Palliative Care in the Emergency Department

Alyssia McEwan, DO, Joshua Z. Silverberg, MD*

INTRODUCTION

Emergency medicine (EM) is generally thought of as a resuscitative specialty, one that revolves around the identification of life-threatening conditions and swift intervention with the goal of curative treatment. The American College of Emergency Physicians defines the specialty of EM as “a medical specialty dedicated to the diagnosis and treatment of unforeseen illness or injury.”

The inherent culture of EM makes discussion revolving around impending death and associated symptoms incongruous with some emergency physicians, because the mere acknowledgment of this discussion may be perceived as failure. “Emergency medicine physicians are trained to save lives, not to manage death” is a statement that resonates with some emergency physicians in training. Statistically, EM residents place training in palliative care to be at a lower priority than do residents in other specialties such as pediatrics and internal medicine.

KEYWORDS

- Palliative care
- Geriatric
- End of life
- Emergency medicine
- Surrogate
- Communication

KEY POINTS

- Shared decision making between physicians and patients/surrogates should be the framework for all conversations and decisions involving palliative and end-of-life care.
- Patient autonomy is the gold standard for decisions pertaining to care. If patients are unable to communicate; focus on prospective autonomy through substitute decision makers and written directives.
- Alleviation of suffering owing to end-of-life symptoms, whether physical or existential, is the responsibility of the emergency physician.
- Familiarity with evidence-based recommendations about symptom management at end of life is essential.

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The reality is that, although the majority of people wish to die at home, a significant number of patients in the final stages of their life visit the emergency department and are under the care of an emergency physician. This number is continually growing as the aging population increases. According to the World Health Organization (WHO), between 2015 and 2050, the proportion of the world’s population over 60 years will double. By 2050, there will be more than 400 million people aged 80 and older worldwide. Experts are acutely aware of this fact and structure is in place for addressing this. In 2006, hospice and palliative medicine was recognized as an EM subspecialty by the American Board of Medical Specialties. In 2007, Education in Palliative and End-of-life Care for Emergency Medicine was implemented to teach clinical competencies in palliative care to EM professionals.

The groundbreaking Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) Trial (JAMA 1995) raised awareness of many of the shortcomings of care for seriously ill and dying hospitalized patients. The principal investigators concluded through their research that the care of seriously ill or dying patients is far from ideal and that “One would certainly prefer to envision that, when confronted with life-threatening illness, the patient and family would be included in discussions, realistic estimates of outcome would be valued, pain would be treated, and dying would not be prolonged.”

**COMMUNICATION WITH PATIENTS AND SURROGATES**

Being comfortable with conversations pertaining to end-of-life and palliative issues is imperative for all physicians working in the emergency department. It has even been proposed that training in communication skills should be integrated with mandatory resuscitation training.

To adhere to best practice communication skills, it is useful to understand the concept of shared decision making and decision frames, and to be aware of certain tools for embarking on a discussion with a patient and/or their surrogate.

**Shared Decision Making**

End-of-life discussions should be centered around a shared decision making model. This approach is often the crux of patient-centered medicine. Shared decision making was first coined in 1988 by the Picker Institute and introduced as one of the fundamental approaches to improving health care delivery in the United States. The Institute of Medicine defines shared decision making as “care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”

**Decision Frames**

The way information is presented by the physician can have a significant impact on the decisions patients and their surrogates make. This phenomenon of “decision frame” was described by Tversky and Kahneman in 1981 in their landmark publication on the psychology of choice. People often demonstrate preference reversal, depending on how the physician frames the information. When choices are presented in terms of gains, people are risk averse and when choices are presented in terms of losses, people are risk seeking.

A 2013 Barnato study demonstrated this effect with a randomized simulation experiment exploring the effects of surrogate emotional state and physician communication strategies on surrogate code status decisions. One of the only factors that had an effect on the cardiopulmonary resuscitation choice was how the physician framed
the decision. The physicians either used the language of do not resuscitate (DNR) or the alternative allow natural death. Using the alternative language caused people to choose that option more often.\textsuperscript{12}

Physicians are not always aware of the way they frame their discussions. In 2015, Lu and associates conducted a high-fidelity simulation study with emergency physicians, hospitalists, and critical care involving an elder with end-stage cancer and life-threatening hypoxia. When debriefed, many of the physicians who used language strongly indicating the necessity of life-sustaining treatment (intubation), felt intubation was actually inappropriate for the patient. The result of this in the simulation was that many times the simulated patient was intubated contrary to their initial wishes and even contrary to what the physician felt was appropriate.\textsuperscript{13}

**Tools and Models to Aid in Communication**

Researchers in palliative care, geriatrics, and oncology have published several tools and models to aid in difficult discussions with seriously ill patients. The Education in Palliative and End-of-life Care 6-step model, also known as the SPIKES model (setup–perception–invitation–knowledge–empathize; \textbf{Box 1}) is one of the most widely

