

Chapter 9

Communication in Palliative Care



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Introduction

Lung disease is a common cause of morbidity and mortality with care trajectories and symptom burden comparable to those associated with cancer [1, 2]. Despite these similarities, studies have shown that patients with lung disease, such as chronic obstructive pulmonary disease (COPD), lack an awareness of death and dying compared to those with cancer. Data indicates that frequency, timing, and quality of palliative care communication between clinicians and this patient population are poor. This is problematic because palliative care communication done well improves patients' symptoms and quality of life, leads to better concordance between patient goals and care delivered, and improves family psychosocial outcomes.

Communication surrounding palliative care rarely occurs in care of patients with advanced lung diseases [3]. As an example, a systemic review showed that most studies exploring palliative communication report rates of discussion regarding treatment preferences and end-of-life issues in less than 30% of patients with COPD [4]. Only a small proportion of patients with moderate to severe COPD have discussed treatment preferences and end-of-life care issues with their physicians, and the vast majority of these patients believe their physicians do not understand their preferences for end-of-life care [5]. When discussions do occur, the quality is often rated by patients as low [4] due to the absence of important elements such as prognosis,

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anticipatory guidance, and spirituality [6]. Patients with COPD are more likely than those with HIV/AIDS and cancer to express concern about the lack of education that they receive about their disease, treatment, prognosis, and advance care planning [7]. Clinicians acknowledge that discussion of goals of care and end-of-life preferences should occur early in the illness and when the patient is stable [8]. However, when discussions do occur, they often take place at advanced stages of the illness or hospitalization when patients may be unable to participate in decision-making, a situation that is burdensome to their surrogate decision-makers.

Herein we will review the existing literature on why effective palliative care communication is important for patients with advanced lung diseases, their families, and the healthcare system, discuss common barriers encountered by clinicians, and consider potential solutions to those barriers.

Why communication is important for patients, their families, and the healthcare system:

Effective palliative care communication includes both a [1] discussion of the values and preferences that shape end-of-life care and [2] exploration of factors contributing to patient suffering and symptom management.

For patients with lung disease, discussions regarding end-of-life care frequently occur at advanced stages of illness when patients are often unable to participate in decision-making. In the absence of early goals of care discussions, patients are at risk to receive unwanted medical care resulting in prolongation of the dying process and undue burden on surrogate decision-makers. When patients are decisionally incapacitated, surrogate decision-makers are asked to collaborate with clinicians to assist in making emotionally and cognitively difficult decisions. This surrogate role has been associated with negative emotional outcomes, such as stress, guilt, or doubt, in at least one third of surrogate decision-makers [9]. Anxiety, depression, and post-traumatic stress disorder have all been described in surrogate decision-makers [10–13]. Families of patients who died in the ICU were found to have higher levels of both PTSD and depression when they experienced discordance between their preferred and actual decision-making roles [14]. Furthermore, a cross-sectional study of bereaved family members found that perceptions on quality of end-of-life care are associated with complicated grief [15] which is known to be associated with poor physical health due to diseases, such as cancer, heart disease, and hypertension, and poor psychosocial outcomes, including anxiety, depression, and suicide [16, 17].

These poor outcomes for surrogate decision-makers are largely due to the burden of making high stakes decisions without knowledge of patients' wishes. This burden may be alleviated by clarifying patients' preferences early in their disease course. One systematic review found that when surrogates knew which treatments were consistent with the patient's preferences, it reduced negative outcomes for surrogate decision-makers such as feelings of guilt and stress. In this study, surrogates who

were confident in their loved one's treatment preferences felt as though they were simply reporting the patient's preferences as opposed to deciding on behalf of their loved one [9]. Other studies have demonstrated that end-of-life discussions were associated with better caregiver quality of life and bereavement adjustment at follow-up [18]. Additionally, terminally ill patient's prognostic awareness has been found to be associated with a higher quality of death reported by their caretakers who were also more physically and mentally healthy 6 months post-bereavement [19].

Physicians' ability to engage in goals of care discussions also contributes to outcomes for healthcare providers and the healthcare system. Caring for patients with advanced lung diseases who are seriously ill, suffer repeated exacerbations, and have limited treatment options makes clinicians vulnerable to moral distress and burnout. One study demonstrated that delivering bad news to patients can contribute to burnout among physicians who feel inadequately trained in communication skills [20]. Training interventions to improve end-of-life communication skills have shown significant improvements in confidence in communicating, attitudes toward psychosocial care, and sense of personal accomplishment [21]. Furthermore, the perception of providing harmful or futile care leads to moral distress and loss of empathy [22] which serves as a common cause of clinician burnout [23, 24]. Physician burnout has significant consequences on physician health with increased rates of depression [25], substance dependence [26], and suicidal ideation [27]. In addition to a moral and ethical cost, there is an economic cost to burnout. Cross-sectional studies have uncovered associations between physician burnout with decreased productivity, increased turnover, and increased medical errors resulting in poorer quality of care [28–30]. Each of these issues presents financial implications for healthcare organizations that subsequently incur significant losses [31, 32].

