

*Jean T. Abbott and Susan Stone***■ PERSPECTIVE**

The emergency department (ED) frequently is the site of critical turns in people's health. It is the place where sudden, unexpected deaths occur and bad news must be delivered to survivors. The ED also is increasingly a source of care for patients struggling with chronic diseases, persons in the late stages of life-limited illness, and people actively dying. Palliative care is the medical specialty that is focused on end-of-life care, and some of its principles are being incorporated into the model of the clinical practice of emergency medicine.¹ The integration of quality management of the dying patient into emergency medicine practice presents challenges but also offers communication and negotiation skills that can be used by emergency physicians in many aspects of their practice.

Death in the ED differs from death in other areas of the hospital in several ways: (1) deaths often are unexpected; (2) the patient and family and their values often are unknown to ED staff; (3) trust needs to be established rapidly; and (4) management decisions often must be based on limited medical information.² These factors contribute to stress for the emergency care team in managing the first few minutes of a critical illness. The initial response to life-threatening presentations in the ED must be to treat aggressively and resuscitate persons in extremis in the absence of knowledge that this is counter to patient wishes. Much of the core of emergency medicine is devoted to preventing untimely death in people with severe trauma, a "heart too young to die," or another sudden, unexpected life threat. However, when resuscitative and rescue efforts fail, when patient wishes to forgo further interventions become clear, or when the natural end to life comes, the emergency specialist should be prepared to withdraw unwanted treatments, to make the patient comfortable, and to lead the staff and the patient's loved ones in giving the patient's death the meaning and respect it deserves.

■ PRINCIPLES OF DISEASE**Epidemiology of Death and Dying**

One hundred years ago, the predominant pattern of dying was a rapid, precipitous death from infectious diseases and accidents. With modern medical advances, chronic diseases have become part of the last years of life for most people. Three diseases—heart disease, cancer, and stroke—accounted for 60% of deaths in the United States in 2000, whereas uninten-

tional injury accounted for only 4% of deaths.³ Most people live with some limitation in their ability for self-care for 2 to 4 years before they die. Four common trajectories of dying have been described (Fig. 201-1). Sudden death (due to cardiac arrest, trauma, or other sudden event) occurs in only 15% of people. The other trajectories are more common and occur with roughly equal frequency. The predictable decline in patients with "terminal illness" over 6 months or less provided the basis for the hospice concept of managing the dying process for patients with cancer and terminal AIDS. In cases of organ failure (e.g., chronic obstructive pulmonary disease [COPD], heart failure, renal failure, and other progressive serious medical diseases), gradual decline is punctuated by intermittent exacerbations (entry-reentry decline). The time of death for people with these progressive and ultimately fatal diseases is not very predictable, and it often happens rather unexpectedly during an acute deterioration. These patients frequently are treated for acute deterioration in EDs. The fourth trajectory of gradual decline, or "frailty," is associated with some form of dementia in 50% of affected persons and a lingering course that can extend over many years, stressing and wearing out caregivers and other support systems as decline in functional abilities progresses.⁴

Several end-of-life skills are important in the practice of emergency medicine. One of these is to rapidly determine, when possible, the patient's wishes for interventions at a time of crisis. Wishes may be transmitted through written advance directives or direct conversation with a patient or proxy about general values or specific management choices that should guide ED management. Invasive interventions may carry greater risk and be less beneficial near the end of life, and patient choices may include spiritual, economic, and community factors that the emergency physician cannot know without clear, rapid communication and establishment of treatment goals.⁵ Likewise, the patient or the surrogate needs the best information possible about the medical and technical aspects of a critical turn.

Studies have shown that physicians may be overly optimistic regarding prognosis, particularly if they know the patient well. Patients and families need to understand prognosis in order to make decisions about what treatments they want and to plan priorities for their remaining life. Functional status is a strong indicator of a patient's prognosis; decline is associated with increasing likelihood of death, particularly in patients with terminal cancer, for which the dying trajectory tends to be most predictable. For other end-stage diseases, however, validated scales to predict survival are commonly used in palliative care

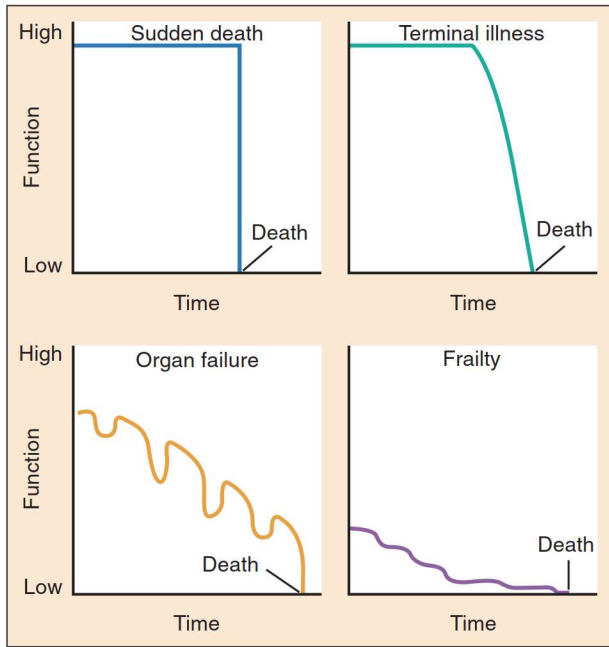


Figure 201-1. Theoretical trajectories of dying. (From Lunney JR, Lynn J, Hogan C: Profiles of older Medicare decedents. *J Am Geriatr Soc* 50:1108, 2002.)

assessments. In the ED setting, rapid assessment of the likely prognosis in a particular case can be accomplished by eliciting information about the patient's ability to perform activities of daily living (ADLs) (i.e., "performance status"). When a patient is not able to spend time out of bed, has reduced appetite, and cannot dress or bathe without assistance, he or she is likely in the last months of life. Such a patient should be eligible for the Medicare hospice benefit. This is the time to involve hospice or palliative care consultants in the ED or during hospital admission. If a patient has already "enrolled" in hospice, it is important to contact the relevant hospice program (accessible around the clock) from the ED before making treatment and disposition decisions.^{1,4,6}

In Western culture, death has become "medicalized" over the last 50 years.⁷ Modern technology often has allowed human control over the timing, site, and pace of dying. Death occurs in an institution for approximately two thirds of people.⁸ Frequently, the dying process is accompanied by invasive diagnostics and medical interventions, even when death is expected and these interventions may increase suffering at the end of life. Death often is seen in modern society as the failure of scientific know-how to keep people alive, rather than the natural end to a life. When death is approached with less fear by both patients and physicians, it is possible to help patients and families make the best of the time remaining to them and to deal with death as the natural ending of life.

Definitions of Death

Biologic definitions of death are currently the subject of considerable debate. Twenty years ago, cardiorespiratory failure defined death, because this was rapidly followed by brain death (which could not be directly measured) caused by failure of oxygenation and perfusion. Death was a distinct biologic event, because all vital systems stopped when one of them failed.

Currently, cardiopulmonary "death" is not necessarily inevitable or irreversible. Ventilation can be maintained externally, and even circulatory support through pharmacologic means or

pump assist can sometimes buttress an inadequate heart. Because of this, a second pathway called "brain death" has been conceptualized. The brain-based determination of death is derived from the irreversible failure of clinical function of the whole brain, manifested by apnea, profound coma with unresponsiveness, and absence of brainstem reflexes.⁹ The most common causes of brain death in adults are traumatic brain injury and subarachnoid hemorrhage. In children, the primary causes are accidental or nonaccidental trauma and asphyxia.¹⁰ Although the consequences of these events are seen with some frequency in the ED, the criteria and irreversibility standards for brain death are seldom met in the first hours after the resuscitative effort. One additional impetus for development of a concept of brain death was the need to define a biologic and ethical boundary to life for procuring organs for transplantation. Declaration of brain death allows harvesting of organs while continuing cardiopulmonary support and organ perfusion and currently accounts for more than 90% of organs harvested from deceased donors.¹¹

In addition, a new protocol designed to increase the pool of organ donors and acknowledge the rarity of complete brain death defines "non-heart-beating" organ donors. Such patients have a dismal prognosis for meaningful survival but will not sustain complete brain death until the time of cardiopulmonary arrest. Pulmonary and cardiac support is withdrawn, death is declared after an interval of several minutes, and organs can be harvested with a minimum of warm-ischemic time.^{10,11} The issues surrounding society's definitions of death are complex, and the struggle with attempts to balance respect for persons and their bodies with the need for transplantable organs is expected to continue.

