



## Palliative and End-of-Life Care in Lung Cancer

### Diagnosis and Management of Lung Cancer, 3rd ed: American College of Chest Physicians Evidence-Based Clinical Practice Guidelines

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**Background:** In the United States, lung cancer is a major health problem that is associated with significant patient distress and often limited survival, with some exceptions. The purpose of this article is to address the role of palliative and end-of-life care in the management of patients with lung cancer and to address the need for good communication skills to provide support to patients and families.

**Methods:** This article is based on an extensive review of the medical literature up to April 2012, with some articles as recent as August 2012. The authors used the PubMed and Cochrane databases, as well as EBESCO Host search, for articles addressing palliative care, supportive care, lung neoplasm, and quality of life in cancer or neoplasm, with no limitation on dates. The research was limited to human studies and the English language.

**Results:** There was no “definitive” work in this area, most of it being concurrence based rather than evidence based. Several randomized controlled trials were identified, which are reviewed in the text. The article focuses on the assessment and treatment of suffering in patients with lung cancer, as well as the importance of communication in the care of these patients over the course of the disease. The aim of medical care for patients with terminal lung cancer is to decrease symptom burden, enhance the quality of remaining life, and increase survival benefit. A second objective is to emphasize the importance of good communication skills when addressing the needs of the patient and his or her family, starting at the time of diagnosis, which in itself is a life-changing event. Too often we do it poorly, but by using patient-centered communication skills, the outcome can be more satisfactory. Finally, the article addresses the importance of advance care planning for patients with lung cancer, from the time of diagnosis until the last phase of the illness, and it is designed to enhance the physician’s role in facilitating this planning process.

**Conclusions:** This article provides guidance on how to reduce patient distress and avoid nonbeneficial treatment in patients with lung cancer. The goal is to decrease symptom burden, enhance quality of life, and increase survival benefit. Good communication and advance care planning are vital to the process.

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**Abbreviations:** EIPC = Early Intervention with Palliative Care; NSCLC = non-small cell lung cancer; RCT = randomized controlled trial; QOC = quality of care; QOL = quality of life; SUPPORT = Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

#### SUMMARY OF RECOMMENDATIONS

**2.4.1.** For patients with stage IV lung cancer and/or a high symptom burden, it is suggested that palliative care combined with standard oncology care be introduced early in the treatment course (Grade 2B).

**3.3.1.** It is recommended that all physicians caring for patients with lung cancer should begin conversations about the patient’s prognosis and goals of care at the time of the diagnosis, and continue these throughout the course of the illness (Grade 1B).

### 3.3.2. It is recommended that all physicians caring for patients with advanced lung cancer should initiate conversations about the goals of care; the pros and cons of life-sustaining treatment and end-of-life care options (Grade 1B).

Lung cancer is a disease with a high morbidity and high mortality rates, often because it is not detected until there has been significant progression of the illness. As a result, it is often associated with a significant amount of suffering and a general decrease in the quality of life (QOL). The major objective of this article is to explain the role of palliative care in the management of patients with lung cancer.

Palliative care is a well-established treatment paradigm providing relief of suffering. Suffering is brought about by physical symptoms, as well as by emotional and spiritual distress, which impact both the patient and his or her family. Unfortunately, palliative care is often introduced late in the progression of lung cancer and is thought of by many people as a treatment modality designed for hospice and/or end-of-life care. The major objective of this article is to educate the reader on advancements in the role of palliative care in patients with lung cancer; included are studies that demonstrate an increase in life expectancy and QOL when palliative care is introduced early in the illness. The goal of palliative care is to relieve suffering and, if possible, to prolong life. The focus is on

hope and control of the disease and its symptoms, as well as its impact on families. In this article, we focus on a definition of suffering and ways in which we can relieve the barriers that prevent the proper application of palliative care.

A second important objective of this article is to help the reader develop communication skills to aid in patient- and family-centered care. Too often, communication consists of the physician talking to the patient and his or her family, instead of spending adequate time listening. We address this with specific techniques that can improve patient understanding of the disease and its impact on the patient's quality and quantity of life. The article provides communication techniques that can enhance the physician's skills, including some practical tips and tools on how to improve communication with patients and their families.

## 1.0 METHODS

This article is based on an extensive review of the medical literature up to April 2012, with some articles as recent as August 2012. There is no "definitive" work in this area, most of it being concurrence based rather than evidence based. The authors used the PubMed and Cochrane databases, as well as the EBESCO Host search screen, to research palliative care, supportive care, lung neoplasm, QOL, and cancer or neoplasm, all in the English language and with no limitations on dates. The research was limited to human studies. Several randomized controlled trials (RCTs) were identified, which are reviewed in the text. The focus of the search included an assessment of suffering in patients with lung cancer, as well as the importance of communication in the care of these patients.

After a systematic search, papers were reviewed and data abstracted. The writing committee drafted recommendations, which were reviewed and ultimately approved by the entire American College of Chest Physicians Lung Cancer Guidelines Panel according to the process described in the methodology article of the American College of Chest Physicians Lung Cancer Guidelines.<sup>1</sup>

## 2.0 SUFFERING

This section explores the tension associated with considering palliative care for illness with poor prognosis for survival. Should palliative care be included simultaneously with the administration of aggressive treatment or deferred until the end of life has arrived? Should palliative care be restricted only to those who are dying and/or already enrolled in hospice? What are the common misconceptions about what palliative care offers?

This article addresses major topics such as skill in accurate prognosis and communication about realistic goals of treatment. The aim of medical care for patients with lung cancer is to decrease symptom burden, enhance the quality of remaining life, and increase the number of functional months of survival

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even if death is still predicted. The goal is also to reduce patient distress and diminish the financial burden through the avoidance of nonbeneficial treatment and a reduction in hospitalization frequency. If the chosen treatment is failing or becomes more of a burden than a benefit, the ideal goal would be to achieve early referral to hospice as the end of life approaches. Where or when in the trajectory of death does the effect of continuing aggressive treatment change from prolonging living to prolonging dying? At what point does continuing aggressive treatment fail to prolong a life with value, dignity, and meaning?