Early goals of care conversations have the potential to mitigate these patient, surrogate, and clinician outcomes. A substantial field of research has established that engaging patients in conversations about end-of-life care is associated with improvement in patient-centered outcomes. This is because a patient's values and preferences help to frame their medical decisions. When patients elect a surrogate decision-maker or complete an advanced directive, they are more likely to have their wishes known and followed [33]. One study found that end-of-life discussions were associated with less aggressive medical care near death and earlier referral to hospice, which in turn were associated with not only better patient but also caregiver quality of life and bereavement adjustment at follow-up [18]. As an example, in a multisite longitudinal study, patients with advanced cancer who reported awareness of their terminal prognosis had lower rates of psychological distress and higher rates of advance care planning [19]. Other studies show that patients with cancer are more likely to receive end-of-life care that is consistent with their preferences when they have had the opportunity to discuss their wishes with a physician. Patients aware of their terminal prognosis were more likely to desire symptom-focused care [34]. While most existing data focuses on patients with advanced cancer and COPD, patients with other advanced lung diseases and their families are likely to benefit as well.

Patients with advanced lung disease experience debilitating physical and emotional symptoms leading to loss of independence and the ability to fulfill social

roles. Palliative medicine specialists approach symptoms as multifactorial, influenced not only by physical but also psychological, social, and spiritual suffering [35]. These symptoms are often best addressed by a multidisciplinary Palliative Medicine Team. However, nonspecialists with experience in the traditional biologic model for symptom assessment and treatment can begin the process of identifying symptoms and attempting treatment with both non-pharmacologic and pharmacologic therapies. When patients' symptoms are not assessed, distressing experiences such as breathlessness, fatigue, anorexia, pain, and mood disorders often go untreated with detrimental consequences on quality of life. A systematic review found that distressing symptoms present at end of life are equally prevalent for patients with end stage COPD as among advanced cancer patients. Specifically, among patients with COPD, 90–95% experience breathlessness, 68–80% fatigue, and 34–77% pain [36]. Early palliative care integration for seriously ill patients with lung cancer has been shown to be associated with improvements in both mood and quality of life [37]. In a meta-analysis, palliative care interventions delivered by a range of palliative care and non-palliative care specialists were found to be associated with improvements in symptom burden and quality of life [38].

The healthcare system also benefits from early, skillful palliative care communication. Clinicians who feel insufficiently trained in communication skills have been shown to have a higher prevalence of depersonalization and low personal accomplishment than those who perceived themselves to be sufficiently trained [39]. A qualitative study exploring oncology physicians' approach to end-of-life care found that those who viewed end-of-life communication and care as an important role reported increased job satisfaction and decreased burnout [40]. Communication skills training is associated with less burnout and work-related stress [20, 41]. Studies directly examining cost at end of life associated with early involvement of palliative care have shown mixed results. One study found that among patients with advanced cancer, those that reported discussing their end-of-life wishes with their physician had better quality of death and significantly lower healthcare costs in their final week of life [42]. A landmark study published in 2010 showed that among patients with metastatic non-small cell lung cancer, early palliative care referral led to less aggressive care at end of life and longer survival [37]. While the study did not measure costs, these findings suggest that timely introduction of palliative care has the potential to mitigate unnecessary societal costs [37].

In response to accumulating data, medical societies, such as the American Thoracic Society, recommend that clinicians who care for patients with chronic or advanced respiratory diseases should be trained in, and capable of, providing recommended basic competencies in palliative care which include communication in goals of care and symptom management [43].

Barriers and Solutions

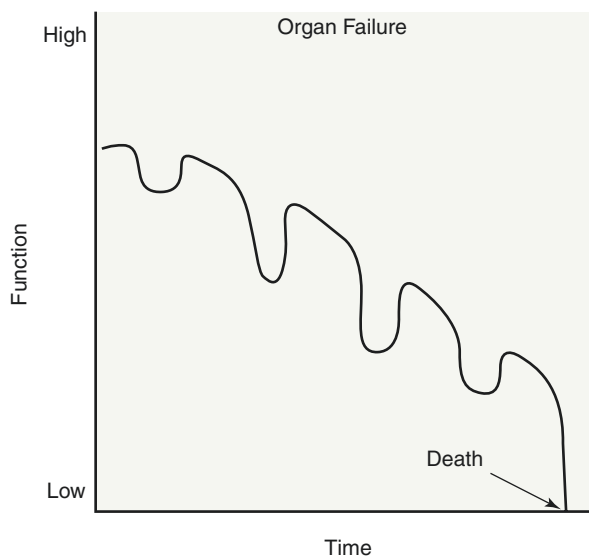
Palliative care communication including discussions about goals of care and symptom management has important consequences for patients, families, and healthcare providers. However, there are significant barriers to providing consistent, skillful communication in these areas. Herein we will present these barriers and discuss potential solutions.

Prognostication

Clinicians view prognostication as one of the most difficult parts of their profession [44], and many are reluctant to provide patients and their families with prognostic information due to fear of erring or losing credibility [45]. Uncertainty regarding prognostication and, therefore, identification of which patients are most likely to benefit from end-of-life conversations are common challenges in patients with advanced lung diseases.

