

**Palliative and End-of-life Care for Patients with Severe COPD**

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**Abstract**

COPD is a leading cause of morbidity and mortality worldwide. For many patients, maximal therapy for COPD produces only modest or incomplete relief of disabling symptoms and these symptoms result in a significantly reduced quality of life. Despite the high morbidity and mortality associated with severe COPD, many patients receive inadequate palliative care. There are several reasons for this. First, patient-physician communication about palliative and end-of-life care is infrequent and often of poor quality. Second, the uncertainty in predicting prognosis for patients with COPD makes communication about end-of-life care more difficult. Consequently, patients and their families frequently do not understand that severe COPD is often a progressive and terminal illness. The purpose of this review is to summarize recent research regarding palliative and end-of-life care for patients with COPD. Recent studies provide insight and guidance into ways to improve communication about end-of-life care and thereby improve the quality of palliative and end-of-life care the patients receive. Two areas that may influence the quality of care are also highlighted: 1) the role of anxiety and depression, common problems for patients with COPD; and 2) the importance of advance care planning. Improving communication, represents an important opportunity to improve the quality of palliative and end-of-life care received by these patients.

## **Introduction**

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of mortality and the 12<sup>th</sup> leading cause of disability worldwide.<sup>1,2</sup> By the year 2020, COPD will be the third leading cause of mortality and the fifth leading cause of disability worldwide.<sup>3-5</sup> For many patients, maximal therapy for COPD produces only modest relief of dyspnea, leaving patient with significantly reduced health related quality of life. Many patients with COPD receive inadequate palliative care. The purpose of this review is to examine problems in the delivery of high quality palliative care to patients with severe COPD and to identify ways to address these problems. Since other articles in this series have discussed treatment of dyspnea and other symptoms and improving quality of life, this review will focus on communication about palliative and end-of-life care.

## **The definition of palliative and end-of-life care**

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of disease or the need for other therapies.<sup>6</sup> The World Health Organization adopted the following definition of palliative care: “Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.”<sup>7</sup> As such, palliative care expands traditional treatment goals to include enhancing quality of life, helping with medical decision-making and identifying the goals of care, addressing needs of

family and other informal caregivers, and providing opportunities for personal growth.<sup>6</sup> By contrast, the term “end-of-life care” usually refers to care concerning the final stage of life and focuses on care to the dying person and their family. The time period for “end-of-life” care is arbitrary and should be considered variable depending on the patient’s trajectory of illness.<sup>8,9</sup> Using these definitions, palliative care includes end-of-life care, but is broader and also includes care focused on improving quality of life and minimizing symptoms before the end-of-life period as depicted in Figure 1. Although “end-of-life care” usually refers to care in the final months, weeks, or days, there is growing evidence that communication with patients and families about their preferences for end-of-life care should occur early in the course of a chronic life-limiting illness to facilitate high quality palliative and end-of-life care. This review will summarize some of this evidence particularly as it pertains to patients with severe COPD.

### **Poor palliative care in COPD and the link to poor communication**

The Study to Understand Prognosis and Preferences for Outcomes and Treatments (SUPPORT), enrolled seriously ill, hospitalized patients in one of five U.S. hospitals with one of nine life-limiting illnesses, including COPD.<sup>10</sup> Compared to patients with lung cancer, patients with COPD were much more likely to die in the intensive care unit, on mechanical ventilation, and with dyspnea.<sup>11</sup> These differences occurred despite most patients with COPD preferring treatment focused on comfort rather than on prolonging life. In fact, SUPPORT found that patients with lung cancer and patients with COPD were equally likely to prefer not to be intubated and not to receive CPR, yet patients with COPD were much more likely to receive these therapies.<sup>11</sup> A study in Britain also found that patients with COPD are much less likely to

