

An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses

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EXECUTIVE SUMMARY

Palliative care aims to prevent and relieve suffering by controlling symptoms and to provide other support to patients and families in order to maintain and improve their quality of living. Although originally conceived and practiced as end-of-life care, palliative care may be applied to all stages of illness, whether terminal or not.

Because its members commonly care for children and adults and their families in need of palliative care due to chronic respiratory diseases or critical illnesses, the American Thoracic Society (ATS) approved formation of an *ad hoc* End-of-Life Care Task Force whose purpose was to develop this statement that focuses on how to better integrate palliative care into standard clinical management (curative and/or restorative care). The statement's goals are both educational and prescriptive. The task force took a principle- and values-based approach in

meeting this goal. It first identified the core values and principles of the ATS, as a professional society, related to palliative care (Table 1). It then applied those principles and values to clinical practice for both children and adults with chronic and advanced pulmonary disorders as well as those with critical illnesses. The task force derived its positions and recommendations based on those values and principles, on expert opinions and experience of members and consultants of the task force, and on a focused literature review.

The statement strongly endorses the concept that palliative care should be available to patients at all stages of illness and should be individualized based on the needs and preferences of the patient and the patient's family (Figures 1 and 2). It also recommends that clinicians who care for patients with chronic or advanced respiratory diseases and/or critical illnesses should be trained in, and capable of, providing a set of recommended basic competencies in palliative care (Table 2). Finally, it recommends that these clinicians should consult with palliative care specialists as appropriate for managing palliative care situations beyond the clinician's level of competence.

The statement also provides clinicians a set of practical recommendations for providing palliative care to adult and pediatric patients with advanced respiratory diseases and critical illnesses. These relate to common symptoms of those terminally ill with advanced respiratory disorders, including management of dyspnea (Table 3) and pain (Table 4) and other physical complications. In addition, the statement discusses the psychological challenges related to suffering and dying as an adult or as a child and approaches to meeting those challenges. The statement endorses hospice care as an appropriate multidisciplinary system to provide palliative care to the patients and their families. It also presents current criteria for enrollment into hospice in the United States (Table 5).

The statement reviews current recommendations related to discussions and decisions when the goals of care in the intensive care unit (ICU) change from primarily curative/restorative care to primarily or entirely palliative care (Figure 2). It also discusses a number of "do's" and "don'ts" relevant to withholding and withdrawing life support for adults and children. One section discusses the concept of the principle of double effect as applied to palliative care of ICU patients or those with advanced respiratory diseases. This includes a description of the clinical practice of "palliative sedation" (formerly referred to as "terminal sedation") and a discussion of its ethical and medical complexities.

Bereavement care both before and after the patient's death is recognized as an essential component of palliative care (Figures 1 and 2). In addition, the statement recommends measures

†Deceased.

An accompanying Patient Education fact sheet on palliative care is available at the back of this issue and at <http://www.thoracic.org/go/patient-education>

to “care for the caregivers”—both family and friend caregivers and professional caregivers.

In conclusion, the statement describes current barriers to patients and families receiving comprehensive and individualized palliative care. It calls on the ATS to work with other professional organizations of health care professionals to support palliative care in terms of enhanced public and professional education and to encourage the funding of further research in palliative care to provide best practices and an evidence-based approach to inform such practices.

INTRODUCTION

Palliative care originated as end-of-life care in the 1960s. At that time, it focused on providing control of symptoms and psychosocial and family support during the terminal phase of a serious life-limiting disease (i.e., end-of-life palliative care) (1). Since then its meaning and scope of practice have expanded far beyond its roots. According to this more recent and broader definition, the goal of palliative care is to maintain and improve the quality of life of all patients and their families during any stage of illness, whether acute, chronic, or terminal. For example, according to the World Health Organization (WHO), palliative care aims to prevent and relieve suffering by early identification, assessment, and treatment of pain and other types of physical, psychological, emotional, and spiritual distress (2) (Tables 6 and 7). Ideally, all patients receiving curative or restorative health care should receive palliative care concurrently, the elements and intensity of which are individualized to meet the patient’s and family’s needs and preferences (Figures 1 and 2).

ATS members routinely care for patients with chronic or advanced respiratory diseases and critical illnesses. The ATS Board of Directors approved the formation of an *ad hoc* ATS End-of-Life Task Force in recognition of the following: (1) the growing importance and complexity of palliative care for patients with life-threatening and life-limiting diseases and disorders and (2) the need for improving professional competence and teamwork in providing such care (3, 4).

Although this statement primarily describes providing palliative care for children and adults with advanced respiratory diseases and critical illnesses, the same professional values and principles and many of the same recommendations also apply to the care of neonates and of patients in intensive care units (ICUs) due to trauma or for perioperative care.

Although this statement endorses the basic concept that palliative care applies to all stages of disease, it focuses primarily on patients with advanced respiratory diseases or critical illnesses to provide a more complete and detailed description of palliative care related to these categories of patients.

This statement’s goals are both educational and prescriptive:

1. To present the ATS’s professional values and principles related to palliative care for adults and children with advanced respiratory diseases and critical illnesses
2. To provide practical recommendations on how to incorporate palliative care into the treatment of such patients
3. To recommend more support for health care provider education and research to improve palliative care for patients and their families

As a statement based on ethics and principles as well as on clinical evidence, the task force did not aim to produce a traditional clinical policy statement (Table 1). Its goal was to provide a set of basic knowledge regarding the application of

TABLE 1. AMERICAN THORACIC SOCIETY’S PROFESSIONAL VALUES AND PRINCIPLES RELATED TO PALLIATIVE CARE

1. **Palliative care is foremost centered on the patient and the patient’s family (with the patient defining his/her family constellation).** It recognizes the right of competent adult patients to determine their goals of care both before and after they face disabling symptoms and approach their end of life. In the case of pediatric patients, medical decision making involves both children and their parents or guardians (25, 26). Children’s preferences are taken into account by respecting their desire to participate and their degree of autonomy as developmentally appropriate.
2. **Palliative care includes identification of, and respect for, the preferences of patients and families.** This should be done through careful assessment of their values, goals, and priorities, as well as their cultural context and spiritual needs.
3. **Palliative care encourages and supports family involvement in planning and providing care to the extent desired by the patient.** This is because chronic or advanced respiratory diseases and critical illnesses impact both patients and their families.
4. **Palliative care should begin when a patient becomes symptomatic and is usually concurrent with restorative and life-prolonging care.** Palliative care is thereafter titrated to meet the needs of the patient and family according to their preferences (see Figure 1). Likewise, for critically ill patients, palliative care should begin at ICU admission and then be adjusted, analogous to curative/restorative care, to meet the needs of the patient and family in accord with their preferences (see Figure 2).
5. **All patients with symptomatic or life-threatening diseases, particularly those with chronic or advanced respiratory diseases or critical illnesses, regardless of age or social circumstances, should have access to palliative care.**
6. **Bereavement care for families is an integral part of palliative care.**
7. **Health care providers should have an appropriate level of competence in palliative care.** Their training and educational experiences should help them to acquire the core competencies necessary to provide compassionate and individualized palliative care (Table 3). They should appreciate the limits of their knowledge and skills and know when to seek consultation from palliative care experts. Competence in palliative care is as important and integral for practitioners of pulmonary and critical care medicine as competence in curative/restorative care.
8. **Psychological and emotional needs of professional and family providers of palliative care should be acknowledged and supported (217–220).**
9. **Health care providers should strive to develop a comprehensive, interdisciplinary approach that provides palliative care sensitive to the patient’s and family’s needs and respectful of their cultural and spiritual values.**
10. **The American Thoracic Society should support efforts of public education about the availability and value of incorporation of palliative care in the care of patients with chronic or advanced respiratory diseases or critical illnesses.**
11. **The American Thoracic Society should advocate for research and professional education to improve the quality and availability of palliative care for all patients in need and their families, especially those with chronic or advanced respiratory disorders and critical illnesses.**

palliative care to common clinical practice situations. Instead of being comprehensive in its lists of clinical information, the statement has provided an extensive set of references to allow the reader to find additional clinical material as needed.

