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**Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases:  
American College of Chest Physicians Position Statement**

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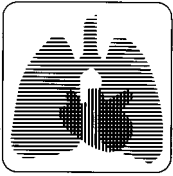
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A M E R I C A N C O L L E G E O F  
 C H E S T  
P H Y S I C I A N S



## ethics

# Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases\*

## American College of Chest Physicians Position Statement

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Acute and chronic pulmonary and cardiac diseases often have a high mortality rate, and can be a source of significant suffering. Palliative care, as described by the Institute of Medicine, “seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure. . . Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs.” The American College of Chest Physicians strongly supports the position that such palliative and end-of-life care of the patient with an acute devastating or chronically progressive pulmonary or cardiac disease and his/her family should be an integral part of cardiopulmonary medicine. This care is best provided through an interdisciplinary effort by competent and experienced professionals under the leadership of a knowledgeable and compassionate physician. To that end, it is hoped that this statement will serve as a framework within which physicians may develop their own approach to the management of patients requiring palliative care. (CHEST 2005; 128:3599–3610)

**Key words:** advance directives; hospice care; palliative care; right to die; spirituality; terminal care

Acute and chronic pulmonary and cardiac diseases often have a high mortality rate, and can be a source of significant suffering. Dame Cicely Saunders, founder of the modern hospice movement, described this suffering as “total pain” with physical, emotional, spiritual, and social elements.<sup>1</sup> Each person experiences death differently, not only by the patient’s particular disease, but also by variables such

as the patient’s family situation, culture, ethnicity, spirituality, and socioeconomic class.

Palliative care, as described by the Institute of Medicine, “seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure. . . Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs.”<sup>2</sup> The American College of Chest Physicians strongly supports the position that such palliative and end-of-life care of the patient with an acute devastating or chronically progressive pulmonary or cardiac disease and his/her family should be an integral part of cardiopulmonary medicine. This care is best provided through an interdisciplinary effort by competent and experienced professionals under the leadership of a knowledgeable and compassionate physician.

Palliative and end-of-life care of patients with terminal cardiopulmonary disease requires the inter-

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action and collaboration of many individuals, including chest physicians, intensivists and cardiologists, nurses, respiratory care practitioners, social workers, and chaplains, and consultants in palliative care. Their daily professional activities provide opportunities for the delivery of quality end-of-life care in the many settings where the dying process may be unfolding, including the critical care unit, hospital room and/or clinic setting, physician's office, patient's home, skilled nursing facility, and hospice unit. A growing number of hospitals have developed a palliative care service to address the needs of seriously ill and/or dying patients and their families (Appendix).

Chest physicians and cardiologists are urged to take a leadership role in providing the patient and family with knowledgeable and competent palliative and end-of-life care in accord with the patient's wishes. Components of quality palliative and end-of-life care are provided in Table 1. Significant advances have been made in this field, and it is the duty of clinicians to be knowledgeable and skilled in this important aspect of patient care. Many resources are available to help physicians and other health-care professionals acquire this knowledge base (Appendix).

#### SUPPORT FOR PATIENT AND FAMILY

##### *Advance Care Planning*

Illness and the therapies aimed at illness frequently lead to diminished mental capacity. Paradoxically, it is during the time of critical illness that extremely important decisions must be made, includ-

ing decisions about initiating or foregoing therapies, undergoing invasive procedures, tube feedings, home health options, and nursing home placement, to name a few. Documents such as a living will, advance health-care directive, and/or other legal documents supported by individual state laws can help in this regard. Such advance care planning efforts strive to articulate and put in motion the care that an incapacitated patient would have desired. Advance care planning also allows patients the peace of mind to know that their priorities will be honored. Furthermore, loved ones and care providers can more clearly understand the values and choices of patients who can no longer speak for themselves. Some may wish to have their surrogate make medical decisions for them even though they still have decision-making capacity, as is permitted in some states.

Notwithstanding the above, there may be a variety of reasons why patients are reluctant to engage in advance care planning.<sup>3</sup> After all, this can be a difficult issue to discuss.<sup>4</sup> Failure of physicians to initiate end-of-life discussions has been identified as a significant barrier to determining patient preferences for end-of-life care.<sup>5</sup> Patient denial also often plays a role. While this may be an adaptive defense mechanism against bad news, it discourages advance care planning. Cultural beliefs may inhibit open discussion of end-of-life preferences<sup>6</sup> and require a knowledge and sensitivity about traditions other than Western biomedical so as to permit culture-appropriate planning to occur.<sup>7</sup> In addition to advance care planning, patients may feel overwhelmed by the task of addressing many other end-of-life issues, including the need for a last will and testament regarding their estate, planning for burial arrangements, and taking leave of loved ones. Sometimes patients consider all of these issues an overwhelming task, and the right or need to express choices about health-care decisions assumes a low priority. Besides these patient-related factors, physicians as well as patients and family members are often confused by ethical and legal issues that pose potential barriers to end-of-life discussions.<sup>8,9</sup>