die at home and to receive palliative care services than patients with lung cancer.<sup>12</sup> Additional studies have documented the poor quality of palliative care and significant burden of symptoms among patients with COPD.<sup>13</sup> Health care for these patients is often initiated in response to acute exacerbations rather than being initiated proactively based on a previously developed plan for managing their disease.<sup>14</sup> A recent study of patients with COPD or lung cancer in the U.S. Veterans Affairs health system also found that patients with COPD were much more likely to be admitted to an ICU and have greater lengths of stay in the ICU during their terminal hospitalization, than patients with lung cancer. These investigators found significant geographic variation in ICU utilization for patients with COPD.<sup>15</sup> Although variation in care may be influenced by many factors including availability, access, and reimbursement issues, such geographic variation suggests a lack of consensus concerning the best approach to palliative and end-of-life care for patients with COPD. In summary, there are important opportunities for research and quality improvement if we are to better palliative and end-of-life care for patients with severe COPD.

### **Challenges in prognostication for individuals with COPD**

In COPD, it may be difficult to identify those patients who are likely to die within six months. The prognostic models used in SUPPORT, which were based on APACHE II, documented this difficulty. These models showed that, at five days prior to death, patients with lung cancer were predicted to have <10% chance of surviving six months while patients with COPD were predicted to have >50% chance.<sup>11</sup> Recent efforts to identify disease-specific prognostic models for patients with COPD do improve prognostic accuracy, but do not predict individual short-term survival as well as can be done for many patients with cancer.<sup>16-18</sup>

Therefore, uncertainty concerning prognosis plays a more prominent role in discussions of prognosis and end-of-life care for patients with COPD than for patients with cancer. As physicians have difficulty discussing prognosis in the setting of uncertainty<sup>19</sup>, it is not surprising that they also struggle with knowing when to raise issues about end-of-life care. Nevertheless, it remains the responsibility of physicians caring for patients with severe COPD to educate them about end-of-life care and to ensure that they receive care consistent with their informed preferences for care at the end of life.

Despite the uncertainty, a profile emerges of the types of patients at high risk of mortality or morbidity over the next 6 months. Physicians should be encouraged to identify patients with COPD for whom discussions about treatment preferences or end-of-life care are especially important.<sup>20</sup> This profile could include an assessment of: FEV1 <30% predicted; oxygen dependence; one or more hospital admissions in the past year for an acute exacerbation of COPD; left heart failure or other co-morbidities; weight loss or cachexia; decreased functional status; increasing dependence on others; and age > 70. The presence of two or more of these prognostic indicators should be a reason for such discussions. Multiple criteria increase the relevance and urgency for the discussion, as they increase the risk for a life-threatening exacerbation and for receiving care at the end of life that is not consistent with their informed treatment preferences.

It is also important that clinicians understand patient preferences for end-of-life care and provide them with an opportunity to discuss these issues. Most patients with life-limiting illness prefer to discuss their preferences for end-of-life care relatively early in the course of their illness<sup>21</sup>, as these discussions are less stressful when the patient is feeling relatively well. Although most patients with COPD will prefer a trial of mechanical ventilation for acute

respiratory failure, raising these issues in advance of the requirement makes it easier to revisit these discussions when patients are unwell.<sup>21, 22</sup>

### **Current state of communication about end-of-life care**

Studies have shown that only a minority of patients with moderate to severe COPD have discussed treatment preferences and end-of-life care issues with their physicians<sup>23-25</sup>, and most believe that their physicians do not know their preferences for end-of-life care.<sup>24, 25</sup> We recently found that only a third of patients with oxygen-dependent COPD had discussed end-of-life care with their physicians and < 25% of physicians had discussed some important aspects of end-of-life care with their patients, including talking about how long the patient might live and what dying might be like for the patient and the family.<sup>23</sup> We also examined the items that patients with COPD rated as being performed most poorly, which included talking about prognosis. Therefore, we need to target improved communication regarding end-of-life care, prognosis and dying.

