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THE CARDIOPULMONARY  
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*Chest* 2003;123:312-331

DOI: 10.1378/chest.123.1\_suppl.312S

**This information is current as of April 15, 2006**

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A M E R I C A N C O L L E G E O F  
 C H E S T  
P H Y S I C I A N S

# End-of-Life Care in Patients With Lung Cancer\*

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**Evidence-based practice guidelines for end-of-life care for patients with lung cancer have been previously available only from the British health-care system. Currently in this setting, there has been increasing concern in attaining control of the physical, psychological, social, and spiritual distress of the patient and family. This American College of Chest Physicians'-sponsored multidisciplinary panel has generated recommendations for improving quality of life after examining the English-language literature for answers to some of the most important questions in end-of-life care. Communication between the doctor, patient, and family is central to the active total care of patients with disease that is not responsive to curative treatment. The advance care directive, which has been slowly evolving and is presently limited in application and often circumstantially ineffective, better protects patient autonomy. The problem-solving capability of the hospital ethics committee has been poorly utilized, often due to a lack of understanding of its composition and function. Cost considerations and a sense of futility have confused caregivers as to the potentially important role of the critical care specialist in this scenario. Symptomatic and supportive care provided in a timely and consistent fashion in the hospice environment, which treats the patient and family at home, has been increasingly used, and at this time is the best model for end-of-life care in the United States.** (CHEST 2003; 123:312S-331S)

**Key words:** advance directive; communication; critical care; end-of-life care; hospice; hospital ethics committee; lung cancer; practice guidelines

**Abbreviations:** CPR = cardiopulmonary resuscitation; DNR = do not resuscitate; HEC = hospital ethics committee; SUPPORT = Study to Understand Prognoses and Preferences for Risks of Treatment; WHO = World Health Organization

After years of neglect, care at the end of life is receiving increasing attention and concern. When end of life is near, the patient is suffering the effects of a progressive and mortal illness, and is coping not only with bodily symptoms, but also with the existential crisis of approaching death.<sup>1</sup> The purpose of this communication is to offer guidelines in this important area, specific to lung cancer, the

most frequent cancer killer of men and women. Although the imperative of care is providing optimal symptom relief and alleviation of suffering, there is clear evidence in the current medical literature that we are failing to do this.<sup>2,3</sup> Despite wide dissemination of pain management guidelines,<sup>4</sup> many patients with lung cancer continue to suffer not only from pain, but also from other troubling symptoms and interpersonal scenarios in their final days. The most effective approach to providing better care in patients with other diseases has been the use of clinical practice guidelines based on the delivery of evidence-based medicine.<sup>5</sup> The ethical and professional challenge to do so is as important as the obligation to cure.<sup>6</sup>

End-of-life care is defined as "the active, total care of patients whose disease is not responsive to curative treatment."<sup>7</sup> The philosophy of this care is to attain maximal quality of life through control of the myriad physical, psychological, social, and spiritual distress of the patient and family.

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Central to ensuring quality of all care at the end of life is communication between the doctor, patient, and family.<sup>8</sup> Teaching how to break bad news has been the subject of 166 articles from 1975 to 1999, the majority published in the past 5 years, but < 15% were based on controlled trials.<sup>9</sup> In addition to the many important tenets relative to the patient, the family and its ethnic, cultural, and religious roots must be taken into account. Although many professionals feel awkward in talking about the end of life, family members face similar challenges in expressing their feelings and asking questions about prognosis. In a study from eight cancer centers, doctors considered that they had more trouble communicating with families than with the patients themselves.<sup>10</sup> Relatives often felt “left out” or “in the way,” which is particularly disturbing since impending death has such a profound impact on the family, with members often recalling in exquisite detail the lack of sensitivity of the doctor and staff. Such memories affect the grieving process, especially how attentive the doctor and staff were in controlling the patient’s distress and physical symptoms.<sup>11,12</sup> In a study of the implications for relatives of 200 consecutive, nonsurgically treated patients with lung cancer, monthly case histories, questioning of nursing staff and house physicians, was supplemented by home visits of nearest relatives to discuss illness and death.<sup>13</sup> Ninety percent of patients died within 1 year, with approximately 40% having no pain, and approximately 25% neither needed nor received any treatment. Approximately 80% of nearest relatives said the illness was not as bad as anticipated, and approximately 20% accepted the clinical course as about what they had expected. Spending time with the relatives who are in the front line and need all the encouragement they can get enhances mutual confidence between the patient and his medical team. Approximately two thirds of close relatives found that a simple sketch of the likely general deterioration of the patient with loss of weight and strength and “a fortnight in bed at the end” made the illness sufficiently tangible that they could deal with it, but in approximately 25% the death was still unexpected, such as with the 10 patients who had sudden massive hemoptysis. Of the approximate 25% who were dissatisfied with management of the illness, pain relief, delayed diagnosis, and nursing care setting were the main problems. Steps advised to improve these deficiencies were as follows: (1) training of doctors in communication skills as critical to ensure quality end-of-life care, (2) clinical research to determine the best teaching methods, and (3) education of family members in the end-of-life physical caregiver role and its psychological impact.<sup>1</sup>

Achieving effective pain management has been a

priority over the past decade. The American Pain Society, Agency for Health Care Research and Policy, World Health Organization (WHO), and National Comprehensive Cancer Network guidelines provide algorithms for decision making in pain management.<sup>7,14–16</sup> Pain is one of the most prevalent symptoms across terminal illnesses, affecting more than one third of patients, and also a source of great fear in anticipation of final days of agony. Considering all types of malignancy, 70 to 90% of patients have pain, and 50% die without adequate pain relief.<sup>17</sup> Pain also impairs psychosocial functioning, causes anxiety and depression, and limits capacity for enjoyment at the end of life. The American Pain Society, National Comprehensive Cancer Network, and Agency for Health Care Research and Quality guidelines provide algorithms for management of nociceptive and neuropathic pain of varying severity and chronicity.<sup>18</sup> Identification of type of pain, use of tools to assess pain severity and response to treatment, evaluation of effect of interventions on mental alertness, and flexibility of treatment regimens are mainstays of pain management. Clinician education of proper dosing and medication combinations facilitates better care, and use of adjunctive psychotropic drugs and behavioral interventions are effective. Implementation of guidelines has been impaired by misconceptions about dependence and addiction, risks of over sedation, and regulatory problems of opiates. (Additional information on management of pain in specific clinical scenarios due to metastatic lung cancer is contained in the chapter on palliative care in these guidelines.)

## REVIEW OF THE LITERATURE

A comprehensive search covering the past five years of English-language medical literature for practice guidelines on end-of-life care for patients with lung cancer, has revealed only specific contributions from the United Kingdom. These guidelines, while comprehensive for their National Health Service, are difficult to apply in medical practice in the United States but are listed for our consideration.

### *British Thoracic Society*

The following recommendations<sup>19</sup> are based on evidence from expert committee reports or the clinical experience of respected authorities: (1) obtaining agreement about the initial organization of the palliative phase with the patient, his or her family, and the primary care physician should be the responsibility of the relevant specialist; (2) all patients should receive regular follow-up by a member of the managing team; frequency depends on cir-

cumstances, and arrangements should be according to the needs and wishes of patients and their caregivers; (3) detailed coordination and liaison between the patient, his or her primary care physician, and specialists are usually best done by a specialist nurse; (4) all patients should be made aware of the doctor(s) supervising their care, and who is the assigned specialist nurse; (5) patients should be aware of who and how to call for urgent problems; (6) patient's wishes should be explicitly sought when there are major decisions to be made about changes in the palliative care pattern; (7) all cancer specialty units should have the facility to admit patients directly from primary care for symptom control; and (8) all correspondence detailing care plans or reviews should be copied to primary care physicians and to specialist nurses.

#### *Scottish Intercollegiate Guidelines Network*

The following recommendations<sup>20</sup> are based on evidence from expert committee reports or the clinical experience of respected authorities: (1) palliation of symptoms, physical and nonphysical, should be an integral part of the care of all patients with cancer; (2) referral to a specialist palliative care unit should be considered to augment support for the patient and caregivers; (3) locally agreed standards of care incorporating current research and best practice should be implemented for each modality of cancer nursing; (4) collaborative care should ensure best practice and care of patients in both primary and secondary settings; (5) ideally, patients with lung cancer and their relatives should have easy access to an appropriately trained specialist nurse throughout their illness; and (6) nursing care of patients with lung cancer should be viewed as collaborative within the wider care team and should focus on family centered care.