METHODS

The task force used a principle- and values-based approach to produce this statement. It first identified the core values and principles of the ATS, as a professional society, related to palliative care (Table 1). The task force identified these principles and values based on the mission of the ATS, the positions that ATS has taken in the past related to ethical issues in its official statements (5, 6), and the ethical and professional duties of its members who are physicians, nurses, or other health care providers. The latter relate primarily to the ethical principles of beneficence and respect for patient and patient autonomy (7).

The task force then applied these principles and values to clinical practice for both children and adults with chronic and

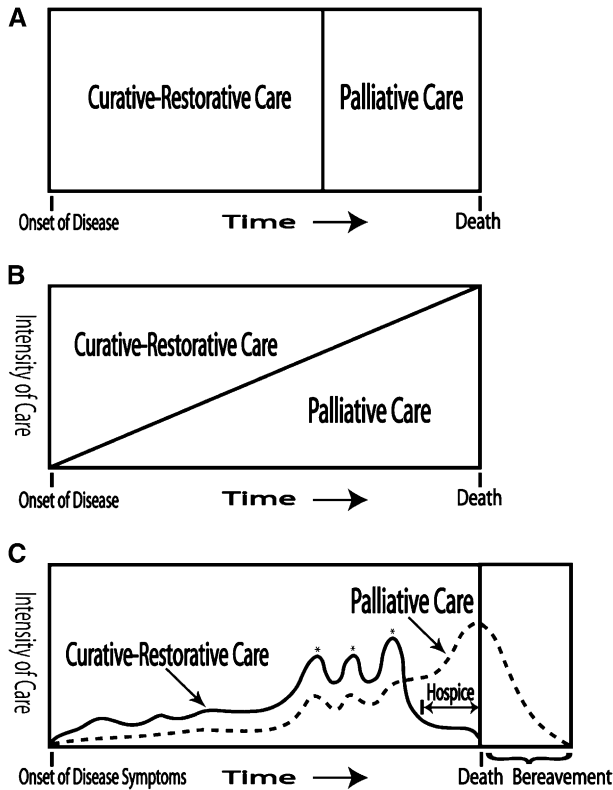


Figure 1. (A) Traditional dichotomous model of palliative care in which patients first receive curative-restorative care and continue receiving it until it fails and then they receive palliative care. (B) Overlapping model of palliative care in which patients receive a gradually increasing degree of palliative care while they receive a gradually decreasing degree of curative/restorative care. In both models (A) and (B), palliative care ends at the time of death. (C) Individualized integrated model of palliative care (which this statement recommends as the preferred approach) in which a patient receives palliative care (dashed line) at the onset of symptoms from a progressive respiratory disease and then concurrently with curative/restorative care (solid line) in an individualized manner. Like curative/restorative care, the intensity of palliative care increases and decreases to reflect the needs and preferences of the patient and the patient's family. The asterisks indicate periods of high intensity of curative/restorative care (e.g., hospitalizations for lower respiratory tract infections). Note that palliative care encompasses both hospice care ("Hospice") and care during the period of bereavement for the family (which may begin before death of the patient). Models in (A) and (B) were adapted by permission from Reference 123.

advanced pulmonary disorders as well as those with critical illnesses. The task force derived its positions and recommendations based on those values and principles, on the expert opinions and experience of members and consultants of the task force, and on a focused literature search.

Operationally, the task force used an iterative modified group process by its members and consultants (see list of members and consultants at the end of the statement) (8, 9). This was initiated at the first general meeting of the task force and many of its consultants during which participants offered their opinions of the most important topics in the assigned field. From these, the task force worked by consensus to identify both the substantive ethical and medical issues and related recommendations to be included in the statement. The task force's two co-chairpersons drafted the initial and subsequent revisions of the statement. Specific medical recommendations and information were first obtained by a combination of group process

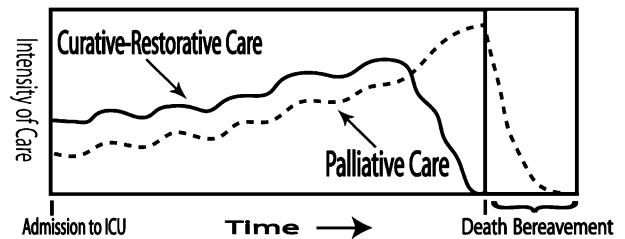


Figure 2. Individualized integrated model of palliative care in which a patient receives palliative care (dashed line) concurrently with curative/restorative care (solid line) from the time of admission to the intensive care unit (ICU) in an individualized manner. Like curative/restorative care, the intensity of palliative care varies to reflect the needs and preferences of the patient and the patient's family. Note that curative/restorative care ends just before death, whereas palliative care peaks at that time and continues after death to address the bereavement needs of the patient's family.

and a focused review of the medical literature, including standard textbooks of palliative care medicine. The focused review also included Medline searches in English using relevant key words (e.g., "hospice care," "palliative care," "terminal care," and "dyspnea"). The writers also searched the Cochrane Database for clinical trials relevant to palliative care and examined both chapters and citations of relevance from multiple textbooks from the United States and the United Kingdom related to palliative care in adults or children or both (4, 10–15). The task force then used an iterative process to modify early drafts of the statement by circulating drafts among members to be discussed at subsequent meetings. Later drafts were circulated by e-mail to members and consultants for comments and critiques. The drafts were then modified further on the basis of that feedback and the comments of anonymous reviewers to arrive at the final product.

GOALS, TIMING, AND SETTINGS FOR PALLIATIVE CARE

The primary goals of palliative care are to achieve the best possible quality of life for patients for as long as they are alive

TABLE 2. CORE COMPETENCIES IN PALLIATIVE CARE FOR PULMONARY AND CRITICAL CARE CLINICIANS RECOMMENDED BY THE AD HOC ATS END-OF-LIFE CARE TASK FORCE

Communication and Relationship Competencies	
• Ability to communicate with empathy and compassion	
• Ability to guide the family during the patient's final hours	
• Ability to help the family during their period of grief and bereavement	
• Ability to identify the patient's values, life goals, and preferences regarding dying	
• Ability to identify psychosocial and spiritual needs of patients and families and resources to meet those needs	
• Advance care planning with patient and family	
• Coordination of care and ability to work effectively in an interdisciplinary team	
• Cross-cultural sensitivity and cultural competence	
• Information sharing, including ability to break bad news skillfully	
Clinical and Decision-making Competencies	
• Ability to apply sound ethical and legal decision making to situations arising from symptom management and withholding and withdrawing life-sustaining therapy	
• Ability to resolve conflicts over fertility, requests for physician-assisted suicide, or active euthanasia	
• Establishing an overall medical plan including palliative care elements	
• Ability to prognosticate survival and expected quality of life	
• Managing withholding and withdrawing life-sustaining therapy and the patient's impending death	
• Pain and nonpain symptom management, including dyspnea	
• Using the shared decision-making model with families and other surrogates for patients lacking full decision-making capacity (32)	

TABLE 3. GUIDELINES FOR TREATMENT OF DYSPNEA

Mild Dyspnea	Moderate Dyspnea	Severe Dyspnea
Treat underlying disease*	Treat underlying disease	Treat underlying disease
Treat psychosocial factors†	Treat psychosocial factors	Treat psychosocial factors
	Pulmonary rehabilitation‡ Consider anxiolytic	Pulmonary rehabilitation Facial cooling (by use of fan) Anxiolytics Opioids§ Noninvasive ventilation (88)

* Treat underlying disease includes anemia, pleural effusions, congestive heart failure, reversible airway obstruction, hypoxemia, main stem bronchial compression or obstruction.

