Published in final edited form as:

Clin Chest Med. 2007 December ; 28(4): 801–vii.

End of life considerations in older patients with lung disease

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Abstract

The goal of palliative care is to prevent suffering and manage symptoms, maintain quality of life, and to provide physical, emotional, and spiritual support for patients and their loved ones. Currently, palliative care measures focus largely on patients with cancer and these models have not been effectively applied to patients with chronic lung disease. Patients with lung disease have a reduced quality of life and a burden of symptoms that is at least as great, if not greater than, patients with cancer, and they commonly experience significant pain, dyspnea, and fatigue. In addition, dementia and delirium can often play a significant role in older patients. Research suggests that patients with chronic lung disease receive suboptimal palliative care due in large part to inadequate communication with their physicians. When patients have made decisions about life-sustaining therapies, physicians often either don't know the patients' wishes or misunderstand them. Additionally, depression, which is common in older patients with chronic illness, may influence patients' decisions about end-of-life care. Clinicians should realize that the vast majority of patients want more information about end-of-life care and that efforts to initiate and improve communication with their patients are important. This article reviews the potential for enhanced palliative care for older patients with chronic lung disease.

Keywords

End-of-life care; communication; decision-making; palliative care; burden of symptoms

Introduction

The United States population, as well as populations throughout the world, is aging at increasing rates, and the proportion of people over age 65 years is growing faster than any other age group.(1) It has been estimated that by 2030, over 20% of Americans will be age 65 or older.(2) This increase in longevity, however, means that the geriatric population comprises a larger proportion of people nearing the end of life and translates into more deaths resulting from chronic, rather than acute, illnesses.(3) The median age at death in the U.S. is now 77 years, with the vast majority of deaths occurring after age 65.(2) Some literature has suggested that the last year of life is often associated with multiple unpleasant symptoms and marked

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reductions in quality of life.(4) Therefore, improvements in palliative care for older patients is an important public health issue.(5)

With the aging population, lung disease has become a major cause of morbidity and mortality worldwide. Chronic obstructive pulmonary disease (COPD) is the 4th leading cause of death in the United States exceeded only by heart disease, cancer, and stroke.(6,7) While mortality from cardiovascular disease, stroke, and cancer has decreased over the last two decades, COPD mortality in the U.S. has doubled and is increasing worldwide.(8-10) Although mortality and morbidity from COPD vary considerably around the world, it is leading cause of death in both developed and developing countries.(7,10) Lung cancer, another category of lung disease that substantially contributes to mortality, is the leading cause of cancer deaths in the United States, and its death rate is rapidly increasing in developing countries.(11,12)

Along with mortality, healthcare utilization among patients with lung disease is also increasing exponentially. Patients with COPD in developed countries are often hospitalized three or four times per year, and many of these hospitalizations are in an intensive care unit (ICU).(13-15) In 2005, the National Heart, Lung, and Blood Institute reported that the annual direct health care costs for COPD were almost \$22 billion, and the indirect costs (lost productivity and work days) were approximately \$17 billion.(16)

Palliative care includes management of symptoms; preservation of quality of life; communication with patients and their loved ones; and support of the physical, emotional, and spiritual well-being for patients and families.(17) As the population ages, the prevalence of lung disease and other chronic diseases increases, the burden of symptoms enlarges, and as there are more deaths from lung disease, there is a strong and increasing need for palliative care and end-of-life services for these patients.(18,19) Some research, mostly in patients with cancer, has shown that delivery of palliative care is associated with reductions in pain and other symptoms, improvements in quality of life, and enhanced family and patient satisfaction.(20-24) Additionally, a recent study has also shown that receipt of hospital-based palliative care services is associated with significantly lower likelihood of admission to an ICU and lower inpatient costs.(25) Therefore, available data suggests that high-quality palliative care leads to both improved patient- and family-centered outcomes and decreased costs. It is the intent of this review to highlight the major factors involved in providing palliative and end-of-life care to older patients with lung diseases.