## 2.1 Suffering, Palliation, and Outcome: Hope

In *The Nature of Suffering and the Goals of Medicine*, Eric Cassell,<sup>2</sup> noting the rapid change in science and medicine, examines the relationship between pain and suffering. Developing medical science with a new understanding of disease and new miraculous discoveries daily are changing concepts in the art and practice of medicine. He suggests that it is the expectations of patients that push their physicians to prescribe treatment and technology that has no value. “Medicine is fundamentally a moral enterprise because it is devoted to the welfare of the persons it treats.”<sup>2</sup> Fulfilling that commitment may require refusal of requests for nonbeneficial care. The practice of medicine focuses on the physical, biologic, and epidemiologic qualities of disease, not on the skills that enable the practitioner to help the patient learn to hope when hope seems no longer possible.

Treatment by its very nature can cause pain and suffering (“The treatment is worse than the disease”). There are also sources of pain and suffering in illness that are not physical in nature. The ability to reshape one’s goals and hopes based on shifting reality and in the face of despair can be a critical survival skill. The loss of hope itself causes suffering, but when a person can change what they hope for, they can also preserve hope and give meaning to life. Viktor Frankl<sup>3</sup> called this “the will to meaning,” the basic motivation for human life.

Sherwin Nuland<sup>4</sup> addresses the issue of different kinds of hope for patients who are dying. He suggests that physicians may delude themselves into a course of action with an unjustifiably low probability of success. Nuland<sup>4</sup> believes that “hope can still exist even when rescue is impossible.” To continue to offer “hope against hope” to a patient in denial, to avoid destroying this hope rather than enabling a new hope, and to escape the conflict and distress associated with giving bad news is a misguidedly easy way out. It sidesteps seeking ways to help the patient face the facts of his or her situation.

Palliative care is a holistic approach to treatment that includes the patient’s family and that addresses the nonmedical as well as the medical aspects of terminal illness, even before death is imminent. Throughout its spectrum, its focus is relief of symptoms. It is important to distinguish between palliative care and the subset of palliative care that includes terminal care, such as a decision for “comfort measures only.” Palliative care is not restricted to those who are near death or to those who are enrolled in hospice. It includes aggressive and invasive measures to control symptoms and signs and should include a mutual patient-physician understanding when such treatment is unlikely to cure the illness—until there is no further redeeming value of that treatment. It has been recommended as a concurrent approach for all patients with either an acute devastating or a chronically progressive pulmonary or cardiac disease.<sup>5</sup>

A detailed review of palliative interventions to optimize QOL and control symptoms has been published previously<sup>6</sup> and is updated in another article by Simoff et al<sup>7</sup> in this edition of the American College of Chest Physicians Lung Cancer Guidelines. Aggressive treatment of symptoms and signs is important, but by itself does not address the situational aspects of the individual patient’s needs, or those of the family. Seeking a more comprehensive approach to care and decision-making requires frank and open discussion about the medical and personal facts of the situation, medical certainties and uncertainties, personal fears of the unknown, and realistic goals of treatment. With evolving circumstances, multiple discussions will be necessary over time.

Learning to hope for a new and different goal in light of bad news may take time and assistance to achieve. There is a medical goal of cure or maximal duration of survival. There may be a personal hope for a specific goal for survival (eg, wanting to go to a daughter’s wedding or see a child grow up), which may make suffering more tolerable or worthwhile. There are personal issues of concern, such as business matters and family/friend relationship loose ends. Determining how much suffering is acceptable given the identified goal takes time and may change over time. Creating time to settle issues requires recognizing the dying process early, rather than waiting until the “bitter end” when the patient no longer has the energy, will, stamina, or capacity to seek closure.

The first prospective randomized controlled outcome study regarding the question of how palliative care, given early and in conjunction with usual medical measures, affects outcomes in patients with non-small cell lung cancer (NSCLC) revealed substantial improvements not only in quality but also in duration of life, despite less frequent use of intervention at the end of life. A single-center study, “Impact of early



intervention with palliative care on QOL in patients with advanced NSCLC” (Early Intervention with Palliative Care [EIPC] trial), randomized 151 patients with newly diagnosed NSCLC to receive either early palliative care delivered according to the National Consensus Project for Quality Palliative Care ([www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)) in conjunction with usual treatment or usual treatment only. Of patients still alive at the follow-up evaluation 3 months after entry, 86% (107 of 124) completed assessments. Patients assigned to early palliative care had better QOL and fewer depressive symptoms and received less aggressive end-of-life care, yet enjoyed a median survival that was significantly longer than that of those not receiving early palliative care (12 months vs 9 months,  $P = .02$ ). Palliative care also contributed to improved mood and QOL.<sup>8</sup>

A survival benefit of early involvement of palliative care in other cancers has not been demonstrated. However, substantial evidence reveals that palliative care, when combined with standard cancer care, leads to better patient and caregiver outcomes. Additionally, there is no evidence to suggest harm to patients or caregivers, or excessive costs, from early palliative care involvement.

