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End-of-Life Care in the Emergency Department

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Introduction

Case vignette *Mrs. Smith is a 75-year old woman with metastatic squamous cell lung cancer who presents to the Emergency Department (ED) for cough, fevers, and chills. Her vital signs include oxygen saturation (SpO_2) on a nonrebreather mask of 88%, blood pressure of 100/50, pulse of 120, and temperature of 101.4F. A chest radiograph shows diffuse multifocal infiltrates. On chart review, it is discovered that this is her third visit to the hospital, having been discharged 3 days ago to a skilled nursing facility. She does not have a Physician's Orders for Life Sustaining Treatment or advanced directive. While calculating her weight-based antibiotic orders, you begin to ponder how to approach a discussion with this patient and her family in the ED setting.*

The role of the Emergency Provider (EP) is to appropriately diagnose and stabilize acute life-threatening injuries and illnesses. Despite good intentions and optimal medical therapies, some patients will not survive their ED course; others will die in the hospital, usually in the intensive care unit (ICU) days after admission. Medicare data shows that over one-third of patients who die receive medical care in the ED and ICU during their last 6 months of life [1]. Patients overwhelmingly prefer to die at home [2]. Unfortunately, studies show that 38% of people die in the hospital, specifically 22% occur in the ICU, often times while receiving maximum levels of care [3]. Since many of these patients are admitted through the ED, it is essential for an EP to be proficient with end-of-life (EOL) care.

The American Academy of Hospice and Palliative Medicine describes that the goal of Palliative Care (PC) is to "prevent and relieve suffering and to support the best possible quality of life for patients, facing life-threatening or debilitating illness, and their families, regardless of the stage of the disease or the need for other therapies [4]." PC is not the same as *hospice* care. Hospice care is a subset of PC focusing on patients with terminal illness and a predicted life expectancy of 6 months or less who forego therapeutic medical interventions in favor of comfort and quality of life.

In 2014, the American College of Emergency Physicians (ACEP), as part of the *Choosing*

"Our ultimate goal, after all, is not a good death but a good life to the very end."
—Atul Gawande

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Wisely campaign, recommended that EPs "(d)on't delay engaging palliative and hospice care services in the Emergency Department for patients likely to benefit." A recent study of ED-initiated PC in advanced cancer patients demonstrated improved quality of life (QOL) with no negative effect on survival [5]. Despite these recommendations and findings, only 18% of residents and medical students receive formal training in EOL care [6]. The goals of this chapter are to review medical ethics, discuss the concept of shared decision-making and goals of care, explore communication strategies for EPs, and examine the concept of medical futility.

Medical Ethics

The four pillars of medical ethics include *autonomy*, *beneficence*, *nonmaleficence*, and *justice* (*see* Box 38.1). Patients with decision-making capacity possess *autonomy*, the ability to make self-focused choices about their medical treatment. The patient may accept or reject any medical care and/or interventions according to their personal preferences and beliefs. The EP should fully explain, without bias, options for treatment and help patients make decisions that align with their own values. When the patient makes a decision, the EP, regardless of their personal preference or opinion, should honor it.

Beneficence is acting in the best interest of the patient. This could mean respecting a patient's prior stated wishes, written or verbal, regarding life-sustaining treatment or other medical interventions (dialysis, artificial nutrition, intubation, etc.).

Box 38.1 Four Traditional Pillars of Medical Ethics

1. Autonomy – The ability to determine self-focused decisions and actions.
2. Beneficence – Promoting what is best for the patient.
3. Nonmaleficence – Do no harm.
4. Justice – Using resources in an efficient, equitable manner. Patients should receive the same high-quality care.

Primum non nocere, meaning, "First, do no harm," is the basis of *nonmaleficence*. Many medical students are familiar with this principle from the Hippocratic Oath, a historical pledge taken by physicians. Procedures and medications all possess the possibility of both benefit and harm to the patient. EPs must weigh these harms with the patient's disease and care trajectory. If one intubates the patient with end-stage chronic obstructive pulmonary disease (COPD) and metastatic lung cancer, will they ever be liberated from the ventilator? Do intubation and mechanical ventilation align with the patient's values and wishes?

Justice refers to the equitable, fair treatment of all patients regardless of race, sex, color, creed, nationality, or socioeconomic status. Healthcare resources are limited. Every decision by the EP affects multiple other patients due to resource constraints. Medical actions will also impact the surrounding family members (i.e., emotional, financial, physical, etc.).

