in end-of-life discussions.^{6,7}

What is discussed and how the information is provided have been previously documented to affect patient choices.⁸⁻¹¹ McNeil and associates¹¹ documented that presenting information in terms of the probability of death as opposed to survival, or vice versa, may result in significant shifts in patients' preferences for radiotherapy or surgery to treat lung cancer. Modifying descriptions of a patient's current health status, available therapeutic alternatives, outcomes or any other relevant information communicated during the decision-making process may be referred

to as "framing."^{9,11} In a small qualitative study,³ we discovered that the respirologists surveyed influenced the decision-making process by modifying information provided to patients despite advocating a shared decision-making approach.

In recent years, increasing societal pressures have shifted decision-making from a physician-centred approach to a patient-centred collaborative exchange.¹²⁻¹⁹ However, little is known about how respirologists view complex end-of-life decisions in light of such changes in health care decision-making. We therefore surveyed respirologists across Canada to determine when they approached patients with end-stage COPD to discuss the use of mechanical ventilation, what information they provided to patients and how they provided it. We also identified patient and physician characteristics as potential factors in the decision-making process.

Methods

Participants

We obtained a list of all physicians with a fellowship in respiratory medicine from the Royal College of Physicians and Surgeons of Canada. We also contacted all of the Canadian medical schools to request the names of area respirologists. Of the 476 respirologists identified, we excluded those who were (a) no longer in clinical practice, (b) living outside Canada, (c) practising pediatric respiratory or (d) unable or unwilling to answer the questionnaire in English.



Questionnaire development and administration

We generated questions from semistructured interviews with Ottawa-area respirologists conducted as part of a related qualitative study and a review of the literature.³ Questions were grouped into four sections: practice characteristics; attitudes and practice patterns; content of discussions and how discussions are approached with patients; and patient characteristics that might affect decisions about mechanical ventilation.

We included questions to determine the timing of discussions and the proportion of patients with whom they are undertaken, where discussions take place (e.g., the emergency department, the intensive care unit [ICU] or the office or clinic) and the stages of COPD at which discussions are initiated (as determined by severity of symptoms, functional status, pulmonary function test results, severity of previous exacerbations and requirement for home oxygen therapy). The content of discussions fell into two categories: information about mechanical ventilation (e.g., the intubation process, functional limitations during ventilation and related discomfort) and prognostic information (e.g., expected survival, quality of life and weaning process). We asked physicians to indicate how frequently they provide this information (always, when asked by the patient or never). We evaluated the manner or approach to decision-making by asking who makes the decision about mechanical ventilation. We also asked whether physicians modify information in order to influence the patient's decision.

Within each section of the questionnaire the selection, content, wording, sequencing and formatting of each question were repeatedly evaluated by us on the basis of their relevance to the study objectives (face validity) and previous data.³ We pretested the questionnaire in a convenience sample of 11 respondents to ensure clarity, understandability and comprehensiveness.

The final questionnaire underwent a formal test-retest assessment. It was administered twice, 1 month apart, to the same 20 respirologists. The respondents selected the same answers the second time (or had a difference in only one level) more than 83% of the time. They thought that the questionnaire was clear and easily understood (89%), fulfilled its objectives (79%), included most of the important elements (100%) and provided the appropriate range of possible answers (95%).²⁰

To ensure a maximum response rate we used a modified version of Dillman's method²¹ to administer the questionnaire. In April 1995 we mailed the questionnaire to all identified respirologists. Nonrespondents were sent reminder postcards after 4 weeks and another copy of the questionnaire after 8 weeks. At 12 weeks after the initial mailing, any nonrespondents were contacted by telephone.

Data analysis

Descriptive analyses were performed on all variables. We used the χ^2 test and the Kruskal-Wallis statistic to examine the relation between physicians' characteristics and (a) the timing of their discussions regarding mechanical ventilation, (b) how they perceive their role in deciding about mechanical ventilation and (c) the frequency with which they modify information in order to influence the patient's decision. Analysis of variance was used to test the association between the amount and type of information provided and physician characteristics. We used the χ^2 test and Spearman's rank correlation to test the relation between respondents' likelihood of offering mechanical ventilation and their recommendations regarding the use of this treatment in patients who are depressed, abuse alcohol or continue to smoke. No adjustments were made for multiple comparisons. Absolute *p* values are reported as two-sided.