#### *National Health Service Improving Outcomes in Lung Cancer*

The following recommendations<sup>21</sup> are based on evidence from nonrandomized trials or observational studies: (1) at every stage, patients and their relatives should be offered clear, full and prompt information in both verbal and written form; (2) all health professionals involved in each patient's care should know what the patient has been told; (3) short courses of palliative radiotherapy should be available without delay for patients with chest pain due to cancer; (4) specialist palliative care should be available for all patients, both within the hospital and in the community.

Based on evidence from randomized controlled trials or systematic reviews of such trials, an additional recommendation would be that effective pain relief should be available promptly, using WHO or other guidelines with stepwise analgesia, and adequacy of control assessed.

#### HOW IMPORTANT IS COMMUNICATION WITH PATIENT AND FAMILY IN END-OF-LIFE CARE IN PATIENTS WITH LUNG CANCER?

There is an increasing body of literature that reveals that patients want more information from their clinician than they receive. They want an opportunity to discuss their preferences and their goals of treatment within the context of the medical facts of their illness. They want to discuss plans for the end of life, but they may need the clinician to initiate the discussion. Death has the power to surprise even the prepared, but many of our patients are not prepared.

We do not yet know how improving communication between patient and physician will change the outcome of an illness.<sup>22</sup> We do know that we are not doing a very good job of communicating with our patients about how they want to face whatever it is that is about to happen.<sup>23-27</sup> Objective studies of interactions between physicians and cancer patients reveal that clinicians spend little time probing the psychosocial aspects of the patient's illness.<sup>25,29</sup> In particular, we are failing to make their actual treatment match their preferences for treatment. Better communication at the patient-surrogate-physician level is needed to improve congruence between patient wishes and the life-sustaining care they actually receive.

Nowhere has this issue been explored better than in the Study to Understand Prognoses and Preferences for Risks of Treatment (SUPPORT).<sup>30,31</sup> In a huge multicenter study that spanned 5 years, it was demonstrated after a 2-year baseline observation period, during which time 4,301 patients were enrolled, there was a mismatch between patient treatment preferences and treatment actually received and that there were clear barriers to communication.<sup>17</sup> These were seriously ill patients with a predicted 50% 6-month mortality. After a year of analyzing results and planning an intervention that, it was hoped, would improve that match, there was a 2-year intervention period that expanded the total patient database to 9,105 seriously ill patients. Trained nurses talked to patients and families to obtain additional information about patient preferences. They provided this information, as well as objective prediction of patient outcome, to the clini-

cians. The clinicians discussed this information with patients and families in only 15% of cases.<sup>17</sup>

Even if patients have written advance directives, their wishes may not be honored. Only 618 of 3,058 patients (20.2%) in the baseline SUPPORT group were found to have advance directives, and in only 70 of 618 patients (11.3%) were these mentioned in the medical record.<sup>32</sup> Only slightly more than half of patients who wished to forego cardiopulmonary resuscitation (CPR) in this group had a do-not-resuscitate (DNR) order, and half of the written DNR orders were placed in the medical record within 48 h of death.<sup>17,32</sup>

Their physicians accurately identified patient preferences for only 861 of 1,513 patients (56.9%) preferring CPR, and for only 380 of 808 patients (47%) preferring DNR in the baseline study group.<sup>33</sup> The intervention produced literally no change in DNR orders or in days spent in pain or other undesirable states.<sup>17</sup> It slightly improved concurrence between patients and physicians on the CPR/DNR question. There is no substitute for the physician in exploring patient prognosis and preferences.<sup>34</sup>

If matters are left until the patient is too ill to participate in decision making, and in the absence of adequate preparation through a preliminary discussion with the patient, there is no guarantee that the family or surrogate will adequately represent what the patient would have wanted.<sup>35–39</sup> Patient self-expressed preferences are relatively stable over time<sup>40</sup>; however, in SUPPORT, 17% of baseline patients and 20% of intervention patients did reverse their preferences for DNR.<sup>17</sup>

### *Talking About Life and Death*

It is remarkably difficult to talk about death and its meaning.<sup>29,41</sup> Clinicians may have their own personal fears and a death anxiety.<sup>29</sup> They may lack training, knowledge, and experience in giving bad news. Formal training communication skills and increasing availability of a wide variety of resources on communication can enhance the clinician's ability to relay difficult information.<sup>29,42–45</sup> This can be done without increasing the patient's emotional distress and without lengthening the patient visit, as shown in a prospective randomized trial of 69 physicians with an 8-h videotaped educational intervention on communication.<sup>46</sup>

Too often we leave discussion about difficult matters until the "ultimate point" in the ICU or when death is imminent and in a setting of crisis.<sup>47</sup> Virtually all patients with lung cancer are at significant risk of death. We do not convey this knowledge to them effectively.<sup>23,24</sup> In a prospective study of 326 patients with cancer at five Chicago hospices, physicians

formulated prognoses in 300 of 311 evaluable patients (96.5%).<sup>23</sup> Physicians reported that they would not communicate any survival estimate 22.7% of the time, and would communicate survival estimates different from the ones they had actually formulated 40.3% of the time. Of these discrepant communications, 70.2% were more optimistic than the actual prediction.

Certainly the patient might be cured by intervention, or might die from an unrelated event before the disease has a chance to kill, but "the seeds that the patient may not be cured should be sown at the very beginning of the management process."<sup>48</sup> A patient-centered model of care from the very beginning enhances and facilitates later transition to a palliative approach to care.<sup>49</sup>

At the same time that the diagnosis is made and decisions about options in treatment are being explored, the physician should initiate discussion about the patient's concerns, preferences, and goals in life as well as goals in treatment. Given the medical facts of the patient's situation (the particular circumstances of the case), given who the patient is as an individual (what is important to him), how do the different options in care match up with optimal quality of life for however much time remains? From these elements, the clinician and patient can weave a plan of care, acknowledging that the plan is subject to change based on the patient's changing circumstances (failure to respond to a chosen option in treatment, development of new and disturbing symptoms). The elements necessary to formulate this care plan include the following<sup>50</sup>: (1) a comprehensive assessment of the medical facts of the individual patient's situation, to include a realistic and as accurate as possible appraisal (not too rosy, not too grim) of what is likely to happen; (2) an understanding of who that person is and what he or she values in life (as well as in death); (3) together, these form the assessment of what kind of quality of life the patient could expect from different therapeutic choices; and finally (4) extrinsic factors must be included (resources, family situation, etc).

The patient should be encouraged to make appropriate arrangements for personal matters. These include updating his or her will, thinking about end-of-life care and advance directives, and discussing these with an appropriate surrogate. All of these discussions should be both compassionate and culturally sensitive. Even something as simple as an extra 40 s of compassion on an educational videotape about breast cancer has been shown to reduce anxiety in 123 breast cancer survivors and 87 women without breast cancer, although it did not improve

recall of the educational information.<sup>51</sup> Above all, the patient should be allowed to express their reaction to the situation.<sup>52</sup>

If there will be a day-to-day contact person who will coordinate care for the patient with all of the different consultants and resources, that person should be present at these discussions to facilitate congruence between patient preferences and care delivered. These conversations should be open minded and nonjudgmental; we must make sure that our own prejudices and beliefs do not overly color this joint discussion-making process.<sup>53</sup> Consider a written treatment plan to enhance communication and understanding of the plan among all parties.<sup>24</sup>

### *Predictions: Truth and Uncertainty*

No time frame should be placed on what the individual patient is likely to experience with different choices in medical treatment. Although they need to know what kind of result most patients like themselves experience (eg, 20% 5-year survival), it must be very clear that we cannot predict with certainty what that individual's outcome will be for different choices in treatment. Most people want to know the probability of being pain free and able to care for themselves in the immediate future. They want to know what to expect 2 months from now and 6 months from now.<sup>31</sup>

