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Primary Palliative Care in the Emergency Department and Acute Care Setting

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> *Cure sometimes, treat often, comfort always*
>
> *—Hippocrates*

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C. Banerjee (ed.), *Understanding End of Life Practices: Perspectives on Communication, Religion and Culture*, Cancer Treatment and Research 187,
https://doi.org/10.1007/978-3-031-29923-0_9

9.1 Introduction

Amidst a global COVID pandemic, the palliative care community and healthcare systems around the country continue to explore opportunities to improve early patient and family access to end-of-life care resources. They need not look any further than the Emergency Departments (ED) located on their campuses and around their communities for this chance. In 2018, there were over 130 million ED visits in America alone, resulting in over 16.2 million hospital and 2.3 million intensive care unit (ICU) admissions [1]. Patients 65 years and older had the highest ED and ICU utilization rates when compared to all other age groups with more than 75% of this demographic visiting the ED at least once in their last 6 months of life [1–3]. As advances in medical therapies continue to extend disease-specific life expectancies and as the American population continues to age, we will continue to see older adults with chronic medical illnesses visiting the ED in their final stages of life [3, 4]. If the ED is to continue to be the primary portal of hospital entry for patients requiring emergent care for acute and chronic terminal illnesses, then it stands to reason that it should also be equally prepared to provide the earliest access to palliative care and advance care planning resources for patients and families who may want and benefit from these services. This chapter will explore the unique horizon of opportunities that exist for emergency medicine and the palliative care specialty to fulfill this obligation.

9.2 History of Emergency Medicine and the “Resuscitation First” Paradigm

Emergency Medicine (EM) as a specialty is relatively young. Established informally by practice in the 1960s and then formally by residency training in the 1970s [5]. Board certification followed shortly thereafter in the 1980s [5]. The field of EM was born out of the need to provide care for a rapidly growing population of patients requiring immediate and unscheduled care for emergent medical conditions. With time, the ED became identified by many as the preferred health care venue to receive care for both acute medical emergencies as well as routine evaluation of non-emergent acute issues [1, 4]. The specialty of emergency medicine has grown immensely over the last six decades and now provides a large variety of complex multi-specialty care to patients with diverse medical conditions. These highly trained emergency medicine teams that provide treatment and stabilization to patients of any age, socioeconomic, ethnic, or cultural background represent the cornerstone and safety net of the American 9-1-1 and healthcare systems.

Historically EM has been centered around the science of resuscitation and a culture of initiating "heroic life-saving measures" in the most critically ill patients. The standard emergency medicine residency curriculum is typically focused on the identification, resuscitation, stabilization, and treatment of the sick and injured. In this historical EM paradigm, what occurs unintendedly to a group of seriously ill patients is the deleterious initiation of unwanted intensely resource-consuming care creating a significant delay in formal goal-directed end-of-life discussions and palliative care consultation. This culture of "resuscitation first, ask questions later" is flawed and can result in resource-consuming, goal-discordant end-of-life care.

9.3 The Evolution of Primary Palliative Care Services in the Emergency Department

Over the last 20 years, leaders within the EM and palliative care community have clearly recognized the importance of the ED as a unique window of opportunity to embrace palliative medicine [6–9]. It began in 2006, when Hospice and Palliative Medicine (HPM) became an officially recognized subspeciality of the American Board of Medical Specialties. By 2012, the American Board of Emergency Medicine (ABEM) created a clear pathway for EM physicians to be eligible for HPM fellowships and formal HPM boarding [9]. Since that time over 150 emergency medicine physicians have been dual boarded in EM/HPM and represent an important delegation of EM palliative leadership reforming EM culture [9, 10]. In 2012, the American College of Emergency Physicians (ACEP) recognized integrating palliative care into the ED as one of its top 5 Choosing Wisely best practices in EM [11]. The message from ACEP was powerful and specifically stated, "Don't delay engaging available palliative and hospice care services in the ED for patients likely to benefit." The College went on to say that "Emergency physicians should engage patients who present to the ED with chronic or terminal illnesses and their families, in conversations about palliative care and hospice services. Early referral from the ED to hospital and palliative care services can benefit select patients resulting in both improved quality and quantity of life" [11]. A message like this from the EM college began to set the stage for continued growth and movement away from the resuscitation first culture of EM.

In parallel, a consortium of emergency medicine and palliative care leaders began developing research, educational resources, tools, quality improvement collaboratives, and courses focused on the ED as an arena of delivery for primary palliative care services [12–17]. Primary palliative care is defined as "basic palliative care skills, including patient-centered communication, advance care planning, and refractory symptom management, that can be and are usually performed by a wide variety of clinicians including emergency physicians, nurses, emergency medical services (EMS), physician assistants, nurse practitioners, and social workers" [17]. The Education in Palliative and End-of-Life Care for Emergency Medicine (EPEC-EM) course and the quality improvement program generated from the Center to Advance Palliative Care's Improving Palliative Care in Emergency Medicine (IPAL-EM) are both outstanding pioneer resources that support healthcare professionals in learning the essential clinical competencies of primary palliative care and advocate for improved end-of-life care in acute care settings [15, 16]. Most recently in October of 2021, an expert multi-disciplinary panel of emergency medicine and palliative physicians, nurses, and social workers convened and published the Best Practice Guidelines for Primary Palliative Care in the Emergency Department [17]. This important paper reviewed two decades worth of EM and palliative care experience and literature and laid out very specific best practice guidelines for frontline ED providers. The authors' recommendations centered around core principles in screening, assessment, and management of palliative care needs in the ED, importance of goals of care conversations, and the coordination of early palliative care and hospice consults that can facilitate safe transitions of care from the ED.