It is important for physicians to be clear about medical language relating to death. The patient is allowed to "die naturally" when the ventilator and cardiac support are removed. A patient who is declared "brain dead" is dead even though the person may appear to be alive, with pulse and chest rise, to the family. A patient in whom "higher" brain function or cognition is lacking is not considered to be "dead" since "whole brain" death requires failure of the brainstem in addition to cortical function. The confusion over medical definitions of death is made greater by cultural and religious variations in conceptions of death. The different criteria also can lead to suspicion among the public that these definitions are "malleable" and serve physician agendas, rather than respecting the patient. In the ED, cardiopulmonary death is the only death that can be recognized. Use of the term *brain dead* is to be avoided.¹² Brain death requires time and strict criteria to diagnose. However, the emergency physician has an important preparatory role in delineating the status of the patient who is breathing and who has a pulse (perhaps from a successful resuscitation effort) but may ultimately die a brain death. It is very helpful to introduce the family to concepts of prognosis, brain injury, and the further steps that will occur over the succeeding hours that will give physicians and family a clearer picture of whether an injury or insult is fatal or not.

Related Issues

Futility

Physicians are not required to offer treatments that are not beneficial.^{13,14} Unfortunately, information available in the out-of-hospital setting or the ED often is insufficient to make the judgment that a particular patient's condition is "terminal" or that treatment efforts would be "futile." In the case of cardiopulmonary resuscitation (CPR), the emergency physician proceeds with full resuscitative measures unless there is a clear

understanding that this is contrary to the patient's wishes. Although the term "futility" can be a nontechnical expression of a physician's assessment that a proposed intervention is nonbeneficial, the definition is unclear and the term is best avoided in medical discussions of critically ill patients. *Futility* may mean treatment for which no survivors have been reported in similar circumstances in well-designed studies. Other definitions attempt to quantify futility as a less than 1% chance of meaningful survival.¹⁴ Rarely does the emergency physician have information about the patient's overall condition that would allow such a determination, even if the physician were to accept the quantitative definition, which continues to be debated. The term *futility* also can be used qualitatively, implying that "meaningful" life will not result from the proposed intervention. This use of the term is likewise problematic because it is a unilateral judgment about values that a patient and family may or may not hold about what constitutes "life."¹⁴

Quality of Life and a "Good" Death

As technology gives physicians the ability to stabilize patients with serious and noncurable diseases and to manipulate the timing of death, and as people are increasingly exercising their autonomy in deciding how to control their dying, more conversations are occurring about what constitutes a "good death." There is evidence that the quality of life for persons who live into their 80s is better than it was 20 years ago.¹⁵ For that, medicine can be proud. But there are also serious deficiencies in end-of-life care. A majority of people wish to die at home, although nearly 70% die in an institution.⁸ In the famous Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) of more than 9000 patients with life-threatening diseases and a 6-month mortality rate of approximately 50%, only one half of the physicians knew when patients did not want CPR. In addition, families in that study reported that one half of the conscious patients were experiencing significant pain at the time of death.¹⁶

In the ED, resuscitation is performed unless patients' wishes to the contrary are clearly known. Information that CPR, intubation, or other invasive treatments are not desired can be conveyed in the form of written advance directives, a state-authorized "no-CPR" or do-not-attempt-resuscitation (DNAR) directive, clear indications from the person assigned the patient's durable power of attorney for medical affairs, or communication with the patient's physician. Unfortunately, fewer than one fourth of people have prepared advance directives of any type.¹⁷ Evidence of wishes from prior conversations between patients and family or physicians also are uncommon and are rarely available in an emergency situation. The lack of knowledge regarding patients' wishes is particularly worrisome because most people—both patients and surrogates—do not understand what "do everything" means. Family and other surrogates also are poor at predicting care that their loved one would want or not want. In one study comparing patient and surrogate choices about life support, surrogates guessed patient wishes only 59% of the time, little better than chance. The best predictor of accurate knowledge of patient wishes in that study and others was a specific discussion between the patient and surrogates about values and wishes.¹⁸

In patients with severe disabilities, physicians and other health care providers likewise have a difficult time judging quality of life and patient wishes at the end of life. Gerhart and colleagues¹⁹ surveyed emergency care providers' hypothetical attitudes toward quality of life after spinal cord injuries and compared their responses with those of high-level spinal cord injury survivors. Only 18% of providers (e.g., emergency

medical technicians, nurses, and physicians) imagined they would be glad to be alive after a severe spinal cord injury, whereas 92% of survivors were glad to be alive. Eighty-six percent of the quadriplegics felt that their quality of life was average or better, whereas only 17% of emergency care providers predicted they would have a similar view of their quality of life in the same condition. It is important to remember that people's assessment of what is a "good life" changes with time, age, and the realities of illness.

What priorities most commonly occupy patients at the end of life? When death is near, patients have both medical and nonmedical concerns about their dying. Singer and associates²⁰ suggest that five topics predominate in people who are dying: having pain and other symptoms adequately relieved, avoiding inappropriate prolongation of dying, achieving control, relieving others of the burden of their dying, and strengthening personal relationships. The only way to know what is important and what brings joy to patients' lives, particularly in the face of chronic or disabling disease, is by asking patients and those close to them.²¹ Most patients want to know prognostic information, although this preference should be ascertained before such information is given. Realistic hope in the dying patient usually centers on desires for dignity, management of symptoms, and resolution of key relationships.⁵

The Goals of Medicine

Medical authorities and philosophers have long debated the proper goals of medicine. Physicians are most familiar with the goal of "curing" diseases. Ellen Fox reminds us of the complexity of our task in medicine: "Although cure is unquestionably an appropriate goal of medicine, other goals are important as well: promoting health, preventing illness and injury, restoring functional capacity, avoiding premature death, relieving suffering, and caring for those who cannot be cured."²² In Western society, the curative model predominates, and physicians are rewarded for being analytic and rational. The disease, not the person, becomes the object of analysis. Symptoms are clues to diagnosis rather than problems to be treated in and of themselves.²² Fox points out that the palliative care emphasis on "relief of suffering, control of symptoms, and restoration of functional capacity" is really just one end of a spectrum of care that a physician provides. Most patients with life-limiting conditions have reversible elements to their disease process; likewise, even the patient with streptococcal pharyngitis wants symptom relief in addition to cure. So the goal of medicine may be to discern where to place the emphasis for the patient: The curative and the palliative models need to be balanced in varying proportions to optimize care for the individual patient.²²

If the physician is to achieve the goal of relieving suffering, he or she needs to understand the difference between *pain* and *suffering*. Eric Cassell first introduced the idea that a primary goal of medicine was the relief of suffering in a landmark article in the *New England Journal of Medicine* in 1982.²³ Cassell emphasizes that pain happens to bodies, but that suffering happens to persons. Suffering derives from the meaning behind the pain or other symptom. It is unique to each person and can only be understood from the patient's perspective. Suffering is "the state of severe distress associated with events that threaten the intactness of the person."²³ Patients may be in severe distress without any physical pain; others may experience their pain with very little distress. Patients suffer, as Cassell points out, "when they feel out of control, when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is chronic."²³

The World Health Organization defines *palliative care* as “an approach that improves quality of life of patients and their families facing the problem 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, physical, psychosocial, and spiritual.” Palliative care usually consists of an interdisciplinary team of experts that offers various support systems for patients and their physicians near the end of life and can provide inpatient care or consultation, as well as patient management in hospice, in long-term care facilities, and in homes.²⁴ Examples of some acute palliative care interventions that can be applied in the ED are described at the end of this chapter.