A recent study by McNeely and colleagues<sup>26</sup> examined the perspectives of Canadian respirologists on communication about end-of-life care for patients with COPD. When respirologists discussed mechanical ventilation for end-stage COPD, the discussions occurred late in the disease trajectory, most commonly taking place in the ICU, with only 23% occurring in the clinic or office.<sup>26</sup> Eighty-four percent of physicians waited until dyspnea was severe and 75% of physicians waited until the FEV<sub>1</sub> was < 30% predicted. A survey of 214 general practitioners in Britain found that, although 82% felt that general practitioners should discuss the prognosis with patients with COPD, only 41% of reported “often” or “always” discussing prognosis with these patients.<sup>27</sup> Furthermore, two thirds of these physicians who reported

infrequently discussing end-of-life care reported feeling inadequately prepared to have such discussions. These studies suggest that communication about end-of-life care is an important area for improvement in the care of patients with COPD.

### **Direction for improving communication about prognosis and about end-of-life care**

There are a number of studies that provide some specific direction for physicians in their communication about end-of-life care for patients with severe COPD. One qualitative study compared patients with severe COPD to patients with metastatic cancer or advanced AIDS, noting that patients with COPD were more likely to express concern about the lack of education that they received about their disease.<sup>28</sup> Patients with COPD wanted more information in the following five specific areas: diagnosis and disease process, treatment, prognosis, what dying might be like, and advance care planning (see table 3).

A qualitative study of patients with severe COPD in Britain also showed that most, but not all patients wanted more information about their prognosis.<sup>29</sup> In a survey of older patients with serious illnesses and limited life expectancy, half (56%) of participants with COPD wanted to know their life expectancy.<sup>30</sup> Oftentimes family members may want this information even when patients do not.<sup>31</sup> Therefore, it is important to determine how much information about prognosis patients and family members want.

Expert recommendations suggest a numeric expressions of risk, (e.g., “8 out of 10 people will have side effects from this drug”) generally lead to better comprehension than do qualitative expressions of risk (e.g., “this drug is very likely to cause side effects”).<sup>32</sup> Moreover, since prognostic information applies to outcomes of groups of patients, experts recommend that prognostic information be phrased in terms of outcomes for populations rather than in terms of



individual outcomes (e.g. “out of a group of 100 patients like your mother, I would expect about 10 to survive this”).<sup>33</sup> In addition, because some individuals do not wish to receive prognostic information, experts recommend the “Ask-Tell-Ask” approach to discussing prognosis.<sup>34-36</sup> For this approach, physicians first seek permission to discuss prognosis prior to doing so and afterwards ask patients and families their understanding of the prognosis to ensure comprehension. Table 2 summarizes some of these recommendations for discussing prognosis.

Another area of communication that was rated as poorly performed by patients with severe COPD was asking about the patients’ spiritual or religious beliefs.<sup>23</sup> Several studies suggest that the majority of patients want to discuss spiritual or religious issues with their physicians, although some patients do not have a strong preference and others have a preference to not have such discussions with physicians.<sup>37-39</sup> Studies from Europe suggest that physicians’ religion may be an important determinant of the care patients receive.<sup>40, 41</sup> Several reviews suggest approaches that physicians can take in determining whether patients want to discuss the patient’s religion and spirituality and having these discussions with patients,<sup>42, 43</sup> although empirical data about which specific techniques improve patient experience are limited.

### **Overcoming the barriers to communication about end-of-life care for patients with COPD**

An important step to improving communication about end-of-life care is to identify the barriers to this communication and implement strategies to overcome them. A recent study of patients with oxygen-dependent COPD examined the barriers to communication about end-of-life care and noted them to be many, diverse, and patient-specific.<sup>22</sup> Although 15 barriers were identified, only two were endorsed by more than 50% of patients, suggesting that an individualized process is required.

The two most commonly mentioned barriers were: “*I’d rather concentrate on staying alive than talk about death;*” and “*I’m not sure which physician will be taking care of me if I get very sick.*” The former suggests the need for skill in talking about a difficult subject, with patients who would rather not discuss it. Although many patients do not wish to discuss dying and death, these same patients often have strong opinions about CPR and mechanical ventilation.<sup>44</sup> Among patients in SUPPORT who did not want to discuss CPR, 25% did not want to have CPR and among those who did not want to discuss mechanical ventilation, 80% did not want to have prolonged mechanical ventilation. Therefore, it may be important to have these discussions even with patients who are reluctant to do so. It may be helpful in these situations to acknowledge that discussions about dying can be difficult but are nonetheless important for patients, families, and physicians to undertake and may provide an opportunity to decrease the burden of decision-making on family members. It can also be useful to explicitly state that such a discussion will not diminish the physicians’ focus on finding therapies to improve survival or quality of life, as some patients worry that such a discussion might cause a physician to “give up” on them.<sup>45</sup> Another useful tool for raising these discussions may be to frame them in the context of “hoping for the best, while preparing for the worst.”<sup>46</sup>