The statement that "every patient is unique" should not be used to avoid this careful discussion of prognosis. There is a strange collusion that may occur between patient and doctor. In a study of 35 patients with small cell lung cancer in the Netherlands, false optimism was observed routinely during early phases of treatment.<sup>54</sup> The doctor does and does not want to tell the patient of a dismal prognosis. The patient does and does not want to know. Both may become focused on the short-term goals of treatment to the neglect of the long-term goals as a result of this dynamic. Care must be given to ensure that prognostic information is not distorted, as survival may be systematically overestimated by clinicians.<sup>23</sup>

In SUPPORT, 4,028 physicians' subjective predictions of patient outcome during the intervention were obtained, paired with objective prediction and actual mortality. Physicians were slightly more pessimistic, but also more accurate than the objective model in the patients with higher probability of mortality, but slightly more optimistic and less accurate for the patients with lower probability of mortality.<sup>55</sup> Other studies have suggested that physician predictions may be too optimistic.<sup>56</sup>

There can be multiple layers of uncertainty in this situation; since we physicians are not good at esti-

imating when an individual is going to die, we may not communicate our estimate accurately to the patient, and the patient may misinterpret or reject our estimate.<sup>54,57</sup> Prognostic information should be vague enough to include the truth (the median time frame until death) but specific enough to help people make appropriate plans.

There is no substitute to talking to the patient, but the family, particularly the patient's surrogate, should also be included to facilitate both congruence between the patient's preferences and actual treatment and also family knowledge about the patient's illness and expected outcome. Quill and Brody<sup>58</sup> propose an "enhanced autonomy" model of decision making in which active dialogue between patient and physician enables the patient to participate in decisions as fully informed of medical realities as possible. Consider using the "SPIKES" six-step protocol<sup>59</sup>: *S* = get the Setting right; *P* = understand the patient's Perception of the illness; *I* = obtain the Invitation to impart information; *K* = provide Knowledge and education; *E* = respond to the patient's Emotion with empathy; and *S* = provide Summary strategy. Communication skills of junior clinicians may be improved by including them in these conversations to provide real-time role modeling for their own professional growth in communications skills.

### *Transitions to Palliative and Comfort Measures*

Patients not only want to be free from pain and suffering as they die, they also wish to have the opportunity to make peace with God, to resolve personal conflicts, and to make financial plans before death.<sup>60</sup> A little compassion goes a long way toward facilitating patient comfort in the face of difficult decisions.<sup>51</sup>

The first hurdle is to acknowledge that the patient is likely to die—to use the "D" word. A euphemism simply will not do; it is too subject to misinterpretation. If the patient (or family) is first asked if they want complete information, there is no reason to withhold the information that the patient is likely to die, and every reason to share this knowledge. This will enable a transition in focus of care, and enhance planning and preparation for death.<sup>52,61–63</sup>

When approaching the patient for whom primary treatment for lung cancer has failed, or for whom the treatment has become worse than the disease, a comprehensive re-evaluation of goals of treatment must be sought. No longer can the patient realistically include cure as a treatment goal, even if that was a possibility to begin with. The choices in therapeutic options are increasingly restrained as the potential benefits of treatment diminish and as the

real burdens of treatment escalate. The level of treatment must be adapted to the individual patient's life goals in the face of death. Potentially useful questions to facilitate this transition were reviewed by Lo et al<sup>52</sup> for the American College of Physicians/American Society of Internal Medicine end-of-life care consensus panel.

All too frequently, the caregivers are not sufficiently in tune with the patient's experience of illness and suffering and fail to address these aspects of the patient's illness adequately.<sup>49</sup> For other cancers, inadequate attention to this has been associated with an increase in patient utilization of homeopathic or alternative medicine. This is presumably out of frustration at the inability of the primary team to deal effectively with such aspects of care.<sup>64-66</sup> Including a palliative care or hospice team with the cancer team has mutual advantages to the clinicians and provides the patient joint access not only to individuals skilled in trying to cure the primary disease and in managing life, but also to individuals skilled at assessing pain and emotional and spiritual distress, and managing death.<sup>67,68</sup>

During whatever period of time the patient will have, the focus of treatment will be on enabling the dying person to live until death occurs. Goals of treatment would be to optimize physical performance and minimize suffering so that the patient can perform at his or her own maximum potential. Goals of treatment should also include assistance with the personal tools to make amends with others as needed, to say goodbye, and to pursue matters with the deepest meaning to the patient so that he or she can face the end of life with a sense of completion.<sup>69</sup> Treatment should be directed toward extending life rather than prolonging death, toward reducing suffering both physical and spiritual, toward achieving acceptance rather than denial or delusion.

Giving bad news is a difficult task and requires physician competence and facility with communication under stressful circumstances. Physicians should avail themselves of the increasing body of educational resources to improve communication at the end of life. Strategies for facilitating a transition of focus of care to palliative and comfort measures include the following<sup>29,59,70</sup>: (1) developing rapport; (2) finding out what the patient and family already know; (3) identifying preferences for receipt of information (amount and complexity); (4) giving the information in a sensitive but straight-forward manner; (5) responding to emotions; (6) establishing the overall goals of treatment given the patient's personal goals, the med-

ical facts, and the available technology; (7) and finalizing the care plan, selecting elements based on goals of treatment.

Giving bad news, establishing the care plan, and counseling in advance care planning can all be coded in the United States under current rules as counseling time. If the patient is already critical and the discussion produces a change in care plan, it can be coded as critical care time. In the critical patient, it must be clear that any change in treatment plan does not represent a change in caring.<sup>71</sup>

Involving the patient and family in decision making enables them to have as much control as possible over the dying process. Death is the ultimate outcome for every life. In general, people meet their deaths the same way they approach life; if they have time before their death, then they need to have the tools to help them use this time wisely. We need to do our best to give them both the time and the tools.

### *Recommendations*

1. For patients with lung cancer at the end of life, it is recommended that clinicians increase their focus on the patient's experience of illness to improve congruence of treatment with patient goals and preferences: (a) be realistic, practical, sensitive and compassionate; (b) listen; (c) allow/invite the patient to express his or her reaction to the situation; (d) provide a contact person; and (e) continually reassess the patient's goals of therapy as part of treatment planning. Evidence: poor; benefit: substantial; grade of recommendation: C
2. For all patients with lung cancer, end-of-life planning should be integrated as a component of assessment of goals of treatment, and treatment planning. Evidence: poor; benefit: substantial; grade of recommendation: C
3. For patients with lung cancer, an experienced clinician should inform the patient of the diagnosis and its meaning. The day-to-day contact person should also be present at this meeting and should coordinate care. Evidence: poor; benefit: substantial; grade of recommendation: C
4. Clinicians treating patients with lung cancer should avail themselves of the increasing body of educational resources to improve communication at the end of life. Evidence: fair; benefit: substantial; grade of recommendation: B
5. With patients with lung cancer, hospice and/or the palliative care service should be involved early in the patient's treatment, as part of the team. Evidence: poor; benefit: substantial; grade of recommendation: C

## HOW EFFECTIVE ARE ADVANCE DIRECTIVES IN FULFILLING THE LEVEL OF CARE REQUESTED BY END-OF-LIFE LUNG CANCER PATIENTS?

After *Cruzan vs Director, MDH*<sup>72</sup> and the Patient Self Determination Act,<sup>73</sup> most patients are aware that they have the right to an advance directive. There is widespread support of these documents both within the medical community and among lay individuals<sup>74</sup>; however, the medical and legal sources, as given below, reveal that both physicians and patients frequently find them less than ideal, and therefore they are often rendered ineffective.