<table>
<thead>
<tr>
<th>Box 1</th>
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<tbody>
<tr>
<td>\textbf{SPIKES model}</td>
</tr>
<tr>
<td>\textbf{Setup}</td>
</tr>
<tr>
<td>• Prepare yourself with the medical facts.</td>
</tr>
<tr>
<td>• Determine who will participate in the conversation.</td>
</tr>
<tr>
<td>• Determine the location of the discussion, preferably a quiet location.</td>
</tr>
<tr>
<td>• Obtain a translator if needed.</td>
</tr>
<tr>
<td>• Let other staff know what you are going to be doing to avoid interruptions.</td>
</tr>
<tr>
<td>\textbf{Perception}</td>
</tr>
<tr>
<td>• Determine the participant's current perception about the situation.</td>
</tr>
<tr>
<td>\textbf{Invitation}</td>
</tr>
<tr>
<td>• Determine how much information the participants want to find out.</td>
</tr>
<tr>
<td>\textbf{Knowledge}</td>
</tr>
<tr>
<td>• Give a \textit{warning shot}, for example, “I have some serious news to tell you.”</td>
</tr>
<tr>
<td>• Deliver information in small parts.</td>
</tr>
<tr>
<td>• Avoid medical jargon.</td>
</tr>
<tr>
<td>• Allow time for comprehension.</td>
</tr>
<tr>
<td>\textbf{Empathize}</td>
</tr>
<tr>
<td>• Address participants’ emotions and allow time for participants to understand their emotions (NURSE mnemonic; see \textbf{Box 2}).</td>
</tr>
<tr>
<td>• Resist the temptation to make things better.</td>
</tr>
<tr>
<td>\textbf{Summary}</td>
</tr>
<tr>
<td>• Summarize everything discussed and allow time for questions.</td>
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</table>

used and accepted models for discussing unfavorable news in the health care setting. This is commonly used in the emergency department for sharing test results, but is also helpful when discussing how to proceed with either aggressive resuscitation or palliation for a patient with progression of an end-stage disease.

If you need to elicit information regarding advance directives or a care plan for something that is happening in real time, an appropriate time to do so would be after going through SPIKES.

Responding to the emotions of the patient is important for communication. The NURSE (naming–understanding–respecting–supporting) mnemonic can help a physician give appropriate responses to the patient’s or surrogate’s emotions (Box 2).

In the emergency department, “ask–tell–ask” (Box 3) is a useful technique for communication when time is limited. It has 3 main steps and is a collaborative way to discuss new developments and discuss a treatment plan. This is an efficient way to get the patient/surrogate information, short of just spouting facts about the current situation.

Similar to SPIKES, after going through ask–tell–ask, it is appropriate to then elicit information about advanced directives and to discuss a treatment plan.

Communication Behaviors to Avoid

Just as there are communication behaviors to foster, there are also communication behaviors to avoid (Table 1).

Box 2

<table>
<thead>
<tr>
<th>NURSE mnemonic for responding to emotions</th>
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<tbody>
<tr>
<td>Naming</td>
</tr>
<tr>
<td>- Name the emotion that the participant seems to be experiencing in a suggestive way, that is:</td>
</tr>
<tr>
<td>o “Some people may feel frustrated in this situation.”</td>
</tr>
<tr>
<td>o “It seems that you might be feeling afraid of what is next.”</td>
</tr>
<tr>
<td>- Avoid telling listener how they are feeling.</td>
</tr>
<tr>
<td>Understanding</td>
</tr>
<tr>
<td>- Try to summarize what you are hearing:</td>
</tr>
<tr>
<td>o “I am hearing you say that you are afraid of telling your siblings about this change in condition.”</td>
</tr>
<tr>
<td>Respecting</td>
</tr>
<tr>
<td>- Match the intensity of your acknowledgment to the intensity of the participant’s display of emotion.</td>
</tr>
<tr>
<td>- Consider praising coping skills of the participant at this point:</td>
</tr>
<tr>
<td>o “I’m impressed with the care you have been giving your father during his long battle with cancer.”</td>
</tr>
<tr>
<td>Supporting</td>
</tr>
<tr>
<td>- Tell the participants how much longer you will be present in the emergency department for support and let them know that you are there for them.</td>
</tr>
<tr>
<td>- Consider involving social worker or another staff member for further support.</td>
</tr>
<tr>
<td>Exploring</td>
</tr>
<tr>
<td>- Ask focused questions or express interest in something that was mentioned to deepen the empathetic connection.</td>
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Communicating News Over the Telephone

As emergency physicians, we are often faced with the task of conveying grave news. This is best done face to face. If a surrogate is not present in the emergency department, it is better to encourage them to come to the emergency department for a conversation in person than to deliver the news over the phone. If it is not possible