The other most common barrier, “*I’m not sure which physician will be taking care of me if I get very sick,*” suggests that patients may fear abandonment by their physicians at the end of life and that discussions of continuity of care between physicians and patients may be an important component of discussions about dying and death. In a qualitative study of patients with severe COPD, metastatic cancer, or advanced AIDS, concerns about continuity of care and abandonment emerged as important for patients with each of these diseases.<sup>21, 47</sup>

The most common physician endorsed barriers to communication about end-of-life care<sup>22</sup>, include: *There is too little time during our appointments to discuss everything we should*; *“I worry that discussing end-of-life care will take away his/her hope;”* and *“The patient is not ready to talk about the care s/he wants if s/he gets sick ”* These barriers suggest that interventions also need to target physicians and address systems-level issues, such as ensuring adequate time for discussions about end-of-life care. Some patients prefer a direct approach to discussing prognosis while others prefer a more indirect approach.<sup>31</sup> There is no relationship between the number of barriers endorsed by patients and the number endorsed by their physicians.<sup>22</sup> This lack of an association suggests that encouraging interventions may be more successful if they target both patients and physicians.

### **The role of depression and health status in communication about end-of-life care**

Although anxiety and depression are common in COPD, they are not well recognized or treated<sup>48-52</sup>. In a recent study, only a third of patients with COPD and clinically significant depression or anxiety were being treated and only half of those with severe depression or anxiety were being treated.<sup>53</sup> Anti-depressants can significantly improve mood among patients with COPD and depression.<sup>54</sup> Furthermore, in patients with COPD and depression, antidepressants can also decrease ratings of dyspnea and other physical symptoms.<sup>54</sup>

Anxiety and depression may modify patients' treatment preferences concerning end-of-life care. Patients with a higher burden of depressive symptoms have a stronger preference against CPR.<sup>55</sup> This association is similar to findings of two prior investigations, one from SUPPORT<sup>10</sup> and one by Blank and colleagues,<sup>56</sup> that assessed preferences for CPR, but not specifically for patients with COPD. Patients with depression are more likely to change their

treatment preferences after depression resolves.<sup>57</sup> They also rate the quality of patient-physician communication about end-of-life care significantly lower than those without depression.<sup>23</sup> It is unclear whether this finding reflects an effect of depression on patients' ratings of the quality of communication or whether the quality of communication is negatively influenced by depression, but regardless of the reason it is important for physicians to be aware of this relationship between depression and quality of communication about end-of-life care. Simply put, the presence of anxiety and depression may influence the patient's ability to understand the impact of decisions that they make and therefore, if possible, these symptoms should be treated prior to end of life decision making.

Another noteworthy finding about treatment preferences was that health status, as measured by the Saint George's Respiratory Questionnaire, was not associated with end-of-life treatment preferences in a population of patients with severe COPD.<sup>55</sup> These data confirm and extend the results of two prior studies performed in elderly outpatients without severe co-morbidities<sup>58</sup> and in seriously ill, hospitalized patients with several different primary diagnoses.<sup>59</sup> Healthcare providers should not assume that poorer health status is necessarily associated with a higher likelihood of refusing life-sustaining treatment. Since physicians consistently underestimate patients' quality of life compared with the patients' own assessments<sup>60, 61</sup> and since there is evidence that physicians' estimates of patients' treatment preferences are influenced by the physicians' estimates of patients' quality of life,<sup>62</sup> it is important that physicians caring for patients with severe COPD examine their own assumptions and directly obtain treatment preferences from patients. A recent survey from Europe showed that physicians and nurses placed more value on quality of life and less value on prolonging life

than patients or family members.<sup>63</sup> Clinicians should keep this difference in mind and avoid inappropriately imposing their values on patients and their families.