Many forms of advanced lung diseases follow the disease trajectory prior to death commonly seen in organ failure [46, 47]. Similarly to patients with heart failure, the course is one of overall functional declines punctuated by intermittent decompensation (Fig. 9.1). During each episode of decompensation, patients deteriorate significantly and either succumb to their disease or recover to a lower level of functioning. It is difficult to predict the outcome of each deterioration. Further complicating the clinical picture, chronic organ failure may represent a comorbidity

Fig. 9.1 Functional decline prior to death due to organ failure. (Lunney et al. J Am Geriatr Soc) Acknowledgment wording: reproduced with permission of the © ERS 2020: Curtis [50]



that patients die with and not of. Physicians frequently cite difficulty in prognostication as a barrier to communication about palliative care and end of life in patients with organ failure [4, 48–51].

Findings from the SUPPORT study demonstrated the difficulty in prognostication of patients with chronic organ failure due to COPD compared to those with lung cancer. Using the Acute Physiology and Chronic Health Evaluation (APACHE) II model, they found that at 5 days prior to death, patients with lung cancer were predicted to have <10% chance of surviving 6 months and those with COPD were predicted to have >50% chance [52]. Despite the development of prognostic models specific to lung disease, prognostic accuracy remains challenging. One such prognostic model is the BODE (body mass index, airflow obstruction, dyspnea, exercise capacity) index. Of patients receiving the highest score on the BODE index, 62.3% were still alive at 3 years [53]. While this represents an improvement from broad prognostic models, such as APACHE II and FEV₁ alone, it is still not predictive of 6-month prognosis.

One potential solution to the challenge of accurate prognostication is shifting focus away from survival estimates and toward identifying patients who are relatively well and may benefit from end-of-life conversations. Universal factors associated with $\geq 50\%$ 6-month mortality in maximally treated disease include poor performance status, advanced age, malnutrition, comorbidities, organ dysfunction,

Table 9.1 Characteristics that should prompt discussion of end-of-life preferences for patients with COPD

FEV ₁ < 30%
Oxygen dependence
One or more hospital admission in the previous year for an acute exacerbation
Left heart failure or other comorbidities
Weight loss or cachexia
Decreased functional status
Increasing dependence on others
Age > 30 yrs
FEV ₁ forced vital capacity at 1 second

Adapted from Curtis [50]

Table 9.2 Disease-specific hospice eligibility criteria for patients with COPD (each criteria required)

1. Severe chronic lung disease as documented by both A and B
A. Disabling dyspnea at rest, poorly responsive or unresponsive to bronchodilators, resulting in decreased functional capacity. FEV ₁ after bronchodilators <30% predicted is objective evidence of disability dyspnea but it is not required
B. Progression evidenced by increasing visits to the hospital for pulmonary infections and/or respiratory infections or increasing physician home visits. Serial decrease of FEV ₁ > 40 ml/yr is objective evidence of disease progression, but is not a requirement
2. Hypoxemia at rest on room air, evidenced by PO ₂ ≤ 55 mmHg or oxygen saturation ≤ 88% on supplemental oxygen, or hypercapnea, evidenced by PCO ₂ ≥ 50 mmHg
3. Right heart failure due to pulmonary disease

and hospitalization for acute decompensation. Societies have proposed various options for identifying which patients are likely to benefit, all emphasizing the importance of early discussion. One such example was suggested by Curtis et al. to prompt discussion about end-of-life care for patients with COPD (Table 9.1) [50]. More broadly, clinicians can ask themselves “Would I be surprised if this patient died within the year?” An answer of “no” should prompt a discussion. This question has been shown to be moderately sensitive in predicting 1-year mortality, with a pooled sensitivity of 67% in meta-analysis [54]. Medicare eligibility for hospice is shown in Table 9.2. These criteria were found to have both poor sensitivity and specificity in identifying patients who would die within 6 months [55].

Each change in clinical status represents an opportunity to reassess the patient’s quality of life, determine whether it remains acceptable, and consider with the patient what brings value to their life. In the absence of definitive prognostic information, which is nearly uniformly elusive in clinical medicine, it is important to acknowledge the uncertainty of each patient’s future when communicating about end of life.

Perception or Fear of Harming the Patient or Provoking an Emotional Response

Clinicians caring for patients with advanced illness report fear of harming the patient by sharing upsetting prognostic information or discussing end-of-life care. In one study, 23% of physicians caring for patients with COPD cited concerns that discussing end-of-life care will take away their patient’s hope, and 21% felt the patient was not ready to talk about the care they would wish for if they got sicker [56]. Some patients do not wish to receive their physician’s prognostic information or discuss advance care planning and end-of-life preferences. In some cultures, it is believed that communicating unfavorable prognoses to the patient becomes a self-fulfilling prophecy. However, existing data suggests that most patients wish to receive this information and expect their physician to initiate discussions [57]. Absence of communication about prognosis has been associated with prolongation of the dying process, undesired hospitalizations, and patient mistrust in the healthcare system [34]. Research has also demonstrated that clinicians’ fear of removing patients’ hope is largely unfounded. In fact, nondisclosure is associated with decreased quality of life and increased rate of depression in survivors [58]. Patients and families with overly optimistic prognostic estimates were more likely to die following receipt of aggressive medical interventions, such as intubation or cardiopulmonary resuscitation, with no difference in outcomes [59].