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Description</th>
<th>Example and/or Rationale Behind Behavior</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blocking</td>
<td>Patient/surrogate raises concern; doctor fails to respond or redirects the conversation.</td>
<td>Patient: “How long do you think I have?” Doctor: “Do not worry about that, how’s your breathing?”</td>
<td>Results in not addressing the patient’s most important concerns.</td>
</tr>
<tr>
<td>Lecturing</td>
<td>Doctor delivers a large amount of information without giving patient chance to respond/ask questions.</td>
<td>Doctors often revert to discussing medical facts when in the face of emotion.</td>
<td>Patient does not absorb information and may result in perpetuation of negative emotions by patients owing to lack of understanding.</td>
</tr>
<tr>
<td>Collusion</td>
<td>Patients do not bring up difficult topics and physicians do not ask them specifically. “Don’t ask, don’t tell”.</td>
<td>Patient assumes that doctor will bring it up if it is important AND doctor assumes that if the patient wants to know, they will ask.</td>
<td>Important conversations do not occur.</td>
</tr>
<tr>
<td>Premature Reassurance</td>
<td>Doctor responds to patient’s concern with reassurance before understanding the emotion.</td>
<td>Often occurs when doctors feel that they do not have enough time to explore patient concerns.</td>
<td>Patient does not feel that they were understood, often leads to repeated questioning.</td>
</tr>
</tbody>
</table>


to have a conversation in person, the SPIKES, ask–tell–ask, and NURSE tools can be used. Below are helpful considerations for delivering bad news over the phone.14

1. Confirm the clinical information and make sure that you are prepared for the discussion.
2. Prevent interruptions by letting others know what you are doing and if interruptions are unavoidable, inform the surrogate in advance.
3. Ask the person on the phone to identify themselves and their relationship to the patient.
4. Ask the surrogate whether it is an appropriate time and place to have a serious conversation. If possible, make sure that the surrogate is not driving or in another situation that could be dangerous for them.
5. Encourage them to express their emotions; ask, “How are you feeling?” Allow time for processing of information.
6. Ask them to explain their understanding of the situation.
7. If the patient has died, give them specific next steps to take. If the patient is living and you wish to ascertain information about advanced directives, do so while being cognizant of framing effects (see “Decision Frames”).

SUBSTITUTE DECISION MAKERS AND WRITTEN DIRECTIVES

The most widely accepted view of end-of-life decision making is that decisions should be made based on the beliefs, preferences, and values of the patient. This emphasis on patient autonomy in decision making is widely accepted. Despite the common perception that everyone wants to make their own decisions, there is a minority of the population that would like those decisions entrusted to a close family member. To ensure a truly patient-centered approach, it is important to first determine the preferences of the patient.15

Patient autonomy is considered the gold standard but cannot always be relied on. Many elderly patients arriving in the emergency department at the end of life are unable to answer direct questions about the care they would like provided, commonly owing to their immediate clinical condition and/or cognitive impairment. In situations where patients lose decisional capacity, we rely on the concept of prospective autonomy, which means that personal values and priorities of patients will continue to dictate decisions about their care. We rely on designated decision makers or written directives for guidance regarding the patient’s wishes for care at the end of life.

To navigate decision making for patients who have lost capacity, it is important to understand the meaning of the terminology used to describe the decision makers, the documents, and implications of various advanced directives. Notably, staff members in the emergency department failing to recognize the significance of the legal decision maker has been cited as a criticism of some family members when questioned about their experiences.16

To defer to a surrogate decision maker, it is necessary for the physician to first determine that the patient has lost decisional capacity. Decisional capacity is the ability of a person to understand his or her medical situation and to weigh the benefits, burdens, and risks of various treatment options. It also requires that the decision(s) made are consistent over time and that the decisions can be communicated. If it is unclear whether the patient has decisional capacity, it may be beneficial to consult psychiatry to help with the determination.
Substitute Decision Makers

After determining that the patient lacks decisional capacity, physicians often turn to a substitute decision maker for guidance. The substitute decision maker steps in only if and when the patient loses capacity to make their own decisions and lasts for as long as that is the case. They evaluate the information and make decisions that they believe the patient would make if they were able. There are different types of substitute decision makers, including health care proxies (HCPs), surrogates, and next of kin.

Health care proxy

The term “health care proxy” (HCP) refers to both the substitute decision maker and the legal document that is signed by the patient which appoints a person this distinction. The HCP must be at least 18 years of age and must be appointed by the patient.

Surrogate

A surrogate is similar to an HCP, but without being legally appointed as the decision maker. They must be a competent adult at least 18, know the patient well, and be familiar with the patient’s wishes regarding their care.

Next of kin

The next of kin is the patient’s closest living relative. The order of hierarchy in determining next of kin in the United States is as follows:

1. Spouse
2. Children
3. Parents
4. Siblings
5. Grandparents
6. Uncles and aunts
7. Cousins

Spouses in this list include same-sex couples following the recent United State Supreme Court decision (Obergefell v Hodges) granting same-sex couples the right to marry.