### **The role of advance directives and advance care planning in patients with severe COPD**

There has been considerable dissatisfaction with the lack of effects of advance directives on end-of-life care.<sup>64</sup> A number of studies suggest that advance directives do not influence the treatments that patients receive<sup>65-67</sup> and do not change end-of-life decision-making.<sup>68-70</sup> It is clear that advance directives in the absence of good communication about end-of-life care do not improve the quality of end-of-life care. However, in the context of good communication between patients, families, and physicians, advance directives may be an important component to end-of-life care. In addition, some studies suggest that the presence of advance directives are associated with decreased levels of stress and increased ratings of the quality of care among family members of dying patients.<sup>71, 72</sup>

Advance directive may be especially useful among patients with COPD because of their likely trajectory of illness with unpredictable exacerbations that may make patients suddenly critically ill.<sup>8</sup> In addition, some patients with COPD have strong feelings about the situations in which they would want to forego CPR or, particularly relevant for COPD, mechanical ventilation for acute respiratory failure. Prior authors have reported on the development of COPD-specific advance directives for this purpose, although there have not been studies showing that these advance directives improve the quality of end-of-life care.<sup>73, 74</sup> Nonetheless, advance directives are a topic that should be discussed with all patients with moderate or severe COPD as part of advance care planning and other aspects of communication about end-of-life care. For patients who have experienced non-invasive or invasive ventilation in the past, physicians have the

opportunity to use patients' prior experiences as a reference point for discussing potential future episodes of acute respiratory failure and those circumstances under which they would not want these types of ventilation. Patients' prior experiences with life support, or with relatives or friends who have required life support, can be important facilitators to patient-physician communication about treatment preferences and end-of-life care.<sup>22</sup>

### **Care of the Patient Dying from COPD and the Role of Hospice**

Some patients with COPD will die from lung cancer or cardiovascular disease<sup>2, 75</sup>, whereas others die from progressive respiratory dysfunction, or a systemic complication of it.<sup>14</sup> Physicians caring for patients dying with severe COPD may need to consider the value of treating their co-morbidities in the setting of advanced and terminal COPD. For example, indications for treatment of hypertension may change as COPD advances. Physicians should consider physiologic changes as patients become progressively closer to death and reassess the risks and benefits of the treatments for these comorbidities.<sup>76</sup>

Improvements in care of the dying have been largely confined to patients in hospice care and specifically to patients with cancer.<sup>77</sup> Patients dying of progressive COPD are less likely to be offered the opportunity to benefit from hospice services when compared to patients with cancer.<sup>12</sup> The illness trajectory among patients with COPD is more likely to be a gradual slow decline interspersed with unpredictable acute exacerbations often followed by an improvement back toward, but not quite reaching their pre-exacerbation baseline.<sup>9</sup> This trajectory does not fit the traditional hospice model well and may be part of the reason that patients with COPD are less likely to receive hospice and palliative care services. However, understanding this trajectory and discussing it with patients and their families may offer an opportunity to adapt hospice and

palliative care services to meet the needs of these patients and their families.<sup>8</sup> Accomplishing this goal represents one of the most important challenges to improving end-of-life care for patients with severe COPD.

Patients with COPD are at risk for respiratory failure and recent advances in the use of noninvasive ventilation raise questions about the use of this technology in the palliative care setting. The use of non-invasive ventilation for patients who choose to forego invasive mechanical ventilation is relatively common in Europe with approximately a third of patients who receive end-of-life care in the hospital receiving non-invasive ventilation as the most aggressive form of ventilation before death.<sup>78</sup> A recent Society of Critical Care Medicine Task Force provides a systematic approach to considering non-invasive ventilation in palliative care settings and concluded that although noninvasive ventilation may be appropriate as a form of life support for patients who choose to forego invasive ventilation, current literature does not support the routine use of noninvasive ventilation for the sole purpose of palliation of symptoms.<sup>79</sup> Furthermore, most hospice settings do not have familiarity with noninvasive ventilation and this lack of familiarity increases the risk for harm and decreases the chance of benefit from non-invasive ventilation.