Results

Physician characteristics

Of the 476 physicians originally identified, 8 could not be located and 67 returned the questionnaire indicating that they were ineligible: 20 were no longer in clinical practice, 18 were pediatric respiratory specialists, 6 could not answer because of language barriers, and 14 gave other reasons (e.g., no longer practising respirology, moved to the United States); the remaining 9 physicians did not provide a reason for their ineligibility. Of the remaining 401 respirologists 279 (69.6%) returned completed questionnaires. The characteristics of respondents are outlined in Table 1.

Timing of discussions about mechanical ventilation

Discussions about mechanical ventilation were reported to occur when the patient's COPD was advanced (Table 2). The discussions were reported to occur more often in hospital wards and ICUs (132 [47.3%] and 113 [40.5%], respectively) than in offices or clinics (reported by 64 [22.9%]).

Information provided to patients

The respondents were asked to consider procedural and prognostic information about mechanical ventilation and to indicate whether, for each item, they would provide the information spontaneously, provide it only when asked or not provide it to patients. Table 3 lists the most relevant findings. For procedural items, most of the respirologists

indicated that they would provide information spontaneously about the intubation procedure (270 [96.8%]) and the patient's inability to speak (240 [86.0%]) or to eat (198 [71.0%]) while being ventilated. For prognostic items, most indicated that they would provide information spontaneously about the strong likelihood of death if mechanical ventilation were not done (243 [87.1%]) and the chance that extubation may not be possible (240 [86.0%]). The information most often chosen as that which the respirologists would provide only if asked pertained to the extubation procedure (193 [69.2%]), the survival rate with mechanical ventilation (159 [57.0%]) and the death rate with mechanical ventilation (160 [57.3%]). The death rate associated with mechanical ventilation was most often chosen (by 72 [25.8%]) as information that the respondents would not provide to patients. There were no significant associations between the type or quantity of information provided and physician characteristics ($p > 0.11$).

Approach to decision-making

How the respondents' perceived their role in advance decision-making about mechanical ventilation is presented in Table 4. Over half of the respondents (154 [55.2%]) described the process as a collaborative effort between the

physician and the patient. The next approach most often selected (by 83 [29.7%]) involved the patient making the decision after considering the physician's opinion.

The respondents' decision-making approach was associated with the number of years they had been in practice. The 24 respondents who described their decision-making process as physician-centred had been practising significantly longer (mean 16 [standard deviation (SD) 9.9] years) than the 91 who described it as patient-centred (mean 10 [SD 7.1] years) or the 154 who described it as collaborative (mean 13 [SD 8.3] years) ($p = 0.009$).

When asked how often they modify information in order to influence the patient's decision, 148 (53.0%) of the respondents stated occasionally, often or always (Table 4).

Table 2: Timing of discussions of end-of-life decisions about mechanical ventilation with COPD patients

Variable	No. (and %) of respondents
Proportion of patients involved in discussions*	
≤ 20%	58(20.8)
21–40%	62(22.2)
41–60%	70(25.1)
61–80%	62(22.2)
81–100%	25 (9.0)
No response	2 (0.7)
Criteria describing when discussions are initiated†	
<i>Degree of dyspnea‡</i>	
Mild	1 (0.4)
Moderate	38(13.6)
Severe	235(84.2)
No response	5 (1.8)
<i>Degree of airflow obstruction (% predicted FEV₁§)</i>	
41–60%	2 (0.7)
31–40%	53(19.0)
≤ 30%	210(75.3)
No response	14 (5.0)
<i>Patient's experience with mechanical ventilation</i>	
Never hospitalized	17 (6.1)
First hospitalization because of exacerbation	172(61.6)
After mechanical ventilation	83(29.7)
No response	7 (2.5)

*Actual question: "In what percentage of your end-stage COPD patients do you have the opportunity to discuss the decision to withhold or provide intubation and mechanical ventilation prior to them requiring this treatment?"