Hospice care is the aspect of palliative care for patients who are likely to be within 6 months of death. The hospice movement, which started in England in the 1950s, initially sought to provide a haven of medical care for persons dying of cancer. Home and inpatient hospice programs now exist throughout the United States and are funded through Medicare. If a clinician would “not be surprised if a patient died within six months if the disease ran its natural course,” a hospice evaluation would be appropriate. The patient is “hospice eligible” if hospice judges that the patient’s lifespan is likely to be less than 6 months and Medicare will certify a patient for hospice. Currently, hospice care is provided for an expanded spectrum of end-stage illness, including cancer, organ failure (e.g., heart, liver, kidney), neurologic diseases, and terminal AIDS.^{1,6}

Confusion about eligibility for hospice care contributes to late referrals. Only approximately 20% of patients die while receiving hospice services, including less than one half of patients with cancer. Referrals occur a median of 20 days before death, leaving insufficient time for many of the services that hospice can offer. Although physicians may have difficulty quantifying a patient’s likely lifespan as less than 6 months, prognostic tools exist, and enrollment criteria are based on (1) lack of curative intent as well as (2) progressive decline in function.^{1,6}

The palliative care movement has developed as an expansion of end-of-life care to include not only hospice-eligible patients but also patients with incurable, debilitating chronic noncancer illnesses (e.g., COPD, congestive heart failure) that require symptom control but with a less clear course to death.⁴ Even though the prognosis at any point in time is uncertain, these diseases are not curable, and goals of care may be better served by switching primarily to enhancing the quality of remaining life for affected patients, keeping them as active as possible, and controlling symptoms. These patients are best cared for by palliative care experts. Palliative care consultation offers patients a mechanism to discuss and review management of symptoms and medical interventions that patients desire or wish to avoid in managing their living and dying with severe chronic diseases, with hospice referral when this is desired and possible.

In 2006, the American Board of Emergency Medicine joined with nine other specialty boards to cosponsor the American Board of Palliative Medicine. This alliance has recognized the real need of emergency physicians to address a wide range of interventions and management decisions that are specific to the end of life. The integration of emergency medicine and palliative medicine has stimulated educational efforts to define the scope of ED-based palliative care and curriculum design.¹

Emergency Medicine and End-of-Life Care

Emergency physicians encounter death more frequently than physicians in many other specialties. Resuscitation and resto-

ration to functional living will always be a primary goal of practice and research in this field. However, seriously ill patients treated in the ED often present with important but less emergent complaints. The physician often does have time for deliberation about choices of care through conversations with patients or family. Even when a patient has a severe chronic disease that is not curable, interventions are available that can improve the quality of life. Also, at the end of the course of chronic disease, death is not always unwelcome. Addressing the needs of patients and their families at these critical times requires a complex set of skills. The rest of this chapter is devoted to out-of-hospital end-of-life concerns and to the aspects of end-of-life care that should be part of every emergency physician’s skill set: delivering bad news, death notification, establishing and honoring patient goals of care and advance directives, symptom control, and palliation.

■ SPECIFIC DISORDERS AND CONCERNS

Out-of-Hospital Considerations

Historically, out-of-hospital systems were designed to provide immediate resuscitation, stabilization, and transport of seriously ill or injured persons to EDs. Aggressive and early resuscitation, through CPR, airway management, defibrillation, fluid resuscitation, and trauma stabilization, has resulted in significant benefits and reduced mortality in patients with critical illness for whom survival is time-dependent and potentially reversible causes of illness or injury threaten life.

Emergency medical service (EMS) systems also are called to transport patients who have died or to assist patients who are in extremis but whose death is expected. As well, EMS is activated for patients with acute decompensation of chronic medical conditions such as heart failure or COPD, and for symptoms that occur in the context of terminal conditions when caregivers at the scene cannot cope. Patients at the end of life may desire aggressive interventions for acute exacerbations of chronic illnesses, or they may prefer only supportive care or transportation to achieve a nonviolent end to their life. In emergency situations, it may not be possible to determine the patient’s underlying medical conditions or where the patient is currently on the arc of living and dying. In some situations, a titrated response is possible, and noninvasive supportive care (such as positioning, suctioning, oxygen, or mask ventilation) during transport can buy time until further evaluation in the ED can clarify the patient’s goals of care.

Field Death Pronouncement

Several physiologic circumstances have been identified in which out-of-hospital providers should not initiate or continue CPR because of uniformly poor outcomes and no benefit from intervention. American College of Emergency Physicians (ACEP) and American Heart Association (AHA) guidelines state that CPR should not be initiated in patients with nontraumatic cardiac arrest and signs of irreversible death, such as decapitation, dependent lividity, or rigor mortis.^{25,26} ACEP policy recommends discontinuing resuscitation in the out-of-hospital setting if the patient remains in asystole or wide-complex pulseless bradycardia after a trial of adequate resuscitation, including CPR, intubation, medications, defibrillation, and pacing.²⁵ The National Association of Emergency Medical Services Physicians (NAEMSP) supports this approach. Termination of resuscitation efforts in nontraumatic cardiac arrest patients should be made in agreement with online medical direction and predicated on access to witnesses

or family, provider comfort with death notification and grief counseling, and safety and logistical considerations.²⁷ If questions arise about resuscitation, CPR and ACLS measures should be initiated and the patient transported. It can be easier and ethically more sound to withdraw care in the ED than to withhold care at the scene.^{28,29}

Honoring Advance Directives to Withhold Resuscitation

There is an increasing movement to develop policies that allow EMS providers to honor patient wishes not to receive interventions at the end of life, even when resuscitative measures might succeed. The 1991 Patient Self-Determination Act recognized that health care providers must honor informed decisions by patients who wish not to be resuscitated. Most providers have experienced situations in which attempted resuscitation is later determined to have been against the patient's wishes. In a Seattle review of out-of-hospital cardiac arrests in which all patients received full resuscitative efforts, 7% of patients were ultimately determined to have had "unwanted" resuscitation, and 25% of patients experienced resuscitation in the context of severe chronic disease.³⁰

Identifying valid directives to withhold CPR or intubation is problematic for out-of-hospital providers. Information about patient wishes and underlying diseases is frequently confusing, DNAR requests may be difficult to validate, and rapid intervention is frequently required. Many state-based programs have been developed to try to identify patients requesting no CPR through bracelets or official registered forms on their persons, allowing supportive care but no resuscitative efforts if the patient experiences cardiorespiratory arrest.^{31,32} The ACEP has recognized the difficulties with respecting patients' desires to forgo resuscitative efforts and issued guidelines for developing out-of-hospital DNAR policies.³³ In some states, statutory authority for EMS personnel to honor DNAR orders has been developed, but provisions vary widely. Written statements or identification bracelets must be consistent, easily recognizable, legally acceptable in that state, and clear about what resuscitative measures the patient would and would not wish to receive.³⁴ A family member or friend who is present at the scene and has valid medical durable power of attorney for health care documentation also may make decisions to initiate or refuse treatment measures on behalf of the patient. The most widespread initiative to provide out-of-hospital written directives to limit life-sustaining care is the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program in Oregon, which uses a clearly recognizable pink form posted on the home medicine cabinet to identify a range of patient wishes near the end of life. This program is being adopted in other states.³⁵

Several concerns about the validity of written advance directives persist: Patient wishes can change over time, nonstandard forms of DNAR requests (such as "medical alert" bracelets, notes on prescription pads, or tattoos) cannot be recognized, and a theoretical concern is that relatives or bystanders may not be accurately relaying the wishes of the patient.³⁶ In one survey of emergency medical technicians (EMTs), more than 20% had experienced ethical conflicts over the execution, honoring, or validity of DNAR wishes or orders at the scene.³⁷ On the other hand, most out-of-hospital providers agree that it is appropriate to withhold resuscitative attempts in terminally ill patients.³⁸

Honoring Verbal Requests to Withhold Interventions in the Field

In most EMS systems, verbal requests to limit resuscitation are not accepted, because of the concern that out-of-hospital

providers cannot confirm that these represent the patient's current wishes.³⁸ In view of the incidence of "unwanted" resuscitation, King County in Washington State has introduced a new protocol of allowing EMTs and paramedics to withhold resuscitation in situations in which family or caregivers indicate that no resuscitation is desired and the patient has a terminal condition (i.e., death is expected and the patient is under a physician's care). EMS personnel do not need direct physician approval to forgo resuscitation. The incidence of non-initiation of resuscitation increased from 5.9% to 11.8% in EMS services adopting the expanded standards. Other regions are testing this protocol, which must be accompanied by population buy-in and legal protections against errors. No adverse consequences have resulted so far, although wrongful death suits remain a theoretical concern. EMS provider comfort level with expanded standards has been high.^{39,40}

Attempts to honor patients' requests at the end of life should be a goal for both out-of-hospital and ED personnel. Out-of-hospital providers need to be aware of the standards for honoring DNAR requests in their respective states.^{32,33} In addition, providers need to be knowledgeable about types of advance directives and surrogate laws for the state in which they practice. In most EMS systems, field pronouncement of death requires physician base-station consultation. Unilateral EMS provider judgment not to start resuscitation has been reported, but snap judgments that patients are "terminal" are not necessarily accurate and should not be the sole criterion for withholding interventions.⁴⁰

Supportive Out-of-Hospital Treatments near the End of Life

Patients at the end of life can benefit from supportive or palliative treatments at the scene and during transport. Positioning, suctioning, and administration of pain medication and oxygen for dyspnea all may be important to maximize patient comfort. Before an intravenous line is established, EMS personnel should ask the patient's permission to do so, because even the pain associated with insertion of the line may be counter to patient wishes. If the patient is being transferred from a long-term care facility to the ED, all care instructions, CPR directives, advance directives, and contact names and numbers are carried with the patient, because these will help guide continuing care in the ED.

