

# Chronic Obstructive Pulmonary Disease: The Last Year of Life

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Nearly one quarter million Americans die with or of advanced chronic obstructive pulmonary disease (COPD) each year. Many patients die after a prolonged functional decline that is accompanied by much suffering. Though difficult prognostically and emotionally, anticipation of death opens the door to planning and preparing for terminal care. Epidemiologists have begun to identify characteristics of COPD patients who are most likely to die within 6–12 months, including severe, irreversible airflow obstruction, severely impaired and declining exercise capacity and performance status, older age, concomitant cardiovascular or other co-morbid disease, and a history of recent hospitalizations for acute care. Clinicians are encouraged to raise the difficult subject of planning for death when many of these characteristics apply. Patients with far-advanced disease are often receptive to the recommendation of a dual agenda: “Hope for and expect the best, and prepare for the worst.” Medical advance planning is best pursued in an out-patient office during a prescheduled, 3-way conversation between patient, health care proxy, and physician. An advance directive can be written after the meeting to summarize the conversation. Clinicians should consider recommending hospice care when a COPD patient is at high risk of respiratory failure from the next chest infection and in need of frequent or specialized home care. Preparation for death should include a realistic appraisal of the prospects for dying peacefully at home and a contingency plan for terminal hospitalization, should the need arise. *Key words: palliative care, terminal care, prognosis, advance directive, living will, hospice, mortality, chronic obstructive pulmonary disease, COPD, respiratory, life support care, withholding treatment, decision-making, respiratory insufficiency, artificial respiration.* [Respir Care 2004;49(1):90–97. © 2004 Daedalus Enterprises]

## Introduction

Chronic obstructive pulmonary disease (COPD) is listed on death certificates as the primary or a contributing cause

of death for more than 220,000 adults who die in the United States each year.<sup>1</sup> That is not only a lot of disease, but also a lot of deaths. Because death from COPD commonly occurs after prolonged functional decline and much

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suffering, there is particular need for palliative care of the many patients who die from this disease. Several comprehensive definitions of palliative care have been proposed in recent years.<sup>2-4</sup> In this report palliative medical care refers simply to symptom relief and counseling during the final 6-12 months of life. I will outline an approach to anticipating and planning for death of patients who suffer from advanced COPD. The focus is on palliative care decision-making for severely impaired out-patients who are at risk for dying of respiratory failure within the coming year.

### Attributes of a "Good Death"

A study published by Steinhäuser et al provides a framework for palliative and terminal care of adults who suffer from an irreversibly progressive chronic disease.<sup>5</sup> To identify attributes of a "good death," they convened 12 focus groups, each averaging 6 adults, drawn from the university and local communities of Durham, North Carolina. Participants included physicians, nurses, chaplains, social workers, patients, and recently bereaved family members who ranged in age from 26 to 77 years. Focus group meetings were conducted, audiotaped, transcribed, and analyzed using accepted techniques of qualitative research. From this process 6 components of a "good death" were identified (Table 1). Most important was pain and symptom management. Patients and family members expressed a strong desire to avoid needless suffering. Patients also wanted clear, timely decision-making and participation in treatment decisions. To prepare for death they wanted to know what to expect, and they wanted to plan for the

events that would probably precede and follow their deaths. Participants conveyed the importance of spirituality and meaningfulness at the end of life, as well as the importance of life review and closure of unresolved issues with family and friends. People want to continue contributing to others as long as possible, and they want to be understood by others as unique and whole persons, even as their function declines. Interwoven through all of these components is the importance of uninhibited, 2-way communication with family members, close friends, and caregivers.

### Recognizing When Death May Be Near

Because several of the features of a "good death" require anticipation and planning, palliative medical care ideally begins with mutual recognition by clinician and patient that death may be near. Since the time of Hippocrates, thoughtful provision of a terminal prognosis has been one of the most important and difficult services provided by physicians.<sup>6</sup> Though rarely straightforward for any progressive illness, anticipating death is exceptionally challenging for patients suffering from chronic lung disease. Indeed, among 19 indications for referral to hospice, only dementia has a more uncertain 6-month prognosis than COPD.<sup>7-9</sup>