Advance directives are legal documents: living wills and durable powers of attorney for health care.<sup>75</sup> They acknowledge patient autonomy<sup>74,76</sup> and attempt to document the patient's wishes regarding medical care when he or she is no longer competent. Despite all good intentions, neither of these documents has always achieved its desired goals. With regards to the durable power of attorney for health care, the proxies "are unable to choose consistently [sic] treatment options conforming to patient wishes, . . . [and] they fall short of providing a meaningful extension of patient autonomy."<sup>35,74,77,78</sup> With regard to living wills, the words frequently mean different things to the physician, the patient, and the family.<sup>74,79</sup> They only take effect when a patient is terminal—but when is a patient terminal?<sup>80</sup> The documents do not itemize all the possible treatment options and, understandably, from the medical perspective, they cannot. Physicians with the best of intentions occasionally feel the need to have the assistance of other individuals when interpreting them.<sup>74</sup> There are studies that show they do not always affect whether or not a patient has an attempted resuscitation, that the patients do not continue to receive the expected level of care, and that they have "little impact on the pattern of care" when compared to those patients without an advance directive.<sup>32,81,82</sup> Even if the medical community could put these findings aside, there is an overabiding concern and considerable evidence within the legal community that there are inherent problems with the statutes themselves, as well as the Patient Self Determination Act, which can cause them to be ineffective.<sup>83–85</sup>

One study within the medical community was SUPPORT published by Teno and colleagues<sup>32</sup> in 1994. This was a very large cohort study of > 3,000 hospitalized patients who were seriously ill. Some of the patients had executed living wills, and others had not. The study found that there was no difference between the groups as to whether or not a DNR order was placed; each group was as likely to have "an attempted resuscitation."<sup>32</sup> These patients are

described only as seriously ill. Were all "terminal?" If not, the conclusion of the study that living wills made no difference as to the care rendered is inappropriate. We as physicians must understand, and patients must be educated, to the fact that a living will does not automatically imply, or give the physician permission to write a DNR order. These are two separate issues, and they must not be considered synonymous. First, a living will addresses only the health-care preferences in the event of terminal illness and patient incompetence. A seriously ill incompetent patient may present to you for care, and have executed a living will that is placed on the chart; but if the patient is not terminal, it is not appropriate to state the patient is DNR based on the living will alone. And second, a DNR order can be written on behalf of any patient regardless of the state of health; patient's have the right to refuse care.<sup>85</sup> This issue can only be dealt with by further physician and patient education. Physician education should be a required topic in continuing medical education (needed for licensure in many, if not all states), and patient education should come from a joint effort between physicians and attorneys to publish in the lay press.

A second study was that of Danis et al<sup>81</sup> published in 1991. The preferences of 175 nursing home patients regarding their future care was recorded. The results showed that approximately three fourths of the patients had care consistent with their wishes, but even with these patients, there was inconsistency as to the level of aggressiveness of their care. Tonelli<sup>74</sup> stated "[that] such a finding hints that the emphasis on advance directives as a way to limit inappropriately aggressive care may be misguided, with the real threat to patient autonomy coming from the side of undertreatment." In keeping with this finding, it is advisable that physicians be educated, collectively and repeatedly, by the legal profession on the interpretation of living wills, not only on the statutory form in their respective state, but also the current legal interpretation of various phrases; our legal system is not static.

It was the conclusion of Johnson et al<sup>82</sup> from a 1991 and 1992 study, that the presence or absence of the advance directive (living will and/or durable power of attorney for health care) had little impact on the "pattern of care." This study looked at 304 patients from a community teaching hospital. A prospective nonrandomized cohort data collection and analysis study was undertaken. Review of the data showed that the patients' ages and duration of stay in ICU were quite similar within each group. Data also showed that the percentage of deaths was essentially the same. The authors admit the limitations of the study, but nonetheless believed that

ultimate patient demise was not affected by the presence or absence of the advance directive. The study attributes this finding to the fact that in many of the patients admitted without advance directives, contact with family or legal representative allowed a DNR order to be placed on the chart.<sup>82</sup>

In addition to the inadequacies mentioned in the medical literature, the legal sources reveal the following: (1) advance directives are written in such a manner as to record a patient's wishes at the time the instrument is executed; they presume that a patient's values will not change as the patient grows older or different circumstances arise<sup>83,84</sup>; (2) the Patient Self Determination Act was enacted for the purpose of protecting patient autonomy and self-determination by informing patients that they have the right to execute a living will; in the form in which it presently exists, simply following "the letter of the law" (following the law precisely, as most hospitals have done) has reduced this act to a process likened to reading a person his Miranda Rights; when patients are informed, "very little is done to inform these patients of how to meaningfully and effectively exercise this right"<sup>84</sup>; (3) in the majority of states that allow the execution of a living will, the enforcement of living wills is in serious jeopardy; "Specifically, if the physician refuses to honor the living will, in most of these states there is no legal recourse which allows the individual to enforce this right."<sup>85</sup>

In light of all of the above, it is imperative that we look at the original intent of Kutner,<sup>86-88</sup> and then Bok,<sup>89</sup> when the idea of "living wills" was put forth in the 1960s and 1970s. "When [they] were initially conceived it was recognized that they can only be vague guides that must be interpreted by surrogates at some later time."<sup>90</sup> But who are these surrogates to be? There are advantages and disadvantages to naming any particular category of persons, *ie*, the physician, the next of kin, or a designee of the court, the surrogate.

Difficult as it may be, it is a necessity that the approach of our society to advance directives evolve. Otherwise, the difficulties that are encountered and troublesome for all parties will continue. The "advance health-care directive" is an idea that has been proposed and codified in 13 states.<sup>91</sup> These statutes combine the elements of a living will and durable power of attorney for health care into one document,<sup>91</sup> thus acknowledging patient autonomy, patient preferences, and the fact that a patient's desires change over time as comorbid conditions arise and life circumstances change.

### Recommendations

6. Each patient with lung cancer should be asked if he or she has an advance directive, and the

clinician should assume responsibility for placing it in the chart. If the patient does not have an advance directive, the clinician should suggest preparing one. Evidence: poor; benefit: substantial; grade of recommendation: C

7. With patients for whom there are questions about the validity or interpretation of an advance directive, seek guidance from the hospital legal counsel or ethics committee. Evidence: poor; benefit: substantial; grade of recommendation: C

### WHAT IS THE ROLE OF THE HOSPITAL ETHICS COMMITTEE IN RESOLVING END-OF-LIFE PROBLEMS IN PATIENTS WITH LUNG CANCER?

The proliferation of hospital ethics committees (HECs) was precipitated by public controversy that burgeoned in the 1970s. Beginning with the case of Karen Quinlan in 1975, a series of highly publicized legal cases disclosed numerous unresolved issues regarding end-of-life care.<sup>92</sup> These cases reflected the substantial uncertainty of patients, physicians, families and health-care institutions regarding the appropriate limits of life-prolonging treatment and the locus of decision-making responsibilities. At the same time, the cumbersomeness of legal review, the adversarial nature of the process, and the inconsistency of the results suggested that the courts were not an adaptable mechanism for the routine review of cases regarding end-of-life care. In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research tentatively endorsed the use of HECs as a review mechanism that might provide a *via media* between purely private decision making and recourse to the courts when difficult end-of-life issues emerge in patient care.<sup>93</sup> The development of HECs was given further impetus in 1992 when the Joint Commission on Accreditation of Health Care Organizations required that health-care institutions establish formal mechanisms for addressing ethical issues relating to patient care.<sup>94</sup>

Although the Joint Commission on Accreditation of Health Care Organizations did not require the establishment of HECs as the sole means for providing these mechanisms, HECs were widely accepted as the most appropriate means for satisfying the mandate. At the time of its 1983 report, a national survey undertaken at the request of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research revealed that only 4.3% of American hospitals with > 200 beds had ethics committees, and 64.7% of facilities with ethics

committees were teaching hospitals. Overall, only 1% of US hospitals had ethics committees, and none were found in hospitals with < 200 beds.<sup>95</sup> A separate national survey conducted in 2001 illustrates the sweeping transformation engendered by the recommendations of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research and the standards of the Joint Commission on Accreditation of Health Care Organizations. Of 346 randomly sampled hospitals, 93% now have functioning HECs, with a median period of operation of 7 years.<sup>96</sup> These committees engage in several critical functions within health-care facilities. All HECs responding to the survey indicated that they are involved in the development of policy, particularly as relates to the withholding of life-prolonging treatment, accounting for 30% of committee time. Education of committee members accounted for an additional 30% of committee time. Finally, 86% of HECs surveyed reported that they engage in clinical case consultation, accounting for 20% of committee time.