Prognostic information provides a framework for patients to make informed treatment decisions and consider important aspects of life care planning, such as legacy planning, addressing personal relationships, and saying goodbye. By

Table 9.3 Discussing prognostic information

<i>Recommendations</i>
Ask how much prognostic information the patient wants
For patients who want explicit information, ask what kind of information
Frame statistical information positively and negatively
Offer to describe survival range in addition to a specific period
Consider a separate conversation with a family member who wants more information, with the patient's permission
For patients who do not want explicit information, explore their perspective

Adapted from Back [60]

balancing hope and reality, clinicians can potentially allow their patients to shift focus toward other, perhaps more attainable, goals while continuing to hold the hope for a better outcome. Clinicians can mitigate the potential for inflicting harm by eliciting patients' preferences for prognostic information. A proposed strategy is detailed in Table 9.3 [60].

Emotional distress associated with receipt of bad news can further be lessened by ensuring discussions take place in an appropriate setting, delivering the information tactfully, allowing the appropriate amount of time free of interruptions, and providing emotional support through verbal and nonverbal expressions of empathy. (See Section "[Lack of Comfort with Palliative Care Topics](#)")

Lack of Comfort with Palliative Care Topics

Medical education has long been deficient in end-of-life care and improving physicians' competencies has increasingly become a topic of focus. In a national survey, both medical students and residents perceived preparation for providing care at end of life was worse than other common clinical tasks [61]. Additionally, a national survey of internists revealed that 56.8% reported inadequate training in prognostication [44]. Teaching of communication skills should include focused skills practice and be integrated with biomedical training. Most clinicians have not received the skills training required to provide high-quality palliative care communication or teach others how to do so.

Symptom Management

Lung disease is a common cause of morbidity with similar symptom burden compared to cancer [1, 2]. However, patients with lung disease are less likely to have their symptoms elicited and, therefore, appropriately managed. Dyspnea is the most common symptom experienced by patients with advanced lung disease; however pain and mood disorders are also frequently encountered. The experience of

dyspnea increases in frequency and severity as death approaches. The primary goal in managing dyspnea is optimizing treatment of the patient's underlying disease. For patients with refractory dyspnea, there are options for non-pharmacologic and pharmacologic therapies. When dyspnea is refractory to non-pharmacologic management, systemic low-dose opiates are the first-line medication, serving as a safe and effective pharmacologic treatment for refractory dyspnea.

Despite numerous studies documenting the safety of opiates for treatment of dyspnea in patients with advanced lung disease, there remains stigma associated with prescribing opiates, and patients suffer from poor control of their dyspnea [62–64]. Commonly cited source of discomfort in prescribing includes insufficient knowledge, lack of experience, and fear of adverse effects [62, 63]. In one of these studies, physicians with palliative care experience were more comfortable prescribing opiates [63]. Interestingly, a study from France showed that despite high rates of refractory breathlessness among COPD patients and reported comfort among the majority of clinicians in prescribing opiates, the rates of prescribing opiates within this population were low [64]. These findings may suggest assessment and treatment of dyspnea lies in a failure to assess breathlessness and provide treatment. Based on these findings, clinicians may benefit from a trigger during outpatient visits to assess common distressing symptoms in patients with advanced lung disease.

Empiric studies have demonstrated that short-term use of opiates reduces breathlessness in patients with a variety of conditions, including COPD and interstitial lung disease [65–67]. A randomized controlled trial showed that sustained-released morphine had a positive effect on disease-specific health status in patients with moderate to very severe breathlessness [68]. Importantly, opioids have not been shown to significantly reduce oxygen saturation, raise arterial carbon dioxide, or reduced respiratory rate; however patients retaining carbon dioxide were excluded in most of these studies [69]. In 2011, the American College of Chest Physicians released a consensus statement recommending the use of opiates for relief of dyspnea in patients with advanced cardiopulmonary disease in consideration of comorbidities and titrated to individual effect [70]. Knowledge about this literature may help clinicians feel more comfortable engaging their patients in conversations about symptom management. Additionally, providers may consider referral to specialty palliative care for patients with advanced lung disease with multiple comorbidities or a baseline elevation in carbon dioxide experiencing refractory dyspnea.

Goals of Care Communication Skills

Specialized clinicians from a variety of fields that frequently care for patients with life-limiting illnesses report feeling inadequately trained to conduct end-of-life conversations [71–74]. Physicians specifically report difficulties with communicating prognoses, facilitating end-of-life decision-making, and managing the emotional responses these conversations naturally uncover [75, 76]. In response, national

leaders and experts in communicating with seriously ill patients have developed multiple frameworks for approaching these core communication skills.

Each of these communication tasks is recommended to take place in a comfortable and private place. Every attempt should be made to minimize interruptions and allow an appropriate amount of time. Prior to engaging in the conversations, clinicians should ask whether the patient would like to have support persons present and assess preferences regarding receipt of prognostic information.

Responding to Emotion

The experience of advanced illness and receipt of medical information challenging patient's hopes and expectations for the future evokes intense negative emotions. While clinicians may be unable to restore a patient's health, research demonstrates that providing support lessens the experience of emotional distress. Additionally, when patients are experiencing emotions, they are unable to process medical information effectively. Attending emotions will also bring them into the person's awareness and allow them to shift away from them toward a cognitive state capable of planning complex behaviors and decision-making. Lastly, studies demonstrate that patients have higher trust for the clinicians when they respond to emotion which leads to greater shared decision-making [77].