Quality of life and burden of symptoms in older patients with lung diseases

Much literature over the past few decades has focused on symptom management and palliative care in patients with cancer.(26) In contrast, only a few studies have examined quality of life and the burden of symptoms in chronic nonmalignant lung diseases, and the vast majority of these are in patients with COPD.

Several studies have found that patients with COPD have a reduced health-related quality of life,(27-31) and in most studies physical, emotional, and social functioning is significantly decreased. Quality of life is also significantly reduced in other lung diseases such as idiopathic pulmonary fibrosis and sarcoidosis.(32,33) The burden of symptoms in these patients is also high and tends to correlate with larger reductions in quality of life.

Using standardized questionnaires and interviews, Gore et al. compared symptoms and morbidity between 50 patients with severe COPD (FEV1 <0.75L and at least one admission for respiratory failure) and 50 patients with inoperable non-small cell lung cancer.(34) The authors found that the patients with COPD had significantly worse physical, social, and emotional functioning ($p<0.05$) and more anxiety and depression (90% versus 52%, respectively) than the cancer patients. Only 4% of patients in each group reported having been

assessed or treated for mental health issues. Additionally, 82% of the COPD patients were housebound, and 36% were chairbound, compared to 36% and 10% of lung cancer patients, respectively.

As part of the U.S.-based SUPPORT project (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments)(35), Lynn et al. studied a cohort of 426 patients with COPD who died within one year of their index hospital admission for a COPD exacerbation. (36) Nearly 40% of patients had three or more comorbid illnesses, and between 15% and 25% of the patients' last six months of life was spent in a hospital. Twenty-five percent of patients had serious pain throughout their last six months of life and 66% had serious dyspnea. Families were also substantially impacted. In another study from SUPPORT that examined burden of symptoms, Claessens and colleagues compared patients with severe COPD to patients with advanced non-small cell lung cancer.(37) These authors found that pain and breathlessness were common symptoms in both groups. Among COPD patients, 56% of patients had severe dyspnea and 21% had severe pain; while among lung cancer patients 32% had severe dyspnea and 28% had severe pain.

A recent retrospective study in the UK by Elkington et al., proxies of patients who died from COPD were queried about their loved ones symptoms in the last year of life.(38) Breathlessness was present in 98% of patients; fatigue, weakness, low mood, and pain were also very common. Finally, Solano et al. recently published a systematic review of studies reporting the prevalence of physical symptoms in patients with five progressive diseases (advanced cancer, the acquired immunodeficiency syndrome, heart disease, COPD, and renal disease).(39) There were three common symptoms that were present in over 50% of patients across all five diseases: pain, breathlessness, and fatigue.

Together, the literature on the experiences of patients with COPD certainly suggests that these patients have a reduced quality of life and a heavy burden of symptoms that is at least as great, if not greater, than patients with advanced lung cancer. The most common symptoms are dyspnea, pain, fatigue, and depression (discussed separately below). While this information is informative and definitely applies to older patients with lung diseases (the average age of all the patients in these studies was approximately 70 years), there are other symptomatic considerations in the geriatric population. Not surprisingly, older patients may differ from younger patients both medically and psychosocially, and they have a higher likelihood of having particular syndromes such as dementia or delirium.(40)

The prevalence of dementia is estimated to be 1% of persons ages 60-65 years and increases to 40% of those over 80 years of age.(41) One recent study by Evers et al. compared palliative care consultations in patients over 80 years to those in younger patients.(42) The authors found that patients over age 80 had a much higher prevalence of dementia and incapacity for decision-making, and a lower prevalence of cancer. Dementia, especially as it progresses, is often associated with a reduced life span, particularly when combined with another event such as a hip fracture or pneumonia.(43) Concomitant dementia affects the prognosis of other chronic illnesses as well as medical decision-making, and since many patients with dementia are unable to make their own decisions, involvement of and communication with loved ones and family members is crucial.