### *The Context of Ethics Consultation*

A prominent feature of modern society is the pervasive pluralism of norms and values cherished by different individuals. This pluralism is highlighted in the health-care setting, where individuals interact who are drawn from widely diverse professional, cultural, and religious communities. As a result, uncertainties or conflicts may arise about the interpretation of moral norms or values in clinical care decisions at the end of life.

Case consultation provided by an HEC may involve individual members, teams, or the committee as a whole. It is a service that is intended to assist patients, families, health-care professionals, and other involved parties in addressing uncertainties or conflicts regarding moral norms or values affecting patient care. Numerous issues engendering uncertainty or conflict arise in the context of end-of-life care. These issues may involve matters such as informed consent, refusal of treatment, patient decision-making competence, medical futility, interpretation of advance directives, patient confidentiality, surrogate preferences, decision making for patients without family, the distinction between palliation and euthanasia, and appropriate allocation of resources. The clinical situations engendering these ethical issues also often involve complex legal, affective, interpersonal, organizational, and economic factors.

### *The Goals of Ethics Consultation*

The fundamental goal of ethics consultation is to improve the quality of patient care by facilitating the identification, analysis, and resolution of ethical issues that arise in particular clinical cases.<sup>97,98</sup> There are three ways in which ethics consultants can facilitate the resolution of moral problems that arise in providing care to patients with lung cancer.<sup>99</sup> One is by providing basic information to the parties consulted regarding relevant statutes, court cases, institutional policies, and professional guidelines. For example, state statutes may specify the priority status of surrogate decision makers when the patient is no longer competent, or outline procedures for implementing advance directives. Similarly, institutional policies may formulate specific procedures to be followed when surrogate decision makers are not available for incompetent patients. Ethics consultants can apprise the relevant parties about these substantive and procedural rules that may constrain the range of choices within particular situations.

The second way in which ethics consultants can assist in resolving ethical issues involves identifying and analyzing the uncertainty or conflict of values and norms that prompted the consultation. One part of this process involves identifying the relevant moral principles that apply in the particular case and clarifying the content of their requirements for patient care. Another component is assisting the relevant parties in examining alternative courses of action and the manner in which these alternatives may respect or fail to respect the moral principles identified. Finally, the ethics consultant may suggest one or more possible solutions to the issue raised that may provide the fullest consideration for the moral concerns identified.

The third manner in which ethics consultants can assist in resolving ethical issues involves facilitating communication and negotiation among the physician, patient, and family.<sup>98</sup> Part of this function involves helping the different parties involved in clarifying their own values and concerns about the situation. Another component involves assisting the parties in communicating their concerns to one another and in explaining the rationale for the outcomes they prefer. Finally, the ethics consultant can assist the parties involved in negotiating and building a shared commitment with respect to how the ethical issue raised by the case should be resolved.

### *Inappropriate Roles for Ethics Consultants*

The assistance of an ethics consultant is properly sought when a clinical situation causes conflicts or uncertainty about the interpretation of moral norms

or values in the care of the patient.<sup>99</sup> The ethics consultant facilitates the interpersonal process of resolving these moral conflicts or uncertainties. This role must be distinguished from several other activities. One is the function of addressing instances of immoral or unprofessional conduct on the part of health professionals. This kind of problem should be referred to appropriate professional or peer review groups. Another inappropriate function involves serving as an advocate for a patient whose interests or rights have been violated. While part of the function of the ethics consultant is to ensure that the patient's perspective is properly considered in resolving end-of-life issues, this does not involve rectifying prior encroachments on the interests or rights of patients. The ethics consultant should also not be regarded as a psychological counselor who assists persons in understanding and resolving their own emotional difficulties related to the clinical situation. While ethical issues in patient care may be stressful for patients, families, and health professionals, the ethics consultant's role is to assist the involved parties in clarifying the relevant norms and values that should guide their decisions. In addition, the ethics consultant should not be regarded as someone whose function is to provide the correct answer to the ethical issues that have been raised. Rather, the solution to an ethically troubling situation should be viewed as a course of action to be constructed based on a shared understanding of the relevant parties regarding the meaning and interpretation of the relevant moral norms and values. Finally, the ethics consultant or HEC should not be assigned decision-making authority regarding the resolution of a moral issue in end-of-life care. This function would improperly preempt the decision-making authority assigned to patients, families, and physicians.

#### *Utilization of HECs for Ethics Consultation*

In the most recent national survey of HECs, the 275 committees performing case consultations reported an average of 8.1 formal consultations and 4.3 informal consultations per year.<sup>96</sup> Patient autonomy and decision-making competence were addressed in 38% of the cases, improving communications in 35%, end-of-life issues in 7%, use of new technologies or research in 7%, and cost-containment issues in 3%. In another study of a busy consultation service in a teaching hospital, 51 consultation requests over 12 months involved issues about withholding life-sustaining treatment (49%), DNR orders (37%), and clarification of legal requirements (31%).<sup>100</sup> A third study reviewing 46 case consultations indicated that major issues raised for review included withdrawing or withholding treat-

ment (38 cases), appropriateness of current treatment (28 cases), resuscitation (22 cases), competency or refusal of treatment (12 cases), and family demands for inappropriate treatment (8 cases).<sup>101</sup> In another study reviewing 104 case consultations in a community hospital, consultation requests concerned decisions to forego life-sustaining treatment (74%), resolution of disagreements (46%), and determination of patient competence (30%).<sup>102</sup> Thus, available studies clearly suggest that the consultation services of HECs are predominantly utilized in addressing issues related to patient autonomy and competence, withholding or withdrawal of life-prolonging treatment, communication issues, and surrogate preferences. Because these categories reflect the most prominent ethical issues posed in end-of-life care for patients with lung cancer, ethics consultation services may have particular relevance in these settings.

#### *The Effectiveness of Ethics Consultation*

Assessment of the outcomes of ethics consultation in end-of-life decision making is limited. Four potential benchmarks for evaluation have been identified: (1) case management that conforms to ethical norms and standards, (2) satisfaction of involved parties regarding the results of consultation, (3) resolution of initial conflict between the parties involved, and (4) the educational impact of the ethics consultation.<sup>103</sup>

Evaluation of whether ethics consultation results in management decisions that conform to ethical standards requires that there is widely shared agreements about the content of such standards. In some aspects of end-of-life care, consensus standards have emerged. For example, the major components of an adequately informed consent have been well formulated.<sup>104</sup> The right of competent adult patients to refuse treatment, including life-prolonging procedures, is well established.<sup>92</sup> The role of advance directives in determining care for incompetent patients has been widely recognized in state law.<sup>105</sup> Criteria for decision making by surrogates have been formulated.<sup>106</sup> However, despite the consensus in many areas related to end-of-life care, there have been no studies to date that assess whether ethics consultation improves the extent to which end-of-life care decisions satisfy ethical norms of professional practice.

Several studies have examined the level of satisfaction among parties who have requested or received the assistance of ethics consultants. A review of 46 case consultations found that > 90% of attending physicians found consultation to be helpful in clarifying ethical issues, educating the health-care

team, increasing the confidence about clinical decisions, and improving patient management.<sup>101</sup> In another evaluation study of 51 ethics consultations, physicians considered the consultation “very important” in 71% of the cases in clarifying the ethical issues, learning about medical ethics, or in determining the management of the patient.<sup>100</sup> Finally, in a 2-year study of 104 ethics consultations, the requesting physician found the consultation “helpful” or “very helpful” in 86% of the cases.<sup>102</sup> Thus, ethics consultation appears to result in a high level of satisfaction among parties either requesting or participating in the process.