It is acknowledged that there are limitations to the widespread implementation of advance directives, including the inability for such documents to encompass the wide range of possibilities available for health care as the end of life approaches.<sup>10,11</sup> Furthermore, there are ethical and legal limits within which even well intentioned physicians may not be able to acquiesce to patient/surrogate requests for treatment or its withdrawal.<sup>12-16</sup> Nevertheless, in the absence of advance care planning, patients for whom decisions about health care are most critical and valuable are often least able to participate in decision making due to illness or sedation. The burden of

**Table 1—Components of Palliative and End-of-Life Care for Patients With Cardiopulmonary Disease**

Support for patient and family
Advance care planning
Maintaining and supporting the patient's dignity, including cultural and spiritual needs
Support for the family, including bereavement services
Care of the patient
Relief of distressing symptoms
Management of the dying process, including withdrawal of life-sustaining treatment
Referral to appropriate hospital and community resources
Quality palliative and end-of-life care in all treatment settings, including institution and home
Responsibility of the professional caregiver
Assurance of professional education and competence in quality palliative and end-of-life care
Support and counseling to address professional caregiver grieving
Development of institutional, professional, and regulatory policies to ensure quality palliative and end-of-life care

decision making naturally shifts to next of kin, who may be poorly informed regarding the patient's wishes, or who may have conflicting emotions affecting their ability to speak for the patient.<sup>17</sup> Advance care planning helps to remove some of the burden of end-of-life decisions for next of kin, and may relieve them of subsequent guilt feelings associated with self-doubts about these weighty decisions. With advance care plans, the patients' actual preferences may be more likely to be implemented.<sup>18,19</sup>

To facilitate advance care planning and its value to patients, their next of kin, and their health care providers, end-of-life discussions about goals of care should be encouraged among all patients, especially those patients who have an advanced and possibly terminal illness. Opportunities to facilitate advance care planning should be offered proactively by physicians and other health-care professionals, with a sensitivity that allows for the patient's value system, cultural practices, social support structure, and individual defense mechanisms.

### *Maintaining and Supporting the Patient's Dignity, Including Cultural and Spiritual Needs*

Dignity is the quality or state of being worthy or esteemed. At the end of life, dignity may also refer to physical comfort, autonomy, meaningfulness, usefulness, preparedness, and interpersonal connection.<sup>20</sup> People are afraid that they will lose their dignity while ill, especially when nearing the end of life. Affirmation of the whole person while treating the illness and assisting patients with gaining a sense of completion is important in this regard.<sup>21</sup> This includes asking patients and families if they would like referrals to community and hospital services specific to their faith beliefs and traditions. While the role of the physician in the prescription of religious activity as it relates to health care is controversial,<sup>22,23</sup> in situations where religion is already an established part of the patient's cultural background, religious rituals such as prayer should be encouraged if in keeping with the patient's practices. Attention to conflict resolution, time spent with loved ones, and saying goodbye help to provide completion for patients, their families, and friends.

Inability to communicate, disruption of sleep, and inflexible visiting hours were found to be highly stressful to critically ill cancer patients.<sup>24</sup> Simple measures may improve the quality of life and therefore dignity for the duration of chronic illness. Talking to patients with skilled translators, actively listening, involving them in planning for their care, and using letter boards and specialized devices (fenestrated tracheotomies, speaking valves) may be useful for patients with cardiopulmonary compro-

mise. Allowing small amounts of food for the pleasure and normalcy of eating even in the setting of enteral or parenteral feeding may be possible. Meticulous attention to personal hygiene, toileting, and oral and skin care are imperative to our most basic sense of dignity. Background music, television, and reading materials should be chosen according to patients' wishes and encouraged to avoid further isolation. Additionally, visitation schedules can be stretched to allow patients to have more human interaction.

We can only know that we are respectful of the wishes and maintaining the dignity of our patients if we know and respect the values and culture in which they live. For example, traditional Chinese culture with interdependence of family and their cultural community may override self-determination.<sup>25</sup> However, a study<sup>26</sup> has shown that there is a desire for more patient involvement in decision-making if the patient has the capacity. In the Hindu and Sikh cultures, the integration of individuals with their extended families and environment and deferral of decisions to a senior member of the family may take precedence over patient autonomy.<sup>27</sup> Any discussion of negative information is viewed as potentially harmful in Navajo traditional culture, limiting the appropriateness of discussion of advance directives.<sup>7</sup> Attitudes also vary among different cultures due to mistrust and prior abuse by the medical system. For example, African Americans and Hispanics are more likely to request life-sustaining modalities regardless of the severity of illness than whites, and there may be great disparity between patients' and caregivers' desires to allow use of these measures.<sup>6</sup> Specific discussion with patients and their caregivers is a necessary first step in understanding the whole person and how their progressive illness affects them. We then must accept that our own beliefs may conflict with our patients', and accept our obligation to respect their customs or transfer their care to providers who will.