Management of Hospice Patients

Although hospice care protocols are written to avoid activating the EMS system, scenarios routinely arise in which the patient is in the dying process and family members panic or cannot handle some terminal situation. There may be anxiety in the last hours of life, a feeling of helplessness, or concern for the patient's perceived or real suffering. There may also be disagreement between family members about the best way to help the dying person. The family may request death pronouncement at home, but out-of-hospital providers should involve medical control to affirm this if necessary. Transport and comfort care should always be offered if the family wishes or if the setting appears uncomfortable for those involved in the dying process.

Special Issues in the Out-of-Hospital Setting

Suicide

Although respect for patient wishes is a core value in today's society, suicidal patients frequently are impaired. Modern belief holds that suicidal depression usually is treatable.⁴¹ Patients near death from suicide should receive full resuscita-

tive efforts unless there is a specific exception, such as physician-assisted suicide in Oregon, with formal documentation and an alternative protocol for out-of-hospital providers to follow. If the patient is dead and meets criteria for not starting resuscitation, the coroner or medical examiner should be notified. The scene needs to be protected to allow an investigation, if needed, because the history is rarely clear or complete during the emergency call. Decisions should be made after consultation with the medical control physician.

Pregnancy

In the case of a pregnant trauma patient, fetal survival is best ensured by aggressive care of the mother. Some unborn babies will die despite major or minor maternal injuries, but field rescue of the baby after the mother is pronounced dead is rarely appropriate and not advised without physician control. A pulseless woman in the third trimester of pregnancy should be transported to the nearest ED capable of performing a perimortem cesarean section for attempted resuscitation of both mother and baby.

Pediatric Deaths: Sudden Infant Death Syndrome

Death of a child is among the most difficult of human experiences. With pediatric deaths, regardless of the cause, a complete resuscitation regimen, including transport, is appropriate. Child abuse should always be considered as a possibility. Transport may be done more for the psychological benefit to the family than in the hope of survival. As sudden infant death syndrome has become more widely recognized and understood by the public, some families wish to avoid “extraordinary measures” of resuscitation once the diagnosis is recognized and the outcome is inevitable. Many desire to be with their infant in his or her last moments. Out-of-hospital personnel should respond to these requests with understanding and compassion; however, the site of pronouncement of death should be in the hospital for almost all pediatric deaths.

Death in the Emergency Department

Delivering Bad News

Every emergency physician will be required to communicate bad news to patients, family members, and caregivers. The manner in which this is done may make a difference in the course of subsequent grief and coping.⁴² Compassionate communication can strengthen trust and foster collaboration in planning between the medical team and the patient and family. Emergency physicians have particular challenges in delivering bad news in that they do not have ongoing relationships with their patients and because the bad news may be abrupt and unexpected. However, the newness of relationships in the ED also may allow a more frank and open conversation about a patient's illness, prognosis, and wishes, particularly when the sudden downturn precipitating an ED visit is part of a severe chronic disease.^{43,44}

The goal of skillfully breaking bad news is to reduce the severity and the duration of stress and encourage engagement of coping mechanisms, both for physicians and for patients and their caregivers. According to a theoretical construct proposed by Ptacek and Eberhardt, staff and physician stress often peaks just before transmission of the bad news, whereas patient or caregiver stress emerges after delivery of the bad news.⁴⁵ Physician stress correlates directly with the severity of the news, as well as any responsibility for the outcome that the medical team may feel, and inversely with the amount of experience delivering bad news. Many providers feel inadequately prepared for death disclosure or delivery of bad news

about a new diagnosis or turn in health status for a patient with a life-limiting illness.^{46,47} Skilled resuscitation, diagnosis, and treatment of patients are key to keeping the external sources of provider stress manageable. Reduction of the anticipatory stress of delivering bad news may occur with use of a structured protocol, practice, planning the physical and social aspects of the setting, and other methods of enhancing experience.⁴⁵ Experience with revealing medical error or other aspects of responsibility for outcomes has not been well studied.

Several initiatives to improve delivery of bad news have been introduced. These encourage training in communication skills, explicit instructional sessions, role playing, use of standardized patients, and observation of colleagues who are comfortable with this aspect of patient care.^{2,44,48,49} Little research has examined the best methods of increasing patient and family satisfaction with this important aspect of patient care.⁴⁷ Physician coping mechanisms may or may not be helpful to patients, but much still needs to be learned about how to be most helpful in this difficult time for patients. If the physician develops patterns to insulate himself or herself from stress that involve lack of sensitivity to the receiver's needs, he or she may cause greater stress to the receiver by use of vague language, delegation to others, or delaying or rapidly disengaging from the encounter.^{43,45}

For the patient and family, the ED typically is the place where bad news is sudden and unexpected. This can certainly make the strain even more severe and overwhelming. Trust between ED caregivers and critically ill patients or their survivors, who were unlinked strangers just a few minutes before, does not come easily. Whereas providers may focus on the content of the information they must convey, patients focus more on the process.⁴² Surveys of patients and families have identified the following factors as desirable for receiving bad news: privacy when receiving news, the ability to express emotions safely, information that is free of unclear language or medical jargon, empathic and caring attitude, allowance for hope, and ability to ask for and receive good medical information.⁴⁵ One technique for encouraging provider empathy is to structure a conversation according to the NURSE mnemonic: The provider *n*ames the emotions observed, *c*onfirms whether this *u*nderstanding of the receivers' feelings is correct, *e*xpresses verbal and nonverbal *r*espect for the receivers' feelings, *s*upports them through expressions of concern, *u*nderstanding and willingness to help, and *e*xplores additional concerns.⁴³

The steps listed in **Box 201-1** and explained in detail in the following paragraphs are designed to shape the interaction to facilitate the patient's or survivors' work through this stress and movement toward coping. This six-step template was adapted from Buckman's work and adopted also by the Educa-

BOX 201-1 DELIVERING BAD NEWS

The steps listed below can help you think critically about how best to communicate at a time when stress is high. See the text for details about each step.

- Step 1: Physician preparation
- Step 2: What does the patient know?
- Step 3: How much does the patient want to know?
- Step 4: Sharing the information
- Step 5: Responding to feelings
- Step 6: Planning and follow-up

Adapted from Buckman R: How to Break Bad News: A Guide for Health Care Professions. Baltimore, Johns Hopkins University Press, 1992.

tion for Physicians on End-of-Life Care (EPEC) teaching project.^{6,43,50} Key to moving through the process of delivering bad news is the “ask-tell-ask” interactional framework in which the physician is guided by the patient and family in regard to the pace, amount of information, and style that will work best to let them feel and hear what they need.⁴³

Step 1: Physician Preparation

Before the physician interacts with the family or patient, preparatory steps are important. These include confirming all medical facts of the case, clarifying the name of the patient, being aware of any uncertainty about the patient’s identity, and knowing the relationships between the patient and those with whom one will be talking. The physical site for the conversation should be quiet and allow for private exchange of information and safe expression of emotions. Sometimes this is difficult in the ED, but a family room or other quiet area usually is available to use. If the patient can be included, moving the patient to a private area may be possible, or key members of the patient’s support group can be gathered around the bedside.