No studies have examined in detail the impact of ethics consultations in resolving conflicts among the parties—physician, patient, and family—involved in clinical care decisions. However, in one review of 16 case consultations, only 2 of 40 staff members and 2 of 6 family members indicated that they disagreed with the consultants’ recommendations.<sup>107</sup> In another study, physicians rated the consult as helpful in 75% of cases in which communication with the family or other staff was a problem.<sup>108</sup>

The educational impact of ethics consultation has not been directly examined by evaluating the knowledge of relevant factors before and after consultation. However, in three studies, the participants reported that the consultation was helpful in identifying ethical issues, clarifying relevant concepts and norms, and in providing practical knowledge useful in clinical case management.<sup>100–102</sup>

### *The Process of Ethics Consultation*

Given the relative newness of the ethics consultation as a function of HECs, there are many variations in the process utilized.<sup>109</sup> One area of variable practice relates to access to ethics consultation. Some protocols permit only physicians to request ethics consultations, while others allow requests from other professional staff members, as well as from patients and families. Another variable relates to process of case review. In some settings, the case presentation and deliberative process include only the attending physician and the consultants, while in other settings professional staff, patient, and family may be included in the process of presenting and deliberating about the resolution of the case. A third variable relates to the results that the consultation is intended to achieve. These might involve only a full discussion of the clinical care options, identification of a range of acceptable alternatives, or the recommendation of a preferred option. Another variable relates to the form in which the results of consultation should be disclosed. Disclosure may be in the form of a verbal or written report, including a

consultation summary inserted in the medical record. Finally, there are alternatives regarding the parties to whom the consultation results should be disclosed, including the attending physician, relevant staff members, patients and families. In light of multiple choices available for fashioning the process of ethics consultation, it is important that the requesting party and consultants clarify beforehand who will be involved, what the objective of the consultative process should be, how the results will be formulated, and to whom the results will be conveyed.

### *Recommendations*

8. In making end-of-life decisions for patients with lung cancer, ethics consultation by HECs should be requested when assistance is needed in clarifying applicable law and policy related to patient autonomy and competence, informed consent, withholding life-prolonging treatments, surrogate preferences, decision making for patients without family, and resource allocation, as well as determining how ethical norms should be interpreted, or negotiating interpersonal conflicts among patients, families, and physicians. Evidence: poor; benefit: substantial; grade of recommendation: C
9. In end-of-life care for patients with lung cancer, given the potential variations in ethics consultations, the requesting party and the consultant should clarify beforehand the specific objectives of the consultation, the selection of the participants, the process to be used in deliberation or negotiation, and the manner in which results will be disclosed and recorded. Evidence: poor; benefit: substantial; grade of recommendation: C

### WHAT IS THE ROLE OF THE CRITICAL CARE SPECIALIST IN THE END-OF-LIFE CARE OF LUNG CANCER PATIENTS?

Spiraling costs and reform of health care have intensified pressure to reduce use of expensive resources, such as critical care services, for patients with poor prognoses, including those with advanced lung cancer. This is understandable, considering that outcomes of ICU treatment for cancer patients are often unfavorable and that intensive care consumes a very large and disproportionate share of health-related expenditures. Potential distress for patients and families from invasive interventions in the critical care setting is another important cause for concern. It is evident from existing literature and clinical

experience, however, that thousands of patients with lung cancer and other malignancies are still admitted to ICUs each year, with reported benefit for some patients. In addition, despite an improved ability to predict ICU outcome using cancer-specific models, certainty remains elusive and, for many patients, only a therapeutic trial can determine the effectiveness of intensive care with an acceptable degree of confidence. It is therefore reasonable to expect that patients with lung cancer will continue to receive care in ICUs, including end-of-life care, and it is appropriate to review the role of the critical care specialist in such care.

### *Lung Cancer in Critical Care*

More than 5 million patients are admitted to ICUs in the United States each year,<sup>110</sup> including a subgroup with lung cancer that is difficult to quantify with precision from existing data. A large-scale survey in 1993,<sup>111</sup> revealed that cancer-related organ failure was the admitting diagnosis for approximately 1% of admissions to the nation's ICUs. Among cancer patients included in recent studies of ICU outcomes, lung cancer was the most common solid tumor and among the most common malignancies overall, accounting for between 20% and 30% of solid tumors in critically ill patients,<sup>25,112</sup> and 16% of all malignancies in cancer patients admitted to a medical ICUs.<sup>113</sup> Indications for ICU admission of patients with lung cancer are diverse, ranging from perioperative care of patients undergoing resectional surgery with curative intent to respiratory failure from exacerbation of underlying chronic lung disease, intercurrent compromise by infection, hemorrhage, or pleural effusion, or advancing malignancy with bronchial obstruction. Appropriately, most clinicians, including intensivists, wish to maximize treatment of reversible, acute illness even in the context of ongoing, underlying disease, while limiting ICU care for patients with irreversible complications. The distinction may be difficult to draw, however, at the time point of presentation to an ICU.

### *Outcomes of ICU Treatment for Cancer Patients*

Decision making about ICU treatment for the patient with lung cancer should be informed by available knowledge about prognosis. Although no mortality prediction model has been developed prospectively and specifically for lung cancer patients with critical illness, a large, multicenter, prospective study by Groeger et al<sup>114</sup> derived and validated a multivariable logistic regression model to estimate the probability of hospital mortality among adult cancer patients admitted to the ICU. This cancer-specific model incorporates a manageable number of

readily available clinical variables and is better calibrated than general ICU prognostic scoring systems, which underestimate the risk of mortality for cancer patients.<sup>111,115</sup> A separate analysis of prospectively collected data was subsequently performed,<sup>112</sup> to identify predictors of hospital mortality for cancer patients requiring mechanical ventilation, which requires prospective and independent validation in the future. Overall, the observed hospital mortality for cancer patients receiving ICU treatment was 42%, but 76% for patients requiring mechanical ventilation. Among the latter group, progression or recurrence of cancer, cardiac arrhythmias, need for vasopressor therapy, and presence of disseminated intravascular coagulation, were among seven variables associated with an increased risk of death, whereas prior surgery with curative intent was protective.<sup>112</sup> These models, like other scoring systems, should not be used in isolation to predict outcome or foreclose ICU treatment for individual patients, but are useful to reduce uncertainty and improve reproducibility in clinical decision making.<sup>116</sup>

A retrospective study<sup>117</sup> documented hospital mortality of 75% among 57 patients with primary lung cancer who were admitted to a medical ICUs, identifying acute pulmonary disease (such as infection or ARDS) and Karnofsky performance status prior to hospital admission as factors predictive of ICU and hospital death; among hospital survivors ( $n = 14$ ), median postdischarge survival was 32 weeks for patients with stage I or II disease, and 16 weeks for stage III or IV. Among 44 lung cancer patients included in a retrospective study of critically ill cancer patients,<sup>113</sup> approximately one half of whom received mechanical ventilation, hospital mortality was 48%. An earlier retrospective study,<sup>118</sup> involving lung cancer patients without prior surgical resection who required mechanical ventilation for respiratory failure, found that 39 of 46 patients died receiving mechanical ventilation and < 10% survived the hospitalization; no patient was liberated from mechanical ventilation after 6 days, a finding consistent with other data associating prolonged mechanical ventilation with dismal outcomes for cancer patients.<sup>119</sup> At the present time, no data exist with respect to functional status or quality of life of patients with lung cancer surviving ICU treatment.

### *Burdens of ICU Treatment*

Potential benefits of critical care for the patient with lung cancer must be weighed against burdens that may be associated with such treatment. Of particular concern is emerging evidence of physical and psychological suffering among ICU patients, including patients with lung cancer and other malig-

nancies. A prospective study of symptom experience self-reported in real-time by cancer patients treated in a medical ICUs,<sup>120</sup> including patients and nonsurvivors receiving mechanical ventilation, revealed that distressing symptoms such as pain, discomfort, dyspnea, depression, and anxiety were prevalent, often at high levels of severity. In the large-scale SUPPORT<sup>121</sup> for seriously ill patients, including a subgroup in ICUs, 35% and 46% of lung cancer patients dying within 2 months reported severe pain and dyspnea, respectively, for at least half of the time during the observed hospitalization. Symptom burden is relevant in ICU decision making, although expert palliative care can be expected to improve patient and family comfort and should be integrated into treatment plans for all critically ill patients—especially those, such as patients with lung cancer, who remain at high risk for hospital death. Financial and other burdens for families of such patients may be significant.

For the health-care system as a whole, the costs of treating cancer patients in ICUs are considerable. ICU patients account for almost 20% of the average hospital's operating budget, but only 5 to 6% of total patient days and, among patients consuming the most expensive ICU resources, mortality rates are particularly high.<sup>119,122</sup> A 1993 analysis,<sup>119</sup> based on hospital charges for patients treated in the ICUs of a university-affiliated, tertiary care cancer center estimated as > \$150,000 the cost per year of life gained at home for those with solid tumors surviving < 3 months, and as > \$1.1 million for hospital nonsurvivors, who represented > 41% of the solid tumor group. Data such as these may influence societal determination of the net value of some or all ICU interventions in the treatment of patients with lung cancer and other conditions associated with high risk of hospital morbidity and mortality. Clinical decision making, however, is appropriately based on a balancing of potential medical benefits and burdens for the individual patient.