In the case of informal/unofficial substitute decision makers (surrogates, next of kin), there are ethical considerations about who to turn to for guidance. With the increased complexity of modern families, legal definitions and hierarchy do not necessarily adhere to the purpose of a substitute decision maker, which is to maintain patient autonomy. Moral criteria for surrogate selection include choosing an individual who is most likely to know the patient’s wishes and who is closest to the patient. This person may or may not be a blood relative of the patient, and the physician should consider this when determining which person will guide decision making.

Written Directives

There are 3 main types of written directives that can guide treatment at the EOL. Regardless of the type, these directives become valid only if/when a person becomes unable to communicate the decisions that they make about their care.

- Advance directives
- Do-not-resuscitate/do-not-intubate orders (DNR/DNI)
- Physician orders for life-sustaining treatment (POLST)
**Advance directives**

Advance directives are further subdivided into the living will and the durable power of attorney for health care (also known as health care power of attorney and HCP, see above).

The **living will** is a legal document that must be written and signed by the patient. For a living will to be honored, in addition to the patient being unable to communicate their own decisions, they must also have a terminal illness or be permanently unconscious. If there is a chance for recovery, a living will does not apply. These forms must be signed by witnesses and notarized. Refer to **Box 4** for a list of people who are usually excluded as witnesses for this document. A living will generally has specifics about what the patient does and does not want to undergo at the end of their life. Examples of information included in living wills are provided in **Box 5**.

The **durable power of attorney for health care** is a legal document in which a person is named as an agent to make all health care decisions if the patient is unable to do so. The ultimate goal of surrogacy is to maintain patient autonomy in the situation of a patient being unable to communicate their wishes. If a patient has previously documented a DNR/DNI request, this durable power of attorney for health care may not override a decision that has been made and documented by the patient when they were able to do so.

**Do-not-resuscitate, do-not-intubate, and do-not-hospitalize orders**

Simply, these orders are to withhold cardiopulmonary resuscitation or intubation and do not extend further than these 2 concepts. All other care would be continued as is standard of care unless further delineated by any advance directive the patient might have.

There are DNR orders specifically for in-hospital and for out-of-hospital scenarios. Out-of-hospital DNR orders are primarily for emergency medical services personnel and are in the form of a written document and, in some states, a bracelet. Some hospitals require a new DNR each time a patient is admitted. There is state-by-state variation in laws pertaining to DNR orders, both in and out of hospitals. This information can generally be found on the Department of Health websites for each state.

DNR and DNI orders have different implications depending on whether cardiac or pulmonary arrest is present. In cardiac or pulmonary arrest, a DNR order inherently includes an order to not intubate the patient. In nonarrest situations, where intubation is indicated, a separate DNI order is required to forego intubation. See **Table 2** for further clarification.

As evident in the third and most rare scenario of “DNI only,” there is a severe limitation on the physician’s ability to provide effective resuscitation.

A do-not-hospitalize order is another type of advance directive that is relevant for some nursing home residents who are impaired in their ability to communicate. This order specifies that, in the case of an acute medical crisis, the resident should not be transferred to a hospital for care.

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**Box 4**

**Witness exclusions**

- Spouses
- Potential heirs
- Doctors caring for the patient
- Employees of the patient’s health care facility
Box 5
Examples of living will content

- Use of equipment (dialysis machines, ventilators)
- Orders pertaining to resuscitation (do-not-resuscitate and do-not-intubate orders)
- Artificial fluids and nutrition
- Symptomatic relief of pain, nausea, other symptoms
- Organ donation

Table 2
Implications of variations in DNR/DNI orders based on scenario

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Cardiac or Pulmonary Arrest</th>
<th>Nonarrest</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. DNR and DNI</td>
<td>No CPR, No intubation</td>
<td>No intubation</td>
</tr>
<tr>
<td>2. DNR only</td>
<td>No CPR, No intubation</td>
<td>Perform intubation</td>
</tr>
<tr>
<td>3. DNI only</td>
<td>Perform CPR, No intubation</td>
<td>No intubation</td>
</tr>
</tbody>
</table>

Abbreviations: CPR, cardiopulmonary resuscitation; DNI, do not intubate; DNR, do not resuscitate.

Physician orders for life-sustaining treatment

The National POLST Paradigm is an approach to advanced care planning that provides patients and their families an opportunity to guide EM personnel actions. A POLST is a medium by which detailed plan about end-of-life care can be communicated. Essentially, it gives specific and actionable details of the care that the patient would or would not like to receive at the end of life. POLST complements advance directives and is not meant to replace it. The POLST form is filled out by a physician after a conversation with patient and their family and is meant to guide treatment that the patient wants to have carried out.

There is substantial variation among different states in the United States regarding POLST. As of 2015, there are only 5 states that do not have some form of POLST: Alabama, Alaska, Arkansas, Nebraska, and South Dakota. Not only does the name of the program vary (ie, POLST, MOLST, MOST, TPOPP, LaPOST, POST, COLST), but the structure of each program has a lot of variation as well. The POLST website, www.polst.org is the primary resource to find out more about POLST in each individual state.

Categories of Care

It is important to understand each category of care as they have different implications. The types of care to be discussed here are palliative care, end-of-life care, hospice care, and comfort measures only care.