These four pillars serve as the foundation for ethical medical practice and decision-making. Returning to this solid ethical base will always help the EP when faced with a challenging EOL case [7].

Establishing Goals of Care

The ED is not the ideal setting for a GOC conversation. It is loud, chaotic, and frantic with little privacy. Interruptions are frequent. Providers regularly treat patients with minimal historical information. Acknowledging these limitations, it is the EP's duty to provide the best care possible to patients with terminal and chronic conditions. Many of these patients with chronic health conditions may benefit from early GOC discussions. The purpose of this conversation is to discuss realistic treatment options available and how they align with the patient's personal preferences regarding QOL [8]. This creates an "individualized roadmap" for future health care. Educating the patient and their family on the concept of *QUALITY of life* versus *the concept of QUANTITY of life* can be helpful to put future potential outcome pathways in perspective. Nonverbal components of communication are essential to the GOC conversation. Sitting down, making eye contact, turning off pagers/cell phone ringers, and showing empathy demonstrate compassion and respect to the patient and their family. Similar to the procedural skills of central venous cannulation or bronchoscopy, communication skills must be honed with practice. (*See* Box 38.2 *for a GOC discussion primer.*)

Some patients arrive to the ED with an advanced directive (AD), living will, appointed durable power of attorney (DPA), and/or a Provider Order for Life Sustaining Treatment (POLST) (*see* Box 38.3). A POLST is a physician-

Box 38.2 Goals of Care Discussion

1. Communicating prognosis
    - (a) Answer two key questions: “What is wrong with patient? What will happen to him/her?”
    - (b) Describe what could be the best and worst outcome for the patient.
    - (c) Discuss the most likely scenario.
2. Eliciting patient values
    - (a) “What is most important to you in your life right now?”
    - (b) If the patient is unable to participate, discuss the decisions the patient makes, if present.
    - (c) Consider any statements made by the patient regarding end-of-life care.
3. Using appropriate language
    - (a) Avoid negative statements (“Do you want us to stop aggressive care?”)
    - (b) Avoid the phrase “do everything” when discussing curative versus palliative care.
4. Reconciling goals of care
    - (a) Sometimes a time-limited trial of therapy is needed to elucidate the patient’s course or facilitate decision-making.
    - (b) Set a plan of action based on decisions.
    - (c) Determine the time and location of a follow-up discussion, if applicable.
5. Recommending a care plan based on the established goals
    - (a) Discontinue any medications or therapies not consistent with the GOC.

Adapted from Rosenberg M, Lamba S, Misra S. Palliative medicine and geriatric emergency care – challenges, opportunities, and basic principles. Clin Geriatr Med. 2013;29:1–29

Box 38.3 Important Goals of Care Definitions

1. Advanced Directive – Documents stating a patient’s desire for future care in the event of serious illness or incapacity.
2. Physicians Order for Life-Sustaining Treatment (POLST) – A standardized form documenting a patient–physician discussion regarding a patient’s desired future medical care and interventions.
3. Durable Power of Attorney – Designated individual acting as a surrogate or proxy for the patient; makes treatment decisions for an incapacitated patient.

signed document of a prior EOL discussion with the patient or their surrogate decision-maker. These documents state a patient's desires for care in certain medical situations (cardiopulmonary resuscitation (CPR), intubation, mechanical ventilation, artificial nutrition, etc.). If present, these documents should be honored, though subsequent discussions with the patient and/or their appointed decision should still remain part of the communication process.

Unfortunately, most patients arrive at the ED without any of the above documents. A 2017 systematic review reported that only 38% of patients with chronic illnesses and 33% of healthy adults complete any form of AD [9]. In the event of an absent AD, the provider should clarify GOC with the patient or a surrogate medical decision-maker. It is imperative that the EP offers accurate prognostic information while making clear the unpredictability of illnesses and the progression of disease. Prior to the discussion, a phone call to the primary care doctor, oncologist, or other involved physician may help clarify patient preferences and prognostic information.

Basic, evidence-based principles of EOL communication are shown in Box 38.4 [10]. When conducting a GOC conversation, remember to avoid negative phrases ("will *not do everything*," "will *not give* antibiotics for the infection"). Instead employ phrases that focus on the treatment and care you will offer to the patient: "WILL provide pain medications," "WILL ensure complete comfort." Use direct phrases such as "death" instead of "passing on" or other euphemistic phrases. Do not rush the family into a decision, but conduct the discussion from an information-sharing perspective. Usually, in the ED setting, patients and their family are suffering an acute change in condition, necessitating deliberation between the patient and/or their family members.