† Treat psychosocial factors: For anxiety, use relaxation techniques, distraction, activity modifications, behavior modifications, and breathing strategies. For depression, use cognitive therapy, antidepressants, or a combination of both.

‡ Pulmonary rehabilitation includes exercise training, psychosocial support, nutritional therapy, and self-management education, including breathing strategies, use of supplemental oxygen, pharmacologic therapy (to relieve airways obstruction), and panic control.

§ Evidence indicates that they do not cause premature death in end-of-life patients when titrated to relieve pain or dyspnea. See Table 4 for types of opioids, and doses and routes of administration. See text for discussion of route of administration.

and to support the patient’s family while the patient is alive and after death.

Clearly, palliative care should be available near the end of life. However, it should also be available at any point during the course of a progressive or chronic respiratory disease or critical illness when the patient becomes symptomatic. An important concept is that, in general, palliative care should be available when curative/restorative care begins, while curative/restorative care continues, after life-prolonging treatments are withheld or withdrawn, and, for the patient’s family, after the patient’s death (Figures 1 and 2).

Although the goals of palliative care are similar in adults and children, social circumstances and treatment of their illnesses differ. For example, children often have special palliative care needs, such as involvement of schools, classmates, and other social structures (16). Causes of death in children with life-threatening respiratory diseases are varied and include congenital, neuromuscular, metabolic, immunologic, and neurologic diseases (17).

Palliative care for adults or children can be provided in many settings, such as the following: in an acute care hospital, including ICUs or specialized in-patient palliative care beds; during outpatient visits; in an independent hospice; in a nursing home;

or at the patient’s home. The patient’s and family’s needs and preferences should guide the choice of the appropriate setting.

DECISION-MAKING PROCESS

Because adults usually have decision-making capacity early in a chronic progressive disease, it is important to try, in a sensitive manner, to determine their immediate and long-term goals of care. Identifying who they want to make decisions on their behalf when they are not able to do so is important. Candid discussion about the availability of palliative care services should be guided by patients’ articulated goals, expressed preferences, and questions. Decision making may occur only after a number of visits in the outpatient setting.

The parents of children should likewise be sensitively informed about the likely trajectory of their child’s disease so that they may take this into consideration when planning for their child’s goals of care, palliative support needs, and related family decisions.

Decision making for patients with advanced lung diseases may include discussions about mechanical ventilation, lung transplantation, and phase I or II clinical trials. These need to be addressed sensitively with realistic descriptions of their benefits and drawbacks, including the potential of having less time with the family (18).

As a phrase, “end of life” suffers from ambiguity but generally refers to the final phase of the patient’s illness when death is imminent or nearly so. It usually varies from a few hours to several weeks—perhaps to 1 month or more in exceptional cases. In some cases, it is obvious to the patient’s health care providers that the patient is in this phase, but in other cases, even experienced clinicians may be uncertain if the end is truly close at hand. That uncertainty adds to the difficulty of communicating clearly to patients and families.

Decision making at the end of life has three major elements. The *first element* is the physician’s candid and compassionate efforts to inform the patient (or the patient’s substitute decision maker [surrogate] if the patient lacks decision-making capacity) that he or she is nearing death. The knowledge and skills necessary to give bad news or make difficult decisions in a compassionate manner can be learned and will enhance end-of-life decision making (19–24). Relevant considerations include the setting of the discussion, determining what the patient or family knows, determining how much the patient or family want to know, sharing the information in understandable terms, responding to the patient’s and/or family’s feelings and questions, and planning for future care decisions.

TABLE 4. STARTING DOSAGES OF OPIOIDS AND THEIR DURATION OF EFFECT IN OPIOID-NAIVE PATIENTS WITH MODERATE TO SEVERE PAIN OR DYSPNEA*

Agent	Adult Duration	Adult	Pediatric	Pediatric	
	IV	Oral	IV	Oral	Oral
Oxycodone	N/A	5–10 mg	N/A	0.05–0.15 mg/kg†	4–6 h
Methadone	2.5–10 mg	5–10 mg	0.1 mg/kg†	0.1 mg/kg†	4–12 h
Morphine	2–10 mg	5–10 mg	0.1–0.2 mg/kg†	0.2–0.5 mg/kg†	3–4 h
Hydromorphone	0.3–1.5 mg	2–4 mg	0.015–0.03 mg/kg†	0.03–0.08 mg/kg†	3–4 h
Fentanyl	50–100 µg	N/A	1–2 µg/kg†	N/A	0.5–1 h

Definition of abbreviations: IV = intravenous; N/A = not available.

* These dosing recommendations do not apply to patients who have previously used opioids because dosages for such patients will be higher and must be individualized. The correct dose and interval for opioid administration in all patients are those that relieve dyspnea or pain without intolerable adverse effects. There is no upper limit—that is, the dose should be increased as needed to produce the desired effect or until intolerable side effects occur. Reassessment of the drug’s effects on the patient and titration of the opioid are the mainstays of successful management.

† Note: Pediatric dosage (adjusted for body weight) should not exceed corresponding adult dose. These dosing recommendations do not apply to neonates, who have distinct pharmacokinetics (228).

TABLE 5. MEDICARE CRITERIA FOR HOSPICE ELIGIBILITY OF PATIENTS WITH ADVANCED LUNG DISEASE

Patients will be considered to be in the terminal stage of pulmonary disease (life expectancy of 6 mo or less) if they meet the following criteria. The criteria refer to patients with various forms of advanced pulmonary disease who eventually follow a final common pathway for end-stage pulmonary disease. (Criteria 1 and 2 should be present. Criteria 3, 4, and 5 will lend supporting documentation):

1. Severe chronic lung disease as documented by both a and b:
 - (a) Disabling dyspnea at rest, poorly or unresponsive to bronchodilators, resulting in decreased functional capacity (e.g., bed-to-chair existence), fatigue, and cough. (Documentation of FEV₁, after bronchodilator, less than 30% of predicted is objective evidence for disabling dyspnea, but is not necessary to obtain.)
 - (b) Progression of end-stage pulmonary disease, as evidenced by increasing visits to the emergency department or hospitalizations for pulmonary infections and/or respiratory failure or increasing physician home visits before initial certification. (Documentation of serial decrease of FEV₁ > 40 ml/yr is objective evidence for disease progression, but is not necessary to obtain.)
2. Hypoxemia at rest on ambient air, as evidenced by Po₂ less than or equal to 55 mm Hg; or oxygen saturation less than or equal to 88% on supplemental oxygen determined either by arterial blood gases or oxygen saturation monitors; OR hypercapnia, as evidenced by Pco₂ ≥ 50 mm Hg. These values may be obtained from recent (within 3 mo) hospital records.
3. Right heart failure secondary to pulmonary disease (cor pulmonale) (e.g., not secondary to left heart disease or valvulopathy).
4. Unintentional progressive weight loss of greater than 10% of body weight over the preceding 6 months.
5. Resting tachycardia > 100/minute.

Modified from Reference 57.

The *second element* is the patient's or surrogate's decision to receive only or primarily palliative care (e.g., hospice care), and to discontinue life-prolonging interventions. A prior ATS statement describes the ethical principles and decision-making process for withholding or withdrawing life-sustaining treatments (5).

The *third element*, the focus of this statement, is the process of coordinating and providing palliative care to patients near or at the end of life.

As the patient's disease progresses, goals of care may evolve, with some objectives and preferences being more emphasized or some less so. Discussions should involve the adult patient and family members to the extent desired by the patient (unless the patient lacks the capacity to choose). In the latter instance,

TABLE 6. WORLD HEALTH ORGANIZATION'S DEFINITION OF PALLIATIVE CARE FOR ADULTS

Palliative care for adults is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual issues.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and with their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Reprinted from Reference 2.