Triggered by the publication of the EIPC trial, the American Society of Clinical Oncology recently conducted a literature search of randomized control trials that provided palliative care interventions by an interdisciplinary or team-based approach to improve cancer outcomes.<sup>9</sup> This review identified seven trials that demonstrated the feasibility of providing various palliative care interventions alongside usual cancer care.<sup>8,10-15</sup> Overall, the palliative care interventions revealed evidence of benefit, including improvement in symptoms, QOL, and patient satisfaction. There was also a reduction in caregiver burden, more appropriate use of hospice, and a decrease in the request for aggressive, nonbeneficial intensive care. Details of these studies can be found in the evidence table published in the American Society of Clinical Oncology’s provisional clinical opinion.<sup>9</sup>

It is not yet known what constitutes the essential components of successful palliative care interventions. Common characteristics of these trials include establishing a team approach to honest communication, including a description of the diagnosis, treatment options, and frank discussion of the prognosis and curability; setting medically appropriate goals of treatment; and using standardized assessment tools for symptom management.<sup>9</sup>

## 2.2 Palliative Care, QOL, and Psychologic Symptoms

Other contemporary literature on suffering and the use of a multidisciplinary palliative care team

or other interventions designed to improve QOL at its end has been primarily descriptive in nature. These reviews were criticized for methodologic limitations and were not designed to take into account the more modern comprehensive palliative care interventions.<sup>9</sup>

In a small prospective study, 103 patients receiving radiation therapy for advanced cancer (0% predicted 5-year survival) were randomly assigned to receive either usual care or usual care plus eight structured sessions of a multidisciplinary intervention directed toward education, behavioral modification, and coping skills. Using a multidimensional assessment of QOL measures, the QOL questionnaire scores of the intervention patients were significantly better than those of the control patients at week 4, particularly in markers of overall spiritual well-being ( $P = .003$ ), but significant differences in QOL could not be measured on subsequent follow-up. The duration of survival in each group was not reported.<sup>16</sup>

QOL issues may be even more important to survival than known prognostic factors. Concurrent QOL assessments were performed in a randomized, non-blinded prospective trial of two different chemoradiotherapy treatment protocols in 243 patients with locally advanced stage II/IIIa,b NSCLC. In this exploratory analysis, those with better baseline QOL scores fared better in terms of long-term survival. QOL at baseline was a better predictor of overall survival than the usual prognostic factors. Five-year survival for patients above the median QOL score on initial assessment was 27%, compared with 11% for those patients scoring below the median.<sup>17</sup> A small subset assessment of EIPC trial patients involved a prospective study of outcome in 43 patients recently given a diagnosis of stage IIIb or IV NSCLC who completed an anxiety-depression assessment upon entry. Major depression was found in 23% of patients. The median survival for patients with depression was four times shorter than for those without depression.<sup>18</sup>

Palliative care includes not only intensive measures to prolong life and reduce medical symptoms, but also interventions to adjust hopes and goals to a new reality. Worries about “therapeutic nihilism” in the palliative care setting even as new medical interventions prolong survival<sup>19</sup> fail to take into account this attention to other issues and goals besides pure months of survival.

Improved QOL and mood during remaining life was demonstrated in an RCT of 322 patients with advanced end-stage cancer randomized to receive either usual care or usual care with a multicomponent psychoeducational intervention led by advanced-practice nurses. This study included 117 patients with lung cancer. However, there were no differences in physical symptom scores, survival outcome, length of stay for any intercurrent hospitalization, or ED visits between groups.<sup>10</sup>

Intervention was shown to reduce symptoms and improve patient satisfaction in those patients compliant with follow-up assessments in a convenience sample of 150 patients with metastatic cancer referred to a palliative care consultant by their oncologists for end-of-life planning and management of pain or other symptoms.<sup>20</sup> A recent review of published literature on the outcome of patients with cancer receiving palliative care revealed eight prospective RCTs that demonstrated that intervention led to an improvement in pain and symptom control, anxiety, and hospitalization requirement.<sup>21</sup> In summary, multiple retrospective cohort studies and RCTs suggest that QOL is an important prognostic factor, and that interventions can improve QOL and reduce symptoms.

### 2.3 Rethinking Palliative Care: It Is Never Too Early

Overall evidence on the impact of early, concurrent palliative care on the outcome of cancer care is just being developed. This reflects the existence of barriers to the incorporation of such care in usual medical management, and the difficulties of applying conventional clinical trial methodologies to the study of psychosocial issues. Barriers to effective palliative treatment include patient, professional, and system barriers. Less than 1% of all National Institutes of Health funding is devoted to palliative care.<sup>22</sup> Additionally, misunderstanding palliative care as “giving up” or as “therapeutic nihilism” is a large cultural barrier. In an educational intervention with patients with cancer to identify such barriers and to help them understand their pain and fatigue, immediate and sustained improvement in physical and psychologic well-being was achieved.<sup>23</sup>

Instead of waiting until illness is “irreversible” or “terminal” (conditions that are difficult to define), shouldn’t the situation of “probably” or “possibly” irreversible prompt a review of goals? When the discussion is about percent 1-year survival, that discussion must include percent 5-year survival and probability of death. The goals of overall treatment must be developed based on the medical facts and the patient’s individual persona, so that when watershed decisions are necessary, the big-picture perspective can effectively inform the “decision in-the-moment.” Sudore et al<sup>24</sup> proposed that “the main objective of advance care planning be to prepare patients and surrogates to participate with physicians in making the best possible in-the-moment decisions.” A physician needs to take a values history to assess the patient’s personal, cultural, and religious attitudes toward sickness, death, and dying and must weave those values into a care plan given the medical facts of the situation.<sup>25,26</sup> This may be the most important service performed by the palliative care physi-

cian in the absence of an actively involved primary care physician.

Hippocrates and Osler are both quoted to have observed that it is more important to know what person has the disease, than what disease the person has. Osler is credited with observing that the good physician treats the disease; the great physician treats the patient who has the disease. A person’s past experiences inform the vision of the future from the position of the present. A person is a member of and has a role in a family group, a culture, and a society. A person has a set of spiritual beliefs. The complexity of the human spirit transcends the mechanical simplicity of cause and effect, rendering the scientific method difficult to use in the study of suffering.<sup>2</sup>

### 2.4 Palliative Care in Oncology Practice

Palliative care programs exist at 98% of National Cancer Institute-designated cancer centers and 78% of community cancer centers.<sup>27</sup> However, the scope of services and the integration of palliative care programs with concurrent oncology care are highly variable.