Until recently little evidence-based information has been available to support clinicians in determining short-term prognosis for patients with advanced COPD. In 1997 the United States Centers for Medicare and Medicaid Services (formerly Health Care Financing Administration [HCFA]) issued empirical guidelines for predicting death within 6 months from COPD.<sup>10</sup> Those criteria were used to investigate hospices for fraud and abuse. Subsequently the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) investigators found that the HCFA guidelines for referral to hospice were not useful in identifying which patients die within 6 months after discharge following hospitalization for COPD exacerbation.<sup>7</sup> The COPD staging system currently recommended by the American Thoracic Society has proved similarly unhelpful for this purpose.<sup>11-13</sup> Even an episode of respiratory failure requiring mechanical ventilation does not, by itself, reliably predict death within 6 or 12 months.<sup>14</sup>

Reasons for the poor correlation between the severity of chronic airflow obstruction and short-term duration of survival are uncertain but may relate to several well-known characteristics of COPD. Compared with other fatal diseases such as lung cancer, COPD progresses at a highly variable rate. Some patients with severe disease appear to remain stable for months or years, while others decline rapidly. Exacerbations that bring about respiratory failure occur suddenly and unpredictably, and the outcome of those exacerbations is often determined by last-minute decisions regarding life support. Also, most patients who

Table 1. Components of a "Good Death"

Attributes of a "good death" as commonly perceived by terminally ill patients and their caregivers

1. Pain and symptom management. People fear dying unattended in distress.
2. Clear decision-making. Patients feel empowered by participating in treatment decisions.
3. Preparation for death. Many patients want to know what to expect during the course of their illness. They want to plan for the events that precede and follow death.
4. Completion. Completion includes faith and spiritual experiences, life review, resolution of conflicts, spending time with family and friends, and saying goodbye.
5. Contributing to others. Many people want to contribute to the well-being of others, even as they decline and die.
6. Affirmation of the whole person. Terminally ill patients appreciate empathic caregivers who understand their current condition in the context of their lives, values, and preferences as whole and unique persons.

(Adapted from Reference 5)

have advanced COPD are simultaneously at risk for other conditions that strongly influence survival, such as cardiovascular disease and aerodigestive tract malignancies.

Recently, epidemiologists have begun to look beyond physiologic measures of airflow obstruction to other indicators that may improve the ability to predict death within 6 or 12 months for patients with advanced COPD. From that research, measures of exercise performance and functional status are emerging as particularly helpful, possibly because these indicators gauge the integrated functional reserve of the cardiovascular and neuromuscular systems as well as the lungs. Within the past several years, 12-min walk distance, maximum exercise capacity, and quality of life measures, especially the activity subscales of those measures, have all been shown to predict short-term survival after hospitalization for a COPD exacerbation.<sup>12-17</sup>

Other predictors of impending death have also been identified from multivariate analyses. Older age, co-morbid diseases, and recurrent hospitalizations appear to predict poor short-term survival. In one noteworthy study, depression and living alone also emerged as strong predictors of death after hospitalization for COPD exacerbation. These results suggest that motivation to survive and the supporting care of a spouse or other care partner may prove to be particularly important determinants of survival in patients with advanced disease.<sup>17</sup>

Studies to date have not been designed to evaluate another potentially important predictor of death from COPD. For patients who already have severe airflow obstruction, recent, progressive decline in functional performance may strongly portend death as well. Lunney et al have shown that many patients with severe, chronic, vital organ disease such as COPD experience episodic loss of functional independence during their final year of life.<sup>18</sup> Thus, recurrent exacerbations with incomplete recovery between exacerbations may also portend death in advanced COPD.

From these recent observations a profile of patients who are terminally ill from COPD is beginning to emerge (Table 2). Additional research is required to refine and verify this profile. As this work proceeds, clinicians may be able to compare individual patients against this profile to identify those who are likely to die within 6-12 months.