### *Support for the Family, Including Bereavement Services*

Family, friends, and other caregivers may have, what is for them, a seemingly overwhelming task of caring for people who are chronically ill or with debilitating disease.<sup>28,29</sup> They are the patient's advocates, personal caregivers, companions, and surrogate decision makers. Communication with personal caregivers requires time, patience, and skills that receive little attention in most training settings. Lack of communication often results in conflict.<sup>28,30</sup> Personal caregivers are often sent home with equipment, medication regimens, and instructions they do

not fully understand. We should begin to teach the designated personal caregivers well before discharge to ensure that devices and medicines will be used safely and effectively. They should be encouraged to participate in the daily care of the hospitalized patient, rather than being asked to leave the room when care is given. They need to be trained and observed in performing routine health-care tasks. Early home nursing visits to reinforce skills and knowledge are needed. Ongoing attention to the health and concerns of the personal caregiver should be stressed at every visit. Personal caregivers and patients should be referred to support groups and/or personal counseling services as needed.

Grieving for patients by their personal caregivers often begins well before the patient dies, and there is great cultural diversity in the bereavement process and rituals surrounding death.<sup>31–33</sup> Personal caregivers may be dealing with their own illnesses and compromising their own health. In addition, they must deal with the psychological and financial preparation for the death of a loved one. Hospice services are as much help for personal caregivers as for patients, treating them as one unit. These include end-of-life medical care, social work services, respite admissions of the patient to hospice units for relief of the personal caregivers, and bereavement services for up to 12 to 18 months after death. Hospice programs may not be available or appropriate for patients who are severely ill but expected to live longer than hospice regulations permit. Nonetheless, the hospice model should be an example of what we should be able to provide to all patients.

The lack of certainty of prognosis (*ie*, survival < 6 months) should not impede access to hospice services. The regulations requiring certification of survival to a confined period of time are guidelines to prevent chronic abuse of hospice resources, but these regulations are guidelines nonetheless, not rigid laws deemed punishable if violated. When appropriate, a certification can be issued that death is likely to occur within 6 months, and if the patient survives beyond the time period, a renewal of the request is reasonable and is honored. Lack of certainty must not preclude proper use of invaluable hospice services for patients who are in need of them.

## CARE OF THE PATIENT

### *Relief of Distressing Symptoms*

Patients with pulmonary and/or cardiac disease may experience significant discomfort as they enter the terminal phase of their illness. These symptoms may include breathlessness, pain, insomnia, nausea,

vomiting, constipation, diarrhea, anorexia, fatigue, and edema.<sup>34–36</sup> It is important for physicians who care for these patients to anticipate the likelihood of distressing symptoms, to counsel patients and families to seek medical therapy when they begin to experience these symptoms, and to intervene to alleviate these symptoms as appropriate. Appropriate pain management may be better achieved by seeking the help of a qualified medical expert in pain control.

A variety of approaches to the recognition and alleviation of distressing symptoms exist (Appendix). As an example, breathlessness is a common complaint and may be due to a variety of causes. Medically, these can include problems such as airway obstruction, bronchospasm, hypoxemia, pleural effusion, pneumonia, pulmonary edema, pulmonary embolism, and thick secretions. In addition, breathlessness can result from anxiety regarding social issues surrounding the disease, such as loss of financial security. Each of these will require appropriate therapy. Moreover, the etiology of the symptom may change over the course of the illness. Vigilance and ongoing communication with the patient will help with the early identification and management of this distressing symptom. Therapeutic options such as oxygen (if there is hypoxemia), opioids, anxiolytics, and nonpharmaceutical interventions each may have a role to play in the provision of the necessary comfort measures as the disease progresses.<sup>37</sup>

### *Management of the Dying Process, Including Withdrawal of Life-Sustaining Treatment*

As patients enter the terminal phase of their illness, the treatment focus changes from curative and/or restorative to palliative in nature. Attention should be directed toward reasonable expectations for living in what is for the patient a functional and meaningful way. As part of this process, it may be necessary to withhold or withdraw treatment measures that can no longer achieve the patient's goals for care. It is appropriate to discuss well in advance of this phase such issues as a living will or an advance health-care directive to name a substitute decision maker. Preferences for cardiopulmonary resuscitation, surgery, mechanical ventilation, dialysis and other life-prolonging measures can be made known. It may be necessary (and preferable) to involve family members (or members from a faith community or other group with whom the patient shares a significant relationship) in these discussions.

A protocol for discussing patient preferences and institution of withholding and/or withdrawing life support has been developed as a guide for the discussion of patient preferences (Appendix). These steps include the following: (1) being familiar with

national and local policies, and legal statutes concerning the withdrawal of life support measures; (2) having an appropriate setting within which to initiate the discussion; (3) asking the patient (and family) what they understand about the disease and its course; (4) having a general informational discussion about the goals of care; (5) establishing the context for the discussion, *ie*, death is inevitable at some point; (6) discussing specific preferences for various treatment options, *eg*, surgery, mechanical ventilation; (7) responding sympathetically to emotions which come as a result of the discussion; and (8) establishing and implementing the agreed on plan. This plan may change as circumstances dictate, and thus should be reviewed periodically.