†Actual question: "Please choose one statement for each of the following categories that best describes when you would typically begin a discussion about the decision to provide or withhold intubation and mechanical ventilation."

‡Wording used to describe dyspnea: "mild = patient walks slower than people of same age on the level because of breathlessness; moderate = stops for breath after walking about 100 yards or after a few minutes on the level; severe = too breathless to leave the house or breathless when dressing or undressing."

§FEV₁ = forced expiratory volume in the first second.

Table 1: Characteristics of Canadian respirologists responding to a survey on how they perceive their role in deciding about mechanical ventilation in end-stage chronic obstructive pulmonary disease (COPD)

Characteristic	No. (and %) of respondents* n = 279
Demographic	
Male	238 (85.3)
Mean age (and standard deviation [SD]), yr	44(8)
Mean no. of years since graduation (and SD)	19 (8)
Affiliation	
University associated	171(61.3)
Community based	106 (38.0)
No response	2 (0.7)
Time spent providing patient care, %	
1–40	59(21.1)
41–100	218 (78.1)
No response	2 (0.7)
No. of COPD patients seen per month	
< 11	24 (8.6)
11–30	124(44.4)
> 30	129 (46.2)
No response	2 (0.7)

*Unless otherwise stated.



There were no statistically significant associations between the respondents' characteristics and the frequency with which they modify the information ($p > 0.23$). In addition, there was no correlation between the stated decision-making approach and the use of framing ($r = 0.065$, $p = 0.787$).

Patient characteristics affecting decision-making

Most (167 [60.0%]) of the respondents indicated that the patient's quality of life was of primary importance when evaluating whether mechanical ventilation was worth while. Patient characteristics most often chosen as those that would discourage mechanical ventilation were advanced dementia (273 [97.8%]), the presence of a severe comorbid condition associated with a life expectancy of less than 1 year (248 [88.9%]) and very poor functional status (defined as being barely capable of getting out of bed) (235 [84.2%]). Patient characteristics that were most often chosen as those that should not influence the decision were absence of family and friends (250 [89.6%]), consumption of more than 10 alcoholic drinks per day (234 [83.9%]), the presence of severe depression (232 [83.2%]) and smoking 2 packs of cigarettes per day (206 [73.8%]). The number of respondents who indicated that mechanical ventilation should not be performed in patients who abuse alcohol increased as the number of years in practice increased ($p = 0.003$). There were no other associations noted between patient characteristics such as quality of life and physician characteristics ($p > 0.183$).

Discussion

In this study most of the respirologists surveyed described the process of deciding about mechanical ventilation in cases of end-stage COPD as either collaborative or patient-centred. A significant proportion of the respondents stated that they modified information presented to patients in an attempt to influence the decision. This is the first large study documenting that respirologists make use of "framing" in daily practice during end-of-life discussions. Many investigators have previously noted that framing information may influence a patient's decision.⁸⁻¹¹ However, whether framing should play a role in decision-making is unclear. On the one hand, framing may remove some of the emotional distress and responsibility of actively participating in decision-making for some anxious or indecisive patients. On the other hand, framing may prevent the patient's values from being incorporated into the decision-making process. Thus, physicians should be aware of the degree to which their personal values and beliefs are modifying what information they provide and how they provide it. The American Thoracic Society has indicated that patient autonomy should be the primary principle guiding the decision to withhold or withdraw life-sustaining therapy.²²

The responses regarding the timing of discussions about mechanical ventilation suggest that the respirologists often do not undertake such discussions or wait until the COPD is in its final stages following a life-threatening

Table 3: Type of information provided by respondents and frequency with which it is provided to COPD patients when discussing mechanical ventilation