In an observational study of the integration of palliative care consultation into an office oncology practice, the patient’s symptom burden was reduced by 21%. There was excellent provider satisfaction such that there was a doubling of referrals by oncologists to the palliative care consultant, with an estimated savings in time of 162 h (just over 4 weeks) to the overall practice in year 2 of the integration.<sup>28</sup> The integration of an advanced-practice nurse with a specialty in palliative care into an outpatient oncology practice at a teaching hospital showed that intervention patients, in comparison with historical control subjects, had reduced hospitalization and improved survival outcome at 4 months.<sup>29</sup>

#### Recommendation

**2.4.1. For patients with stage IV lung cancer and/or a high symptom burden, it is suggested that palliative care combined with standard oncology care be introduced early in the treatment course (Grade 2B).**

### 2.5 Palliative Care Merging Into Hospice

Palliative care is not synonymous with hospice care because eligibility is based on patients’ needs, independent of prognosis. In contrast, hospice care is an insurance benefit providing palliative care specifically limited to the care of dying patients who must have a prognosis of 6 months and agree to forego insurance coverage for treatments aimed at curing their illness.<sup>30</sup> How palliative care in conjunction with usual medical care merges into hospice care at the end of life is fraught with tension. The issue of timing

appears to be important: Just as adequate forewarning appears to be necessary to patient/family adjustment to the imminent outcome, it takes time for hospice to be effective if it is to be the method of providing multidisciplinary palliative care. It is estimated that it takes about 80 to 90 days for hospice to reach its full impact in providing support to a dying patient and his or her family.<sup>31</sup>

The first step in seeking palliative care consultation or even hospice enrollment requires facing a misperception that palliative or hospice care means “giving up” or “hastening death,” a perception that exists on the part of physicians as well as patients and families. A decision to choose hospice as a course may actually be associated with a temporary improvement. Talking frankly about death and dying in conjunction with hospice referral may be misconstrued as “taking away hope,” which would negatively affect outcome, but this conclusion is based on fear not fact. In actual fact, patients receiving hospice tend to have a better sense of hopefulness and a longer survival.<sup>32,33</sup>

A potential barrier to hospice referral is the belief that the treatment of moderate symptoms of discomfort at the end of life actually hastens death. A retrospective statistical review was done of 4,493 Medicare patients with cancer or congestive heart failure who died within 3 years of “indicative marker date,” or the first date on which the terminal phase of the illness could be identified as “beginning.” Factors associated with a delay in hospice referral, such as a physician switching from presumably failed treatment within 3 to 6 months of death to another combination of treatments, were reviewed. Only one-half of the patients (47%) were referred to hospice before death; among those with lung cancer, 54% were referred to hospice. The mean survival time of patients referred to hospice was 29 days longer, particularly for patients with congestive heart failure, lung cancer, and pancreatic cancer. It was only marginally improved for patients with colon cancer, and not for those with breast or prostate cancer. There was a positive correlation between length of hospice stay and survival days, with an estimated longer survival of 0.8 times the number of days actually in hospice.<sup>32</sup>

There is a misconception that hospice care is only for the last hours to days of life. The literature and our culture fail to consistently draw a clear distinction between incorporating palliative care into a treatment plan and moving to a “comfort measures only” decision.<sup>34</sup> Although these are best viewed as different steps on a trajectory or continuum of care, many barriers exist. Open-access hospice provides all hospice services with selected aggressive treatments, and home palliative care services provide all life-sustaining treatments with some hospice services. In the hospice choice, the patient must waive Medicare Part A

for his or her terminal diagnosis and related care and elect the Medicare Hospice Benefit for treatment directed toward comfort and palliation as opposed to treatment to prolong life.<sup>35</sup>

Logistic and financial requirements such as a maximal 6-month predicted survival also interfere with potential candidacy for hospice. Access to aggressive measures may be limited if the hospice course is chosen, depending on the financial resources of the hospice to provide expensive treatment. Hospice may require a choice to seek a different hope in care.<sup>36</sup> Physician overestimate of remaining survival limits timely access by patients to hospice services. Delay in referral until death is near may reduce the potential value of hospice services at consolidating grief preparation and acceptance; the average length of hospice enrollment before death is 2 months (below the 80- to 90-day mark), and almost 30% of all hospice patients arrive in hospice in the last week of life.<sup>37</sup> Arrival in hospice when death is imminent provides death care but not the other elements of care associated with the end of life.

## *2.6 Comfort Measures Only and Continuous Palliative Sedation to Unconsciousness*

Once the treatment becomes worse than the disease, a decision for “comfort measures only” occurs when all potential treatments have either failed or been rejected by the patient and/or family as excessively burdensome. This is not the same decision as a decision for sedation to unconsciousness, which should only be considered if good palliative care is failing. An international panel of palliative care specialists reviewed the issue of sedation to medicate intolerable suffering from intractable symptoms even with optimal palliative care. They differentiated deep sedation at the end of life from euthanasia because it has the intent of symptom relief and the goal of treatment is not to produce death. Their recommendations applied to patients with terminal illness and a life expectancy of a few weeks or less, who still suffered refractory physical and or psychologic symptoms after careful attention to the social, emotional, and existential dimensions of the symptoms.<sup>38</sup>

These recommendations do not differ substantially from bedside management in the ICU for a patient transitioned from “aggressive invasive measures” and “life support” to “comfort measures only.” Comfort measures only is a different approach to caring at the end of life. When “aggressive invasive measures” are failing or becoming too great a burden compared with any measurable benefit, a change in approach to care is indicated. Palliative sedation at the end of life, when nothing else has worked, with the goal of comfort during the dying process, can be employed using



the “doctrine of double effect.”<sup>37</sup> This medical ethics doctrine is credited to Thomas Aquinas. It morally justifies an act that has two possible effects, one that is desired (good) and one that is not desired (bad) (eg, relief of severe dyspnea with a narcotic, even though this may increase the chance of dying). The intended effect is the good result (relief of dyspnea), not the bad (death), which makes the act morally acceptable. The focus is the intent.