Ethical guidelines for withholding and withdrawing life support are available.<sup>38-41</sup> The actual process of the withdrawal of life support is unique to each patient. Appropriate discussion with the patient and family should be undertaken, and an agreed-on plan of care instituted. Members of the health-care team, including hospice, nursing, and pastoral care, may each have a significant role to play. At all times, patient comfort should be paramount and the guiding influence on the process. Appropriate introduction of anxiolytics, opioids, and manipulation of the inspired oxygen levels should occur. Nonpharmacologic interventions such as music or prayer may play a significant role in providing comfort as death approaches.

#### *Referral to Appropriate Hospital and Community Resources*

Comprehensive care of the patient at the end of life requires more than appropriate medical care.<sup>42,43</sup> Proper attention must also be given to emotional, psychological, spiritual, and cultural needs, as well as pain control and other comfort measures. Inpatient palliative care services may include consultants in pain management and psychiatry, chaplains and faith community leaders, social workers, occupational and physical therapists, and dietitians for the seriously and terminally ill. The current movement to shift care from inpatient to outpatient settings has made attending to this spectrum of needs challenging, and has led to a proliferation of such services for home health care. These services include a variety of palliative and end-of-life care resources, some reimbursed by insurance plans and Medicare, and others offered by charities, religious organizations, and volunteer groups.

Hospice care is one of the best known services for end-of-life care, due in part to codification by the Medicare law in the early 1980s.<sup>44</sup> To obtain Medicare reimbursement for hospice care, physicians

must certify that the patient has a life expectancy of  $\leq 6$  months. As noted earlier, patients may be recertified for additional benefit periods, but the certification requirement and misunderstandings about the law do create barriers to hospice services. Furthermore, there is the psychological impact of certifying an illness as terminal that may deter some patients or family members from accepting hospice services even when clearly needed. The gravity of certifying a terminal illness may put physicians in the awkward position of appearing callous, depriving their patients of hope, or mistakenly signaling abandonment of the care. Much work is needed to change these perceptions so as to improve access to hospice care and to publicize the many other resources available to improve end-of-life care.

#### *Quality Palliative and End-of-Life Care in All Treatment Settings, Including Institution and Home*

An estimated 2.5 million people die each year in the United States. As many as 60% of them die in hospitals (commonly in a critical care unit), another 25% in nursing homes and health-care facilities, and only 15% in their homes.<sup>45,46</sup> The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments found by surveying family members that more than half of the dying patients suffered from inadequate pain control, one fourth from emotional distress and almost one fourth from social isolation and feelings of abandonment.<sup>47</sup> The factors most commonly associated with a request for physician-assisted suicide are patients' fears of losing control of mental faculties, becoming a burden to others, and experiencing severe pain.<sup>48,49</sup> When presented with options for care at the end of life including refusal and withdrawal of life support, physician-assisted suicide, active euthanasia, and the principle of double effect, a substantial proportion of respondents to a survey in Oregon demonstrated a lack of understanding of their treatment options.<sup>50</sup> There is clearly a need to improve the quality of care as death approaches.

The initial steps in improving care at the end of life are to understand what "quality" means to patients who are dying, and to develop a conceptual framework to provide quality care.<sup>42,43,51</sup> The end point would be a good death, described as "one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards."<sup>2</sup> Factors that are considered to be important at the end of life by patients, their families, and care providers have been identified.<sup>42,43</sup>

As many deaths occur in the ICUs of hospitals, deficiencies in end-of-life care in this setting has received particular attention. The Robert Wood Johnson Foundation Critical Care End of Life Peer Group members have proposed seven domains,<sup>52</sup> along with quality indicators that can be used in ICUs. Three expert groups have published frameworks that comprise 6 to 10 domains for quality palliative and end-of-life care.<sup>2,53,54</sup> Singer and associates<sup>55</sup> compared these expert-derived domains to domains of quality end-of-life care from the patients' perspective. While there were similarities, the patient-derived domains were more specific and more outcomes focused. Patient groups, including those undergoing dialysis, with HIV disease, or residing in a long-term facility, identified five domains of quality-end-of-life care important to them. These are described below and include receiving adequate pain and other symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden of loved ones, and strengthening relationships.