### Conveying a Terminal Prognosis

Given the uncertainties inherent in predicting death for individuals with advanced COPD, many clinicians are reluctant to offer their patients any prediction of survival. In agreement with several previous studies, a recent survey of Canadian pulmonologists revealed that many respondents initiated discussions about mechanical ventilation late in the progression of advanced lung disease, if at all.<sup>19</sup> While understandable, this approach is counter to patient expectations. Virtually all of the study participants in a survey of

Table 2. Emerging Profile of COPD Patients at Risk for Dying of Respiratory Failure Within 1 Year

Best FEV <sub>1</sub> <30% of predicted
Declining performance status, with increasing dependence on others for activities of daily living
Uninterrupted walk distance limited to a few steps
More than one urgent hospitalization within the past year
Left-heart and/or other chronic co-morbid disease
Older age
Depression
Unmarried

COPD = chronic obstructive pulmonary disease  
 FEV<sub>1</sub> = forced expiratory volume in the first second  
 (Adapted from References 12-18)

pulmonary rehabilitation patients expressed interest in discussing end-of-life decisions with their physician.<sup>20</sup> Reluctance to discuss prognosis inhibits terminally ill patients from speaking openly about their hopes and fears and from planning actively for death.

When a patient with COPD has many of the characteristics listed in Table 1, a physician can broach the subject of prognosis honestly and compassionately with this statement: "We are not very good at predicting death from COPD. It is possible that you will live for another 1 or 2 years, or even longer. If your condition turns for the worse, you could die much sooner." Further discussion can be guided by the patient's questions and comments.

One common concern warrants special mention. While it is true that many patients with advanced COPD die during an exacerbation of their disease, many patients who know this greatly restrict their social interactions—with grandchildren for example—out of inordinate fear that they will "catch" a fatal infection. This fear should be sought and openly addressed during discussions about prognosis. Also, because prognosis is so easily misunderstood, physicians are encouraged to test patient comprehension at the end of the discussion or early in a subsequent visit by asking, "I want to be sure that you understand. How would you explain your prognosis to someone else?"

### Medical Advance Planning

Frank disclosure of a terminal prognosis opens the door to medical advance planning. For more than 30 years the primary tool in the United States for planning health care near the end of life has been the medical advance directive.<sup>21</sup> These legal documents were introduced in the late 1970s as a way for physicians to obtain protection from litigation and prosecution in the event that someone challenged the decision to withhold or withdraw life support. Reflecting their legal origins, advance directives were often called "living wills" or "durable powers of attorney."

Thousands of court cases later, the fear of legal sanction that gave rise to these documents is no longer justified in the United States, provided the physician acts in the best interest of the patient, with full regard for the patient's expressed or imputed wishes.<sup>22</sup> From a current perspective, conventional written directives perform a limited planning function at best.<sup>22-25</sup> Standardized, pre-printed forms, signed at the kitchen table and filed away in safe deposit boxes, frequently enter late into medical decision-making, if at all. Except for some patients who fall unexpectedly into permanent unconsciousness, standardized medical directives often serve to validate rather than to drive decisions actually made for patients by others.

Given those considerations, experts in end-of-life care are increasingly recommending a primarily medical approach to advance planning for pre-terminal health care that is constrained, but not dictated, by legal concerns.<sup>22</sup> Physicians can open a discussion of medical advance planning without denying uncertainty about the timing of death or undermining hope by stating simply: "I encourage you to hope for and expect the best, but it is also wise to prepare for the worst." If initial reticence is encountered, the physician might respond with: "I share your hope—and I will work hard to help keep you going as long as you possibly can. But bad things happen. I don't think you want to leave all of the responsibility for decision-making to your family members if you suddenly become very sick. Let's take a few minutes to talk about some decisions that are best considered in advance." This dual approach of encouraging and sharing hope while also planning and preparing for death has recently been described in detail by Back et al.<sup>26</sup>

Medical advance planning is best pursued as a 3-way conversation between a patient, the patient's designated medical proxy, and the patient's principal physician. Preferably, the discussion should be held in an out-patient setting during a visit that was pre-scheduled for this specific purpose. The physician might begin with a brief statement about the goals of the meeting and the patient's current condition or prognosis. Then the physician should turn to the patient with an open-ended invitation to speak, "I expect that you have been thinking about this meeting. What are your thoughts?" Other helpful, open-ended questions include, "What are your hopes for the future?" and "What are your greatest fears and concerns for your future?" Answers to these broad questions remind physicians that patients with advanced lung disease often have other concerns that may be more important to them than the technical aspects of medical life support or cardiopulmonary resuscitation. The patient's surrogate is given an opportunity to speak next. Finally, the physician raises or clarifies specific medical decisions that should be considered in advance. The characteristics of a "good death"

identified by Steinhäuser et al (see Table 1) can serve as a general guide for the discussion.