TABLE 7. WORLD HEALTH ORGANIZATION'S DEFINITION OF PALLIATIVE CARE FOR CHILDREN

- *Palliative care* for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers, and even in children's homes.

Reprinted from Reference 2.

health care providers should share decision making with one or more surrogates previously designated by the patient, mandated by state law, or determined on ethical grounds (5). End-of-life decisions with surrogates should be made on the basis of the patient's preferences or values, if known, or, otherwise, on the basis of the patient's best interests (5).

Parents or guardians, with the advice of health care providers, should make the end-of-life decisions for infants and small children. Because the latter have not developed a sense of values or decision-making capacity, the parent or guardian should be guided by a "best interests" model of decision making (5, 25). However, children's wishes should be respected concerning activities that may be burdensome, such as testing, treatment, and monitoring. Physicians must provide parents with a realistic assessment of the benefits and burdens of such interventions as well as the prognosis and estimated time when death is likely to occur. Parents and siblings must be told the truth in a sensitive and caring manner, and feelings of guilt, anger, and disbelief must be dealt with similarly. Because the age at which children are mature enough to actively participate fully in decision making varies, only roughly approximating chronological age, this should be assessed on an individual basis (26). Decision making in adolescents is more complex because they are able to understand and take part in the process, while at the same time they may have strong feelings about continued treatment (27). Shared decision making involving adolescent patients and their parents should be promoted. Unique family rituals, cultural, and religious beliefs should also be encouraged to comfort the patient and family and aid in decision making (28–30). Finally, continuing school activities may be important to some children.

The degree of involvement of the health care team in sharing the decision making should reflect patients' or surrogates' preferences (31, 32). Some may prefer that the health care team primarily have an advisory role, whereas others may prefer that the team have a shared or even a primary decision-making role. Patients may want to change their role in the decision-making process as their disease progresses and they become more dependent.

ADVANCE DIRECTIVES

Most patients do not have an advance directive. However, the majority of adult patients who do create advance directives do not change their preferences over time (33). Several studies report on their limitations (i.e., advance directives are inconsistently followed or subject to multiple interpretations) (34–38). However, this statement still advocates for their use as they allow patients to codify and inform others of their preferences. Patients who want to make a written advance directive (e.g., durable power of attorney or living will) should be encouraged to engage in discussions with their surrogates and physicians so that there is a clear understanding of the patient's goals for end-

of-life care and preferences regarding use of life-supporting interventions (e.g., intubation, cardiopulmonary resuscitation [CPR]). Copies of advance directives should be given to the patient's family, loved ones, and physician. A mechanism should be put in place to ensure that these codified preferences can be made known to the patient's health care providers.

Advance directives for adolescents may be appropriate in certain circumstances—for example, when they face the potential of respiratory failure (39). It may be comforting to parents of young children to discuss specific treatments, such as CPR, to ensure that such interventions are not used if judged to be burdensome and without meaningful benefits.

CARE PLANNING AND DELIVERY

An interdisciplinary approach to providing palliative care is an effective way to meet all of the needs of the patient, family, other loved ones, and caregivers (40, 41). Such an institutional health care team includes a physician, nurse, and social worker, and may include a chaplain, volunteers, and counselor depending on the circumstances. Additional members, no less important, are the patient's or family's spiritual advisor, home health aide, and therapists (physical, occupational, respiratory, speech, art, and music). Teachers, school nurses, and art and music therapists may be especially helpful for ill children, their siblings, and their parents.

Within the hospital setting, an organized palliative care team can provide coordinated care (42). If there is no such team or the patient is in an ICU or outpatient setting, the attending physician should generally be responsible for coordinating a team approach. In a home hospice setting, a registered nurse can best evaluate needs with onsite visits and coordinate care for the patient, with the social worker and chaplain providing important support. Both in and out of the hospital, the patient and family should be considered integral members of the palliative care team. Continuity of care with a stable care team that comes to know the patient and family is extremely important. A care team with pediatric hospice expertise is preferred for pediatric patients.

As a rule, most patients will receive elements of both curative/restorative (life-prolonging) care and palliative care concurrently (Figures 1 and 2). For example, a time-limited therapeutic trial may be appropriate in circumstances in which temporary recovery from a self-limited process (e.g., acute bronchitis resulting in respiratory failure) is possible. As the trial progresses, if the hopes for reversal of a temporary process wane, palliative care should be emphasized more than curative/restorative care.

Patients with chronic obstructive pulmonary disease (COPD) constitute a large group of symptomatic patients with a common, chronic, and generally progressive respiratory disorder. Recent studies indicate that patients in this group, on the whole, receive less palliative care in their terminal phase than patients with lung cancer (43). This disparity may relate to barriers to good communication between health care providers and patients with COPD relating to palliative care. Depression among patients with COPD and lack of advance care planning have been reported to contribute to the barriers for such communication (44). Advance care planning is discussed above and depression in COPD is discussed below.

HOSPICE CARE

Palliative care often includes hospice care before or at the end of life. Hospice care is defined as the support and care for patients and their families in the last phase of an incurable disease so that they may live as fully and comfortably as possible (1, 45, 46). Before a patient is considered eligible for hospice,

Medicare, Medicaid, and other insurers require that a treating physician and the hospice medical director certify that the patient's prognosis is terminal—that is, *more likely than not* having less than 6 months of life. It is important to realize that the physician who certified that a hospice patient is terminal does not “guarantee” death within 6 months. Indeed, if a patient in hospice survives beyond 6 months, Medicare and other reimbursement organizations will continue to reimburse for more extended periods of treatment if patients still meet enrollment criteria (47, 48). Another Medicare requirement is for patients to agree in writing that only hospice care (and not other Medicare services, e.g., curative care) can be used to treat their terminal illness (47). Despite the explicit emphasis on comfort care for patients enrolled in hospice programs, patients do not need a “do not attempt resuscitation” order to be enrolled in hospice programs. (Indeed, it is illegal under the Patient Self-Determination Act for Medicare-funded hospice programs to exclude patients if they don't agree to forgo CPR). In such cases, hospice programs will inform the patient that they do not provide CPR but will call 911 if the patient requests resuscitation). Patients in hospice programs can be withdrawn from such programs if their condition unexpectedly improves.

Hospice care can be provided in multiple settings, dependent on the patient's and family's needs and preferences. Although most patients prefer to die at home, being able to die where one wishes to die may not be possible (49, 50). Studies suggest that the determinants of patients who died in the hospital reside in their local health system (i.e., greater availability and use of acute hospital beds and less availability of hospice and nursing home resources) (49). Children with complex medical conditions die in hospital about 75% of the time and at home about 15% of the time (51). Medicaid reimbursement for palliative and hospice care often mirrors Medicare reimbursement guidelines and may influence the setting of care and services available for both adults and children.

Patients with nonneoplastic advanced lung disease face a number of difficulties in getting referred to hospice. First, whereas most adult patients with lung cancer referred to hospice die within a 6-month period, the prognosis of noncancer patients with advanced lung diseases (e.g., COPD or interstitial lung disease) is more difficult to determine (52, 53). Second, some physicians may be reluctant to discuss hospice because of their lack of skill or training in acknowledging or communicating to patients that death is near (54). Third, physicians may fail to recommend hospice care at home or in another setting for noncancer patients because they are unaware of its availability. Finally, physicians may also be unaware of the criteria for eligibility of noncancer patients to hospice (55). Fortunately, these obstacles to referral are partially offset by an increasing alignment of home care organizations with palliative and hospice care.