*Pain and Other Symptom Management:* Barriers to effective symptom control include inadequate assessment, deficiencies in technical skill, and persistent unfounded fears by physicians, patients, and families about opioid overdose and addiction.<sup>56–58</sup> A survey of physicians on cancer pain identified factors that hampered adequate management. These included a discrepancy between the physician and patient in judging the severity of pain, attributing pain to a nonmalignant cause, older patient age (> 70 years), female gender, and the physician's perception that the patient's performance status is inconsistent with the severity described.<sup>59</sup>

*Avoiding Inappropriate Prolongation of Dying:* In a survey of health-care professionals, 78% of respondents believed that sometimes the treatments they offered were overly burdensome.<sup>60</sup> Nonpalliative treatments are often continued in incurable patients with metastatic carcinoma and advanced dementia.<sup>61</sup> One key issue affecting the quality of care identified by bereaved family members and experts is the inadequacy in end-of-life communication.<sup>62,63</sup> Physicians may use informed consent discussion for specific treatments as a proxy for the larger issues facing dying patients and their families. The focus of discussion on the use of life-sustaining treatments should be on realistic and attainable goals of care.<sup>55,64</sup>

*Achieving a Sense of Control:* The expressed desire of patients to retain control of their end-of-life

care when they are capable (and their health-care agent when they are incapable) does not specifically relate to a desire to dictate or manage every treatment decision of their physician. Rather, it relates to an inner need to have a voice in their end-of-life care.

*Relieving Burdens and Strengthening Relationships:* Relieving burdens and strengthening relationships are interconnected domains. Patients commonly desire to relieve the physical and emotional burden on their loved ones. Concurrent with this desire is the patients' need to seek active involvement of those close to them in order to overcome their sense of isolation. They also want their loved ones to maintain a connection with them during the dying process. Professional caregivers' tendency to focus on acute disease management, and often inflexible hospital regulations, can be barriers to the full and active participation of the family and other loved ones in the care of the dying patient.

As a result, it is important to include the loved ones in advance care planning and in all palliative and end-of-life care communications. This can occur during outpatient appointments and hospital rounds, preparing all for what lies ahead and thus helping the patient feel less isolated. In addition, the dying person has the opportunity to reconcile past differences and to strengthen relationships with loved ones.<sup>65</sup> Current approaches to the end of life, influenced by Western bioethics, focuses on the patient as an individual. It is preferable to view each patient in his or her family, social, and cultural context.

It is difficult to develop reliable and validated measures of quality of care at the end of life, as traditional models of quality of care that focus on mortality and morbidity do not address the outcomes that are most important to dying patients and their families. However, the five domains identified earlier are easily usable with dying patients to assess the quality of care and can be taught to students of all disciplines at all levels. Physicians need to continually ask themselves whether their actions are improving these domains for their patients.<sup>66</sup> In addition to these, there are several tools of assessment available (Appendix).<sup>67,68</sup>

The hospice model, based on palliative care principles and using an interdisciplinary team, also has been shown to improve quality of life in patients dying of cancer in specialized palliative care hospital units.<sup>69</sup> The principles and models of end-of-life care used in hospice programs and palliative care units should be adopted and adapted to improve quality of life in all settings (Appendix).

## RESPONSIBILITY OF THE PROFESSIONAL CAREGIVER

### *Assurance of Professional Education and Competence in Quality Palliative and End-of-Life Care*

Most of the comments provided here are on physician education but also are applicable to other health professionals. Until recently, there were no mandated requirements for education in palliative and end-of-life care for physicians in the United States and, not surprisingly, major deficiencies in this area have been documented.<sup>70–76</sup> Medical schools in the United States are now mandated to include end-of-life care in the curriculum, and end-of-life content will be included on test questions of the United States Medical Licensing Examination (Appendix).<sup>77</sup>

Palliative care is also becoming a part of graduate medical education (residency and fellowship), but the requirements for palliative care listed by the Accreditation Council for Graduate Medical Education show great variability among programs.<sup>78</sup> Programs in family medicine, neurology, internal medicine, and the subspecialties of hematology/oncology and geriatrics already have substantial requirements in place. The Accreditation Council for Graduate Medical Education adopted six general competencies that are applicable to all graduate training programs (Appendix). It is notable that two of the competencies—interpersonal communication skills and professionalism—are essential elements of competent end-of-life care.

For physicians beyond their residency/fellowship training period, there is no national requirement for knowledge and skills in end-of-life care, but on a state level there is some movement in this direction. For example, California mandates 12 continuing education hours in pain and end-of-life management for almost all licensed physicians (AB487). The American Medical Association, supported by the Robert Wood Johnson Foundation, developed an education program and encourages its members and other physicians to participate in Education for Physicians on End-of-Life Care (Appendix).

Several groups in and outside of the United States have worked to define the components of a palliative care curriculum.<sup>79–81</sup> There is general agreement that the major educational domains are as follows: pain assessment and treatment; non-pain symptom assessment and treatment; ethical principles and legal aspects; communication skills and personal reflection; psychosocial aspects of death and dying; and working as part of an interdisciplinary team.