This is usually reserved for patients who cannot be made comfortable despite aggressive interdisciplinary care. However, does existential suffering count as an unrelieved symptom? How close to death should a patient be before this alternative can be morally entertained?<sup>37-42</sup> A somewhat objective measure that has been proposed to assess whether sedation-to-unconsciousness is ethically conscionable is an estimate that time to death from disease is less than or equal to predicted time to death from sedation-to-unconsciousness-induced dehydration.<sup>43</sup>

## 2.7 Distressing Symptoms

In a population-wide summary of data collected prospectively in patients with cancer over the last 6 months of life in Ontario, Canada, symptoms for which intervention was poor worsened, especially over the last month prior to death. In particular, shortness of breath, drowsiness, lack of well-being, lack of appetite, and tiredness increased over time as the patient declined.<sup>44</sup> A recent Cochrane Database review concluded that no effective pharmacologic intervention for fatigue has yet been identified.<sup>45</sup>

Pain and dyspnea from cancer are problems that will likely require narcotics, even if death is not imminent; cognitive and behavioral strategies as part of a multimodal approach to cancer pain management should be used to supplement but not replace appropriate analgesia.<sup>46</sup> Methadone, step 3 of the World Health Organization analgesic ladder, has been recommended as a cancer pain treatment for patients with renal failure or for those with unacceptable adverse effects from other opioids, particularly because of its low cost, good bioavailability, long-lasting analgesia, and lack of active metabolites.<sup>47</sup> As a general rule, the therapeutic goal in pain management is to provide relief of symptoms while preserving function, but the goal of preserving interactional function is not always possible at the end of life. The relief of suffering may become the primary therapeutic goal.<sup>40</sup> Effective treatment of pain in patients with cancer at the end of life, even with high doses of narcotics, does not change survival outcome.<sup>48</sup> Aggressive palliation with narcotics may be necessary.

Existential pain is mostly used as a metaphor for suffering and may include guilt issues, religious fears,

feelings of meaninglessness, and fear of annihilation and impending separation. It can be expressed as physical pain and may even be a primary cause of pain at the end of life.<sup>49</sup>

## 2.8 Requests for Assisted Suicide

In locations where assisted suicide is legal, physicians must decide what they will do when one of their patients wishes to commit suicide. Where this is not legal, physicians must still decide how they will deal with such requests. Oregon has kept records since 1998; as of 2009, 460 people had received physician-assisted suicide there. Loss of autonomy was 91% of the reasons given for suicide. In a summary of the 2009 outcome of Oregon’s *Death with Dignity Act*, it was reported that 59 patients died as a result of taking medications for the purpose of ending their suffering (estimated 19.3 *Death with Dignity Act* deaths per 10,000 total deaths). This represented more than 50% of patients receiving prescriptions from their physicians for that purpose. The most frequently mentioned end-of-life concerns were loss of autonomy (97%), loss of dignity (92%), and decreasing ability to participate in activities that make life enjoyable (86%).<sup>50</sup>

## 2.9 Impact on Families

In the previous edition of this article by Griffin et al,<sup>51</sup> the section on palliative care focused as much on the grief experience of survivors as on the experience of the patient facing cancer who has access to palliative care. In particular, adequate forewarning of impending death was important to both patient and survivor.

Patients who are parents with dependent children are, with their whole family, particularly vulnerable to adjustment issues; they are the most difficult victims to whom to deliver bad news, have the greatest reason to live, and shoulder the largest number of responsibilities. In the Coping with Cancer project, a multiinstitutional longitudinal project funded by the National Cancer Institute and the National Institute of Mental Health, 20% of the patients (135 of 668) were parents of dependent children. Compared with patients without dependent children, these parents were more likely to be worried ( $P = .006$ ), and their spousal partners were more likely to be suffering from a major depressive disorder ( $P = .01$ ), generalized anxiety ( $P = .02$ ), and panic ( $P = .05$ ). These parents were also more likely to have made advance plans ( $P \leq .01$  for all elements of advance planning) and had a greater propensity to choose aggressive measures ( $P = .03$ ) than did patients without dependent children. They also had the worst QOL in the last week ( $P = .04$ ) as rated by their physicians and caregivers. They were much more likely to meet the

criteria for panic disorder themselves ( $P = .0004$ ) and were one-half as likely to feel peaceful ( $P = .01$ ) about their situation, compared with patients with no dependent children. Of the 74 patients with lung cancer (22% total), 15% were parents of dependent children.<sup>52</sup> Parents with dependent children are in particular need of a holistic approach to the management of their diagnosis, yet may be the most difficult patients for us to face.