Clinicians can show emotional support by listening and expressing empathy both verbally and nonverbally. The acronym N-U-R-S-E [78] summarizes how to respond verbally to emotion (Table 9.4).

Table 9.4 Verbal responses to emotion

Recommendation	Example
N: <i>Name</i> the emotion	"This news is so shocking."
U: <i>Understand</i> the emotion	"I can't imagine what you are going through."
R: Respect (praise) the patient or surrogate	"I can see you have been here and advocated for your mother every step of the way."
S: <i>Support</i> the patient or surrogate	"You are not alone in this."
E: <i>Explore</i> the emotion	"Tell me more."

Table 9.5 Delivering serious news

Recommendation	Example
<i>Ask</i> : Assess the patient's understanding of the situation	"What have you been told about your current medical condition?" "What is your sense of how things are going."
<i>Tell</i> : Provide medical information and frame how the information impacts outcomes meaningful to the patient	"We are worried she may not be able to return to living independently after this hospitalization."
<i>Ask</i> : Check understanding	"What questions do you have?"

Table 9.6 Goals of care discussions

Recommendation	Example
R: <i>Reframe</i> the situation, why the status quo is not working	“Things have changed over the past few months. Your lungs are getting sicker and I’m worried time is short.”
E: Expect <i>emotion</i> and empathize	“This must be shocking news.”
M: <i>Map</i> what is important	“Given this information, what worries you the most?” “What are you hoping for?”
A: <i>Align</i> with the patient and family values	“It sounds like you are hoping for more good time, interacting with family and being at home, and less time in the hospital.”
P: <i>Plan</i> medical treatments that match patient values	“I recommend we continue treating your symptoms aggressively and work to keep you at home. When your body gets sicker, we will respect that and allow you to pass naturally.”

Giving Serious News

Sharing serious news is difficult for clinicians who struggle with feelings of apprehension at the prospect of causing distress, fear of provoking an emotional response, and professional failure when unable to protect their patients from disease. Despite these difficulties, patients require an understanding of the medical situation to make value-based treatment decisions and plan for the future.

Evidence-based recommendations for giving serious news are organized into the Ask-Tell-Ask framework summarized in Table 9.5 [79]. The first “Ask” refers to eliciting the patient’s understanding of the medical situation. This is followed by “Tell,” consisting of labeling the news to give them a chance to emotionally prepare for the news. When the news or headline is then shared, clinicians should be concise, use simple language, and refer to outcomes that are meaningful to the patients. The last “Ask” is to check understanding or check in with the patient.

Engaging in Decision-Making

VitalTalk designed REMAP as a road map for goals of care conversations to increase the quality and efficiency of conversations and make communication skills easier to learn [80]. The acronym serves a conversation guide toward reaching a patient-centered and shared decision. Table 9.6 details each step with accompanying example statements. The conversation begins with clinicians ensuring the patient or their surrogates are on the same page in terms of medical information. Sometimes, clinicians will have additional news to communicate (see sharing serious news above.) Throughout the conversation, clinicians will need to recognize and respond to emotion, particularly after communicating difficult news. If the patient or their surrogate is on the same page as clinicians and is prepared to talk further, the next step is to explore values and preferences in light of the medical situation. Throughout the conversation, it is also recommended to reflect what you are hearing to ensure you are aligned with the patient and family. Lastly, after gathering sufficient

Table 9.7 Summary of barriers and potential solutions for clinicians when communicating about palliative care issues

Barriers	Potential solutions
Difficulty with prognostication	<p>Ensure early goals of care discussion by identifying patients at risk for death when patients are relatively well. When prognosis is uncertain, acknowledge uncertainty and focus on patient's values and goals</p> <p>Consider using the following criteria to identify patients at risk for death and trigger conversations in the outpatient setting:</p> <p>Universal factors associated with $\geq 50\%$ 6-month mortality in maximally treated disease:</p> <p>Poor performance status, advanced age, malnutrition, comorbidities, organ dysfunction, and hospitalization for acute decompensation</p> <p>Characteristics recommended for patients with COPD:</p> <p>FEV₁ < 30% predicted, oxygen dependence, one or more hospital admission in the previous year for an acute exacerbation of COPD, left heart failure or other comorbidities, weight loss or cachexia, decreased functional status, increasing dependence on others, age > 70 years (Curtis, Eur Resp J, 2008)</p> <p>Surprise question: "Would I be surprised if this patient died within the year?"</p>
Fear of destroying hope or provoking an emotional response	<p>Existing data shows that most patients wish to receive prognostic information and expect their physician to initiate discussions [57]</p> <p>Clinician's fear of removing hope is largely unfounded. Nondisclosure is associated with decreased quality of life and increased rate of depression in survivors [58]</p> <p>Alleviate emotional distress associated with receipt of serious news by eliciting preferences for prognostic information and providing emotional support [60]</p>
Lack of comfort with palliative care topics	<p><i>Symptom management:</i></p> <p>Include trigger for evaluation of distressing symptoms during outpatient visits for patients with advanced lung diseases</p> <p>Knowledge of existing literature and experience with palliative care may mitigate clinicians' concerns regarding prescription of opiates for dyspnea</p> <p>Physicians may consider referral to specialty palliative care providers for symptom management</p> <p>Frameworks exist to assist clinicians in navigating communication tasks (see Tables 9.3, 9.4, 9.5, 9.6, and 9.7) including:</p> <p>Responding to emotion</p> <p>Giving serious news</p> <p>Goals of care discussions</p> <p>Training programs emphasizing these frameworks allow clinicians to practice communication skills through interactive case-based sessions. These training programs have been shown to demonstrate improvement in clinician communication skills</p>
Fragmented healthcare system	<p>Collaborate with your patient's general and other subspecialty providers to decide who is primarily responsible for discussing end-of-life issues and symptom management</p> <p>Designate a site within the electronic medical record where documentation regarding patients elected surrogate decision-maker, values, preferences, and goals of care conversations can be found and iteratively refined over the course of their illness. Healthcare systems should collaborate to make documentation readily accessible to providers from different systems</p>