Detailed curricula can be developed within each domain; two examples are curricula that deal with

pain<sup>82,83</sup> and communication skills.<sup>84</sup> Both the American College of Physicians and the American Academy of Family Physicians have published an end-of-life care curriculum for graduate medical education.<sup>85,86</sup> The American Academy of Hospice and Palliative Medicine developed a curriculum with 22 modules for medical educators and practicing physicians, as well as a basic series of eight monographs called UNIPACs.<sup>87</sup> The American Academy of Hospice and Palliative Medicine curriculum as well as the Education for Physicians on End-of-Life Care curriculum can be adapted to learners in various health professions. The End-of-Life Physician Education Resource Center is an excellent source for curriculum guides (Appendix). A curriculum for nurses, the End-of-Life Nursing Education Consortium, has been developed by the American Association of Colleges of Nursing (Appendix).

Physicians in subspecialties can further their education in palliative care by utilizing the resources noted above and through their subspecialty organizations. These organizations should take the lead to formulate position papers and practice guidelines, and to develop a detailed curriculum on palliative care topics that are most pertinent to the subspecialty. National meetings of these organizations could then provide structured learning opportunities in palliative care topics that are ideally based on a needs assessment<sup>88</sup> of its members. These educational experiences can be evaluated by reliable tests<sup>89,90</sup> for their quality and importantly on their impact on physician behavior and patient care. With these skills, chest physicians and cardiologists should play a leadership role in developing palliative care services in their hospitals (Appendix) and then researching the therapies to learn which are most effective.

### *Support and Counseling To Address Professional Caregiver Grieving*

There are many caregiver stressors that can be involved in the care of dying patients and their families. These can include work overload, patient/family/team communication problems, fear of criticism by colleagues, feelings of inadequacy and inexperience, and the conflict of often worrying whether treatment of the patients' symptoms might hasten their death.<sup>91</sup> This can lead to a sense of burnout, often experienced more by nurses, social workers, and other nonphysician caregivers who bear the conflict of having responsibility for the patient's care without always having the power to make a change.

They may struggle with seeing the patient and family in distress yet not getting appropriate support from the physician to treat these burdens. This stress

can be compounded by the death of patients with whom the caregiver has developed personal relationships over time. This is particularly evident in hospice care in which essentially no patients survive.

These experiences can lead to a feeling of *compassion fatigue* that can affect clinical performance and decision making, with professional caregivers mourning over the multiple losses they have experienced over time. Some feel that they do not have time to grieve for one person before another one has died. Caregivers often respond by developing a “numbing” of these emotions until such time that this accumulated grief pours out in a “flooding,” bouncing back and forth between numbing and flooding.<sup>92</sup>

The authors Henri Nouwen<sup>93</sup> and Daniel Sulmasy<sup>94</sup> both describe the “wounded healer,” pointing out that all caregivers must be aware of their own wounds and learn to bind them in anticipation of the time when the caregivers will be needed by their patients. This begins with an analysis of the caregiver’s personal awareness, aptly described as “calibrating the instrument,” in which the caregiver assesses his/her own identity, values, and personal responses to death and the dying patient.<sup>95,96</sup> Ideally, every death should be a teaching, accepting the patient’s gift of inviting the caregiver to participate in this intimate experience. This is dependent on each caregiver’s personal coping mechanisms and sense of reward that can come from the care of the patient. In all of this, the physician must protect his/her team of caregivers from stress by support and role modeling, as well as providing direction and a sense of purpose. Together, the team can bolster and strengthen each other’s efforts. Consideration should be given to providing ongoing support from the pastoral care and/or social services departments to nursing units and other hospital departments who care for critically ill and for dying patients.

#### *Development of Institutional, Professional, and Regulatory Policies To Ensure Quality Palliative and End-of-Life Care*

Every health-care institution should develop policies to guide the staff in addressing the needs of dying patients and their families, the goal being to establish a standard by which the staff is expected to perform. These might include clinical pathways for supportive end-of-life care of the dying patient and policies on advance directives, organ donation, patient’s rights, withholding/withdrawing life support, pain management, conflict resolution, and care of the dying patient. Some are mandated by the Joint Commission on Accreditation of Healthcare Organizations.<sup>97</sup> Individual departments within the health-

care institution should develop standardized procedures that address specific needs of the dying patient and his/her family. These might include a procedure for respiratory care practitioners and physicians to follow when withdrawing a ventilator from a dying patient. Nursing procedures could address management of pain, anxiety and delirium, organ donation, pronouncement of death according to local statutes, and the care of the patient’s body after death, while at the same time being sensitive to cultural and/or religious practices and customs that might affect such care.

Many professional health organizations on both national and state levels have developed position statements and policies on end-of-life care to guide their members.<sup>98</sup> Many can be accessed on the Web sites of the organizations (Appendix). These serve to provide motivation and guidance to their members, as well as define their position for patients and the public.

Quality end-of-life care sometimes can be hampered by limitations of regulatory and reimbursement policies that make this care uneven in its availability and depth. This is particularly true in hospice care, which is not universally and/or adequately provided. Professional associations and patient advocate groups should work together to ensure adequate hospice coverage by governmental and other third-party payers.