Box 38.4 Basic Principles for End-of-Life Communication

1. Be truthful regarding prognosis.
2. Do not delay discussions of end-of-life goals with patients.
3. Anxiety is normal for both patient and clinician during these discussions.
4. Patients have unique goals and desires about their care.
5. Encourage patient and family discussion on medical and nonmedical goals of care.

Adapted from Bernacki et al. [10]

Shared and Surrogate Decision-Making

The widespread adoption of shared decision-making (SDM) instituted a fundamental change in the practice of medicine. Instead of paternalistic physicians dictating the care plan for a patient and their family, the responsibility for patient care decisions is *shared* between the medical team and the patient/surrogate. Physicians provide medical expertise and experience and surrogates provide their personal knowledge of the patient [11]. Together, the two parties develop a patient-centered medical plan. SDM is characterized by active patient/surrogate involvement, a sharing of information between parties, consensus building, and agreement on which treatments to implement [12].

Studies have evaluated SDM in various disease processes, including pediatric lacerations and rehydration options, pediatric fever, and low-risk chest pain. A systematic review of SDM involving these disease processes showed improvement in patient knowledge and satisfaction with the explanation of their care [13].

In the event of incapacity, the patient needs a surrogate decision-maker. If the patient has an appointed DPA for Health Care, that individual should be used. In the majority of cases, there is no appointed surrogate. Many, but not all, states have a legal order of surrogacy (i.e., spouse or offspring). There are currently two types of default surrogate consent laws: (1) hierarchy surrogate consent laws and (2) consensus surrogate consent laws. In states with hierarchy surrogate consent laws, the decision falls to family members or offspring close with the patient. A few states have consensus statues requiring all "interested persons" come to a consensus to name a surrogate [14]. The EP should be familiar with their state laws when identifying a surrogate.

The surrogate's job is to act as the voice for the patient through the substituted judgment standard. They should decide what the patient would want, if they were present. The surrogate should not inject their own values and wishes when making medical decisions for the patient even if they have different values. Even with the best intentions, surrogate decision-makers have been found to follow patient treatment preferences only 68% of the time [15].

Withdrawing/Withholding Medical Treatment

Once the decision is made to allow natural death, how should the imminently dying patient be managed in the ED? If the patient or surrogate decides to pursue strictly comfort care, certain invasive or potential harmful medical treatments will need to be withdrawn. Focus should be placed on the comfort of the patient and the family. The patient should be moved to a private room, if possible, and offered all privacy measures available (corner area, curtains drawn) [16]. Many articles suggest relaxing visitor limitations if it does not interfere with the care of other ED patients.

Some patients will need prior interventions withdrawn. Consider a patient, not unlike the initial case vignette, arriving to the ED in a critically-ill unstable state. An acutely ill patient may be immediately intubated and started on vasopressors if they arrive without a documented AD. Later in their ED course, their family arrives and produces a signed DNR/DNI document. How does one proceed? What factors are associated with withdrawal of life-sustaining measures?

Usually, withdrawal of life support is equated to withdrawal of mechanical ventilation. However, other life supportive measures such as vasopressors, artificial nutrition, dialysis, and/or antibiotics also fall into this category. Prior to withdrawal, it is important to explain the dying process to the family. Thoroughly describe signs and symptoms such as "agonal" and noisy breathing from airway secretions ("death rattle"). Acknowledge the unpredictability of death; for example, consider saying, "It could be minutes to hours before your loved one dies, one is unable to predict the exact time frame." A spiritual care provider service, such as the hospital chaplain is a great resource to help guide and support the family.

Mechanical ventilation can be removed in one step or a graded fashion. There are no consensus guidelines for withdrawal of mechanical ventilation. Some providers argue that a terminal wean prolongs the dying process while others believe that it improves patient comfort. The authors of this chapter recommend following your hospital guidelines for terminal extubation. If no protocols exist, ensure that the patient is free of pain, using narcotics if necessary and discontinue the endotracheal tube while frequently reevaluating the patient for signs of dyspnea or discomfort [17].

Comfort measures include pain, delirium, and anxiety control (*see* Box 38.5). For pain, opioids are the preferred therapy. No evidence exists to support one pain regimen or opioid over another. Many providers and ICUs use opioid drips to control pain, allowing easy titration to patient symptoms. Benzodiazepines are the preferred treatment for anxiety and agitation. Similar to opioids, there is no evidence to support one agent over another. Attention to the patient's comfort is necessary when withdrawing life-sustaining treatment. Remember there is no maximum dose for medications when providing comfort care. There is ethical and legal consensus that although respiratory depression or hypotension may be a foreseeable consequence of these medications, if the intent is to relieve specific symptoms such as pain or dyspnea, it is essential to treat in adequate doses despite the possibility that death may be hastened. The concept of providing preemptive deep sedation to avoid patient suffering at the end-of-life is termed palliative sedation.