Physicians should identify themselves and their position, directly address the patient (when present) or the key persons receiving the news, and refer to the patient by name. Before beginning the discussion, the physician should sit down close to the patient, make direct eye contact with the patient (or close relatives), and be physically and mentally open to their concerns and needs.

Step 2: What Does the Patient Know?

It is useful to know what the patient or family understands before the delivery of news. An introductory question can be used, such as “What do you understand about your illness?” or “What have you been told happened to [name of spouse/sibling/other]?” This information helps the physician to see the event as the patient and family are seeing it thus far and to adjust the mode of delivering this news to their understanding. In the ED, when patients and families may expect “the worst,” this tactic can be perceived as delaying. In a less critical situation, however, asking about previous testing, conversations with physicians, and understanding of the patient’s illness can help the subsequently delivered information fit into the patient’s perspective and expectations.

Step 3: How Much Does the Patient Want to Know?

Every patient has the right to accept or refuse medical treatments based on informed consent. This also is true for information. Most patients appreciate the direct, simple truth about their condition and prognosis. There will, however, be some patients who do not want to receive the information that the provider is about to deliver. These patients may wish to designate a friend or family member to represent them. This choice should be respected if possible. It is important to remember that people process information and make decisions in many different ways, based on their own cultural and religious views and previous experiences. The Western principles of truth-telling and individual decision-making are cultural values and may be foreign to some families and communities.⁴³

Sometimes the family learns of a diagnosis and prognosis before the patient does and requests that the patient not be told. The physician’s alliance with both patient and family is important, although responsibility to the patient is primary. Physicians should explore why families do not want the patient told bad news: Is it a cultural tradition? Are they afraid of what harm it will cause the patient? Have they had previous bad experiences? The physician is still required to ask the patient how much he or she would like to know. Sometimes it is

helpful for the physician to invite family members to be present for this discussion. This important information should be learned or asked using an independent interpreter (rather than a family member) if the patient does not speak the same language as the physician.

Step 4: Sharing the Information

In general, patients and families want to know bad news in a timely fashion.⁴⁵ This is sometimes uncomfortable, particularly when important information may not yet be known—a common occurrence in the ED. At the very least, it is recommended that patients and family be given a preparatory warning after introductions, such as “I am afraid I have some bad news.” In delivering the information, it is important to use simple nonmedical language and to make sure that the patient comprehends the information. Space should be allowed for patients and family to absorb the news, to react, and to begin to ask questions. The patient and family stress response will lag behind that of the physician, because the physician has had at least a few minutes to adjust to the current situation, but the family has not.⁴⁵

Although using the phrase “I’m sorry” can be a reflection of empathy, it can be misinterpreted. Some physicians have suggested using expressions such as “I wish things were different” instead, as a sign of solidarity.⁵¹ Providing survival data when the discussion is about a severe or terminal diagnosis may be better reserved for a later time, but it is important to know how to access this information. The physician’s message should include some realistic hope and also reassurance that the patient will not be abandoned by the medical care team, even when cure or survival is unlikely.

Step 5: Responding to Feelings

The reaction to bad news often is unpredictable and can range from sadness to rage. It is important for ED clinicians to be aware of the wide varieties of responses that will be seen. The patient and family should be allowed to express their feelings, even if this is uncomfortable. Acute grief is painful but important. The emergency physician must be prepared both for persons who turn inward and those who rage outwardly. Practicing and reflecting on these situations will allow the physician to deliver bad news and support the survivors. In the ED, it often is helpful to invite members of the team into this meeting (e.g., social worker, nurse, or chaplain) who will not be pulled away to other care needs, can provide emotional support, and can help the family navigate through the early stages of grief, as well as the technical details necessary.

Step 6: Planning and Follow-up

The ED is an entry point into the hospital if the patient survives. Family members should be encouraged to stay with the patient, particularly if it is possible that the end of life is near. Prognosticating may be difficult, in view of the limited information that can be obtained in the initial assessment. When initial management has stabilized a patient with an acute, critical turn, it may be appropriate to look ahead to decompensation that could occur later in the hospitalization. Some experts have suggested a “hope for the best and prepare for the worst” kind of conversation.⁵² The physician can share the success, however transient, of any ED interventions and the positive news and hope that this provides. At the same time, he or she can prepare the patient or family for the possibility of later setbacks and have them consider what actions may or may not be appropriate if “the worst” happens.⁵ If the patient does not have written advance directives, the emergency physician can facilitate the conversation, initiate written wishes, or at least advise the patient that the admitting physician will need to

have an early conversation about future plans and goals for the patient. The physician should assure the patient and family of what the next steps will be, including hospital admission or discharge from the ED, consultation with specialists, support group referral, or chaplain services. It is important to make sure that the patient and family do not feel abandoned. Even when dying is near, providing active care and comfort is a major task for the medical team.

Death Notification

One of the most difficult forms of “bad news” to deliver is death notification. Emergency physicians need to practice this skill specifically (Box 201-2). In general, the format can follow the guidelines for delivering bad news from Box 201-1. With death notification, however, diagnosis is certain, and actions required are more definite. Families do not have time to adjust or think about options, and the message is more stark.

Death notification usually occurs after an unsuccessful resuscitation attempt. Physicians should be sure they are presentable and wear a name badge. If possible, it is recommended to ascertain beforehand the names of the persons who will receive the notification, their relation to the patient, and what they know about the patient’s condition. Other members of the medical team may have met them already and can be a source of background information. Sometimes the family initiated the 911 call and recognized that their loved one had died at that time. On the other hand, a family summoned to the ED may have absolutely no idea that they are about to be informed that their loved one has been critically injured or has died. For this reason, it is useful to have a nurse or colleague advise the family briefly about the general nature of the event and the status of resuscitation as soon as possible. When giving the news, physicians should use clear “dead” or “died” language to be sure that there are no misunderstandings about the outcome being conveyed. Survivors should be assured, if at all possible, that their responses to the emergency were appropriate, that the medical care team did all that was possible, and that the victim did not experience unnecessary discomfort. Appreciation of their presence in the ED, or even in the resuscitation room, also is important to emphasize.

Phone Notification

If the first contact with survivors of an ED death is by telephone, it is recommended that the survivor be told to come to

the ED if at all possible.² Although family members may ask or even demand to know if death has occurred, allowing some time for assimilation of news by delaying information about the final outcome may be more helpful for the grieving process.⁵³ Nonphysician staff are particularly useful to summon survivors and can inform the relative that the patient has been involved in an accident or is seriously ill and that things are not going well.

When the notification is to somebody who is more than an hour away or otherwise unable to physically come to the ED to receive the bad news, it must be given by phone. The physician should (1) make sure that the relative has someone present in the room if possible, (2) ask the relative to be seated, and (3) name the person involved. It is best to start with brief information about the circumstances and provide a warning that bad news is coming before breaking it to them. Even a few seconds of preparation in these circumstances can serve to partially attenuate the acute psychic pain. As indicated by the perceived response, the physician may need to ask, “Are you able to talk for a few minutes?” Some individuals may be unwilling or unable to continue after they hear the initial news, and they should be given an “out,” but a definite time to reconnect must be established (e.g., 10 to 15 minutes).^{2,53} Long-distance loved ones cannot view the body to facilitate confirmation and acceptance and inevitably have questions not addressed in the initial conversation. The relative should be given a telephone contact of someone who actually provided care for the patient. Otherwise, if a relative calls back, a lack of information about what transpired on another shift may cause frustration or even feed the person’s denial or false hope that this tragedy has not happened.

Viewing the Body

At some time immediately after death, an opportunity to view the body should be offered to the family. This may be the first exposure to the body for the survivors and can make concrete what has up to now been only abstract and unreal. Although a majority of survivors find viewing the body helpful, no attempt should be made to force this procedure on survivors, and they should not be made to feel that it is wrong not to view the body. If viewing is presented as an alternative and an aid in the mourning process, it is usually considered helpful.

If possible, the body should be moved to a small room, preferably away from the main treatment area. This not only ensures privacy but also makes the family feel more at ease. Family members should be warned of what to expect, such as color and temperature changes, injuries or invasive pre-mortem procedures, and the presence of endotracheal and intravenous tubing. With sufficient preparation, most people are not shocked by the deceased person’s appearance.