Information	No. (and %) of respondents			
	Provided spontaneously	Provided only when asked	Not provided	No response
Procedural				
Intubation procedure	270 (96.8)	5 (1.8)	2 (0.7)	2 (0.7)
Inability of patient to speak while ventilated	240 (86.0)	34 (12.2)	4 (1.4)	1 (0.4)
Inability of patient to eat while ventilated	198 (71.0)	75 (26.9)	5 (1.8)	1 (0.4)
Disruption of sleep pattern	86(30.8)	149(53.4)	41(14.7)	3(1.1)
Extubation procedure	47(16.8)	193(69.2)	37(13.3)	2(0.7)
Prognostic				
Strong likelihood of death if mechanical ventilation not done	243 (87.1)	31 (11.1)	3 (1.1)	2 (0.7)
Chance that extubation may not be possible	240 (86.0)	31 (11.1)	7 (2.5)	1 (0.4)
Survival rate with mechanical ventilation	52 (18.6)	159 (57.0)	65 (23.3)	3 (1.1)
Death rate with mechanical ventilation	42 (15.1)	160 (57.3)	72 (25.8)	5 (1.8)
Expected quality of life	168(60.2)	92(33.0)	15 (5.4)	4(1.4)



exacerbation. Findings from studies about other life-sustaining treatments and do-not-resuscitate orders have been similar.^{2,4} If not given the opportunity to discuss mechanical ventilation and other options before an acute event, patients are often unable to participate in the decision-making process. Under such circumstances decisions are made primarily by family members or health care providers and often do not accurately reflect a patient's preference for life-sustaining therapy.²³⁻²⁵

A minority of respirologists stated that a history of alcohol abuse (16%), severe depression (17%) or heavy smoking (26%) would lead them to discourage a patient from undergoing mechanical ventilation. Why would a potentially treatable mental illness or socially undesirable habits cause some physicians to recommend withholding a life-sustaining therapy? Perhaps these physicians felt that such patient characteristics would worsen the overall prognosis. Alternatively, the responses may be more reflective of physician attitudes regarding these factors than of actual recommendations made to individual patients. At the very least, this observation suggests that physicians should question their beliefs and biases when making end-of-life recommendations.

Although we observed a number of differences in the respirologists' responses, we did not find a significant difference in association with their demographic characteris-

tics. Characteristics that were not evaluated (e.g., ethnic, cultural and religious backgrounds) may play an important role in end-of-life discussions. In our survey, there was no mention of issues related to the style of practice, including the type and frequency of support and follow-up offered to patients. Increased opportunities for interaction between patients, physicians and other caregivers may directly influence the frequency with which patients and physicians discuss such end-of-life issues.

One of the limitations of this study may have been the choice of participants. Respirologists may not have the opportunity to discuss mechanical ventilation with many of their patients simply because they are seen only after a life-threatening exacerbation has occurred. If general practitioners primarily discuss mechanical ventilation and other end-of-life issues with patients who have COPD, then the respirologists' responses regarding the frequency, timing and location of such discussions may represent a biased perception. By the same token, we are unsure whether our observations apply to general practitioners or other health care professionals.

Despite this limitation, we believe that our study raises interesting questions. When is the optimal time to approach COPD patients? What information should be conveyed to them? Should it be modified to reflect an assessment of the patient's prognosis and overall health status? Should patients' social, ethnic, religious and cultural backgrounds influence one's approach to these discussions? Future studies should explore ways to involve patients further in making decisions about end-of-life treatment and to improve the decision-making process for both patients and physicians.

Table 4: How respondents perceived their role in deciding about mechanical ventilation and the frequency with which they modify information provided to COPD patients

Variable	No. (and %) of respondents
Perceived role in decision-making process	
Patient decides	8 (2.9)
Patient decides after physician gives opinion	83 (29.7)
Patient and physician collaborate to make decision	154 (55.2)
Physician decides after patient gives opinion	22 (7.9)
Physician decides	2 (0.7)
Other	9 (3.2)
No response	1 (0.4)
Reported frequency of modifying information	
Never	58 (20.8)
Rarely	64 (22.9)
Occasionally	88 (31.5)
Often	50 (17.9)
Always	10 (3.6)
No response	9 (3.2)

Clinical implications: The modifying (framing) of information presented to patients with COPD when discussing end-of-life issues and mechanical ventilation may interfere with their ability to make choices congruent with their values and beliefs.

Study limitations: The self-reported information in this survey may not reflect actual practices of respirologists or primary care physicians.

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Reprint requests to: Dr. Paul C. Hébert, Department of Medicine, Division of Respiratory Medicine, Rm. N14, Ottawa General Hospital, 501 Smyth Rd., Ottawa ON K1H 8L6