In 1996, the National Hospice Foundation published admission criteria for adult patients with advanced (noncancer) lung disease to a hospice program (56). Medicare and other insurers subsequently incorporated these recommendations into their enrollment criteria for hospice (Table 5) (57), even though some studies suggest that these criteria do not accurately predict death within 6 months (52).

As noted above, there is a need for a validated predictive model to give estimates of likelihood of death within 6 months for patients with COPD. Although the BODE (body mass index, airflow obstruction, dyspnea, and exercise capacity) index provides prognostic information over periods of time from 12 to 52 months, it has not been validated for determining a risk of mortality greater than 50% at a 6-month time period needed to qualify for hospice care (58). Additional considerations besides those in the BODE index are the presence of comorbidities and

a rapidly declining course. Others have proposed additional "common sense" criteria for hospice referral (59). These include circumstances wherein (1) despite optimal treatment, a chronic respiratory disease has progressed to the point that the patient may die at any time because of a common intercurrent illness such as bronchitis, (2) the patient has severely distressing symptoms or limited performance status that can be most humanely and reasonably managed by hospice care, or (3) the patient accepts that death is near and wants to avoid needless prolongation of suffering. There are no comparable criteria suggested for enrollment of children with advanced respiratory diseases into hospice.

Respite care programs may be helpful to family caregivers (60) by providing time away from the psychological distress and physical demands of caring for the chronically ill or dying patient. Respite care is provided by temporary admission to a nursing facility. This is especially important for spouses or elderly caregivers or families with young siblings who may feel ignored and harbor conflicting feelings toward the dying patient. Attention to them is reassuring and important for their own grieving process. Parents should feel that there is always an alternative care option available to them if and when home care of their dying child becomes unmanageable.

ALTERNATIVE END-OF-LIFE DECISIONS

Patients often lose a desire to eat or drink at the end of life. In addition, some adult patients make a voluntary decision to stop eating and drinking as a way to control and/or accelerate the dying process (61, 62). Although refusal of medical treatment, including refusal of artificial nutrition and hydration (63), is a time-honored legal and ethical right of patients in modern medicine (5, 64), voluntary cessation of eating and drinking does not equate with stopping nutrition and hydration via a feeding tube. Some have raised concerns about its relationship to suicide and to another option of last resort, terminal sedation, discussed below (61, 62). There is no compelling evidence that dehydration or forgoing nutrition in the dying patient leads to significant suffering (62). Nor does relieving possible thirst by wetting the patient's lips result in significant rehydration. If an imminently dying patient with the capacity to make decisions chooses to forgo nutrition and hydration, health care providers should respect the decision and support the patient and family by continuing to provide palliative care. Providers whose personal moral codes prevent their involvement in such cases should facilitate transfer of the patient's care to another provider who is willing to be involved.

SYMPTOM MANAGEMENT

Dying patients fear dyspnea and pain (65). Therefore, symptom control is one cornerstone of palliative care (66). In controlling such symptoms, one seeks to balance the patient's ability to be aware and communicate with satisfactory relief of the symptoms. This balance can generally be achieved when experienced caregivers provide pharmacologic, psychological, and spiritual care that is guided by physical exam findings, symptom assessment scales, psychological evaluation, and laboratory tests. In some instances, a hospice patient may have to be admitted to the hospital to achieve satisfactory symptom control. Optimal control requires continual reassessment. Although sometimes inaccurate, family members' assessments of a dying adult patient's symptoms, especially pain and anxiety, are generally helpful (67). Family members may also feel helpful and find solace by playing an active role in monitoring and helping to control symptoms.

In addition, parents and siblings often become expert in recognizing the nuanced changes in the dying child's level of comfort (68). They often learn how best to relieve these symptoms with both medical and nonmedical maneuvers. It is important for health care providers to acknowledge their expertise. It is also important to note that drug regimens used to treat adults in the palliative care setting cannot simply be assumed to be effective when used in children with weight-adjusted dosing (68, 69). Metabolic and body composition differences may require different dosing regimens for children.

For both children and adults, symptoms can develop insidiously and result in stepwise initiation of feeding tubes, tracheostomy tubes, and home mechanical ventilation. Although these interventions can provide symptom relief and be life prolonging, health care providers should realistically help patients, family, and parents of dying children to weigh the chances of the desired short- and long-term benefits against their likely burdens. Furthermore, they should be aware that the use of such technologies does not preclude a later decision to withdraw support when it is no longer desired or inappropriately prolongs suffering or both.

Dyspnea Management

Dyspnea is a prominent symptom of the patient with advanced respiratory disease of any cause. For example, nearly all patients with COPD in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) had dyspnea during the last 3 days of their lives (70, 71). Unfortunately, there are no completely satisfactory treatments for the various forms of dyspnea. Nonetheless, palliative care measures that incorporate regular assessment and reassessment, opioids, counseling, and care coordination can often provide considerable relief (Table 3). Treatment should focus on both the psychological and physical components of dyspnea, and rely on visual or analog dyspnea scales to assess the severity of symptoms and effects of treatment (72–78). Patients should be encouraged to join pulmonary rehabilitation programs early in the course of their chronic, progressive lung disorder (e.g., after developing dyspnea during activities of daily living). Such programs can teach measures for controlling dyspnea at the present stage of disease (79, 80) and they may also be helpful for alleviating anxiety at the end of life. A detailed discussion of dyspnea control in patients with primary or metastatic lung cancer can be found in a number of resources that focus on this topic (81–85).

Patients with dyspnea may get relief from use of invasive or noninvasive home ventilators and other equipment that can appear threatening to the family (86–88). Training in the use of this equipment is critical to promote a family's confidence and sense of control. Children are often exquisitely sensitive to their parents' level of discomfort with such devices. Although noninvasive positive-pressure ventilation is typically used with life-prolonging intent, hospital policies to restrict such use to ICU settings may not be appropriate when it is used for symptom relief in dying individuals (89).

The physiologic component of dyspnea may be relieved by supplemental oxygen, noninvasive positive-pressure ventilation for hypercapnic adult patients, or blowing cool air on the face using a fan (90–92). Opioids and anxiolytics are the primary pharmacologic treatments of dyspnea for adults and children (Table 4). Opioids can be given orally, subcutaneously, or intravenously (Table 4) (84, 93–96). Although use of nebulized opioids has been reported anecdotally as a treatment for dyspnea (97), systematic reviews have concluded that nebulized opioids are no more effective than nebulized placebo (98).

A dyspnea scale should guide dose adjustment with the dual goals of providing adequate dyspnea relief and minimizing the sedative effects. Dyspnea with anxiety may be partially relieved by relaxation therapy, acupuncture, or other alternative or complementary medicine methods (99). Mucolytics and occasional courses of antibiotics may be useful adjuncts in decreasing dyspnea for patients with excess tenacious secretions (100). Although oxygen therapy is traditionally used for relief of dyspnea in patients with advanced lung disease, little controlled evidence supports its utility for dyspnea in the absence of hypoxemia (101).

Concern occasionally arises about the moral acceptability of opioids to relieve dyspnea or pain because of the belief that opioids may hasten death through respiratory depression. Importantly, several observational studies found no evidence that the appropriate use of these drugs hastens death (102–104). Furthermore, the “principle of double effect” addresses the potential for harm by use of opioids in palliative care (105). Although not without its critics (106), this principle holds that relief of suffering is adequate justification for the use of opioids to control dyspnea or pain, and that hastening death by the use of opioids, if it occurs, is morally acceptable provided that the intent of the physician or nurse is confined to relief of dyspnea. Consistent with this principle, health care providers should titrate the dose of opioid to its effect in relieving dyspnea—that is, dosing interval and quantity based on frequent symptom assessment using a dyspnea scale or physiologic manifestations of dyspnea. Dosages of opioid that exceed what is necessary to relieve symptoms are illegal (except in Oregon and some European countries) and morally suspect, and should be avoided because such circumstances signify some intent other than symptom relief.