A staff member should remain in the room or within close range at all times. This contact allows the staff to help make the viewing an important and supportive aspect of the grieving process. At times, it may be necessary to touch the body to assure the family that this is appropriate. Survivors should be allowed to remain with the body for as long as seems appropriate. When gross disfigurement has occurred, the viewers should be warned about this, and the body should be discreetly covered where necessary. Survivors may even find that helping to clean and prepare the body (particularly with a pediatric death), holding a loved one, or preparing for transport may allow a final expression of caring.

Family Presence during Resuscitation

It is increasingly common to invite a close family member to attend resuscitation attempts. Offering this option has been endorsed in the 2005 AHA Emergency Cardiac Care guide-

BOX 201-2 ELEMENTS OF AN EMPATHIC DEATH DISCLOSURE

- Introduce self/role.
- Sit down.
- Assume comfortable communication distance.
- Use acceptable tone/rate of speech.
- Make eye contact.
- Maintain open posture.
- Give advance warning of bad news.
- Deliver news of death clearly (use “dead”/“died”).
- Tolerate survivor’s reaction.
- Explain medical attempts to “save” patient.
- Use no medical jargon; use language that is clear and easily understood.
- Offer viewing of deceased.
- Offer to be available to survivor.
- Conclude appropriately.

From Quest TE, et al: The use of standardized patients within a procedural competency model to teach death disclosure. *Acad Emerg Med* 9:1326, 2002.

lines²⁶ and by the EPEC curriculum.¹ Emerging evidence suggests that presence during procedures and resuscitations may be beneficial to surviving patients and family members who choose to stay. Less consensus exists among providers, and they often express discomfort with the concept.⁵⁴ If resuscitation is to be witnessed by a family member, a staff member who is dedicated to supporting that person should always be present.

Sedation for Survivors

Requests for tranquilizers, sedatives, sleeping medications, or just “something for the nerves” are common. The grieving process is important and difficult work. Prescriptions for a light sedative for a few days may be appropriate but usually require direct evaluation of the survivor by the physician. The survivor needs to know that the psychic pain is to be expected and where to turn for help and support during this difficult time.²

Autopsy and Closure

The “event” of death notification should be concluded with a physician expression of condolences and concern for the survivors—all physicians can honestly express the wish that they did not need to be the bearer of such life-changing news.⁵¹ In many hospitals, chaplains or social workers or nurses are trained in informing the family about arrangements for the body, including notification of a mortician and interface with a coroner, which is not uncommon in ED deaths. If the ED practitioner desires an autopsy, this is an appropriate time to request permission. Autopsies not only are valuable in contributing to the advancement of knowledge, education, quality assurance, and public education but also can be indispensable in minimizing guilt and blame associated with the death of a loved one. Additionally, findings of unknown pathology may be important for family members if there is a genetic factor.

Consent for Procedures on the Newly Dead

The use of the newly dead to teach procedural skills is currently being debated in the medical community. It is important to educate residents in procedural skills, and emergency physicians often need to review procedures that they perform very rarely. The newly dead have been a silent source of learning in the past. Although some evidence indicates that the public generally supports the practice, serious questions about respect for bodies and the need for informed consent also have been raised.⁵⁵ The American Medical Association recently published a policy affirming that consent should be obtained from survivors.⁵⁶ In emergency medicine, it has been argued that obtaining consent is not feasible: Finding authorizing survivors is difficult, voluntary consent is questionable in a stressful situation of sudden death, and time pressures require early resumption of other ED activities. Some authorities have tried to distinguish between invasive or major procedures (e.g., thoracotomy, peritoneal lavage, venous cutdown) and minor or less invasive ones, such as intubation. The current ACEP position is that informed consent must be obtained from relatives before any procedures are performed on the newly dead. The performance of involuntary, nontherapeutic invasive procedures, including those performed during CPR, should be regarded as an ethically unacceptable departure from a standard of care that emphasizes the centrality of respect for the patient, the patient’s well-being, and the requirement for informed consent.⁵⁶⁻⁵⁸

Grieving and Bereavement

Grief is defined as emotional pain induced by sorrow and loss. It is associated with a constellation of symptoms and behaviors

that are influenced by cultural and personal issues, other current life stressors, and the relationship of the survivor to the deceased. Survivors are often the “patients” toward whom the emergency physician needs to direct his or her best expertise in the case of an ED death. Giving bad news and sharing in the beginnings of the grief response are among the most difficult situations physicians need to handle. Patients and loved ones also experience grief responses when a sudden medical crisis brings a patient to the ED and is seen as a threat to life and wellness. *Bereavement* is the situation of having experienced the death of a significant person in a survivor’s life.⁵⁹ It is important to understand the range of what can be expected acutely, and to be able to identify those survivors at risk for complicated grief. Recognition of survivors at higher risk for complicated grief may help stimulate referral and decrease the risk of development of major depression and other stress disorders.⁴²

The initial response to any death, whether expected or unexpected, is acute psychic pain that is associated with shock, disbelief, numbness, and inability to process further information.² Some persons display anger, loud screaming, crying, and occasionally acute anxiety or syncope. Alternatively, the physician may observe a false calm or no reaction. In addition to the initial emotional shock, other, more cognitive reactions, including denial, guilt, sadness, fear, shame, and anger, may be exhibited. Reactions may be based on the cultural and personal backgrounds of the survivors. This wide range of expressions is normal and expected; there is no “right” way to grieve. In the ED, outward reactions will in many instances be perceived as problematic and disruptive. The goal of the emergency physician is to help as much as survivors allow and to avoid taking personally the survivors’ anger, resentment, and other outward emotional expressions, even if directed at ED staff.² Likewise, it is important to accept that some survivors will leave the ED still in denial and not emoting; they may need and want to postpone their grieving for what they feel is a more appropriate setting.

A variety of delayed emotional and physical symptoms can emerge as the survivor assimilates the reality that death has occurred. Physical symptoms include fatigue, anorexia, palpitations, hyperventilation, restlessness, headache, irritability, and insomnia. Emotional symptoms, in addition to guilt, anger, depression, and denial, include difficulty in concentrating, lack of organization, fear, and preoccupation with the deceased. These grief responses are to be expected. Special memories can trigger the grief response after the initial grieving period, and the memory and emotional pain of the loss may last a lifetime. Symptoms of grief, including psychic pain, numbness, intrusive thoughts, and disorganization, continue to occur during the recovery of most survivors, gradually becoming attenuated but recurring over months or years without clear “stages.”^{59,60}

Risk factors for difficulty navigating the work of grieving can sometimes be recognized, even in the ED. Such factors include death of a child or long-term spouse, social isolation of the survivor, and a very dependent or conflicted relationship with the deceased.² The physician may be able to alert the survivors’ primary physician or support staff, or even the at-risk survivor directly, that ongoing work will be required to see this grief to resolution.

Grief Reactions in Staff

The impact of death in emergency medicine is significant for the staff, including physicians. Stressors that exacerbate grief and the emotional impact of ED work include exposure to premature deaths of young people or to the injuries of victims of random and senseless violence, care for those who may have

caused an accident or injury, and care that must be delivered rapidly on the basis of scant knowledge, but which other professionals can later second-guess. The ED clinician also carries a personal history that may include circumstances that make particular emergencies hit a raw nerve of which colleagues may not be aware, as, for instance, an alcoholic parent, a sibling who committed suicide, or a friend killed by a drunk driver.

Because of the sometimes overwhelming contact with death and dying in the ED, it is important to have intradepartmental mechanisms in place for helping address staff grief responses. At morbidity and mortality conferences, some discussion should be allotted to ethical, sociologic, and emotional sequelae of the cases being presented. The morbidity and mortality analysis process itself helps “make sense” of difficult situations and is part of the grieving process for health care practitioners. Case conferences, including a full range of medical personnel, chaplains, and social workers, are useful to articulate and share sadness, anger toward patients, and other emotional and cognitive work required for healing. This is particularly important to offer staff after major community disasters. Although for some people denial is a positive coping mechanism, for others the opportunity to share and express emotions is needed to begin to move forward and resume the work of caring for patients.⁵⁹

Palliative Care in the Emergency Department

Providing quality palliative end-of-life care is important in the ED. Education in Palliative and End-of-Life Care for Emergency Medicine (EPEC-EM) is a curriculum specifically designed to provide emergency clinicians with the information and skills to practice ED-based palliative care.¹ The evidence that we do not know what others want for themselves or family members at the time of critical illness is discussed in the first part of this chapter. In the case of a cardiopulmonary arrest or major trauma resuscitation, attempts at curative intervention are always indicated unless the emergency physician has clear instructions from the patient or surrogate to the contrary. In less critical situations, however, guidance about the goals and direction of ED care is needed, and management strategies should be “patient-centered.”¹ Although some would argue that it is time-consuming and unnecessary for emergency physicians to develop a nuanced approach to end-of-life care, it is no longer appropriate to provide all patients with maximal medical treatment and to “let the admitting doctors sort out the other issues.” Comfort and optimal quality of life become a higher priority for many patients with severe chronic diseases, such as cancer, COPD, heart failure, renal insufficiency, or dementia. Some of the procedures that are normal interventions in emergency care may not be appropriate in this subset of patients.