Depending on the circumstances, several practical issues are often appropriate for shared decision-making between patient, family, and physician in meetings devoted to advance planning for terminal care (Table 3). First, is the patient likely to die at home or in an institutional setting? Many who express a desire to die at home considerably underestimate the associated effort and expense and the degree of expertise necessary to ensure their comfort and hygiene.<sup>27</sup> Victims of advanced lung disease may be confined to bed on and off or continuously for weeks or months before they die. For some or much of this time they cannot be left unattended. With rare exceptions, health insurance policies do not provide for prolonged, continuous bedside care at home. Because of work or family commitments or their own health care needs, many family members are ill-equipped to provide this level of home care for longer than a few days. Consequently, the physician should focus this component of medical advance planning on the caregiver(s). What level of care can they realistically support at home? Which family members and friends are available to help out? Even families who are particularly well-equipped to provide terminal care in the home may be best served by recognizing that urgent hospitalization may be appropriate under certain circumstances. Three-way agreement on this point helps to allay the initial resistance or subsequent guilt of family members if a patient who prefers home care ultimately requires care in a hospital or nursing home.

Agreement on an open-ended approach to terminal care sets the stage for a second goal of medical advance plan-

Table 3. Terminal Care Medical Planning Issues

1. Discuss the most appropriate location for terminal care: the patient's or a family member's home versus an institutional setting
2. Identify preferred providers for terminal home or institutional care: Home care organization Hospice Acute care hospital Skilled nursing facility
3. Determine patient preferences for initiation and termination of life support: Should mechanical ventilation be initiated in the event of respiratory failure? Terminal withdrawal of life support in the event of irreversible impaired consciousness? Terminal withdrawal of life support versus institutional care in the event of prolonged dependency on mechanical ventilation?
4. Plan for anticipated "what ifs": "What if I find him unconscious on the kitchen floor?" "What if she starts coughing up blood again?" "What if I think he would be best served by transfer to another hospital?"

ning, which is to identify preferred providers for specialized care. Whenever possible the patient and family should choose an acute care hospital, a skilled nursing facility, and a home care agency well in advance of need. Avenues for communication may be the most important issue in choosing an acute care hospital or skilled nursing facility. Will the physicians and nurses at the facility be receptive to and respectful of the patient's preferences for terminal care? Many people do not know that a patient can be transferred promptly to another hospital or skilled nursing facility after initial stabilization in the nearest hospital emergency department. When choosing a home care agency for a patient with advanced COPD, the most important consideration may be the availability of specialized respiratory services and facilitated access to an accredited hospice.

Because patients with advanced lung disease only rarely experience sudden cardiac arrest, discussions regarding cardiopulmonary resuscitation with this group of patients should focus primarily on decisions regarding ventilatory support. There are limited choices to consider, and these should be laid out in the same manner that a physician describes options for the treatment of lung cancer. A patient with advanced emphysema might, for example, be guided through the following options as a starting point for discussion: (1) provide home care only, (2) hospitalize if indicated for comfort care, including short-term, noninvasive ventilation, but do not intubate or initiate major cardiac life support, (3) provide appropriate life support, to be continued only so long as the physician and the proxy both believe there is a reasonable chance for recovery to functional independence, or (4) provide life support indefinitely, so long as the patient retains the potential for self-awareness, to be continued in a long-term nursing facility if necessary.

These options encompass a spectrum in the timing and circumstances of a transition from life-sustaining care to palliative care, which can be refined by further discussion. If the patient favors a limited trial of life support (third option), the role of the patient, the proxy, and the physician in the decision to abandon the trial should be clarified in advance. If the patient chooses indefinite ventilatory support (fourth option), the impact of that decision on the patient's financial resources and family should be discussed openly.

If the planning session predates major surgery such as lung transplantation or lung-volume-reduction surgery, the physician should discuss the special considerations that apply to intraoperative and immediate postoperative care.<sup>28</sup> In the perioperative period the need for cardiopulmonary resuscitation or other life-supporting interventions often has a more favorable prognostic importance than at other times. Indeed, many surgeons and anesthesiologists consider perioperative life support an integral component of

the surgical procedure. If, as is often recommended, the patient's general preferences are to be suspended at the time of surgery, the transition back to those preferences should be discussed in advance.