Delirium is also a very common in older patients. It is present in approximately 30% of all hospitalized older adults and 50% of all older adults undergoing surgery.(44) More than half of nursing home patients and more than 80% of dying patients develop delirium.(45,46) Delirium often happens during acute illness, and a subsequent prolonged period of cognitive impairment can follow.(47) Delirium is also a risk factor for mortality, functional decline, and institutionalization.(48-50)

Overall, physical symptoms such as pain and dyspnea are highly prevalent in older patients with lung disease as are syndromes such as dementia and delirium. These symptoms and conditions in older patients are major causes of suffering and play a significant role in morbidity, and it appears that they may be under-recognized and under-treated in this group of patients.

Palliative care, communication, and decision-making about end-of-life issues

Several studies have suggested that the quality of and access to palliative care is not adequate for patients with chronic lung disease, particularly with COPD. The SUPPORT study found that patients with COPD were significantly more likely to die in the ICU and on mechanical ventilation, when compared to patients with lung cancer, despite generally wanting care that focused on comfort.(37) In the study by Gore et al. comparing patients with advanced COPD to those with inoperable lung cancer, none of the COPD patients had been offered or received input from palliative care specialists, while 30% of the cancer patients had received such care and 56% were aware of these services.(34) Additionally, Au et al. recently published a large cohort study comparing health care utilization at the end of life between US veterans with COPD and lung cancer.(51) During the last six months of life, patients with COPD were two times more likely to be admitted to the ICU, were five times more likely to be in an ICU longer than two weeks, and received fewer palliative medications.

While it appears that patients with nonmalignant lung diseases receive less palliative care than patients with cancer, the reasons for this discrepancy are not entirely clear. Whereas patients with cancer often predictably decline until death, patients with chronic respiratory diseases such as COPD usually deteriorate slowly until an unpredictable exacerbation changes prognosis or leads to death.(52) Hence, some authors have suggested that the differences may be due to physicians' inability to provide accurate prognostic information toward the end of life in patients with COPD since estimating life expectancy is difficult in chronic lung disease.(53) The SUPPORT study found that both physicians and prediction models were quite poor at predicting death in COPD patients, even five days prior to death.(37) Additionally, although disease-specific predictive models for death in COPD patients at the population level have been developed,(54,55) it is likely that accurate prognostication in an individual will remain difficult due to the variability inherent with chronic lung diseases. This has led to the proposal that educating patients and families about the uncertainty in prognosis of lung diseases must be an essential feature of end-of-life care and decision-making.(53)

Research has also shown that physician-patient communication about end-of-life issues and treatment preferences is commonly inadequate. Heffner et al. asked 105 patients with chronic lung disease about their attitudes regarding advanced directives.(56) Less than half of the patients had completed an advanced directive, and while nearly all participants wanted information about advanced directives and life support, less than 20% had had such discussions with their doctors and fewer than 15% felt that their doctors understood their wishes. In a study of 115 patients with oxygen-dependent COPD, Curtis et al. found that only one third of patients had discussed end-of-life care with their physicians.(57) Most patients reported that their physicians did not discuss how long the patients had to live, what dying might be like, or patients' spirituality. Additionally, in a qualitative study, Curtis and colleagues found that in comparison to patients with AIDS and cancer, patients with COPD were more likely to be troubled about the lack of education they had received about their disease and were more likely to want more information from their physicians about a number of topics including prognosis, advance care planning, and what dying might be like.(58)

Since patient-physician communication about the end-of-life appears to be insufficient and leaves many patients with unmet needs, it is important that we understand the barriers to

effective communication. Two studies have investigated such barriers, one a U.S. study of perceptions of both patients and physicians(59) and the other a UK study of the views of general practitioners.(60) Barriers for patients to communicate about palliative care include wanting to focus on staying alive, unwillingness to discuss being sick, changing treatment preferences, and lack of knowledge about the type of care and about who the treating physician will be in the event of an acute illness. Barriers for physicians include feeling ill-prepared to discuss the issue adequately, lack of accurate prognostic information, lack of time, and finding it difficult to start these discussions with patients.