Palliative Care

The WHO defines Palliative Care as “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, physical, psychosocial and spiritual.” A patient does not need to be at the end of their life to be a candidate for palliative care.
End-of-Life Care

An obstacle when discussing issues surrounding the “end of life” is the lack of a coherent, widely accepted definition of this term. It can be defined by diagnosis, prognostic criteria, symptom expression, hospice eligibility, and other factors. Lorenz and colleagues propose that “the broadest approach to ‘end-of-life’ refers to a chronologically indefinite part of life when patients and their caregivers are struggling with the implications (eg, symptoms, practical support needs) of an advanced chronic illness.” Most commonly, the terms “end-of-life care” and “hospice care” are interchangeable.

Hospice Care

Hospice care is care focused on symptom relief at the end of life and is most commonly provided for patients with a life expectancy of 6 months or less. According to the National Hospice and Palliative Care Organization, hospice care is defined as “a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well.”

The Medicare Hospice Benefits booklet (updated in January 2015) explains hospice further: “When you choose hospice care, you’ve decided that you no longer want care to cure your terminal illness and related conditions, and/or your doctor has determined that efforts to cure your illness aren’t working.” Once hospice care is chosen, Medicare ceases to pay for a multitude of health care related costs, including care in an emergency room (unless visit is unrelated to the terminal illness or related condition; Table 3).

<table>
<thead>
<tr>
<th>Table 3</th>
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</thead>
<tbody>
<tr>
<td><strong>Comparison of palliative care and hospice</strong></td>
</tr>
<tr>
<td><strong>Palliative Care</strong></td>
</tr>
<tr>
<td>Palliative and curative treatments can be provided at the same time.</td>
</tr>
<tr>
<td>Some treatment and medications may be covered by Medicare/Medicaid.</td>
</tr>
</tbody>
</table>

Comfort Measures Only

The Joint Commission National Quality Core Measures Manual defines comfort measures only as “medical treatment of a dying person where the natural dying process is permitted to occur while ensuring maximum comfort.” These actions are not designed to hasten the end of life; they are designed to make it less difficult. Although patients have the right to opt out of certain treatments, they may still choose to engage in other types of treatments and interventions. The emphasis should not be on “withholding care,” but instead should be placed on providing care that is in line with the patient’s wishes.

SYMPTOM RECOGNITION

It can be challenging for a physician to determine whether some geriatric patients are experiencing discomfort or unwanted symptoms, especially in patients with dementia. This is likely the reason that patients with dementia receive less pain medication than their cognitively intact counterparts. Patients with dementia are less likely to be able to self-report symptoms owing to loss of language skills and other cognitive deficits.
Although self-report is the gold standard for identifying pain and other unwanted sources of suffering (such as hunger, emotional distress, constipation, and cold), it is crucial to modify your approach when dealing with patients with dementia. Relying heavily on self-reported symptoms may result in an increased risk of underdiagnosis and inadequate treatment.\textsuperscript{26} This becomes increasingly important as the number of new cases of Alzheimer’s disease and other dementias is projected to double by 2050 with increasing life expectancy in the United States.\textsuperscript{29}

In this population, pain may manifest differently than in cognitively intact patients, often with decreased mobility and agitation, and increased confusion as the only signs indicating pain.\textsuperscript{29} The PAINAD observational pain assessment tool was developed in 2003 by Warden as a way to identify pain in patients with advanced dementia who are noncommunicative.\textsuperscript{30,31} Several studies have compared different pain scales and the PAINAD scale has fared well in comparison.\textsuperscript{29,32} The PAINAD tool requires observation of the patient for 5 minutes, focusing on 5 different behaviors: breathing, negative vocalization, facial expression, body language, and consolability. The total score is a compilation of scores from individual categories: 10 being severe pain and 0 being no pain (\textbf{Table 4}) According to Zwakhalen,\textsuperscript{33} a score of 2 on the PAINAD scale can be used as an indicator of probable pain and initiation of pain treatment.

Despite the potential usefulness of pain assessment tools, they must not be used to the exclusion of self-report. An attempt to elicit information regarding patient’s level of comfort by speaking with the patient must be done first.

**SYMPTOM MANAGEMENT**

At the end of life, managing unpleasant symptoms can often make more of a positive difference than aggressive interventions. When managing patients at the true end of life, there are some general considerations that can make the process easier for patients and their loved ones.

\begin{table}
\centering
\begin{tabular}{|l|c|c|c|}
\hline
Observation & 0 & 1 & 2 \\
\hline
Breathing independent of vocalization & Normal & Occasionally labored, short period of hyperventilation. & Noisy labored breathing, long period of hyperventilation, Cheyne–Stokes respiration. \\
\hline
Negative vocalization & None & Occasional moan or groan. Low level of speech with a negative or disapproving quality. & Repeated trouble calling out. Loud moaning or groaning. Crying. \\
\hline
Facial expression & Smiling or inexpressive & Sad, frightened, frown. & Facial grimacing. \\
\hline
Body language & Relaxed & Tense, distressed pacing, fidgeting. & Rigid, fists clenched, knees pulled up, pulling or pushing away, striking out. \\
\hline
Consolability & No need to console & Distracted or reassured by voice or touch. & Unable to console, distract, or reassure. \\
\hline
\end{tabular}
\caption{Pain assessment in advanced dementia (PAINAD) scale}
\end{table}