Establishing Goals of Care

The primary skill that emergency physicians must have in managing patients near the end of life is the ability to communicate. In a true emergency, such conversations must take a back seat to resuscitation interventions. In many patients, however, it is not imperative to treat before discussion or diagnosis. In the ED setting, several useful methods can be to establish what treatments patients want near the end of life.

Reviewing and Honoring Advance Directives

Written advance directives can help guide treatment decisions in the ED as well as on hospital admission. Although such

documents often do not foresee the particular medical emergency that precipitates an ED visit, their existence indicates that a patient has considered how medical care should or should not look. Advance directives may indicate that aggressive lifesaving interventions are desired, or that a patient is in the dying process and wants to be kept comfortable. People’s wishes change over time, and written advance directive requests should be reconfirmed at the time of an acute crisis. The emergency physician should be well versed in the technicalities of the various forms of written legal advance directives that exist.

Processing Verbal Requests

Verbal requests to titrate or limit procedures can be made by the patient or the patient’s surrogate. The emergency physician should determine whether the patient has decision-making capacity and, if such capacity is lacking, who will be the spokesperson for the patient. Invasive tests and procedures may not be performed on patients without their consent. In emergency situations, physicians rely on the “emergency exception” to informed consent and act to preserve life, or at least to buy time to consider options. Many situations in the ED, however, do not require immediate intervention, or they allow for a less invasive alternative (such as mask ventilation for respiratory failure) while the patient’s goals are discussed.

Initiating a Conversation on Goals of Care

Emergency physicians see many sick patients who do not have written advance directives but are temporarily stable enough to have meaningful conversations about their needs and goals, their perception of where they are in the course of their disease, whether they wish to cure an intercurrent problem, which symptoms require management, and how much effort they wish to have undertaken if resuscitation is needed to preserve their life. Patients with seemingly lethal conditions may be aggressively pursuing curative or at least disease-modifying options, whereas the heavy burden of suffering other patients are experiencing may not be obvious until they are asked specifically about their illness. The only way to determine the patient’s needs is to ask.

Questions that can be useful for initiating this conversation are listed in [Table 201-1](#). Pulling up a chair, sitting with the patient and family, and spending a few minutes clarifying the patient’s values and view of the present and of the future may make a big difference in designing the patient’s care and disposition.

It is useful to start the “goals of care” conversation with a global understanding of the patient’s illness, values, fears, and expectations. This makes the “procedures” part of the conversation flow naturally. The physician can then suggest to the patient and family what treatments will be useful (or not) in the context of overall goals and values. Antibiotics may be appropriate for an acute pneumonia, but they may not be indicated in a patient with advanced dementia who has been bedridden and unable to communicate for several years. Intubation will be acceptable to some patients with COPD, whereas others who have struggled on the ventilator before may not wish to experience that discomfort again. Intravenous hydration is useful to correct dehydration but may merely increase secretions in the patient who is actively dying. All of these interventions need to be considered in the context of caring for the patient and enabling them to achieve their goals.

Initiating Advance Directives and DNAR Orders

Several authors have suggested that the ED may be an important link in initiating advance directives because it often is the

Table 201-1 Representative Questions for Initiating the Discussion about End-of-Life Issues

DOMAIN	REPRESENTATIVE QUESTIONS*
Goals	Given the severity of your illness, what is most important for you to achieve? How do you think about balancing quality of life with length of life in terms of your treatment? What are your most important hopes? What are your biggest fears?
Values	What makes life most worth living for you? Would there be any circumstances under which you would find life not worth living? What do you consider your quality of life to be like now? Have you seen or been with someone who had a particularly good death or particularly difficult death?
Advance directives	If with future progression of your illness you are not able to speak for yourself, who would be best able to represent your views and values? (health care proxy) Have you given any thought to what kinds of treatment you would want (and not want) if you become unable to speak for yourself in the future? (living will)
Do-not-attempt-resuscitation order	If you were to die suddenly, that is, if you stopped breathing or your heart stopped, we could try to revive you by using cardiopulmonary resuscitation (CPR). Are you familiar with CPR? Have you given thought as to whether you would want it? Given the severity of your illness, CPR would in all likelihood be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?
Palliative care: pain and other symptoms	Have you ever heard of hospice (palliative care)? What has been your experience with it? Tell me about your pain. Can you rate it on a scale of 1 to 10? What is your breathing like when you feel at your best? How about when you are having trouble?
Palliative care: “unfinished business”	If you were to die sooner rather than later, what would be left undone? How is your family handling your illness? What are their reactions? Has religion been an important part of your life? Are there any spiritual issues you are concerned about at this point?

*It is important to give the patient an opportunity to respond to each question. Follow-up questions and responses should be based on careful listening to the patient, with use of the patient's own words whenever possible.

From Quill JE: Initiating end-of-life discussions with seriously ill patients: Addressing the “elephant in the room.” *JAMA* 284:2502, 2000.

patient's portal of access to the hospital.⁶¹ Wrenn and Brody described a small series of patients for whom the emergency physician wrote DNAR orders on admission.⁶² Balentine and colleagues described another series in which few negative responses were obtained from the families who were approached.⁶³ Both papers point out that fragmentation in health care may mean that previous wishes are not translated into hospitalized settings, and that the ED may be the best place to establish or renew documentation of the patient's wish to forgo resuscitation at the outset of the hospitalization.⁵

Treating Symptoms Requiring Palliation

When a patient is suffering from a disease that is not curable, he or she may still want a variety of medical interventions as part of care: antibiotics for intercurrent infections, drainage of effusions that cause shortness of breath, wound care for decubitus ulcers, decompression of bowel obstructions, and aggressive pain management. On the other hand, the best way of maximizing patient function and quality of remaining life may require de-emphasizing diagnosis and primarily addressing symptoms. The most common reason that patients with end-stage illness seek emergency care is for control of intolerable symptoms such as nausea, vomiting, dyspnea, severe constipation or diarrhea, and pain (Box 201-3).

The emergency physician may encounter several unfamiliar concepts when attempting to treat symptoms in frail persons near the end of life. One of the more “foreign” concepts to most emergency physicians is the treatment of symptoms without diagnosing the underlying cause, even though this often is the appropriate option. Additionally, concerns regarding “drugging” patients or overtreating them, although common, are mostly unwarranted. Nevertheless, worry about unintended consequences may lead to underdosing medica-

BOX 201-3 PALLIATIVE MEDICAL TREATMENT OPTIONS TO ENHANCE QUALITY OF LIFE

- Pain control
- Control of fluid and electrolyte imbalance
- Nausea/vomiting/constipation management
- Radiation therapy for bone pain, cord compression, hemorrhage from tumors
- Drainage tubes for malignant effusions/obstructions
- Treatment of intercurrent infections
- Management of incontinence
- Supplemental oxygen
- Anxiolytics, antidepressants, appetite stimulants when appropriate

tions, leaving patients without desired relief. This problem frequently arises with the use of opioids to control pain. Concerns about respiratory depression arise, leading to inadequate pain control, even though the risk of respiratory depression is minimal when the dose is titrated to the patient's desired endpoint. The EPEC and EPEC-EM curricula are excellent resources for learning about strategies that are unique to palliative care for patients.^{1,6} The following “pearls” from those programs may be useful.