Family members who provide home care for terminally ill patients are often concerned about certain "what ifs" such as "What should I do if I find him unconscious on the kitchen floor?" or "What if an ambulance takes her to a local hospital that we do not trust?" Not every eventuality can be anticipated and planned. Nevertheless, home caregivers appreciate guidance in advance on how they might respond if an uncontrolled or frightening situation develops suddenly or at an inconvenient hour. Who should be called? Should the patient be transported urgently to an emergency room? How should the patient's preferences be communicated to emergency personnel? This planning is essential to respect the wishes of those patients who want to limit life support, and particularly those who prefer to die at home.

Shortly after completion of initial discussions, the patient (ideally) or the proxy or physician should write a brief summary of the decisions that were made, in the form of a letter or declaration. In addition to defining the role of the proxy and the primary physician in medical decision making should the patient become incapacitated, the document lays out goals of therapy, limitations on treatment that can be identified in advance, and outcomes to be avoided. If circumstances warrant, the document can then be modified in form, with the help of a lawyer, to meet the requirements of applicable state laws. In addition to the patient, both the proxy and the physician might also sign the document, indicating that they will do their best to ensure that the patient's stated wishes are fulfilled. Copies should be filed by all 3 participants in readily accessible locations.

Unlike a pre-printed form signed by the patient in an attorney's office or at home, a medical advance planning document developed this way benefits from the guidance and advice of a physician and is tailored to the patient's individual circumstances. During the planning discussion the patient can ensure that both the proxy and the principal physician are in agreement with the plan. Just as important, the initial discussion opens the door to continuing discussions with other caregivers, including nurses and respiratory therapists (RTs). The professional staff members in pulmonary rehabilitation programs are particularly suited to pick up the planning process where the initial 3-way discussion left off.

### Hospice Home Care

Patients with advanced lung disease should be encouraged to consider hospice home care.<sup>29-31</sup> The hospice movement developed in the United States primarily as an ex-

tension of medical oncology. Even today many hospices report that most of their patients suffer from incurable cancer, even though terminally ill patients with diagnoses other than cancer are also likely to benefit from hospice care and professional assistance.<sup>32,33</sup> Although many hospices welcome patients with other diagnoses, they receive relatively few referrals of patients with advanced lung disease.<sup>30</sup> The reason is unclear but may relate in part to common misperceptions about hospice among physicians who care for patients with advanced lung disease.

Prior to enrollment in a hospice program, Medicare and most other insurers require both the referring physician and the hospice medical director to certify that the patient is expected to die within 6 months if the disease takes its usual course. As described above, there is no "usual course" for patients with advanced COPD. Even for the most severely impaired patients, duration of survival differs considerably. Because of concern over this certification requirement, many physicians delay referral to hospice for COPD patients until the last several days before death, or miss the opportunity for referral altogether.

Fortunately, there is no penalty to the patient for failing to die within 6 months. Hospice can be extended indefinitely, provided that the patient remains in a terminal state. Given the uncertainty inherent in prognosis for advanced lung disease, Abrahm and Hansen-Flaschen have proposed 3 alternative "common sense" guidelines for referral to hospice that are not based directly on predicted duration of survival (Table 4).<sup>30</sup> These guidelines target patients with advanced, irreversible lung disease who have little or no cardiopulmonary reserve and are likely to benefit from the specialized services offered by hospice.

In the United States, certified home hospices receive a fixed, daily payment from Medicare Part A for the comprehensive care of qualifying patients (approximately \$120 per day for routine hospice home care and approximately \$600 per day for short-term continuous home care). All medical expenses other than physician's fees are covered by the payment, including the cost of medications, supplies, durable medical equipment, and long-term oxygen.