Palliative care support is not just for the patient; it is for the family as well. Good advance care planning has the potential to substantially relieve family members of the burden of decision-making. In a recent review of research exploring the impact of being put, as the patient's decision maker, in the position of having to decide for a loved one, substantial negative emotional burden was observed, sometimes lasting for years. Knowing what the patient would have chosen for him- or herself was cited as an assist in reducing this negative effect.<sup>53</sup> Families of patients near the end of life reported to the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) investigators a substantial amount of life change in the family as a result of the patient's illness, including having to quit work to provide care. Almost one-third of families reported loss of most or all of the family savings, and 29% reported loss of the family's major source of income. More than one-half reported a major practical negative impact on the family, with 12% of families affected by stress-related illness or loss of ability to function.<sup>54</sup> Families of critically ill patients with a high probability of dying report a high prevalence of stress-related physical and psychological distress symptoms.<sup>55</sup> It has been recommended that palliative care be incorporated into ICU management to help clarify issues and to support the family as well as the patient and is a clinical practice guideline for critical care.<sup>5,50,56</sup>

In a retrospective follow-up, the SUPPORT investigators stratified the satisfaction of survivors with care received by their loved one prior to death, based on the location in which death finally occurred. In their sample of 1,578 decedents, 33% of patients died at home, and 49% of those died with hospice services provided. From a family perspective, those patients receiving hospice services in their homes had a better quality of care (QOC) and were treated with respect as they were dying more frequently than was any other group.<sup>33</sup> In a convenience sample of 180 patients with cancer, 90% preferred to die at home.<sup>57</sup>

## 2.10 Costs and QOC

Smith and Hillner<sup>58</sup> recently responded to a challenge by Howard Brody<sup>59</sup> of the Institute for Medical Humanities for each medical specialty to identify at

least five areas of opportunity to reduce costs without reducing medical benefit. They proposed that medical oncologists have such an opportunity in both their behavior and in their attitudes and practice. In the area of concrete behavior, they proposed that oncologists restrict surveillance testing to tests with documented benefit, limit second- and third-line therapies for most metastatic solid tumors to sequential monotherapy, restrict chemotherapy to patients with good baseline performance unless disease is highly responsive to treatment, reduce the use of WBC-stimulating factors by reducing chemotherapy dose in metastatic solid tumors, and continue aggressive treatment of patients who have already failed three consecutive regimens only within the context of a clinical trial. They recommended better integration of palliative care into usual oncology care as an attitude and practice change. In their opinion, concurrent palliative care provides so much opportunity to improve treatment decisions, patient satisfaction, and QOL and reduce cost that it should become routine in oncology practice.<sup>58</sup>

It has been proposed that "overly aggressive" cancer treatment of patients with incurable cancer is a QOC issue. Any overuse of treatment known to be ineffective or underuse of treatment known to be effective is a QOC concern.<sup>59</sup> The National Cancer Policy Board also defines poor QOC when services of equivocal effectiveness are given according to provider rather than patient preference. In a review of Medicare data from 1991 to 2000 for patients with solid tumors, there was a continual increase in the proportion of patients prescribed chemotherapy within the last 14 days of life. Although overall hospice use increased over that time frame, many of those patients referred to hospice were not referred until they were within 3 days of death. At that point, hospice is providing death services, without enough time to provide hospice services.

## 2.11 Costs at the End of Life

Direct cancer costs continue to rise in the United States, with projections of more than \$173 billion.<sup>19,61</sup> In a 2-year observational Department of Veterans Affairs cooperative study of patients who had end-stage illness, palliative care was received by 18% of the 3,321 patients. Costs were reduced by \$464 per day and ICU admissions were reduced for those patients receiving palliative care.<sup>62</sup>

In fact, many patients with cancer prefer a conservative approach. In an observational series of 380 sequential patients with cancer or their surrogates completing questionnaires about preferences for specific aggressive treatments such as resuscitation and mechanical ventilation, chemotherapy,



antibiotics, transfusions, feeding tubes, and artificial hydration, it was noted that 42% of patients wanted no or only one intervention. Younger patients ( $P < .0001$ ), those with better baseline performance, and those with surrogates involved with decisions were those who wanted more aggressive interventions. Based on decade of age, patients aged  $\leq 30$  years preferred 0.69 of these seven interventions, decreasing with each decade to 0.25 in the 70- to 80-year age group. Patients with lung cancer (25% of the group) preferred only 0.31 of these seven interventions.<sup>63</sup> However, in a review of 1,476 consecutive hospitalized patients discharged with a diagnosis of lung cancer, palliative care consultations occurred late in the patient's hospital stay or when death was imminent, after a substantial hospital and/or ICU course, rather than early in the patient's course.<sup>64</sup>

Patients with terminal cancer are not the only terminal patients who could benefit from support from their specialists in end-of-life planning. In a prospective observational study, Janssen et al<sup>65</sup> found that most outpatients with COPD of GOLD (Global Initiative for Chronic Obstructive Lung Disease) stage III or IV, or congestive heart failure of New York Heart Association class III or IV, were able to formulate decisions about life-sustaining treatments. They could take into account concepts of burdens of treatment, predicted outcome of treatment, and probability of predicted outcome but rarely discussed these issues with their specialists. Patients with cancer had the longest median survival in a review of 5 years of prospectively collected observations for inpatient palliative care consultation including 1,794 total patients (47% had cancer diagnoses). Reasons for consultation included, in descending order of frequency, the need to clarify treatment goals, pain management, discharge planning, relief of dyspnea, and other aspects of symptom control.<sup>66</sup> For patients with distressing breathlessness poorly responsive to treatment, regardless of the underlying illness causing dyspnea, palliative care and end-of-life issues should be addressed.<sup>67</sup>

## 2.12 Summary

Palliative care can be integrated with a cancer care plan that systematically addresses symptom control, psychosocial distress, spiritual issues, and practical needs for the patient and family throughout the continuum of care. In a culturally sensitive manner, the patient's values, preferences, goals (both medical and personal), and beliefs are elicited over time, with regular reassessment of benefits and burdens of treatment. Palliative care can be delivered concurrently with aggressive treatment or as the main focus of treatment.<sup>68</sup> The World Health Organization recommends palliative care as an essential element in

cancer care, offering a multimodality approach to addressing spiritual and psychologic concerns at the end of life and physical symptoms and treatment, and including a support system to help families cope with the illness and with their own bereavement.<sup>69</sup> Additionally, the European Society for Medical Oncology and the Society of Surgical Oncology have endorsed supportive and palliative care as an essential service that must be part of comprehensive cancer care.<sup>70,71</sup>