Pain

For patients presenting with acute pain or chronic pain of moderate intensity (rated 5/10 or above) opioid use is appropriate (see Chapter 187). A thorough medication history must be obtained to determine tolerance and dose adjustments that may be needed. Pain assessment is different for patients with chronic pain, because they may not show the abnormal vital

signs or outward expressions of discomfort commonly observed with acute pain. Patients with advanced illness and pain may be tolerant to opioids and require high doses to reach comfort. This inevitably causes discomfort on the part of the provider. Patients suffering from malignant pain may need continuous infusions of opioids to obtain relief. These concepts are reviewed in the EPEC curriculum, and many other resources for learning about dosing of analgesics in these situations are available.^{1,64}

When available, palliative care consultation should be sought for treatment of malignant pain. However, pain and palliative care consultation is not uniformly available, particularly during the evening and night hours. Therefore, emergency physicians must have the basic knowledge to treat severe pain. Rapid opioid dose escalation is the most important principle in patients with cancer on opioids. Doubling of the dose may be required until successful analgesia is reached.⁶⁵ Understanding dosing is key as well. With intravenous administration of morphine, serum levels will be maximal in 6 minutes, which translates to the need to rapidly reassess and redose if the patient is in severe pain. Providing analgesic stability is important, and this is done by providing a long-acting formulation (e.g., MS Contin), with an immediate-release short-acting agent for breakthrough pain. Side effects from opioids must be anticipated as well. Rising serum levels of opioids stimulate the chemotactic trigger zone, causing nausea. Educating the patient that nausea will subside within days is helpful. Minimizing fluctuations by using long-acting agents whenever possible can limit this form of nausea. Constipation is a common effect of opioids, and tolerance will not develop to this very frustrating complication of narcotics. Prevention is far easier than treatment, and a stimulant laxative should be part of all narcotic prescriptions for malignant pain. The use of nonsteroidal anti-inflammatory drugs may be helpful in potentiating the effects of opiates in cancer patients. Recognizing neuropathic pain also is important, because medications such as gabapentin may be added. It is important to clearly explain the proposed treatment plan to the patient and caregivers, to monitor the response to treatment and side effects, and to coordinate changes in treatment regimens with the primary care physician.^{1,6}

Nausea and Vomiting

Nausea and vomiting arise from triggers in the gastrointestinal tract, cerebral cortex, vestibular apparatus, or the chemoreceptor trigger zone in the fourth ventricle. The neurotransmitters involved include serotonin, dopamine, acetylcholine, and histamine. Successful treatment of nausea and vomiting involves selecting the drugs that will target the right receptors. In addition to usual antiemetics, dexamethasone, octreotide (which reduces secretions and may be useful in cases of intestinal obstruction), and tetrahydrocannabinol may be important adjuncts for the control of nausea.^{1,6,66}

Constipation

Constipation is multifactorial near the end of life; causes include decreased mobility, medications, mechanical obstruction, and dehydration. Stimulant laxatives and then osmotic laxatives should be tried in escalating doses, and combinations may be needed. Opioid-related constipation can be a major problem; tolerance does not develop to this side effect of chronic and high-dose use. Every attempt should be made to prevent rather than treat constipation by anticipating the need for stimulant softener combinations when opioids must be used chronically. In cases of mechanical small bowel obstruction, medical management with clear liquids, loper-

amide, and octreotide results in resolution in a majority of patients.^{1,6}

Anorexia and Cachexia

Anorexia and cachexia develop in patients with advanced diseases and may be more stressful for the family than for the patient. Parenteral nutrition does not necessarily reverse these processes, nor do they affect life expectancy, although infections of the esophagus should be considered. Appetite stimulants are sometimes useful.⁶

Shortness of Breath

Shortness of breath also can be part of the last stages of airway disease or cancer involving the lungs. There are many causes, and several treatments may be helpful. Options include symptomatic treatment with oxygen (which may not work if central triggers are operating), anxiolytics, and low-dose opioids, which may decrease the sensation of breathlessness. Malignant effusions may require drainage. In the actively dying patient, morphine and atropine can be used to dry secretions, slow breathing rates, and decrease the work of breathing.⁶

Depression

Psychosocial distress is exceedingly common in patients suffering with incurable illness. Anxiety and depression have been found to have a negative impact on survival and to decrease quality of life. These issues are best addressed by the primary care provider. Emergency providers can provide empathy and support and recognize that these symptoms are not inevitable components of the dying process and therefore deserve attention.

Special Situations and Diseases

Advanced Dementia

Alzheimer's dementia is a prolonged and relentless chronic disease with a course that can extend up to 20 years. With severe dementia, patients may be combative, incontinent, and unable to ambulate. In the terminal phases of the disease, they are bedridden, mute, and dysphagic and suffer from intercurrent infections.⁶⁷ In the demented patient, invasive procedures often require restraints and sedation, and the emotional burden to the patient is high. Even hospitalization, administration of intravenous fluids or antibiotics, and other common interventions are frightening to patients with dementia. As an example, percutaneous gastrostomy or feeding tubes do not prolong life in these patients, and their qualitative benefits are questionable. They do not prevent aspiration, provide palliation, or improve function in a progressive severe disease like dementia.^{68,69} For the emergency physician, the increased burden in combination with decreased benefit, even of the simplest procedures such as administration of antibiotics, means that interventions should be thoughtfully chosen and discussed beforehand with surrogates when there is time to do so. Addressing concerns of caregivers also is particularly important in dealing with families of patients with dementia. Depression is common in caregivers; the burden of caring for patients is very heavy, and grieving may occur before death as the person that they knew disappears in front of them.

Renal Failure

Dialysis has been a technical success in prolonging life for patients without kidney function. Because it is now so common,

physicians do not realize that the annual mortality rate is greater than 25% for patients with significant comorbid illness.⁷⁰ Understanding that dialysis is a choice and not a mandatory intervention may be a useful attitude to affirm in discussing long-term choices with patients and their families in the ED. In the patient with dementia or cancer, electing not to treat renal failure is an option that should be offered to patients and families.⁷¹

Heart Failure and Chronic Obstructive Pulmonary Disease

Although the physiologic parameters of terminal heart failure and COPD are well described, death from these diseases is commonly unexpected and may occur as part of a sudden acute deterioration that is not remediable. As a consequence of the entry-reentry pattern of dying associated with CHF and COPD, many patients will not receive good palliative care until the last days of life. However, some guidelines are available to assist the provider in determining prognosis.^{72,73} When death occurs, it is important to remind the survivors that the underlying disease is the real cause of mortality.

On the other hand, if the patient presenting with acute decompensation becomes stabilized, the emergency physician may be the best person to have a conversation concerning advance planning with the patient and family to establish what kind of resuscitation measures should be performed if the patient suffers a cardiac or respiratory event in the hospital and who should make decisions on behalf of the patient if he or she should become incapacitated at some time during the admission. In patients with many types of chronic diseases of the entry-reentry type (see Fig. 201-1), the period after an emergency has resolved (at least temporarily) often is the best time to establish what interventions would be appropriate if decompensation occurs again. In terminal stages, an undue focus on diagnostics is more common in these patients than in patients with cancer, particularly if the lethality of these conditions is not acknowledged. Palliative care or hospice referral often is useful in assisting the patient with understanding and acknowledging prognosis and establishing intentional and realistic projects and goals for their remaining life.

KEY CONCEPTS

- In emergency medicine, it is essential to act rapidly, with the presumption of curative goals, and it often is impossible to withhold initial interventions.
- Advance directives and patient wishes should be honored whenever possible, including withdrawal of invasive support if the patient's desire to not receive such treatments is determined after initial ED intervention.
- Suffering is not the same as physical pain: The body experiences pain, whereas persons experience suffering, particularly when physical changes threaten their future.
- Patients have individual perceptions of burdens and benefits when they live with chronic illnesses. The only way to understand a person's quality of life and whether treatment is "right" for a patient is to have a conversation.
- An important aspect of the initial ED evaluation of a patient with a life-limiting illness is to ascertain the patient's general wishes regarding resuscitation and related issues. The conversation with family and patient can begin by asking the following questions: "What kind of resuscitation do you wish to receive if an emergency occurs after admission?" "Whom do you want to make decisions for you if you cannot?"
- A discussion of goals of care is more effective if it starts by clarifying the patient's broad values and goals. From the broad discussion, the clinician can suggest what procedures may or may not be useful in attaining the patient's goals.
- The purposes of hospitalization for persons with severe terminal diseases should be clear and in line with the patient's values.

The references for this chapter can be found online by accessing the accompanying Expert Consult website.