Table 4. Referral to Hospice: Common-Sense Guidelines for Patients With Advanced Lung Disease

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Patients with advanced lung disease should be considered for referral to hospice if all 3 of the following apply:

1. Cardiopulmonary functional reserve is so limited that the patient may die at any time from an ordinary respiratory infection
2. Because of distressing symptoms or severely limited performance status the patient can be expected to benefit from the specialized services offered by a hospice program
3. The patient accepts that death may be near and does not want to suffer needlessly

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(Adapted from Reference 30)

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Home assessment, education, and counseling are provided by nurses, social workers, dietary counselors, pastoral counselors, and RTs, as appropriate. Telephone consultation and coordination of care is generally available 24 hours a day. Home health aides are typically provided for 2 or 3 hours a day. Home nursing care may be available for up to 24 hours a day during a medical crisis. Some hospices provide volunteers for transportation to a doctor's office or to cover family caregivers for short trips out of the house. Brief hospitalizations for symptom control and up to several days of in-patient respite care to provide caregivers with personal time may also be covered by the hospice program.

The flexibility of the Medicare hospice benefit serves many terminally ill patients well. Unfortunately, Medicare capitated payments for hospice services work against some patients with advanced lung disease who are dependent on unusually expensive therapies that must be included in the capitation payments. The high cost of home mechanical ventilation and such drugs as nebulized tobramycin, transplant immunosuppression drugs, inhaled dornase alfa (Pulmozyme), and intravenous epoprostenol (Flolan) effectively preclude enrollment in hospice, especially for those who already incur the expense of home oxygen. Continuous intravenous epoprostenol infusion is especially problematic in that patients with severe pulmonary hypertension risk sudden death if this drug is discontinued, even momentarily. Thus, most Medicare patients with severe pulmonary hypertension must relinquish their hospice benefit for life in order to receive intravenous epoprostenol, because few hospice organizations can afford the cost of this treatment in addition to other hospice services.

Terminally ill patients who are unwilling or unable to enroll in a hospice program may obtain some of the same benefits from a visiting nurse agency, although most insurers restrict the quantity and duration of palliative home care services available by this route.

### Terminal Care

Although most patients with advanced lung disease express a desire to die at home, relatively few in North America actually do so.<sup>34</sup> Unless a fatal complication supervenes, many spend an extended period of time confined to bed completely dependent on others for sustenance, hygiene, and comfort. Constant attendance and considerable skill are often required. Dyspnea at rest and accompanying anxiety/panic are distressing to onlookers and difficult to manage, even under the best of circumstances. For many patients with advanced lung disease, terminal care is best provided in an acute care hospital or a skilled nursing facility. Some hospitals have established specialized in-patient units designed specifically for palliative care.<sup>35</sup> At other hospitals the intensive care unit is well suited to

provide short-term terminal care because the nurses and RTs who work there have particular knowledge and experience in the treatment of respiratory distress. Hospitals should be prepared to provide attentive, compassionate care for patients who are dying of respiratory failure, whether this care is provided in a specialized unit or on a regular ward. Respiratory care departments should play an active role in the preparation and provision of that care.

Patients who face death by suffocation from advanced COPD have options that many caregivers may be reluctant to discuss. Recent surveys of hospice and long-term care nurses revealed that an important fraction of elderly patients in the terminal stage of a chronic illness choose to hasten death by voluntarily foregoing food and water.<sup>36-37</sup> When all food and water intake ceases, a bed-bound patient lapses into coma after about a week and death generally occurs within about 15 days. Hospice nurses report that death by this route is associated with comparatively little suffering and is relatively peaceful. They tend to rate death by voluntary refusal of food and fluid as a "good death." This option is considered legal across North America. Health care practitioners can legally counsel patients on the consequences of foregoing food and water. They can also counsel family members on the expected bodily changes and the bedside care of patients who choose to die this way.

Some patients who are dependent for survival on high concentrations of inspired oxygen also have the opportunity to hasten death by voluntarily removing their supply of supplemental oxygen. This option is analogous to patient refusal of out-patient hemodialysis, though death occurs more quickly and may be associated with dyspnea. Little is known about this legally permitted practice, which may be more common than is currently appreciated.

Physicians, nurses, and RTs who care for patients with advanced COPD are encouraged to recognize that death is not a failure, but an opportunity to practice a form of professional care that is as old as medicine and as gratifying as any other services we offer.

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## Discussion

**Mannino:** Do you recommend marriage or cohabitation for your single, end-stage COPD patients, or do you think the fact that married people survive longer is just a marker for something else?