## 3.0 COMMUNICATION AND END-OF-LIFE CARE

Physician-patient communication successes and failures generate more complaints and gratitude than any other aspect of end-of-life care.<sup>72,73</sup> From the perspective of patients and families, physicians often fail to adequately communicate diagnosis, prognosis, and treatment options. Poor communication results in emotional distress<sup>74,75</sup> and missed opportunities<sup>76</sup> and thwarts informed decision-making about end-of-life care. This section of the article covers specific communication techniques intended to improve the physician-patient-family dialogue at the end of life. First, basic communication principles are discussed, followed by a look at specific communication tasks common in end-of-life care. The goal is to provide physicians with a communication tool kit they can use with patients and families. Several randomized trials of intensive communication training programs have demonstrated that physicians' communication skills can be improved and that these improvements are enduring.<sup>68,69,77,78</sup> However, there is a paucity of empirical information to support specific communication strategies, and the techniques described are based primarily on expert opinion.<sup>79,80</sup>

### 3.1 Using Patient-Centered Communication Skills

**3.1.1. Active Listening and Allowing Patients Adequate Time to Speak:** An important principle for physicians to understand and apply is patient-centered rather than physician-centered communication.<sup>81,82</sup> One implication of patient-centered communication is that physicians should focus more on listening to and addressing patients' and families' concerns rather than focus primarily on their own agenda. Unfortunately, this is relatively uncommon, and one study of oncologists found that physicians dedicated only 23% of their time to discussing QOL issues and missed discussing topics that were important to patients.<sup>83</sup> However, in an RCT, these same investigators found that physician communication behaviors could be improved through the use of standardized QOL assessments and that physicians developed increased appreciation for these areas in the context of caring for

patients with cancer.<sup>84</sup> Similar findings have been reported in observational studies of physician-family conferences in ICUs, in which physicians consumed 71% of the total speech time vs 29% for families. Notably, communication ratings were higher in this study when families consumed a greater proportion of the total speech time.<sup>85</sup> The skill of active listening will help physicians understand the informational needs of patients and families confronting end-of-life issues and thus be better able to meet those needs. A helpful technique to remember is the “ask-tell-ask” strategy for patient communication. The physician first asks patients for their perspectives and understanding of the situation, then relays the necessarily medical information, and then asks for questions and confirms understanding of the medical information being provided.

**3.1.2. Empathically Addressing Emotion:** A second, fundamental component to patient-centered communication is acknowledging and addressing emotion.<sup>86</sup> Important opportunities exist for physicians to improve this aspect of communication. One study of 298 patients with cancer visiting their oncologists found that physicians responded to just 28% of emotional cues, as compared with 72% of informational cues.<sup>87</sup> Although clinical information is important to decision-making, when confronting end-of-life concerns, the emotional and psychosocial issues assume increasing importance. In fact, emotional and psychosocial support is one of the four primary domains for quality palliative care.<sup>88</sup> It is encouraging that several studies conducted among oncologists found that physicians’ skills in supporting emotion can be improved through intensive communication skills training<sup>68,77,78</sup> and furthermore, that physicians’ attitudes and beliefs about these issues can be improved through intensive communication skills training. One helpful mnemonic for physicians to remember when addressing patients’ and families’ emotions is NURSE, which represents “Naming, Understanding, Respecting, Supporting, and Exploring.”<sup>86</sup> The principle is that explicitly stated or nonverbally communicated emotional responses should prompt physicians to proactively name the emotion and offer a respectful and supportive response. Furthermore, the basis for the emotion should be explored, especially at the end of life.

**3.1.3 Supporting Religious and Spiritual Needs:** The importance of religion and spirituality is especially acute at the end of life, and, thus, supporting religious and spiritual needs is another primary issue of quality palliative care.<sup>88</sup> Patients and families grapple with worries over the meaning and purpose of life, hope, despair, and whether a higher power exists.

In fact, experts have asserted that spiritual issues “lie at the very center of the existential crisis that is terminal illness.”<sup>89</sup> When patients’ spiritual needs are largely or completely supported by the medical team, patients report higher QOL, more hospice care, and less intensive, life-prolonging treatments at the end of life.<sup>90</sup> Also, several psychotherapy interventions that explicitly integrated spiritual support into group therapy for patients with terminal illness have been tested in small clinical trials.<sup>91-94</sup> Participants in the religion/spirituality-support interventions reported reduced rates of depression and an increased sense of meaning and purpose.<sup>91-93</sup> Finally, there is substantial evidence that when physicians strive to understand patients’ values, including religious and spiritual values, communication is improved.<sup>68,76</sup> Thus, physicians caring for patients confronting the end of life should inquire about religious and spiritual needs, take a brief spiritual history, offer support, and make referrals to spiritual care experts as appropriate.<sup>95,96</sup>

### 3.2 Specific Communication Tasks Common at the End of Life

The following section reviews several of the specific communication tasks commonly encountered in end-of-life care and offers some practical guidance on how physicians may accomplish these in a patient/family-centered manner.<sup>97</sup> The suggested techniques are not intended to be proscriptive, and physicians should adapt them as suits their individual communication styles and patient populations.