information, VitalTalk recommends at least three mapping questions, you can offer a patient-centered recommendation based off the information provided.

Palliative Care Communication in a Fragmented Healthcare System

Over the past decade, patient care has become increasingly complex. An individual's exposure to healthcare is likely to be spread across multiple providers, practice settings, and even healthcare systems. The resulting diffusion of responsibility and difficulty accessing prior medical documentation make iterative communication about goals of care and symptom management challenging and compound the barriers to communicating about palliative care (Table 9.7).

We know that patients often expect their providers to initiate discussions regarding prognosis and goals of care [51]. However, prior studies have demonstrated that a physician's decision to share prognosis is often based on whether the patient made a specific request [57]. A survey of general practitioners caring for patients with COPD in the United Kingdom found that 41% reported discussing prognosis often or always and 15% rarely or never and 30% left it for patients or their relatives to raise the subject [81]. There is also ambiguity among providers about who is responsible, specialists or general practitioners. A systematic review and narrative synthesis found that no single group of healthcare providers felt that their roles, relationships with patients, or work setting made them the most appropriate to have goals of care conversations with their patients with COPD [48]. Primary care physicians report uncertainty regarding their role in goals of care discussions when specialty providers are involved [51].

Further challenges arise with the documentation of goals of care conversations. A variety of clinicians may engage patients with advanced lung diseases in conversations about goals of care without communication or documentation to guide further discussions as the patient continues along the trajectory of their illness. Even if a clinician documents goals of care conversations, it may not be easily retrieved or accessible to providers from other healthcare systems. Among patients who had previously completed an advance directive, only 26% had it recognized during a hospitalization [82]. There is no standardization for the location of advance care planning or goals of care documentation [51]. A study exploring the location of advance care planning documentation within an electronic health record showed only 33.5% of patients with documentation had a scanned document and the remainder were within a progress note or problem list [83]. Lastly, the situation may be further complicated when visits with outpatient providers and hospital exposures occur across different healthcare systems with distinct EHR that do not communicate.

When multiple clinicians are caring for a patient, the oncologic literature recommends collaboration among providers to decide who will be primarily responsible for discussing prognosis and end-of-life care then ensuring the other providers are

aware of the outcome of discussions [84]. Healthcare systems would benefit from a designated site within the EHR where an iterative account of the patient's wishes, values, and preferences in light of the current medical situation can be located. Ideally, this site would be readily accessible across healthcare systems.

References

1. Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*. 2000;55(12):1000–6.
2. White P, White S, Edmonds P, et al. Palliative care or end-of-life care in advanced chronic obstructive pulmonary disease: a prospective community survey. *Br J Gen Pract*. 2011;61(587):e362–70.
3. Curtis JR, Engelberg RA, Wenrich MD, Au DH. Communication about palliative care for patients with chronic obstructive pulmonary disease. *J Palliat Care*. 2005;21(3):157–64.
4. Tavares N, Jarrett N, Hunt K, Wilkinson T. Palliative and end-of-life care conversations in COPD: a systematic literature review. *ERJ Open Res*. 2017;3(2):00068–2016.
5. Heffner JE, Fahy B, Hilling L, Barbieri C. Attitudes regarding advance directives among patients in pulmonary rehabilitation. *Am J Respir Crit Care Med*. 1996;154(6 Pt 1):1735–40.
6. Houben CH, Spruit MA, Schols JM, Wouters EF, Janssen DJ. Patient-clinician communication about end-of-life care in patients with advanced chronic organ failure during one year. *J Pain Symptom Manag*. 2015;49(6):1109–15.
7. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Patients' perspectives on physician skill in end-of-life care: differences between patients with COPD, cancer, and AIDS. *Chest*. 2002;122(1):356–62.
8. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the “elephant in the room”. *JAMA*. 2000;284(19):2502–7.
9. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med*. 2011;154(5):336–46.
10. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995;274(20):1591–1598.
11. Cameron JI, Wittenberg E, Prosser LA. Caregivers and families of critically ill patients. *N Engl J Med*. 2016;375(10):1001.
12. Cameron JI, Chu LM, Matte A, et al. One-year outcomes in caregivers of critically ill patients. *N Engl J Med*. 2016;374(19):1831–41.
13. Kross EK, Engelberg RA, Gries CJ, Nielsen EL, Zatzick D, Curtis JR. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. *Chest*. 2011;139(4):795–801.
14. Gries CJ, Engelberg RA, Kross EK, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *Chest*. 2010;137(2):280–7.
15. Miyajima K, Fujisawa D, Yoshimura K, et al. Association between quality of end-of-life care and possible complicated grief among bereaved family members. *J Palliat Med*. 2014;17(9):1025–31.
16. Prigerson HG, Bierhals AJ, Kasl SV, et al. Traumatic grief as a risk factor for mental and physical morbidity. *Am J Psychiatry*. 1997;154(5):616–23.
17. Boelen PA, van den Bout J. Complicated grief and uncomplicated grief are distinguishable constructs. *Psychiatry Res*. 2008;157(1–3):311–4.
18. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665–73.