**Hansen-Flaschen:** That would be great, wouldn't it? I can only speculate, as the authors of that article did, on what that surprising finding meant.<sup>1</sup> Other studies showed what an incredible burden it is to take care of someone who is dying of organ failure.<sup>2,3</sup> It's a full-time job (or equivalent) for family members. It's not just about getting somebody their medicines and being sure they're wearing their oxygen. It's about recognizing when they're doing poorly and seeking help and bringing them into the hospital and heading off death. So I would speculate that staying alive with very advanced COPD happens best with teamwork between a patient and a partner.

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**Heffner:** John, you seemed to imply a central role for the physician in this end-of-life counseling. What are your thoughts regarding other caregivers? Physicians traditionally haven't done a very good job with this; they tend to vacate their role. And would you focus on RTs in your comments?

**Hansen-Flaschen:** I hope we can set the stage to break open the barriers of what we used to teach 30 years ago, and still teach in many parts of the country, which is, "Don't tell him that he's dying." Can we break open the barriers and set up receptivity to frank, open conversations about what people are thinking and what they're afraid of? Can we open that barrier and go on to other things? A family primed for those conversations carries forward with it at home, and I hope—and would very much love to see—nurses and RTs follow through.

Once the door is open, I would hope that RTs would be key people to follow through and engage in those conversations and answer questions. You know, these patients become very needy and once you say, "Let's talk about it," there's a lot to talk about. I'd like to see RTs take a few minutes in pulmonary rehabilitation to ask patients an open-ended question about planning for death. "Have you prepared an advance directive?" "Have you discussed your preferences for life

support with your doctor?" Then take the conversation forward wherever it may go.

**Giordano:\*** John, you brought up the hospice benefit, and I'm glad you described how a person can qualify for hospice if expected to die within 6 months. My sense is that hospice is still underutilized by COPD patients, and yet we're anxious to get RTs out into patients' homes. This is a golden opportunity. Could you describe in a bit more detail what physicians and patients are eligible for and the possibility of using RTs and the respiratory therapy component?

**Hansen-Flaschen:** Medicare and other insurers pay a hospice about \$105 to \$110 a day. There's a list of things hospices are supposed to do with that, but you can add as well. One of the nice things about hospice is that they are paid by Medicare and many other insurers on a capitation system, and the hospices are given a great deal of latitude in how they spend their available money in the service of their patients. So within that context a hospice can contract with a chaplain, with lay counselors, with RTs, with speech therapists, music therapists, dance therapists—wherever they want. They are fully capable and able to contract

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with an RT to provide specialized services in the home. So there is not a contractual or legal obstacle to RTs becoming very active in home hospice or in hospice in-patient care. I think that would be very appropriate. These patients have lung disease. They use oxygen. They may have noninvasive mechanical ventilation. An RT would be actively participating in their care if they were in an ICU. Why not in the home as well?

**Hill:** You highlighted the challenges of managing the anxiety and in particular, the paroxysmal dyspnea panic attacks that these patients have, and it can certainly be very challenging. Anecdotaly, I just want to mention that I've had good success with noninvasive ventilation in *some* of those patients, but certainly not all of them.

But I was a little bit surprised by your remarks about the lack of effective pharmacotherapy for these problems, because, although I would certainly allow that we don't have *ideal* pharmacotherapy, I've had pretty good success with opiates in some of those patients. There have been descriptions in the literature of *inhaled* morphine.<sup>1</sup> I don't think that morphine is really any more effective by the inhaled route than any other route, but I've been able to manage some of these patients for *many* months before they eventually died at home using inhaled morphine, and I think pretty successfully.

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**Hansen-Flaschen:** In fairness, an individual patient may get comfort and relief from an opioid or a benzodiazepine, and I will use those medications across the spectrum. I'm not afraid to use benzodiazepines or tricyclics or opioids for CO<sub>2</sub>-retaining COPD patients. A given individual may get relief from it and go with it by all means and manage the complications.

But there is no dyspnea receptor in the brain. There's no blocking some specific pathway that creates dyspnea. The benefit here has got to be a pretty indirect one. Who knows how we're really benefiting those people? So my point is not to be a total nihilist about drugs but to recognize that our drugs are weak enough that we better also rely on counseling if we're going to help our patients. If all you do is write a prescription, most of the time you're going to serve your patient poorly.