#### CONCLUSION

In summary, the need for quality palliative and end-of-life care has become paramount in the United States.<sup>99</sup> Many efforts have been made to stimulate physicians and other professional caregivers to focus on this important aspect, and to obtain the necessary knowledge and skills to provide this care. Chest physicians and cardiologists are urged to take the lead. It is our hope that this statement will serve as a platform from which the process can begin.

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#### APPENDIX: INTERNET RESOURCES FOR QUALITY PALLIATIVE AND END-OF-LIFE CARE

##### *General*

Americans for Better Care of the Dying. Available at: [www.abed-caring.org](http://www.abed-caring.org)  
American Academy of Hospice and Palliative Medicare. Available at: [www.aahpm.org](http://www.aahpm.org)

Center to Advance Palliative Care. Available at: [www.capc.org](http://www.capc.org)  
Education in Palliative and End-of-life Care. Available at: [www.epec.net](http://www.epec.net)  
End-of-Life Nursing Education Consortium. Available at: [www.aacn.nche.edu/elneec/](http://www.aacn.nche.edu/elneec/)  
Last Acts Organization. Available at: [www.lastacts.org](http://www.lastacts.org)  
Innovations in End-of-life Care. Available at: [www2.edc.org/lastacts/](http://www2.edc.org/lastacts/)  
Project on Death in America. Available at: [www.soros.org/death/html](http://www.soros.org/death/html)  
End-of-Life Care Links From the American College of Chest Physicians. Available at: [www.chestnet.org/about/links/endoflife/](http://www.chestnet.org/about/links/endoflife/)  
Clinical Practice Guidelines for Quality Palliative Care. Available at: [www.aahpm.org/NCPguidelines.pdf](http://www.aahpm.org/NCPguidelines.pdf)  
British Medical Journal. End-of-life. Available at: [www.bmj.com/cgi/collection/end\\_of\\_life\\_decisions](http://www.bmj.com/cgi/collection/end_of_life_decisions)  
Growthhouse: Inter-Institutional Collaborating Network on End of Life Care. Available at: [www.growthhouse.org/iicn.html](http://www.growthhouse.org/iicn.html)  
American College of Physicians. End-of-Life Care Consensus Panel. Available at: [www.acponline.org/ethics/eolc.html](http://www.acponline.org/ethics/eolc.html)  
National Institute of Health. Bioethics Resources on the WEB. Available at: [www.nih.gov/sigs/bioethics/endoflife.html](http://www.nih.gov/sigs/bioethics/endoflife.html)

### Support for Patient and Family

*Advance Care Planning*  
California Coalition for Compassionate Caring. Available at: [www.finalchoices.calhealth.org/advancedirective.htm](http://www.finalchoices.calhealth.org/advancedirective.htm)  
Ethical Wills. Available at: [www.ethicalwill.com](http://www.ethicalwill.com)  
Five Wishes. Available at: [www.agingwithdignity.com](http://www.agingwithdignity.com)  
Partnership for Caring. Available at: [www.partnershipforcaring.org](http://www.partnershipforcaring.org)  
Respecting Choices. Available at: [www.gundluth.org/eolprograms](http://www.gundluth.org/eolprograms)  
Sacramento Healthcare Decisions. Available at: [www.sachealthdecisions.org/guide.html](http://www.sachealthdecisions.org/guide.html)  
*Maintaining and Supporting the Patient's Dignity, Including Cultural and Spiritual Needs*  
End-of-Life Care Links From the American College of Chest Physicians. Available at: [www.chestnet.org/about/links/endoflife/](http://www.chestnet.org/about/links/endoflife/)  
National Institute of Health. Bioethics Resources on the WEB. Available at: [www.nih.gov/sigs/bioethics/endoflife.html](http://www.nih.gov/sigs/bioethics/endoflife.html)  
*Support for the Family, Including Bereavement Services*  
End-of-Life Care Links From the American College of Chest Physicians. Available at: [www.chestnet.org/about/links/endoflife/](http://www.chestnet.org/about/links/endoflife/)  
Family Caregiver Alliance. End-of-Life Decision-Making. Available at: [www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=401](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=401)

### Care of the Patient

*Relief of Distressing Symptoms*  
Education on Palliative and End-of-Life Care. Available at: [www.epec.net](http://www.epec.net)  
Innovations in End-of-Life Care. Available at: [www2.edc.org/lastacts/](http://www2.edc.org/lastacts/)  
End-of-Life Care Links From the American College of Chest Physicians. Available at: [www.chestnet.org/about/links/endoflife/](http://www.chestnet.org/about/links/endoflife/)  
City of Hope Medical Center. Southern California Cancer Pain. Available at: [www.sccpi.coh.org](http://www.sccpi.coh.org)  
Beth Israel Hospital. NY Palliative Care and Pain Management. Available at: [www.stoppain.org](http://www.stoppain.org)  
*Management of the Dying Process, Including Withdrawal of Life-Sustaining Treatment*  
End-of-Life Care Links From the American College of Chest Physicians. Available at: [www.chestnet.org/about/links/endoflife.html](http://www.chestnet.org/about/links/endoflife.html)