Even when communication between physicians and patients does occur, there may be a mismatch of expectations when making decisions about end of life treatment preferences. In a study of over 5000 seriously ill patients (one third had COPD or respiratory failure), Wenger et al. found that 64% of patients wished to receive cardiopulmonary resuscitation (CPR) and 36% of patients wanted to forgo it.(61) When patients wanted to receive CPR, physicians clearly understood their preferences 86% of the time. However, physicians only understood the patients' wishes 46% of the time among patients wanting to forgo CPR. As a result of this misunderstanding, many patients who wished to forgo CPR in this study underwent a resuscitation attempt, most of who died in the hospital.

One aspect of communication with older adults that is important for physicians to understand is the increased importance that older adults place on the burden of treatments. For younger adults, the burden of treatments is relatively less important, but it becomes a much more important issue with increased age.(62,63) Consequently, physicians should include a discussion of the potential burdens of short and long-term mechanical ventilation in their discussions of treatment preferences with older adults.

Current available data indicates that palliative care for patients with lung diseases is often inadequate. This inadequacy may be due in large part to poor or infrequent patient-physician communication about end-of-life care and treatment preferences. Many barriers to effective communication exist, and understanding these barriers is likely an important step toward improving communication.

Role of depression in decision-making

As discussed above, depression frequently complicates the care of both older patients and patients with chronic lung diseases. Approximately 2% of older people in the community and 9% of older chronically ill adults are depressed compared with 6% of the general adult population.(64) Geriatric inpatients and nursing home residents have a much higher prevalence of depression, estimated between 36% and 47%.(65,66) Using the Geriatric Depression Scale and the Medical Outcome Survey--Short Form 36 (SF-36) to assess depression in 109 patients with severe COPD (mean age 71 years), Lacasse et al. found that 57% of patients had significant depressive symptoms and that 18% were severely depressed.(67) Only 6% of patients who met the criteria for depression were taking an antidepressant drug. In another investigation, van Manen et al. examined depressive symptoms in COPD patients and in controls and found that the prevalence of depression was 25.0% in patients with severe COPD (forced expiratory volume in one second [FEV₁] < 50% predicted), 17.5% in controls, and 19.6% in patients with mild moderate COPD.(68)

We examined 101 patients with oxygen-dependent COPD (mean age 67.4 years), and 45% of patients had symptoms suggestive of depression as measured by the Center for Epidemiologic Study – Depression (CES-D) survey.(69) We found that a higher burden of depressive symptoms in these patients was significantly associated with a preference against CPR. These findings are similar to two other studies, neither of which specifically investigated patients with COPD.(70,71) A prior report from the same group of patients showed that patients with

depression rated the quality of patient-physician communication about end-of-life care significantly lower than those without depression.(57) It is not clear whether this finding reflects an effect of depression on patients' ratings of the quality of communication or whether the quality of patient-physician communication is negatively influenced by depression.

The fact that depression may influence decision-making about life-sustaining therapies implies that treatment of depression might change end-of-life treatment preferences for these patients, and several studies have examined this hypothesis. The SUPPORT study found that among patients who initially preferred do not resuscitate (DNR) status, those whose depression score improved substantially over two months of follow-up were five times more likely to change treatment preferences to wanting CPR than those patients whose depression scores did not improve.(71) Ganzini et al. examined the treatment preferences of forty-three elderly depressed patients before and after treatment of the depression and found a clinically evident change in the preferences of the eleven patients who had initially been rated as more severely depressed. (72) Eggar and colleagues also investigated the CPR preferences of forty-nine older depressed patients before and after depression treatment and found that sixteen of seventeen patients who initially declined CPR accepted CPR after treatment for depression.(73)

Coexisting depression plays a significant role in decision-making at the end of life because it appears that depression may influence treatment preferences for life-sustaining therapies. Since prior research suggests that clinical depression among patients with severe COPD responds to anti-depressant therapy,(74) clinicians caring for older patients with lung diseases should evaluate patients for depression and should realize that spontaneous or therapy-induced improvement in depressive symptoms should warrant a reassessment of patients' treatment preferences.