Pain Management

Dying patients frequently, but not inevitably, experience pain. It is estimated by family members that about half of adult patients with cancer have pain, with half of these gauging the pain to be moderate or severe in quality (107, 108). Family members often feel that pain is inadequately treated at the end of life (70). Because pain often does not simply represent a physical symptom but presents social, psychological, and spiritual dimensions as well (109), its assessment requires the patient’s active cooperation. Each dimension should be assessed. For the dying patient, pain assessment using a functional scale (110, 111) should be considered another “vital sign” (112, 113).

Pain in young children often results as much from diagnostic and therapeutic procedures as from the disease itself (114, 115). Indeed, children not adequately treated for pain during the initial procedure may suffer greater pain with subsequent procedures (116). Thus, use of parental presence, local anesthetics, information, and distraction techniques, as well as anticipatory dosing of analgesics and anxiolytics before procedures, is recommended. These types of adjunctive measures may be helpful for children and adults to avoid aversion to subsequent care.

The original WHO concept of an “analgesic ladder” in which mild pain is treated initially with acetaminophen and nonsteroidal antiinflammatory drugs and then opioids and adjuvant drugs (e.g., corticosteroids, tricyclic antidepressants) are added for more severe pain is well accepted (112, 117). Although opioids are the first line of treatment for severe pain regardless of cause, neuropathic pain may be difficult to treat with opioids alone and may require adjunctive agents, including tricyclic antidepressants, anticonvulsants, corticosteroids, local anesthetics, neuroleptics, α_2 -adrenergic agonists (e.g., clonidine), and baclofen (118, 119).

Initial dosing of opioids to treat pain is summarized in Table 4. Additional details of recommended dosages of opioids and

their routes of administration are available in other resources (11, 12, 112, 117, 120–128). Because strict adherence to the recommendations for dosing may not relieve symptoms, one should consider these recommendations only as guidelines. The correct dose is the dose that relieves the symptom; there are no maximum doses of opioids. Consultation with a pain management or palliative care specialist (129, 130) should be requested in difficult cases and may prove useful in other cases as well.

The physical aspect of pain can be controlled in the majority of patients with oral or combined oral and intravenous or subcutaneous opioids. Transdermal opioids should only be used for chronic stable pain or dyspnea. Starting doses should be higher than shown in Table 4 if the patient has acquired a tolerance because of prior opioid use. Refractoriness of pain generally requires escalation of dosing. Barriers to successful pain management include not only failure to assess and treat the pain using a functional scale but also misinformation and concerns of the patient, family, and health care provider about addiction and tolerance.

Because constipation as an opioid side effect is predictable, a bowel stimulant and stool softener should be started with the initiation of the opioid. Its dosage should be titrated to achieve the desired effect and increased as opioid dose is escalated. Some patients will have other side effects, such as nausea. The latter is often transient and can usually be relieved by antiemetics (e.g., prochlorperazine or metoclopramide) or, in persistent cases, by trying a different opioid (124). Somnolence after starting opioids is likewise often transient until tolerance to this effect develops, usually in days to weeks (124).

On occasion, suffering at the end of life may be refractory to traditional palliative care treatments (131). In such circumstances, some clinicians have advocated the use of “terminal sedation” or “total sedation” (61, 62, 132). This type of sedation has more recently been referred to as “palliative sedation,” which avoids the implication that it is the sedation that is causing the patient’s death (133–136). Palliative sedation is generally defined as the relief of otherwise intractable pain, dyspnea, delirium, cough, or existential distress by the use of medications that intentionally cause sedation in a patient who is otherwise close to death (137, 138). Because there has been no standardized definition and because palliative care expertise varies widely, reports of the frequency of its use also vary widely (138). Benzodiazepines or barbiturates are commonly used (61, 137, 138).

Because the intent is to relieve symptoms, the dose is titrated to the patient’s comfort. This may be achieved with only mild sedation in some patients, whereas others require deep sedation to relieve suffering. Palliative sedation *per se* does not preclude the use of artificial nutrition and hydration, but it often occurs without them. It differs from euthanasia or assisted suicide in that its intent is to relieve intolerable suffering, whereas the intent of euthanasia or assisted suicide is to cause the patient’s death. Although not addressing the legality of this procedure *per se*, a unanimous 1997 U.S. Supreme Court ruling noted these distinctions, which some have interpreted as giving this type of sedation considerable legal support (64, 139). Because the intents are different, the doses and monitoring of their effects differ significantly. In practice, however, blurring of intent of palliative sedation (e.g., intent to hasten death as well as control of symptoms) has been reported (138). Because of this and because palliative sedation often does not include nutritional support and hydration, ethical concerns have arisen about its use (140).

The following are guidelines for clinicians who are considering use of palliative sedation with cessation of nutrition and hydration:

1. Because patients who are refractory to traditional palliative care are rare, obtain palliative care consultation to assess whether the patient has received all appropriate elements of traditional palliative care and still has intractable suffering.
2. Discuss this modality and cessation of nutrition and hydration fully with the patient or surrogate and patient's family to be sure that the patient or surrogate gives informed consent and that the family understands what is being considered.
3. Consider obtaining consultation with a mental health professional to assess whether the patient has a treatable emotional disorder (e.g., major depression) that is the root cause of the intractable suffering.
4. Consider obtaining consultation with the hospital ethics committee or other institutional ethics resource to review the use of this modality and its intentionality. If a clinician's personal moral code prevents participation in palliative sedation, then she or he should facilitate transfer of the patient's care to another health care provider who is willing to participate.

Delirium may masquerade as pain (and vice versa) in dying patients and can cause much caregiver misinterpretation, especially in the ICU setting (141, 142). For example, delirium rather than pain may cause a dying patient to groan when stimulated. Conversely, agitation in delirious patients may represent the only sign of pain and justify a trial of pain medications or other interventions together with an evaluation for the underlying etiology.

Management of Psychological and Spiritual Distress and Suffering

Psychological distress is common in patients with advanced respiratory diseases (70, 143–152). They are at higher risk than healthy persons for depression, anxiety, and panic attacks. Although dyspnea commonly is regarded as a cause for anxiety and panic attacks, the converse is also hypothesized—that is, that anxiety *causes* dyspnea. These psychological conditions compromise patients' quality of life, decrease how well patients respond to emergency therapies during acute exacerbations, and lead to more frequent hospitalizations (153).

Studies in adult hospice patients demonstrate that, although pain-related symptoms are associated with anxiety, functional impairments are more often associated with *depression* (154). Clinicians should note that depression is associated with preferences to limit life-sustaining therapy and that these preferences may change after successful treatment of the depression (155). Therefore, end-of-life preferences should be reevaluated after patients have had sufficient time to respond to treatment for depression (for which a rapidly acting antidepressant, e.g., methylphenidate, is indicated).

Moreover, caregivers of patients with advanced respiratory disease commonly experience depression. Up to one-third of such caregivers have scores on survey instruments indicative of risk for clinical depression. Caregivers of patients on ventilators—either in a health care institution or at home—are at greatest risk (156, 157). Clinicians should monitor these caregivers for depression, discuss with them their vulnerability for depression, and offer support and referral resources for evaluation and treatment, as appropriate.

Treatment approaches for patients with depression, anxiety, and panic attacks include counseling with or without pharma-

cotherapy. Although studies evaluating drug treatment for depression in patients with COPD have shown mixed results (158, 159), antidepressants are worth consideration, especially if counseling is ineffective. For example, one randomized clinical trial of nortriptyline in treating depression in patients with COPD showed significant improvement in anxiety and depression (160). Pharmacologic treatment for depression in this setting includes methylphenidate (when rapid relief is important, the patient is not anxious, and the patient has no contraindications), serotonin selective reuptake inhibitors, or, less commonly, tricyclic antidepressants. Selection of an agent should be based on potential efficacy and rapidity of onset plus consideration of the agent's adverse effects and potential benefits (e.g., certain tricyclic agents may also be useful for insomnia).