**3.2.1 Giving Bad News:** There are numerous instances in which physicians caring for patients with lung cancer may be required to give patients bad news, including offering initial diagnosis and discussing disease progression, treatment failures, and end-of-life issues. If the general principles of patient/family-centered communication described earlier are integrated into a structured and systematic approach to giving bad news, these difficult conversations may become easier for physicians, patients, and families. One example of a structured, six-step approach to delivering bad news is represented by the mnemonic SPIKES.<sup>98</sup> SPIKES seeks to fulfill four critical objectives in physician-patient communication: (1) information gathering, (2) information giving, (3) supporting the patient and family, and (4) developing care plans. The technique is described below.

S is for setup and it prompts the physician to plan in advance what is to be discussed and the potential ramifications of the bad news. It may be helpful to have colleagues, such as nurses or social workers, present to support the patient. Physicians should also

anticipate the patient's emotional responses as described earlier.

P is for perception, and it prompts the physician to first ask about the patient's perceptions of how things are going or what their understanding is about why they are meeting. Although this may seem apparent to the physician, it may not be for the patient; thus, understanding the patient's baseline comprehension gives the physician important knowledge about where in the clinical trajectory to initiate the information giving.

I is for invitation and may include giving a "warning shot." A warning shot is a way to prepare a patient psychologically for bad news. For example, the physician might start by saying, "Unfortunately I don't have very good news for you. Are you ready to hear the news?" Individuals confront bad news in various ways. Some patients want a straightforward and blunt provision of information. Other patients may need to prepare mentally for hearing bad news, and a warning shot can provide them the needed time.

K is for knowledge, and it represents the bad news that the physician needs to convey to the patient. The information should be communicated in simple, direct language appropriate to the patient's level of education. In general, pathophysiologic discussions are not helpful and are potentially confusing.

E represents empathy. It is common for patients to have an emotional response after hearing bad news. This may manifest in nonverbal ways, and physicians should be prepared to address and support emotions. The NURSE mnemonic can help physicians remember how to do this.

S is for summarize and strategize. Patients typically want to know what comes next in their treatment. After conveying bad news and discussing clinical decisions going forward, physicians should conclude the discussion with a summary statement of the information that was discussed and the plans for the future.

**3.2.2 Advance Care Planning:** The Patient Self-Determination Act enacted >20 years ago provides a mechanism for patients to make known their preferences for treatment in the face of serious or terminal illness. Although this effort has had some success, there have been a variety of challenges, most notably a low use rate, with approximately 20% of Americans completing advance care planning documents. Thus, the following sections focus not on medical-legal considerations but on establishing an open and trusting physician-patient relationship and honest dialogue regarding diagnosis, prognosis, and goals of care. The recommended approach is to work toward aligning patient and family expectations with clinically achievable treatment goals. It is important to acknowledge that patient goals can and often do evolve during can-

cer treatment and that physicians need to iteratively address prognosis and treatment options and adjust treatment recommendations based on changing clinical circumstances as highlighted earlier in this article.

**3.2.3 Communication With Other Providers and Interdisciplinary Teams:** Patients with lung cancer will encounter a variety of physicians during the diagnosis, staging, and treatment phases of the disease. When disease progression occurs and palliative care becomes important, the primary physician should work toward aligning other physicians around common clinical goals. It is important that patients and families receive clear and consistent information from physicians, and, thus, an investment of time and effort may be necessary to achieve alignment among treating physicians. Recent reports highlight the importance of a multidisciplinary team in helping patients and families confronted with advanced lung cancer cope with religious/spiritual issues and psychosocial needs.

**3.2.4 Conducting a Family Meeting:** The principles of patient-centered communication described previously should be applied when a family meeting is conducted. Physicians should prepare for family meetings in a considered and intentional manner, as with other important clinical interventions. It is useful to think of family meetings as having three stages: (1) prior to the family meeting, (2) during the family meeting, (3) and after the family meeting. Prior to a family meeting, physicians should confirm common and shared clinical goals for the patient's care, arrange for provision of multidisciplinary support if available, and establish a quiet and convenient location for the family meeting. During the family meeting, the SPIKES mnemonic outlined earlier offers a useful framework, and the NURSE mnemonic can help address emotional responses. Other practical guidance includes having each member of the clinical team and each member of the family introduce themselves and explain their connection to the patient before discussing the reasons for the family meeting. It is also important that each participant of the meeting be heard and be given adequate time for questions and clarifications. The process of moving toward end-of-life care is often iterative, and clear consensus may not be achieved during an initial discussion. Thus, physicians need to recognize when patients and families need time to process information and be willing to reconvene if necessary. The summarize and strategize step of SPIKES is a simple way to conclude a family meeting and helps confirm that all participants are on the same page with regard to what was discussed and what decisions have been made. It is also important that the physicians explicitly acknowledge and affirm the efforts a patient and family have



invested in the meeting and explicitly support any decisions that have been made.

**3.2.5 Transitioning to Hospice Care:** As highlighted in other sections of this article, provision of early palliative care to patients with advanced lung cancer improves important patient-centered outcomes and is a recommended best practice. If the concepts of palliative care are integrated early in the trajectory of cancer treatment, then transition to end-of-life care or hospice care need not be abrupt. Although hospice enrollment has steadily increased, the median length of stay prior to death remains less than 1 month, highlighting important opportunities to improve end-of-life care among patients with lung cancer. Hospice care is highly rated by patients and families coping with terminal cancer and offers important resources to support physical, psychosocial, and spiritual needs. However, there is significant variation in hospice resources by region, so physicians should become familiar with the local resources in their practice setting to help guide patients and families moving through the final phase of life.

#### Recommendations

**3.3.1. It is recommended that all physicians caring for patients with lung cancer should begin conversations about the patient's prognosis and goals of care at the time of the diagnosis, and continue these throughout the course of the illness (Grade 1B).**

**3.3.2. It is recommended that all physicians caring for patients with advanced lung cancer should initiate conversations about the goals of care; the pros and cons of life-sustaining treatment and end-of-life care options (Grade 1B).**

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