Talking about end-of-life care with patients and their families

When should we talk about end-of-life care with patients and families?

It is difficult to be prescriptive about the "right" time to discuss end-of-life care with older patients who have chronic lung disease, except to say that we should talk about it as soon as possible and earlier than we usually do. Oftentimes, clinicians fail to discuss end of life issues and treatment preferences while their patients are relatively well and able to participate in decision-making. If these discussions do not take place and goals of care are not established, and the patient requires hospitalization or even an ICU stay where he or she may be unable to communicate wishes, the burden of decision-making then falls on family members and loved ones who may not know the patient's preferences. A potential solution to these difficulties is to begin discussions with patients who have chronic lung diseases early in the course of their care. These discussions can occur over the course of several outpatient visits where the focus can be on prognosis, goals of therapy, minimally-acceptable quality of life, and the patient's values and attitudes toward medical therapy. These discussions may foreshadow or set the stage for subsequent discussions about withholding life-sustaining treatments, depending upon each patient's wishes.

How Should We Talk About End-of-Life Care?

Because discussing end-of-life care with patients and families is an important part of providing high quality medical care, we should approach these discussions with the same care and planning that we approach other important medical procedures. Box 1 outlines some of the steps that may facilitate good communication about end-of-life care, and these are described in more detail below.

a) Making Preparations Prior to a Discussion—A common mistake is to embark on a discussion about end-of-life care with a patient and family without having prepared for the discussion. Clinicians should review the medical record and the patient's disease process including the prognosis, treatment options, and likely outcomes. It is also important for the clinician to review what they know about the patient and their family including their attitudes toward illness, treatment, and death. It is also useful for the clinician to consider his or her own feelings of anxiety or guilt. Acknowledging these feelings explicitly to oneself can help the clinician avoid projecting feelings or biases onto the patient or family. Finally, if the patient has many health care providers, the clinician leading the discussion should attempt to ensure that all appropriate clinicians are consulted about their opinions of the patient's prognosis. It may also be appropriate to invite other providers to be present at one of more of the discussions about end-of-life care.

b) Holding a Discussion about End-of-Life Care—These discussions often start with opening comments and introductions followed by an exchange of information where the clinician updates the patient and family about the patient's illness and treatments and the clinician, in turn, is made aware of the patient's values. The conversation often turns to discussion of the future including prognosis for survival and for quality of life. If the patient's illness is advanced and survival is limited, this is also when the discussion of death and what dying might be like occurs. Finally, there is often a discussion of the decisions to be made either at this conference or in the future and closing comments by the patient and the clinicians.

If family members are present during the information exchange, not everyone will have the same level of understanding of the patient's condition. Therefore, it is often helpful to first find out what the patient or family understands of the patient's illness. This can be a useful way for the clinician to determine how much information can be given, the level of detail that will be understood, and the amount of technical language that can be used. Clinicians should be careful to avoid unnecessary technical jargon. It is important to avoid the temptation to give too much detail about the physiology or pathophysiology as a way to avoid our own discomfort, but we should be aware that some patients or families may want to hear this type of detail.

During these discussions, it is important to discuss prognosis in an honest way that is meaningful to patients and their families. For example, median survival is not very meaningful to most patients. Most experts recommend that clinicians use quantitative estimates of prognosis (such as 50% chance of surviving one year) rather than qualitative statements (such as a "poor" prognosis) as this increases the chances that patients will understand. In discussing prognosis, clinicians should also be honest about the degree of uncertainty in the prognosis, but it can be helpful to provide this information in a way that makes it clear that the clinician cares for both the patient and the family.