Pharmacologic treatment of anxiety includes benzodiazepines and buspirone, whereas drugs of choice for panic attacks are serotonin selective reuptake inhibitors (161). Nonpharmacologic interventions, such as cognitive-behavioral therapy, are also important.

Agitated delirium may occur when death is imminent or during hospitalization in ICU settings (141, 162, 163). Agitated delirium can be initially managed with haloperidol when rapid relief is important (141, 163). Combination therapy (e.g., oral haloperidol or a second-generation neuroleptic agent with a benzodiazepine) may be needed for long-term therapy for patients with prolonged agitation (162, 164, 165). Details and doses of the recommended pharmacologic treatment of depression, anxiety, panic attacks, and delirium may be found in other, more comprehensive sources (10, 11, 13, 161, 166–171). For hospitalized patients, especially those in the ICU, minimization of environmental stimuli, such as excessive noise, day–night reversal, and disorientation to time and person, can be achieved by the following easily implemented strategies. These include earplugs, eye covers, decreasing the volume of the alarms, elimination of overhead paging, frequent orienting cues, easy access to family, personal music choices through headphones, and low lights at night.

For many patients, chronic, progressive, life-threatening illnesses provoke questions of existence, meaning, purpose, regret, and destiny. Resolution of these spiritual questions in ways that are acceptable and satisfying to the individual is an important task for the dying patient and constitutes “spiritual healing.” This type of healing may in turn contribute to emotional well-being, and lessen physical morbidity in the remaining moments in the lives of these patients (172). Most clinicians have neglected this aspect of care. However, the unique position of the clinician and the importance of spiritual issues to dying patients argue for a greater role for the clinician in facilitating the ability of patients who choose to pursue the spiritual dimension of their lives. Although a challenge, approaches to providing spiritual care and promoting spiritual healing in patients with progressive and fatal illnesses have been described (172). They assume that spirituality ultimately has to be patient centered and patient driven, with the physician as a supporter, catalyst, or facilitator. The physician's efforts do not replace the contributions of others (e.g., nurses or clergy) but rather focus on enabling the patient to mobilize the resources (personal, religious, or community) needed to address spiritual concerns.

Related to the spiritual and existential suffering noted above, Cassell has described suffering resulting from a threatening feeling caused by fear, by the patient's perception of their symptoms, or by concerns for the future (173–175). Because it is highly personal, the same symptom of suffering in two patients may have entirely different meanings. As noted above, modern physicians, used to dealing with objective findings but not feelings, may be uncomfortable and/or untrained to inquire and listen to patients talk about their distress. It can be enormously

rewarding for patients when caregivers care enough to listen even if they can offer no answers to the existential distress.

It can be even more rewarding for patients when caregivers can successfully offer meaningful support. Existential suffering does not lend itself to pharmacotherapy. Every effort should be made to assess its presence in patients and to help the patient and family by empathetic communication and by encouraging the patient and family to seek spiritual assistance when appropriate. An interdisciplinary approach (e.g., health care providers, social worker, and religious advisors) increases the likelihood that the patient's and family's needs for support can be met.

The psychological needs of dying children and adolescents, their familial caregivers, and their professional caregivers must be recognized and addressed appropriately (4, 10, 16, 27, 31, 69, 176–182). At times, drugs, behavioral therapy, or psychotherapy may be necessary to relieve the child's suffering. If the child is of school age, the importance of maintaining ongoing relationships with his or her peers and continued class work should be recognized and encouraged. Adolescents may have especially difficult problems as they attempt to gain an identity and independence while becoming progressively more dependent on their families. Younger children may benefit from nonpharmacologic strategies, including child-friendly surroundings, distraction, and integrated medical techniques such as massage therapy. A child life specialist or others trained to work with children may do much to alleviate a child's distress.

WITHDRAWAL OF MECHANICAL VENTILATION

Process of Decision Making

Although withdrawal of mechanical ventilation is common in ICUs (183), it may also occur in chronic ventilator facilities or even at home (184). Physicians should begin discussions regarding the decision to withdraw mechanical ventilation when patients or their surrogate(s) broach the issue, when health care providers believe that continued mechanical ventilation is no longer meeting the patient's goals, or it has become more burdensome than beneficial to the patient. When a patient lacks decision-making capacity, the patient's prior directive, or the decision makers identified by the patient, should then guide the decision-making process. In the absence of an advance directive, this is usually a joint surrogate–medical team decision (185).

Decision making over limiting treatment is a process; at times, it may be lengthy and emotionally draining. Discussions about goals of care and corresponding appropriate level of treatment should be started early in all treatment settings but especially in the ICU (186, 187). Meetings with family should be conducted frequently as the ICU patient's condition evolves. All curative/restorative treatments should be viewed as time-limited trials and systematically reevaluated to determine if the care plan is achieving its goals. If patients and families are regularly apprised of the situation, they will be better prepared when the assessment is made that the interventions are no longer helping.

The attending physician should facilitate these discussions, which should take place in a private and personal environment, and involve the patient, all relevant surrogates, and members of the health care team. Although resources for physician training in graduate and continuing medical education provide excellent guidance and support (19–24), it may be difficult for physicians to initiate these types of discussions. Studies of the end-of-life care for children and adults with cystic fibrosis suggest that providers often do not routinely discuss end-of-life care or hospice options or, if they do, they wait until death is close. For example, in one study, most children received intravenous antibiotics and even oral vitamins during the last 12 hours of life, suggesting that a full

transition to palliative care had not occurred (89). In another study of deaths of patients with cystic fibrosis, palliative care was not discussed until the final month of life in 40% of patients and not discussed at all in another 25% (189).

It may be helpful, particularly in contentious circumstances, to initially avoid making a recommendation to withdraw (or withhold) mechanical ventilation, but to first review the patient's health status and goals of care, his or her prior statements about similar circumstances, the family's experiences in similar situations in the past, and their feelings about the process and outcome of those experiences. After that review, one can then discuss possible treatment options and how they relate to the patient's goals of care. Such an approach is more likely to allow the decision makers to arrive at a joint decision (189).

It is important to recognize and acknowledge the feelings and interests of the patient and surrogates as they work through the decision-making process (189). This includes attention to the patient's and family's cultural and spiritual context (28–30, 190–192). Attending physicians should make recommendations regarding appropriate level of medical intervention based on their understanding of the patient's values and goals (if known) or on a best-interests basis (if the patient's values and goals are not known). Nursing, pastoral care, and hospice support may be especially helpful at these times (186). Consensus among caregivers, patient, and family is usually reached if the health care team invests adequate time and effort in the process and does so skillfully and sensitively (Table 2) (185).

One essential aspect of such discussions is to not only talk about what will be discontinued but also talk about what will be continued to ensure the patient's and family's comfort and well-being. In addition, such discussions should include plans to acknowledge and respect the patient through development and facilitation of an individualized plan—for example, playing music, saying prayers and conducting spiritual ceremonies (193), making clothing choices for the patient, grooming, connecting with family and friends, and providing opportunities for life review. If the patient is a child, some parents may find that doing certain activities for the last time after withdrawal of ventilatory support highly meaningful—for example, bathing and dressing a child, holding the child, or rocking the child in rocking chair (194).

Once a decision has been made to withdraw mechanical ventilation, a consensus should be reached on when and how this will occur, and who will be present, especially if withdrawal is occurring at home. The family should appreciate that it is difficult to predict how long a patient will continue to breathe after ventilator withdrawal. Whether in the home or other care setting, the family should be told beforehand what they may expect to see and hear during the dying process, and should be given assurances that any discomfort will be minimized or controlled by vigilant nursing and medical care (113).