During critical illness, most patients lack decision-making capacity,<sup>123</sup> yet their preferences for life-supporting treatment and other components of critical care are poorly predicted by surrogates, including close relatives and long-standing primary doctors.<sup>77,124</sup> Unfortunately, communication during<sup>125</sup> critical illness is often inadequate and the preferences of most patients are not known, although data indicate that patients are generally willing to discuss preferences, prognosis, and care goals, if the opportunity is provided.<sup>126</sup> A large-scale observational study,<sup>127</sup> conducted in 15 ICUs in four countries recently demonstrated that explicit advance directives continue to be uncommon during the first 24 h in the ICU. Among patients with

explicit directives, the directive was DNR for 50%, whereas the “default” directive implied for all patients who had not explicitly stated their preference was to perform CPR. Even explicit directives are often contingent on a prognosis that may still be uncertain at the onset of critical illness, and other limitations of such directives have also been identified.<sup>81,128</sup> To the extent that critical illness can be anticipated, early discussion with the patients with lung cancer about likely outcomes and burdens of ICU treatment will help to promote concordance of care goals and plan with the patient's own preferences.

#### *Provision of Palliative Care by the Critical Care Specialist*

For patients with lung cancer treated in ICUs, as for other patients at substantial risk of hospital death, it is not appropriate to postpone palliative care until death is imminent. Death may come suddenly and unexpectedly, as it did for many patients with cancer and other serious illnesses in SUPPORT, whose median predicted 2-month survival was 20% on the day before they died.<sup>129</sup> In addition, accumulating evidence from critical care and other settings suggests that patient suffering is associated with unfavorable outcomes including higher mortality, whereas relief of distressing symptoms and improved communication about treatment goals may promote favorable clinical and utilization outcomes. Consensus is therefore growing in support of an integrated approach, combining palliative care with critical care for all ICU patients, including those still pursuing life-prolonging therapies as well as those more obviously at the end of life.<sup>130</sup> In some institutions, clinicians with expertise in palliative medicine, specific areas of physical or psychological symptom management, and/or ethics may be available to assist those with primary responsibility for critically ill patients, but the critical care specialist should have fundamental knowledge and skills in management of comfort and communication needs of ICU patients and their families. Randomized controlled trials of palliative interventions for critically ill patients are a research priority, but these will require further development of appropriate instruments and outcome measures,<sup>131</sup> and may always be limited by practical and ethical constraints. At the present time, practice recommendations are guided by evidence from observational studies, nonrandomized or uncontrolled interventional trials, qualitative research, and expert opinion.

#### *Recommendations*

10. For the patient with lung cancer, decision making about ICU treatment should incorpo-

rate available knowledge about prognosis, including the use of a cancer-specific outcome prediction model to complement clinical judgment, and weigh reasonably expected benefits of critical care against potential burdens, including distressing physical and psychological symptoms. Evidence: poor; benefit: substantial; grade of recommendation: C

11. In the inoperable or unresectable patient with lung cancer, prolonged mechanical ventilation is discouraged in view of dismal reported outcomes. Evidence: fair; benefit: small; grade of recommendation: D
12. In the critically ill patient with lung cancer, palliative care, including expert management of symptoms and effective communication about appropriate goals of treatment, should not be postponed until death is imminent, but should be an integral component of the diagnostic and treatment plan for all patients, including those still pursuing life-prolonging therapies as well as those more obviously at the end of life. Evidence: poor; benefit: substantial; grade of recommendation: C

#### WHAT IS THE FREQUENCY OF USE AND SATISFACTION WITH HOSPICE ENVIRONMENT IN THE END-OF-LIFE CARE OF PATIENTS WITH LUNG CANCER?

Lung cancer is the most common cause of cancer deaths in both men and women, with only 15% of all patients living for 5 years.<sup>132</sup> Since the majority of patients with lung cancer will die of their disease, it is imperative that end-of-life care be incorporated into their routine management. The goal of this palliative end-of-life care should be to achieve the best possible quality of life for patients and their families. In 1998, the American Society of Clinical Oncology Task Force on Cancer Care at the End of Life developed a statement strongly supporting the need to provide excellent end-of-life care for patients with cancer.<sup>133</sup> The task force emphasized a humane system of cancer care and identified several principles for dealing with end-of-life care. They recommended that cancer care should be centered on a long-standing and continuous relationship with the primary care provider and the patient. Cancer care should be responsive to the patients wishes, and should be based on truthful, sensitive, empathic communication with the patient while optimizing quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual, and psychosocial needs of the patient and family.

Patients often fear a lonely, painful death with technologies that are out of their control and only delay the natural process of dying. Cancer care should be a longitudinal involvement from diagnosis, treatment of the cancer and its symptoms, managing recurrences, and end-of-life supportive care. The physician must recognize a turning point in the patient's condition when anticancer treatments fail to work and physical and emotional support become the primary mode of treatment.

The physician should be aware that symptoms of weakness, pain, fatigue, and nausea and vomiting are continuing clinical problems throughout the course of a terminal illness.<sup>134,135</sup> In a study evaluating end-of-life care in 939 patients in five teaching hospitals between 1989 and 1994, severe dyspnea occurred in 32% of patients and severe pain in 28% of patients.<sup>121,134</sup> These and other symptoms are the focus of end-of-life care in the patient with lung cancer.

Dyspnea can become an extremely important challenge at the end of life in patients with lung cancer. The uncomfortable sensation of labored breath is a terrifying experience and often increases near the end of life. Careful evaluation of the cause of dyspnea can often lead to temporary control of this symptom. Treatment of pulmonary infection, chronic lung disease, cardiac failure, and arrhythmias may improve the patient's comfort. Obstructive pulmonary lesions with atelectasis may be treated with short courses of radiation therapy.<sup>136</sup> Malignant effusions can often be treated with thoracentesis. Parenteral opioids can be used for the treatment of dyspnea without causing significant deterioration of pulmonary function.<sup>57,137</sup>

Pain is often a major symptom of patients with lung cancer, and the treatment of pain by physicians is often inadequate. Pain increases many physical symptoms such as fatigue, sleeplessness, constipation, and nausea.<sup>138</sup> Pain can lead to a sense of loss of control and diminished usefulness. It also can cause distress in the family causing physical and financial burdens. Also the patient sees pain as a sign that the disease is worsening. Several excellent reviews have been written on the management of pain in cancer patients.<sup>69,139,140</sup> Several important considerations about pain control should be emphasized when managing terminal patients with lung cancer. With careful evaluation and management, pain should be controlled in 85 to 95% of cases.<sup>141</sup> The WHO has developed a useful treatment ladder for starting treatment with escalation of drug doses as needed.<sup>142</sup> Oral morphine should be the standard opioid therapy, using around the clock analgesia with breakthrough doses when needed using whatever dose controls the pain.

A very common complication of lung cancer is nausea and vomiting. Prevalence of this symptom is 40 to 46% in the last 6 weeks of life<sup>143</sup> Causes for nausea and vomiting should be worked up and treated aggressively. Fear, anxiety, and pain can cause nausea and vomiting, and should be treated. Gastric irritation should be treated with acid-blocking agents. Overfeeding should be avoided because it can cause nausea and vomiting, and hepatic metastases can be treated with nonsteroidal anti-inflammatory drugs and corticosteroids with cytoprotectants. Other symptoms that may occur in lung cancer such as weight loss, insomnia, and anorexia may become irrelevant at the end of life, but troublesome oral and respiratory secretions, myoclonus, and drowsiness may be important end-of-life symptoms that require careful management.