It is extremely important in discussions about end-of-life care that the patient and/or family understand that if the decision is made to withhold life-sustaining treatment such as mechanical ventilation, that clinicians themselves are not withholding from "caring" for the patient. This may seem obvious to some clinicians, but it should be stated explicitly to patients and families to avoid any misunderstanding. Patients and families want to know that no matter what treatment preferences they may have, they will be cared for, comfortable, and not abandoned by their health care providers.

After discussing prognosis and treatment options, it is important to spend some time exploring the patient's reaction to what was discussed. It can be helpful to repeat what the patient has said as a way to show that the clinician has heard them. This form of active listening can be particularly useful when the clinician and the patient have differing views. Second, it is important to acknowledge emotions that come up in these discussions. It is useful for the

clinician to acknowledge the emotion in a way that allows the person with the emotion to talk about their feelings. In acknowledging such emotions, it can be useful for the clinician to use reflection to show empathy and to encourage discussion about the emotion. For example, a clinician can say “It seems to me that you are very scared of getting sicker; can you tell me more about that?” as a way to show some empathy and to allow the patient to talk about his or her feelings. It can also be helpful for clinicians to provide support for decisions that patients make by acknowledging the difficulty of the situation and valuing patients’ comments. Finally, another technique clinicians can use in discussions with patients is to tolerate silences. Sometimes it is after what seems like a long silence that patients or family members will ask a particularly difficult question or express a difficult emotion.

c) How Should We Finish a Discussion about End-of-Life Care?—Prior to finishing a discussion about end-of-life care, there are several steps that clinicians should make. First, it is important that clinicians make recommendations during the discussion. With the increasing emphasis on patient autonomy, there may be a tendency for some clinicians to describe the treatment options without making a recommendation. On the contrary, it is important that clinicians offer their expertise to patients and part of offering their expertise is making a recommendation. Second, it is important to remind patients that their decisions are not permanent and can be changed at any time if they wish.

Prior to finishing discussion about end-of-life care, clinicians should also summarize the major points and ask patients if there are any questions. This is a good time to tolerate silence, as it may take a while for the uncomfortable questions to surface. Also, before completing a discussion about end-of-life care, clinicians should ensure that there is an adequate follow-up plan. This often means a plan for ongoing discussions at future visits. Finally, it is also important to outline the steps that patients should take to make their wishes known and recorded so that these wishes can be carried out in the event that their condition deteriorates (see below).

How Can We Help Patients With the Decision to Withhold Cardiopulmonary Resuscitation (CPR) or Mechanical Ventilation?

Frequently, part of the decision for patients with lung disease is whether he or she would want to receive CPR in the event of cardiac arrest. It is our opinion that in helping patients make this decision, it is important that Advanced Cardiac Life Support (ACLS) not be broken into components, but instead be presented as a package. Breaking ACLS into components (chest compressions, anti-arrhythmic drugs, vasopressor agents, intubation) makes these decisions unnecessarily complex and can lead to an absurd resuscitation status such as compressions and all drugs, but no intubation. With regard to mechanical ventilation in the event of respiratory failure, the procedures of intubation and mechanical ventilation should be explained to the patient in understandable terms.

How Can We Help Patients Carry Out Their Wishes?

Once patients have decided upon their wishes for end-of-life care, there are several important steps to be taken that should be explained to the patient. First, clinicians should advise patients to legally designate a Durable Power of Attorney for Health Care (DPOAHC) who should be a person the patient trusts to carry out his or her wishes at the end of life. This is particularly important if the person the patient would choose is not the person designated by state law. Second, the patient should clearly communicate all of his or her wishes to the DPOAHC so that they are well understood. These wishes should also be clearly communicated with the patient’s health care providers. Lastly, if the decision has been made to forgo CPR, the patient should complete an advance directive and tell the DPOAHC where it is kept so that it can be found at a later date if needed.