Process of Withdrawing Mechanical Ventilation

There is no single correct way to withdraw treatment at the end of life, and this holds for ventilator withdrawal (195–200). Both terminal extubation (removal of the endotracheal tube) and terminal weaning (gradual reduction of inspired oxygen concentration and/or mandatory ventilator rate) have been used. The chosen method of withdrawal should be influenced by the same balance of benefits and burdens and respect for patient's (or surrogate's) preferences that apply to all medical decision making. The patient (if capable) and his/her family members should be similarly involved in the decision as to how to proceed.

The patient should be assessed for responsiveness with verbal and tactile stimuli. Neuromuscular blockers, if being used, should be discontinued and their effects allowed to wear off or be reversed. The patient should be given anticipatory titrated

doses of opioids and benzodiazepines to alleviate any signs of dyspnea after withdrawal of mechanical ventilation (Tables 3 and 4). Benzodiazepines will also relieve anxiety and provide sedation. Especially in the ICU setting, health care providers should be vigilant to regularly assess for signs of dyspnea and pain after removal from assisted breathing.

In all settings after withdrawal of mechanical ventilation, health care providers should continue to titrate opioids and benzodiazepines to maintain satisfactory control of any signs of discomfort. ICU patients off assisted breathing may need such close monitoring to control their symptoms that they need to remain in the ICU (6). Others may benefit from continued ICU care because it can provide continuity of caregivers and familiarity of location for the family. If demand for an ICU bed exceeds supply, however, and palliative care needs can be satisfactorily met in alternative in-patient settings, extubated patients may be transferred out of the ICU (6).

Antibiotics and other life-prolonging treatments, particularly intravenous fluids that can cause respiratory congestion and gurgling, are usually discontinued before ventilator withdrawal.

Although some clinicians prefer terminal extubation, and others terminal weaning, the latter helps avoid noisy breathing due to airway secretions that may disturb the family (199, 201). Clinicians should be adept at both methods of withdrawal. Clinicians should be aware that some view terminal weaning as controversial (127). If the patient has a tracheotomy, withdrawal is similar to that of the patient who has the ventilator withdrawn while still intubated. A health care team member should be available to the patient and the family until death occurs.

Approximately one-quarter of imminently dying patients have noisy breathing, termed “the death rattle” (201). Some families experience distress in witnessing noisy breathing due to retained secretions even when they are reassured that the patient is not suffering. Efforts to suppress or eliminate the death rattle, therefore, may be appropriate to relieve family distress. If a death rattle results from bronchial secretions, elimination of intravenous fluids and treatment with anticholinergic agents may be effective (201). Noisy breathing due to intrinsic lung pathology usually resists therapy.

In the minutes before death, patients may exhibit “agonal breathing” which is slow, irregular, and noisy breathing that mimics grunting, hiccupping, or gasping (202, 203). Families should be informed in advance of agonal breathing so they can view it as a part of the dying process rather than a sign of patient discomfort. If one uses the term “agonal breathing,” one should help the family to understand that it does not imply that the patient is in agony. By themselves, a death rattle and agonal breathing are not indications for increasing the dose of opioid administered.

BEREAVEMENT CARE

Health care to the patient stops with the patient’s death, but the suffering of the family and other loved ones goes on and so should bereavement care (Figures 1 and 2) (108, 204). Pulmonary and critical care physicians should recognize the resources for bereavement counseling both before and after their patients’ death (205). Social workers, nurses, and bereavement counselors, who can spend significant amounts of time with families, should be sought to aid in this process. Health care providers should learn and be able to describe to families the normal grieving process and refer them to sources of support, such as hospice-sponsored grief recovery support groups (41, 206, 207). Proactive, family-centered, end-of-life conferences by health care providers that allowed time for families of dying patients in ICUs to talk plus a brochure on bereavement have been found

to decrease the risk of subsequent emotional morbidity of those family members during bereavement (208, 209). These conferences used a structured format that facilitated communication by focusing on listening and understanding (210).

Particularly when families have been close with providers, attending funeral and memorial services can be therapeutic for both families and providers (211). Sending a sympathy card or letter of condolence can also serve the same purpose (206).

When children die, their parents and siblings may require extensive counseling (212). Clinicians should encourage honest discussion about what happened and what may happen in the future. Young siblings may fear for their own health or feel responsible for the death of a sibling, whereas older children may feel awkward about returning to school after a sibling’s death (212). Such situations should be anticipated and parents should be encouraged to deal sensitively with these concerns. Bereavement counselors should be available to the family.

Health care team members may benefit from meeting together several weeks after the death (213). This allows not only for expression of their emotions and review of patient management but may also serve as a teaching opportunity to aid in future patient care. Parents of a deceased child or close family members of the deceased adult may find a meeting with their caregivers several weeks after the death to be valuable. It would give the health care team an opportunity to answer questions (especially if there was an autopsy), check on the parents’ or family’s well-being, and give the parents or family members an opportunity to say a final goodbye to their favorite caregivers.

BARRIERS TO PALLIATIVE CARE

One barrier to timely initiation of palliative care is the discomfort that some physicians have with candid discussions about end-of-life care with their patients (89, 188). Early consultation with a palliative care consultant or team can facilitate this discussion. Another barrier is the uncertain short-term prognosis of many patients who have advanced lung diseases other than cancer and most patients admitted to the ICU (52, 71, 214–216). Additional barriers include lack of knowledge and skills necessary to provide adequate palliative care, reimbursement issues, and time required to ensure adequate palliation. Finally, professional and family caregiver stress and burnout can also contribute to the problem (217–220).

In children, another barrier to palliative care is that the system is modeled after the Medicare adult palliative care program. As such, Medicaid or other insurers may not reimburse some services (e.g., antibiotics or long-term home ventilation). In addition, no well-documented criteria for entry into a hospice program have been developed for noncancer pediatric patients. Finally, many palliative care programs have no pediatric expertise.

PROGRAM DEVELOPMENT, EDUCATION, TRAINING, AND RESEARCH IN PALLIATIVE CARE

ATS members should encourage the development of palliative care clinical programs locally in their hospitals and health care organizations. They should give support to those programs and to palliative care educational programs in their teaching institutions and communities. ATS members should become familiar with multiple resources that provide educational materials and workshops related to palliative care for practicing physicians. Two notable examples of resource-rich web sites include the Center to Advance Palliative Care (<http://www.capc.org/>) and the Robert Wood Johnson Foundation–supported Promoting Excellence in End of Life Care (<http://www.promotingexcellence.org/>).

Another example is the list of quality indicators for palliative care in the ICU developed by the Critical Care End-Of-Life Peer Workgroup members also sponsored by the Robert Wood Johnson Foundation (221). The American College of Chest Physicians (ACCP) and the Society of Critical Care Medicine have both published helpful guidelines or position papers related to palliative care and pulmonary disorders and critical illnesses, respectively (127, 222). In addition, the ACCP Ethics Committee has developed a comprehensive Internet resource bibliography that is the appendix to their position paper (222).

On a broader national and international scale, the ATS should work to enhance funding of research that advances best practices in palliative care and improves clinically relevant outcomes. The ATS should work with other organizations of health care professionals with similar commitments in promoting palliative care as evidenced by their publications (3, 14, 31, 127, 222–227) to further promote education, training, and research funding in palliative care.

Finally, enhanced professional education and training and support for increased research funding in palliative care are the agents of change for improved clinical practice in palliative care. The ultimate goal that the ATS and its members should be working toward is to ensure that all patients with advanced respiratory diseases or critical illnesses and their families have access to a level of palliative care that successfully meets their needs.

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