Hospice is the best model for end-of-life care in the United States. This approach to end-of-life care attempts to treat the patient and family at home. Under the Tax Equity and Fiscal Responsibility Act of August 1982,<sup>144</sup> terminally ill patients  $\geq 65$  years old became eligible for hospice services under the Hospice Benefit of the Medicare program. In order to qualify, one had to be "terminally" ill with  $< 6$  months to live. Medicaid covers hospice care in 43 states and the District of Columbia. Unfortunately, this form of care is often underutilized or utilized too late to be helpful to the patient. A recent study<sup>145</sup> evaluating 6,457 patients enrolled in hospice programs and followed up for a minimum of 27 months found that the most common diagnosis was lung cancer, making up 21% of all patients. Patients with lung cancer had a median survival of 36 days with 15% dying within 7 days. These data suggest that patients with lung cancer may be admitted to hospice programs too late in their disease to fully benefit from hospice care. It has been shown that the advantage of hospice care is that it can be delivered in the patient's home and the patient can die at home,<sup>146</sup> it can optimize pain relief,<sup>147</sup> it increases patient satisfaction,<sup>148</sup> and some studies suggest it may be more cost-effective than hospital care.<sup>149</sup> Hospice provides nursing care, physician services, medical appliances, drugs, short-term hospitalizations, services of homemakers, home health aids, physical occupational and speech therapy, psychological counseling, and social services. Eighty percent of hospice services are provided in the home.

There are a number of clinical barriers that exist that interfere with this optimal level of end-of-life care. Physicians are reluctant to talk about death at the end of life, and they may consider progression of disease to be a therapeutic failure. Fear of opioid addiction by the physician and patient may lead to underreporting of pain and undertreatment with

narcotics. Further barriers to optimal care include the lack of available multimodality palliative care teams, fragmentation of care by multiple physicians, and no designated team leader directing the overall care. It is important for the primary care provider to be well versed in palliative care programs incorporating pharmacists, psychologists, nurses, social workers, pastoral care providers, pain specialists, and ethicists.

There are multitudes of educational deficiencies that limit the optimal delivery of palliative care in the patient with terminal cancer. The American Medical Association Graduate Medical Education Report for 1993 noted that only 26% of US residency programs offered a formal course in end-of life care.<sup>150</sup> Most physicians do not receive adequate education in end-of-life care in medical schools.<sup>151</sup> Physicians are left learning on the job and often lack role models with expertise in caring for the terminally ill. Courses during clinical clerkship, residency, and fellowship should provide didactic and practical experience in palliative care with a team approach.

Comprehensive research into the multiple aspects of palliative care has received little funding and is completely lacking in many areas. Pain management has been the subject of extensive research, but cachexia, asthenia, and chronic nausea have received little attention. Other areas receiving limited investigation have been anxiety, depression, and suicide. Studies have shown that spirituality has a positive impact on the quality of life of patients with terminal cancer.<sup>152</sup>

### *Recommendations*

13. For patients with lung cancer at the end of life, the goal of palliative care should be to achieve the best quality of life for the patients and their families. Evidence: poor; benefit: substantial; grade of recommendation: C
14. In patients with lung cancer receiving hospice care, end-of-life management needs to be considered part of the longitudinal care of these patients. Evidence: fair; benefit: Substantial; grade of recommendation: B
15. At the end of life in patients with lung cancer, multimodality palliative care teams should be developed and encouraged to participate in their management. Evidence: fair; benefit: substantial; grade of recommendation: B

### CONCLUSION

No American clinical practice guideline is currently available that is specifically for end-of-life care

for patients with bronchogenic carcinoma. Since the majority of those patients with an established diagnosis of non-small-cell lung cancer will die within 1 year, it is imperative that, with the possible exception of approximately 20% who might benefit from a complete surgical excision, extensive communication about the entire expected course of their disease occur between patients, their physicians, and their families at the earliest opportunity. It is unfortunate that in its present form and application, the advance care directive has been difficult to utilize effectively in the terminal care of patients with lung cancer. The HEC, with a multidisciplinary team quite capable of assisting in the resolution of many problems concerning these patients and their families, is rarely consulted in clinical practice. Although use of a critical care specialist is usually considered too expensive and likely futile, there are nevertheless many circumstances in which a concurrent and possibly reversible condition might be successfully treated in this setting. The growing popularity of the hospice movement is largely due to its proven effectiveness in the more satisfactory control of troublesome symptoms in the patient with far-advanced lung cancer, as well as its ability to provide a return to the home environment with participation of family and friends in end-of-life care.

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#### SUMMARY OF RECOMMENDATIONS

1. For patients with lung cancer at the end of life, it is recommended that clinicians increase their focus on the patient's experience of illness to improve congruence of treatment with patient goals and preferences: (a) be realistic, practical, sensitive, and compassionate; (b) listen; (c) allow/invite the patient to express his or her reaction to the situation; (d) provide a contact person; (e) and continually reassess the patient's goals of therapy as part of treatment planning. Evidence: poor; benefit: substantial; grade of recommendation: C
2. For all patients with lung cancer, end-of-life planning should be integrated as a component of assessment of goals of treatment and treatment planning. Evidence: poor; benefit: substantial; grade of recommendation: C
3. For patients with lung cancer, an experienced clinician should inform the patient of the diagnosis and its meaning. The day-to-day contact person should also be present at this meeting and should coordinate care. Evidence: poor; benefit: substantial; grade of recommendation: C

4. Clinicians treating patients with lung cancer should avail themselves of the increasing body of educational resources to improve communication at the end of life. Evidence: fair; benefit: substantial; grade of recommendation: B
5. With patients with lung cancer, hospice and/or the palliative care service should be involved early in the patient's treatment, as part of the team. Evidence: poor; benefit: substantial; grade of recommendation: C
6. Each patient with lung cancer should be asked if he or she has an advance directive, and the clinician should assume responsibility for placing it in the chart. Evidence: poor; benefit: substantial; grade of recommendation: C
7. With patients for whom there are questions about the validity or interpretation of an advance directive, seek guidance from the hospital legal counsel or ethics committee. Evidence: poor; benefit: substantial; grade of recommendation: C
8. In making end-of-life decisions for patients with lung cancer, ethics consultation by HECs should be requested when assistance is needed in clarifying applicable law and policy related to patient autonomy and competence, informed consent, withholding life-prolonging treatments, surrogate preferences, decision making for patients without family, and resource allocation, as well as determining how ethical norms should be interpreted, or negotiating interpersonal conflicts among patients, families, and physicians. Evidence: poor; benefit: substantial; grade of recommendation: C
9. In end-of-life care for patients with lung cancer, given the potential variations in ethics consultations, the requesting party and the consultant should clarify beforehand the specific objectives of the consultation, the selection of the participants, the process to be used in deliberation or negotiation, and the manner in which results will be disclosed and recorded. Evidence: poor; benefit: substantial; grade of recommendation: C
10. For the patient with lung cancer, decision making about ICU treatment should incorporate available knowledge about prognosis, including the use of a cancer-specific outcome prediction model to complement clinical judgment, and weigh reasonably expected benefits of critical care against potential burdens, including distressing physical and psychological symptoms. Evidence: poor; benefit: substantial; grade of recommendation: C
11. In the inoperable or unresectable patient with

lung cancer, prolonged mechanical ventilation is discouraged in view of dismal reported outcomes. Evidence: fair; benefit: small; grade of recommendation: C

12. In the critically ill patient with lung cancer, palliative care, including expert management of symptoms and effective communication about appropriate goals of treatment, should not be postponed until death is imminent, but should be an integral component of the diagnostic and treatment plan for all patients, including those still pursuing life-prolonging therapies as well as those more obviously at the end of life. Evidence: poor; benefit: substantial; grade of recommendation: C
13. For patients with lung cancer at the end of life, the goal of palliative care should be to achieve the best quality of life for the patients and their families. Evidence: poor; benefit: Substantial; grade of recommendation: C
14. In patients with lung cancer receiving hospice care, end-of-life management needs to be considered part of the longitudinal care of these patients. Evidence: fair; benefit: substantial; grade of recommendation: B
15. At the end of life in patients with lung cancer, multimodality palliative care teams should be developed and encouraged to participate in patient management. Evidence: fair; benefit: substantial; grade of recommendation: B

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## End-of-Life Care in Patients With Lung Cancer

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*Chest* 2003;123:312-331

DOI: 10.1378/chest.123.1\_suppl.312S

**This information is current as of April 15, 2006**

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