19. Ray A, Block SD, Friedlander RJ, Zhang B, Maciejewski PK, Prigerson HG. Peaceful awareness in patients with advanced cancer. *J Palliat Med.* 2006;9(6):1359–68.
20. Ramirez AJ, Graham J, Richards MA, et al. Burnout and psychiatric disorder among cancer clinicians. *Br J Cancer.* 1995;71(6):1263–9.
21. Clayton JM, Butow PN, Waters A, et al. Evaluation of a novel individualised communication-skills training intervention to improve doctors' confidence and skills in end-of-life communication. *Palliat Med.* 2013;27(3):236–43.
22. Dzeng E. Moral distress amongst physician trainees regarding futile treatments. *J Gen Intern Med.* 2016;31(8):830.
23. Rushton CH, Batcheller J, Schroeder K, Donohue P. Burnout and resilience among nurses practicing in high-intensity settings. *Am J Crit Care.* 2015;24(5):412–20.
24. Dzeng E, Curtis JR. Understanding ethical climate, moral distress, and burnout: a novel tool and a conceptual framework. *BMJ Qual Saf.* 2018;27(10):766–70.
25. Bianchi R, Schonfeld IS, Laurent E. Burnout-depression overlap: a review. *Clin Psychol Rev.* 2015;36:28–41.
26. Oreskovich MR, Kaups KL, Balch CM, et al. Prevalence of alcohol use disorders among American surgeons. *Arch Surg.* 2012;147(2):168–74.
27. Shanafelt TD, Balch CM, Dyrbye L, et al. Special report: suicidal ideation among American surgeons. *Arch Surg.* 2011;146(1):54–62.
28. Shanafelt T, Sloan J, Satele D, Balch C. Why do surgeons consider leaving practice? *J Am Coll Surg.* 2011;212(3):421–2.
29. Shanafelt TD, Balch CM, Bechamps G, et al. Burnout and medical errors among American surgeons. *Ann Surg.* 2010;251(6):995–1000.
30. West CP, Huschka MM, Novotny PJ, et al. Association of perceived medical errors with resident distress and empathy: a prospective longitudinal study. *JAMA.* 2006;296(9):1071–8.
31. Wright AA, Katz IT. Beyond burnout - redesigning care to restore meaning and sanity for physicians. *N Engl J Med.* 2018;378(4):309–11.
32. Dzau VJ, Kirch DG, Nasca TJ. To care is human – collectively confronting the clinician-burnout crisis. *N Engl J Med.* 2018;378(4):312–4.
33. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med.* 2010;362(13):1211–8.
34. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol.* 2010;28(7):1203–8.
35. Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Soc Sci Med.* 1999;49(6):727–36.
36. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manag.* 2006;31(1):58–69.
37. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010;363(8):733–42.
38. Kavalieratos D, Corbelli J, Zhang D, et al. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *JAMA.* 2016;316(20):2104–14.
39. Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM. Mental health of hospital consultants: the effects of stress and satisfaction at work. *Lancet.* 1996;347(9003):724–8.
40. Jackson VA, Mack J, Matsuyama R, et al. A qualitative study of oncologists' approaches to end-of-life care. *J Palliat Med.* 2008;11(6):893–906.
41. Graham J, Potts HW, Ramirez AJ. Stress and burnout in doctors. *Lancet.* 2002;360(9349):1975–6; author reply 1976
42. Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med.* 2009;169(5):480–8.
43. Lanken PN, Terry PB, Delisser HM, et al. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med.* 2008;177(8):912–27.

44. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med.* 1998;158(21):2389–95.
45. Christakis NA. *Death foretold : prophecy and prognosis in medical care.* Chicago: University of Chicago; 1999.
46. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc.* 2002;50(6):1108–12.
47. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. *JAMA.* 2003;289(18):2387–92.
48. Momen N, Hadfield P, Kuhn I, Smith E, Barclay S. Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis. *Thorax.* 2012;67(9):777–80.
49. Crawford A. Respiratory practitioners' experience of end-of-life discussions in COPD. *Br J Nurs.* 2010;19(18):1164–9.
50. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J.* 2008;32(3):796–803.
51. Bernacki RE, Block SD, American College of Physicians High Value Care Task F. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med.* 2014;174(12):1994–2003.
52. Claessens MT, Lynn J, Zhong Z, et al. Dying with lung cancer or chronic obstructive pulmonary disease: insights from SUPPORT. Study to understand prognoses and preferences for outcomes and risks of treatments. *J Am Geriatr Soc.* 2000;48(S1):S146–53.
53. Esteban C, Quintana JM, Moraza J, et al. BODE-index vs HADO-score in chronic obstructive pulmonary disease: which one to use in general practice? *BMC Med.* 2010;8:28.
54. Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NK. The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ.* 2017;189(13):E484–93.
55. Fox E, Landrum-McNiff K, Zhong Z, Dawson NV, Wu AW, Lynn J. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. SUPPORT investigators. Study to understand prognoses and preferences for outcomes and risks of treatments. *JAMA.* 1999;282(17):1638–45.
56. Knauff E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest.* 2005;127(6):2188–96.
57. Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med.* 2007;21(6):507–17.
58. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol.* 2005;23(6):1278–88.
59. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA.* 1998;279(21):1709–14.
60. Back AL, Anderson WG, Bunch L, et al. Communication about cancer near the end of life. *Cancer.* 2008;113(7 Suppl):1897–910.
61. Billings JA, Block S. Palliative care in undergraduate medical education. Status report and future directions. *JAMA.* 1997;278(9):733–8.
62. Janssen DJ, de Hosson SM, bij de Vaate E, Mooren KJ, Baas AA. Attitudes toward opioids for refractory dyspnea in COPD among Dutch chest physicians. *Chron Respir Dis.* 2015;12(2):85–92.
63. Young J, Donahue M, Farquhar M, Simpson C, Rocker G. Using opioids to treat dyspnea in advanced COPD: attitudes and experiences of family physicians and respiratory therapists. *Can Fam Physician.* 2012;58(7):e401–7.
64. Carette H, Zysman M, Morelot-Panzini C, et al. Prevalence and management of chronic breathlessness in COPD in a tertiary care center. *BMC Pulm Med.* 2019;19(1):95.
65. Ekstrom M, Nilsson F, Abernethy AA, Currow DC. Effects of opioids on breathlessness and exercise capacity in chronic obstructive pulmonary disease. A systematic review. *Ann Am Thorac Soc.* 2015;12(7):1079–92.

66. Allen S, Raut S, Woollard J, Vassallo M. Low dose diamorphine reduces breathlessness without causing a fall in oxygen saturation in elderly patients with end-stage idiopathic pulmonary fibrosis. *Palliat Med.* 2005;19(2):128–30.
67. Parshall MB, Schwartzstein RM, Adams L, et al. An official American Thoracic Society statement: update on the mechanisms, assessment, and management of dyspnea. *Am J Respir Crit Care Med.* 2012;185(4):435–52.
68. Verberkt CA, van den Beuken-van Everdingen MHJ, Schols J, Hameleers N, Wouters EFM, Janssen DJA. Effect of sustained-release morphine for refractory breathlessness in chronic obstructive pulmonary disease on health status: a randomized clinical trial. *JAMA Intern Med.* 2020;180(10):1306–14.
69. Barnes H, McDonald J, Smallwood N, Manser R. Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. *Cochrane Database Syst Rev.* 2016;3:CD011008.
70. Mahler DA, Selecky PA, Harrod CG, et al. American College of Chest Physicians consensus statement on the management of dyspnea in patients with advanced lung or heart disease. *Chest.* 2010;137(3):674–91.
71. Buss MK, Lessen DS, Sullivan AM, Von Roenn J, Arnold RM, Block SD. Hematology/oncology fellows' training in palliative care: results of a national survey. *Cancer.* 2011;117(18):4304–11.
72. Kelley AS, Back AL, Arnold RM, et al. Geritalk: communication skills training for geriatric and palliative medicine fellows. *J Am Geriatr Soc.* 2012;60(2):332–7.
73. Arnold RM, Back AL, Barnato AE, et al. The critical care communication project: improving fellows' communication skills. *J Crit Care.* 2015;30(2):250–4.
74. Holley JL, Carmody SS, Moss AH, et al. The need for end-of-life care training in nephrology: national survey results of nephrology fellows. *Am J Kidney Dis.* 2003;42(4):813–20.
75. Jones L, Harrington J, Barlow CA, et al. Advance care planning in advanced cancer: can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Palliat Support Care.* 2011;9(1):3–13.
76. Wenrich MD, Curtis JR, Ambrozy DA, Carline JD, Shannon SE, Ramsey PG. Dying patients' need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *J Pain Symptom Manag.* 2003;25(3):236–46.
77. Tulsky JA, Arnold RM, Alexander SC, et al. Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Ann Intern Med.* 2011;155(9):593–601.
78. Smith RC, Hoppe RB. The patient's story: integrating the patient- and physician-centered approaches to interviewing. *Ann Intern Med.* 1991;115(6):470–7.
79. Back AL, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. *CA Cancer J Clin.* 2005;55(3):164–77.
80. Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: a framework for goals of care conversations. *J Oncol Pract.* 2017;13(10):e844–50.
81. Elkington H, White P, Higgs R, Pettinari CJ. GPs' views of discussions of prognosis in severe COPD. *Fam Pract.* 2001;18(4):440–4.
82. Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT investigators. Study to understand prognoses and preferences for risks and outcomes of treatment. *J Am Geriatr Soc.* 1998;46(10):1242–50.
83. Wilson CJ, Newman J, Tapper S, et al. Multiple locations of advance care planning documentation in an electronic health record: are they easy to find? *J Palliat Med.* 2013;16(9):1089–94.
84. Back AL, Young JP, McCown E, et al. Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: loss of continuity and lack of closure. *Arch Intern Med.* 2009;169(5):474–9.