General Considerations for the Dying Patient in the Emergency Department

When caring for dying patients in a busy and hectic emergency department, many challenges exist that may not exist if the patient were in their own home or even in an inpatient bed. The fact that the patient is dying in the emergency department does not mean that they do not deserve the maximum amount of dignity and respect possible.

In her 2013 EMCrit lecture on Critical Care Palliation, Dr Ashley Shreves offers some salient advice about selecting the appropriate environment for the dying patient in the emergency department: “When looking at a patient who is clearly at the end of their life, imagine that it is your family member and (ask yourself if you) would be comfortable with the environment that has been created for them.”34 The most appropriate place for these patients is a private quiet room. If this is not possible, try to arrange things such that the patient and their loved ones have some semblance of privacy. It is important that, after an ideal environment has been created for the patient and their loved ones, they are not then promptly forgotten. The families of dying patients should not be left feeling ignored after being placed in a quiet room.

“There is no place for monitors in the care of the actively dying patient who is endorsing comfort as their goal.”34 Alerts and other sounds from monitors have the potential to distract the patient’s loved ones (during the dying process and take them out of their experience) during their last moments together. Dr Scott Weingart offers advice about monitors at the end of life in his EMCrit podcast discussing End-of-Life and Palliative care in the emergency department.35 He suggests that leaving a pulse oximeter on the dying patient, with alarms turned off, can give you an unobtrusive way to assess the waveforms and oximetry, which can guide you about when the appropriate time is to reassess the patient’s status.

Selection of Therapy for the Symptomatic Geriatric Patient at the End of Life

Although many of the medications and treatments commonly used in younger, healthier adults are the same medications used in the geriatric population to manage symptoms at the end of life, there are additional pharmacokinetic considerations in this population.36 Some physiologic changes that occur during aging may have a clinically significant effect on drug handling. Taking these changes into account is important when choosing the appropriate pharmacologic regimen to manage symptoms at the end of life in the geriatric population.37

Reduced blood flow to the gastrointestinal tract, liver, and kidneys cause medications to be absorbed and metabolized differently than they might in a younger person. Decreased blood flow to the gastrointestinal tract leads to an increased risk of gastrointestinal-related side effects, such as opioid-related decreased gut motility. Decreased hepatic blood flow causes a reduction in first pass metabolism that may lead to an increase in drug bioavailability. Decreased renal blood flow may reduce excretion of drugs and metabolites leading to accumulation and prolonged effects.37

Decreased body water, increased body fat, and a lower concentration of plasma proteins lead to changes in drug distribution. Thus, water-soluble drugs have reduced distribution, lipid soluble drugs have a longer half-life, and there is an increased potential for drug–drug interactions.37

Hepatic metabolism is affected not only because of reduced hepatic blood flow. There is also a reduction in liver mass and functioning liver cells, which may lead to a prolonged half-life owing to reduction in oxidation reactions.37
Pharmacodynamic changes of decreased receptor density and increased receptor affinity may lead to increased sensitivity to drug effect, both with therapeutic response and significance of side effects.37

**Most Common End-of-Life Symptoms**

The WHO analyzed a tremendous amount of evidence to determine the symptoms occurring most commonly at the end of life (Table 5).38 The WHO last updated their Model List of Essential Medications in palliative care based on most common end-of-life symptoms in July 2013. The list is created after extensive research about the most common causes of death, the most distressing symptoms in palliative care, and identification of medicines recommended for treatment of the symptoms based on evidence (Table 6).39 Below are specific treatment options for dyspnea, a common symptom seen in the emergency department particularly at the end of life.39

**Treating Dyspnea**

The most commonly used therapies for dyspnea at the end of life are oxygen, opioids, and noninvasive positive pressure ventilation. A “distress protocol” (DP) for acute respiratory emergencies in terminally ill patients has also been proposed.

**Oxygen**

The use of oxygen for dyspnea in palliative care is controversial. There is clear evidence that oxygen for hypoxemia is an important and beneficial treatment; however, oxygen therapy for normoxemic patients is generally not beneficial for patients who are near death.40,41 Although there is a significant body of evidence discussing the uncertainty of appropriateness of oxygen use in palliative care for normoxemic patients, there is an ongoing dilemma. Kelly41 explored this phenomenon and discovered that there are multiple factors that lead to (possibly inappropriate) oxygen use in palliative care: to appease patients and families who expect oxygen, to help health care workers feel better about themselves in the caring role, and to appease health care workers’ own frustration and guilt in futile situations.