## **Conclusions**

In summary, palliative care is an important component in the treatment of patients with severe COPD. There is strong evidence to suggest that patients with COPD receive poor quality palliative care compared to patients with cancer.<sup>11, 12, 14</sup> One reason these patients may receive poor quality palliative care is that patient-physician communication about end-of-life care is unlikely to occur or only occurs late in the illness.<sup>23-25</sup> The quality of this communication is

likely to be poor and current models for training physicians in communication about end-of-life care are inadequate.<sup>23, 27, 80</sup> Understanding the barriers to this communication may be an important step to improving it.<sup>22</sup> Furthermore, recognizing the importance of anxiety and depression, will also be important when discussing palliative and end-of-life care.<sup>55</sup> Advance directives and good advance care planning offer an opportunity for improving the quality of palliative care received by patients with severe COPD. Finally, hospice and palliative care services represent an important opportunity for improving end-of-life care, but clinicians caring for patients with COPD must find more effective ways to utilize these services.



Figure 1: Schematic diagram for use of terms “palliative care” and “end-of-life care”

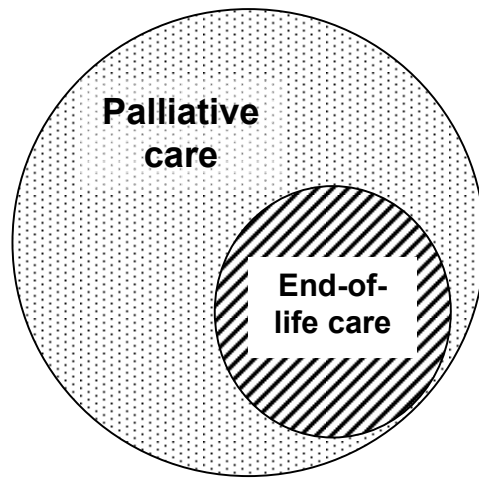


Table 1: Characteristics that should trigger a discussion on preferences about end-of-life care.

- FEV<sub>1</sub> <30% predicted
- Oxygen dependence
- One or more hospital admissions in the past year for an acute exacerbation of COPD
- Left heart failure or other co-morbidities
- Weight loss or cachexia
- Decreased functional status
- Increasing dependence on others
- Age > 70

Table 2: Components of end-of-life care that patients would like to discuss with their physician<sup>28</sup>

1. Their diagnosis and disease process
2. The role of the treatments in improving symptoms, quality of life, and duration of life.
3. Their prognosis for survival and for quality of life
4. What dying might be like
5. Advance care planning for future medical care and exacerbations

Table 3: Tips for talking about end-of-life care, prognosis, and advance care planning

Initiating Discussions about End-of-life Care

- Frame this discussion as an important part of care for all patients with severe COPD
- Identify whether the patient or someone close to the patient has been seriously ill whereby they were not able to make their own medical decisions and use these situations to facilitate discussion
- Inquire as to whether a family member or other person should be present for the discussion

Discussing Prognosis

- Use “ask-tell-ask” to ask if patients are willing to discuss prognosis, then deliver prognosis, and then confirm understanding
- Use numeric expressions of risk rather than qualitative statements
- Frame prognosis as referring to groups of people rather than individuals
- Explicitly discuss uncertainty in prognostication

Discussing Advance Care Planning

- Frame as being important to “hope for the best and prepare for the worst”
- If appropriate, clarify that discussing advance care planning with the physician will not diminish the physician’s focus on maximizing the patient’s survival
- Discuss particular importance of advance directives if patients have strong opinions about use of CPR, mechanical ventilation or other treatments
- Discuss importance of advance directives if patients have a preference for the person to make medical decisions for them if they are not able and especially if that preference does not match the default surrogate decision-maker according to local laws
- Identify whether there are specific health states that the patient would consider “worse than death”
- Explicitly discuss a commitment to non-abandonment
- Offer patients the opportunity to raise issues about patients’ spirituality or religion that they would like their physicians to be aware of

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