Education on Palliative and End-of-Life Care. Available at: [www.epec.net](http://www.epec.net)  
Recommendations for End-of-Life Care in the ICUs. The Ethics Committee of the Society of Critical Care Medicine. Available at: [www.sccm.org/professional\\_resources/guidelines/table\\_of\\_contents/Documents/EndofLife.pdf](http://www.sccm.org/professional_resources/guidelines/table_of_contents/Documents/EndofLife.pdf)  
*Referral to Appropriate Hospital and Community Resources At the Close of Day* by Lance Davis, MD, MPH, and Albert Keller, DMin. Available at: [www.atthecloseofday.com/Growthhouse](http://www.atthecloseofday.com/Growthhouse). Inter-institutional Collaborating Network on End of Life Care. Available at: [www.growthhouse.org/iicn.html](http://www.growthhouse.org/iicn.html)  
National Hospice and Palliative Care Organization. Available at: [www.nhpco.org](http://www.nhpco.org)  
Americans for Better Care of the Dying. Available at: [www.abed-caring.org](http://www.abed-caring.org)  
American Academy of Hospice and Palliative Medicare. Available at: [www.aahpm.org](http://www.aahpm.org)  
Last Acts Organization. Available at: [www.lastacts.org](http://www.lastacts.org)  
Project on Death in America. Available at: [www.soros.org/death/html](http://www.soros.org/death/html)  
*Quality Palliative and End-of-Life Care in All Treatment Settings, Including Institution and Home*  
Time. Toolkits of Instruments to Measure End-of-Life. Available at: [www.chcr.brown.edu/PCOC/TOOLKIT.HTM](http://www.chcr.brown.edu/PCOC/TOOLKIT.HTM)  
Center to Advance Palliative Care. Available at: [www.capc.org](http://www.capc.org)  
End-of-Life Care Links From the American College of Chest Physicians. Available at: [www.chestnet.org/about/links/endoflife/](http://www.chestnet.org/about/links/endoflife/)

### Responsibility of the Professional Caregiver

*Assurance of Professional Education and Competence in Quality Palliative and End-of-Life Care*  
Education on Palliative and End-of-Life Care. Available at: [www.epec.net](http://www.epec.net)  
American Academy of Hospice and Palliative Medicine. Available at: [www.aahpm.org](http://www.aahpm.org)  
Medical College of Wisconsin. End-of-life/Palliative Education Resource Center. Available at: [www.eperc.mcw.edu](http://www.eperc.mcw.edu)  
American Association of Colleges of Nursing. End-of-Life Care. Available at: [www.aacn.nche.edu/elneec/](http://www.aacn.nche.edu/elneec/)  
Center to Advance Palliative Care. Available at: [www.capc.org](http://www.capc.org)  
United States Medical Licensing Examination. 2005 Orientation Materials. Available at: [www.usmle.org/Orientation/menu.htm](http://www.usmle.org/Orientation/menu.htm)  
Liaison Committee on Medical Education. Available at: [www.lcme.org/standard.htm](http://www.lcme.org/standard.htm)  
Accreditation Council For Graduate Medical Education. Available at: [www.acgme.org/outcome/comp/compFull.asp](http://www.acgme.org/outcome/comp/compFull.asp)  
End-of-life/Palliative Education Resource. Available at: [www.eperc.mcw.edu](http://www.eperc.mcw.edu)  
*Support and Counseling To Address Professional Caregiver Grieving*  
*At the Close of Day*, by Lance Davis, MD, MPH, and Albert Keller, DMin. Available at: [www.atthecloseofday.com/](http://www.atthecloseofday.com/)  
Tests of Traumatic Stress, PTSD. Compassion Satisfaction and Fatigue. Available at: [www.isu.edu/~bhstamm/tests.htm](http://www.isu.edu/~bhstamm/tests.htm)  
Article on Compassion Fatigue in ACCP Pulmonary Perspectives. Available at: [www.chestnet.org/downloads/about/pp/march04.pdf](http://www.chestnet.org/downloads/about/pp/march04.pdf)  
*Development of Institutional, Professional, and Regulatory Policies To Assure Quality Palliative and End-of-Life Care Innovations in End-of-Life Care*. Available at: [www2.edc.org/lastacts/](http://www2.edc.org/lastacts/)  
*At the Close of Day*, by Lance Davis, MD, MPH, and Albert Keller, DMin. Available at: [www.atthecloseofday.com/](http://www.atthecloseofday.com/)  
Promoting Excellence in End-of-Life Care. Innovative Models and Approaches for Palliative Care. Available at: [www.promotingexcellence.org/](http://www.promotingexcellence.org/)

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**Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases:  
American College of Chest Physicians Position Statement**

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