The use of air provides similar relief of breathlessness to oxygen—the mechanism of which is based on facial cooling and airflow. A simple handheld fan with air directed toward the face can reduce dyspnea.41 Using a nasal cannula can cause skin irritation and can be uncomfortable, especially if there is a significant amount of flow of oxygen through the nares.

**Opioids**

Opioids are a mainstay treatment for dyspnea in palliative care because they diminish respiratory drive in response to hypoxia and hypercapnia. A Cochrane Review of opioids for dyspnea supports the use of oral and parenteral opioids for dyspnea in advanced disease.42 Opioids have the added benefit of treating pain and anxiety, which are contributors to suffering during periods of breathlessness.43 A peripheral mechanism acting on lung parenchyma also exists, inhibiting the bronchoconstrictive

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Most common EOL symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia</td>
<td>Depression</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Constipation</td>
<td>Dyspnea</td>
</tr>
<tr>
<td>Delirium</td>
<td>Fatigue</td>
</tr>
</tbody>
</table>
response provoked by vagal stimuli. Because of this, morphine for intractable cough in advanced cancer has been proposed as per 2 case studies with promising results.44 Many physicians are fearful that administering opioids for dyspnea in patients with terminal disease will hasten death by causing respiratory depression. Although there is a small risk of causing respiratory depression in opioid naive patients, respiratory depression is very unlikely and the effects can be easily reversed by administering naloxone. The most appropriate way to administer opioids is careful titration of long-acting opioids with the addition of intermittent short-acting opioids for breakthrough pain.

Noninvasive positive pressure ventilation
A randomized control trial by Nava45 studied the effectiveness and mortality rate after use of NPPV in elderly patients greater than 75 years old with a DNI order. This randomized, controlled trial concluded that NPPV should be considered and offered as an alternative in patients with DNI status and/or those considered poor candidates for intubation. Schettino46 looked at this same topic and determined that in patients with a DNI order and chronic obstructive pulmonary disease and cardiogenic pulmonary edema, NPPV successfully reversed acute respiratory failure and in-hospital mortality, but this was not observed in patients with end-stage cancer, hypoxemic respiratory failure, or postextubation failure.

Distress Protocol
Godbout39 discussed the use of a “distress protocol” (DP) to induce transient sedation in respiratory emergencies in terminally ill patients with chronic obstructive pulmonary disease or lung cancer. This is different from palliative sedation: it is not aimed at prolonging sedation until death. This is emergency sedation to treat unbearable symptoms that are common in terminal illness and at the end of life. The protocol involves subcutaneous injection of a combination of 3 medications: an anxiolytic, an opioid, and a muscarinic antagonist. The specific protocol discussed by Godbout can be found in Box 6. This cocktail may be repeated after 15 minutes if not effective in minimizing distress. Use of this cocktail did not hasten death, because there was no difference between time to death from admission in patients who did and did not receive DP.39 The

<table>
<thead>
<tr>
<th>Class of Medication</th>
<th>Symptom(s) to Treat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opioids (morphine)</td>
<td>Air hunger</td>
</tr>
<tr>
<td></td>
<td>Acute pain</td>
</tr>
<tr>
<td></td>
<td>Dyspnea</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>Anxiety</td>
</tr>
<tr>
<td>(diazepam, lorazepam)</td>
<td>Immediate anterograde amnestic properties</td>
</tr>
<tr>
<td></td>
<td>Sedative</td>
</tr>
<tr>
<td>Antipsychotics</td>
<td>Agitation</td>
</tr>
<tr>
<td>(haloperidol)</td>
<td></td>
</tr>
<tr>
<td>Antiemetics (metoclopramide)</td>
<td>Nausea and vomiting</td>
</tr>
<tr>
<td>NSAIDs (ibuprofen)</td>
<td>Pain</td>
</tr>
<tr>
<td>Antimuscarinics</td>
<td>Respiratory secretions</td>
</tr>
<tr>
<td>(hyoscine butylbromide)</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: EML, Model List of Essential Medications; NSAIDs, nonsteroidal antiinflammatory drugs; WHO, World Health Organization.
individual effects of the medications in the DP are aimed at relieving the most likely symptoms the patient is experiencing. If the DP does not induce sedation, it will likely at least alleviate some of the distressing symptoms that the patient is experiencing. Before widespread acceptance in the United States of this protocol, further evaluation is necessary, but it has the potential for decreasing distress in patients experiencing respiratory emergencies caused by terminal illness (see Box 6).

### Palliative Sedation

End-of-life symptoms can be extremely distressing and at times unbearable. Respiratory distress, intractable pain, and severe hemorrhage are some of the most traumatizing symptoms for patients and their families, and unfortunately, are very common at the end of life. Palliative sedation is defined as using medications to lessen patient consciousness for the purpose of limiting intractable and intolerable suffering. It is on the spectrum of palliative and hospice care and is an appropriate therapy to consider in very specific circumstances.