Box 38.5 Pharmacology of palliative sedation agents

Opioid	IV Push dose	Infusion dose	Half-life	Metabolism
Morphine	2–4 mg IV q1–2h	2–30 mg/h	3–4 h	Glucuronidation
Hydromorphone	0.2–0.6 mg IV q1–2 h	0.5–3 mg/h	2–3 h	Glucuronidation
Fentanyl	0.35–0.5 mcg/kg IV q0.5–1 h	0.7–10 mcg/kg/h	2–4 h	CYP3A4/5
Benzodiazepine				
Midazolam	0.01–0.05 mg/kg	0.02–0.1 mg/kg/h	3–11 h	Hepatic
Lorazepam	0.02–0.04 mg/kg (≤0.02	0.02–0.06 mg/kg q2-6h prn or 0.01–0.1 mg/kg/h. (≤ 10 mg/h)	8–15 h	Hepatic
Antipsychotic				
Haloperidol	0.5–10 mg	N/A	14–26 h	Hepatic
Anticholinergic Glycopyrrolate	0.2 mg SC Q4 h			

Adjunctive medications for comfort include antipsychotics (such as haloperidol) for symptoms of agitated delirium, and anticholinergics (such as glycopyrrolate or scopolamine) to decrease secretions.

Futility

"Futility" stems from the Latin word *futilis,* meaning leaky. The concept of futility originates from Greek mythology and the tale of the daughters of Danaus, who were condemned in the underworld to repeatedly fill a bathtub with leaky buckets. Schneiderman et al. defined futility as *quantitative* or *qualitative*. Quantitative futility is any intervention to produce an effect which "reasoning or experience suggest is highly improbable and cannot be systematically produced" with a 1% probability of improvement suggested. Qualitative futility is any therapy that does not change the patient's condition and/or complete dependence on intensive medical care [18].

Throughout the course of a career, EPs face numerous instances of presumed futility. For example, if our patient at the beginning of the chapter were to become asystolic, would cardiopulmonary resuscitation provide any benefit? Simon et al. described "bridge to nowhere" therapies in the ED when there is no survivable clinical endpoint. Examples include providing CPR on patients with metastatic cancer or imminent death from brain herniation, offering intubation on a patient unlikely to be liberated from the ventilator, or performing recurrent procedures or invasive interventions on chronically critically ill patients.

Regardless of the EP's personal views, it is essential to speak with the patient or their surrogate decision-maker about their personal preferences and values. Early and open communication can help align the medical treatment with the patient's personal GOC. Additionally, some patients and families may not reach a clear consensus in the ED, but the initiation of open and honest dialogue from the ED setting may help a family during future GOC discussions.

Conclusion

Let us return to Mrs. Smith from our case vignette at the start of the chapter. You join the family in the pre-identified ED family consultation room sit down, and ask open-ended questions about her life. You find out that prior to her cancer diagnosis, she gardened every day and retired 5 years ago from the public school system after more than 40 years as a science teacher. She has three living daughters, a husband, and multiple grandchildren. Her husband is the designated POA. There is no AD currently because the family was waiting for a time everyone could decide together. The daughters and husband note a precipitous decline over the past 2 months and acknowledge that Mrs. Smith would never want to be dependent on anyone for her care or live in a nursing home for a prolonged period of time. You state that intubation would likely not change her ultimate course but instead simply "prolong her dying process." The family and patient agree that CPR or intubation would not get Mrs. Smith the QOL she wishes. The patient is admitted to the medical floor, so loved ones may visit overnight. The next day, she is placed in inpatient hospice and dies with her family at her bedside.

Chapter Summary "CRITICAL POINTS"

1. Discuss end-of-life care with appropriate patients and families.
2. Early GOC conversations should focus around the patient and their wishes regarding medical treatment.
3. During a GOC discussion: (1) ask open-ended questions (2) make eye contact and (3) avoid negative terminology (i.e., "we will not…").
4. Identify if an AD is present or the patient has an appointed POA.
5. Use SDM when appropriate.
6. Opioids are the treatment of choice for pain and discomfort at the EOL.

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