Understanding Clinicians' Own Discomfort Discussing Death

Discomfort discussing death is universal. This is not a problem unique to physicians, nurses, or other health care professionals, but has its roots in our society's denial of dying and death. With many medical schools, nursing schools, and healthcare textbooks providing little education about end-of-life care, it is not surprising that many clinicians have difficulty discussing this topic with their patients and families. Furthermore, clinicians may also feel that a patient's eventual death reflects poorly on their skills as a health care provider and represents a failure on their part to save the patient's life.

It is important for clinicians to recognize the difficulty they have discussing dying and death. If clinicians acknowledge this difficulty, they can work to minimize some of the common effects that such discomfort can take. For example, discomfort discussing death may cause clinicians to give mixed messages about a patient's prognosis or to use euphemisms for dying and death. This discomfort discussing dying and death can even cause clinicians to avoid speaking with a patient or a family. Recognizing this discomfort and being willing to confront it is the first step in overcoming these barriers to effective communication about dying and death with patients and their families.

Conclusions

The intent of palliative care is to prevent and relieve suffering and to support a reasonable quality of life for patients and their loved ones. Over the past few decades, palliative care measures have largely focused on patients with cancer. Malignancy-based palliative care models, however, have not been effectively applied to patients with chronic lung disease.

Patients with lung disease have a reduced quality of life and a burden of symptoms that is at least as great, if not greater than, patients with cancer. Patients with lung disease commonly experience significant pain, dyspnea, and fatigue. In addition, dementia and delirium can often play a significant role in older patients. Research suggests that patients with COPD receive suboptimal palliative care, which may be due to inadequate communication with their physicians. When patients have made decisions about life-sustaining therapies, physicians often either don't know the patients' wishes or misunderstand them. Additionally, depression, which is common in older patients with chronic illness, may influence patients' decisions about end-of-life care. Clinicians should realize that the vast majority of patients want more information about end-of-life care and that efforts to initiate and improve communication with their patients are important. Further research that investigates and defines interventions to improve and optimize communication and delivery of high-quality palliative care is sorely needed for patients with chronic lung disease.

Discussing end-of-life care and death with patients and their families is an extremely important part of providing a good quality medical care. While there is little empiric research to guide clinicians in the most effective way to have these conversations, there is an increasing emphasis on making this an important part of the care we provide. Much like other medical procedures or skills, providing sensitive and effective communication about end-of-life care requires training, practice, and preparation. Different clinicians may have different approaches and should change their approach to match the needs of individual patients and their families.

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Box 1Components of a discussion about end-of-life care

I. Making Preparations Prior to a Discussion about End-of-Life Care:

- Review previous knowledge of the patient and/or family
- Review knowledge of the disease, prognosis, treatment options
- Examine clinician's own personal feelings, attitudes, and biases

II. Holding a Discussion about End-of-Life Care:

- Introduce everyone present
- If appropriate, set the tone in a non-threatening way: "This is a conversation I like to have with all of my patients and their families..."
- Find out what the patient or family understands
- Discuss prognosis frankly in a way that is meaningful to the patient and demonstrates that the clinician cares for the patient and family
- Avoid temptation to give too much medical detail
- If the discussion leads to wishes to withhold life-sustaining treatment, make it clear that deciding to withholding such treatment is NOT withholding caring
- Use active listening and provide patient and family adequate time to speak
- Acknowledge strong emotions and use reflection to encourage patients or families to talk about these emotions
- Respond empathetically to tears or other grief behavior
- Tolerate silence

III. Finishing a Discussion of End-of-Life Care:

- Achieve common understanding of the disease and treatment issues
 - Make a recommendation about treatment
 - Ask if there are any questions
 - Ensure basic follow-up plan and make sure the patient and/or family know how to reach you for questions
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