Palliative sedation is most commonly used for situations of refractory pain, dyspnea, agitated delirium, and convulsions. The definition of a refractory symptom is one that cannot be controlled adequately despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness. Cherny and Portenoy further define a refractory symptom to be one in which further invasive and/or noninvasive interventions meet any of the following criteria:

- Incapable of providing adequate relief
- Associated with excessive and intolerable acute or chronic adverse effects
- Unlikely to provide relief within a tolerable time frame

There are many ethical considerations that arise regarding palliative sedation. One of the primary discussion points is whether it hastens death. A 2015 Cochrane review assessing evidence for the benefit of palliative pharmacologic sedation discussed this issue. Although there were some methodologic limitations to the studies, 13 studies (of 14 reviewed) measured survival time to death from time of admission or referral and found no differences between the groups of sedated versus nonsedated patients. The other most common ethical consideration for palliative sedation is that family members and staff may have concerns that it is a form of euthanasia. Euthanasia is the “deliberate termination of life of a patient by active intervention at the request of the patient in a setting of uncontrolled suffering.” The goal of palliative sedation is not to hasten death or to terminate life; it is to provide relief from intolerable and intractable suffering. Thus, the distinction between palliative sedation and euthanasia is intent. The use of palliative sedation is supported by legal precedent if appropriate informed consent is obtained for this therapy. Supreme Court rulings (Vacco v Quill, 1997 and Washington v Glucksberg, 1997) supported the concept of sedation to relieve intractable suffering. Informed consent must include the discussion about sedation preventing them from being able to eat and drink; implementation of artificial feeding and hydration should be discussed and considered.

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**Box 6**

Distress protocol (in combination, subcutaneous route)

- 5 mg midazolam
- 10 mg morphine
- 0.4 mg scopolamine
The impetus for intolerable and intractable suffering is not confined to physical suffering. There is a large body of literature discussing the issue of existential suffering at the end of life and whether palliative sedation would be appropriate in this situation. Rousseau proposed a set of guidelines by which sedation for existential suffering would be appropriate (Box 7).

Once it has been determined that palliative sedation is appropriate and agreed on by all deciding parties, the medications can be selected. There are no controlled trials comparing the efficacy of medications with sedating side effects. See Table 7 for proposed agents and dosages. The infusion should be initiated and titrated until the patient seems to be comfortable.

Many patients undergoing palliative sedation are already prescribed opioids, and they should not be withheld during sedation. Although opioids themselves are not used generally as a primary agent for sedation, some physicians believe that they are most appropriate in the care of the patient with a terminal disease who is primarily seeking comfort care because most symptoms are due to pain.

The most appropriate course of action is to assess the patient fully and do your best to elucidate the cause of their emergent intractable and intolerable suffering—overwhelming pain crisis, asphyxiation, terminal dyspnea, and massive hemorrhage—and then tailor therapy to address the particular problem which they are facing.

### Box 7

Proposed guidelines for considerations before sedation for existential suffering

- The patient must have a terminal illness.
- All palliative treatments must be exhausted, including treatment for depression, delirium, anxiety, and so on.
- Psychological assessment by skilled clinician.
- Spiritual assessment by skilled clinician or clergy.
- A do-not-resuscitate order is in effect and informed consent has been obtained and documented.
- Informed consent obtained from patient/surrogate.
- Nutrition/hydration issues must be addressed before sedation.
- Consideration given to a trial of respite sedation.


### Table 7

Medications for palliative sedation

<table>
<thead>
<tr>
<th>Medication</th>
<th>Bolus Dose</th>
<th>Infusion Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midazolam (SC, IV)</td>
<td>5 mg</td>
<td>1 mg/h</td>
</tr>
<tr>
<td>Lorazepam (SC, IV)</td>
<td>2–5 mg</td>
<td>0.5–1.0 mg/h</td>
</tr>
<tr>
<td>Thiopental (IV)</td>
<td>5–7 mg/kg/h</td>
<td>20–80 mg/h</td>
</tr>
<tr>
<td>Pentobarbital (IV)</td>
<td>1–2 mg/kg</td>
<td>1 mg/kg/h</td>
</tr>
<tr>
<td>Phenobarbital (IV, SC)</td>
<td>200 mg (can repeat q10–15 min)</td>
<td>25 mg/h</td>
</tr>
<tr>
<td>Propofol (IV)</td>
<td>20–50 mg (may repeat)</td>
<td>5–10 mg/h</td>
</tr>
</tbody>
</table>

Abbreviations: IV, intravenous; SC, subcutaneous.
SUMMARY

As an emergency physician, it is just as important to be prepared to care for the geriatric patient suffering at the end of their life as it is to care for the young trauma patient. There is always something that we can do, and we should never tell a patient or their loved one that there is “nothing that we can do.” Even if it is something as simple as actively listening to a patient, to acknowledge their suffering and to offer them compassion. By understanding how our communication can have an effect on outcomes, how to navigate advance directives, and how to recognize and treat common symptoms in the geriatric population, we can provide better care to this ever-increasing population.

REFERENCES