9.4 Educational Initiatives and Resources

Opportunities abound as EM and palliative care teams beginning to partner and engage one another to bring awareness and enhance distribution of educational resources. Medical schools, specialties, and subspecialties in medicine have recognized that physicians and nurses in training should have at least an introduction to the field of hospice and palliative care [18–20]. This often comes in the form of both classroom lectures as well as clinical training scenarios or Objective Structured Clinical Exam (OSCE) as it is frequently termed. Outstanding primary palliative care resources from EPEC-EM [15], IPAL-EM [16], Wisconsin Fast Facts [21], and multiple other resources are available for physicians, nurses, and other palliative champions to access [22–24]. A variety of well-developed educational resources and tools developed to facilitate improved primary palliative care in the acute setting are available and listed in Table 9.1.

However, the raw emotion that is experienced in the moment, when the provider realizes their traditional approach of treatment is not working and then engages the family about end-of-life wishes, is something that cannot be taught but must be experienced. Clinical rotations with specialized palliative care teams and in the ICU are invaluable opportunities for growth for learners and should also be encouraged. Major educational initiatives are underway exploring core competencies for emergency medicine residents to advance their emergency primary palliative care skills [25–27]. These competencies have been developed and published as resources for EM residency leaders to incorporate into their training curriculums which are creating the next generation of EM physicians in this country [27].

Table 9.1 Excellent emergency medicine palliative care resources

EM palliative care resource	Internet address
Palliative Care Network of Wisconsin Fast Facts and Resources [21]	https://www.mypcnow.org/fast-facts/
Education in Palliative and End-of-Life Care for Emergency Medicine [15]	https://www.bioethics.northwestern.edu/programs/epec/
Integrating Palliative Care Practices in the Emergency Department [16]	https://www.capc.org/toolkits/integrating-palliative-care-practices-in-the-emergency-department/
Vital Talk [22]	https://www.vitaltalk.org/
End-of-Life-Nursing Education Consortium [23]	https://www.aacnnursing.org/ELNEC/About
Compassion and Choices: Dementia Values and Priority Tools [24]	https://compassionandchoices.org/end-of-life-planning/assess/dementia-values-priorities-tool

9.5 Initial ED Screening and Assessment of Palliative Care Needs

The starting point for reversing the "resuscitate first" culture that previously defined EM, is recentering the importance of early screening and assessment of a patient's palliative care needs. This change begins by ED providers formally pausing during complex patient encounters and trying to assess whether a patient may benefit from some component of primary palliative care or advance care planning during this ED visit. A variety of factors go into this, including the assessment of a patient's disease severity and trajectory, frequency of healthcare visits, and the outward physical and emotional distress they are presenting with. Some scenarios are obvious and include critically ill patients who are post-cardiac arrest, in respiratory failure or shock. In this group of patients, screening is transparent and mandates an early assessment of palliative care needs and focused goals of care conversations with patients and their families. Multiple prognostication tools exist to assist clinicians with the screening of patients that may benefit from early palliative care consultation and are described in detail in Chap. 7 of this textbook.

In the ED and acute care settings, one of the most effective screening tools studied was the "surprise question" [28]. This tool works by simply asking yourself the question, "Would I be surprised if the patient died within the next year?" If your answer is no, then this is a patient who may directly benefit from goals of care conversation exploring their understanding of their illness and better defining their wishes. The "surprise question" gains even more specificity and urgency by simply asking the same question but with shorter timelines, "Would I be surprised if the patient died within the next month or even during this hospital admission?" If the answer to these questions is no, then formal initiation of primary palliative resources from the ED is warranted as well as referrals to and consultations from specialized palliative care and hospice teams. Always remember that the patient's decision to pursue palliative care services does not exclude continued evaluation and attempted curative management of disease processes and vice versa. Palliative care and traditional curative care are not mutually exclusive and are often most effective when used in combination to create an integrated goal concordant care plan for patients with severe illness.

9.6 Palliation of Refractory Symptoms in Acute and Chronic Illness

It is not uncommon for patients with severe end-stage diseases like cancer, dementia, congestive heart failure, chronic obstructive pulmonary disease, renal failure, and many other pathologies to visit the ED because of an exacerbation of their illness. These patients are often suffering and struggling at home but working with their primary care and palliative care teams to manage their symptoms in the outpatient setting. When they do present to the ED, they are often decompensated and may present for breakthrough pain, nausea, vomiting, dehydration, dyspnea, constipation, and fatigue. Beyond their medical symptoms, there may be a decline in function usually represented by a decrease in their ability to conduct activities of daily living (ADL). When this occurs, it often comes with great emotional stress, anxiety, and fear for patients as well as their families and caregivers. In many cases, the ED serves as the ideal venue for these patients to be evaluated. Immediate symptom palliation can be started while simultaneously initiating the diagnostic testing necessary to identify reversible causes of presentation. If the patient's symptoms can be managed and their fears and concerns addressed, then they may benefit from continued outpatient management with very close follow-up with primary care and palliative teams. If their primary complaints are not well addressed, then continued inpatient care with early palliative care consultation is always an option. Table 9.2 provides some basic guidance on how to pharmacologically manage some of the most common refractory symptoms encountered in the acute care setting [29].

9.7 Creating Meaningful and Skilled Goals of Care Conversations

The appeal to pursue emergency medicine for many is the unknown of what can come through the doors. Each shift can and often is drastically different from the next. Sadly, many of our patients did not wake up that morning knowing today would be their last day. Certainly, their family members and loved ones did not plan for what to do in that scenario. What makes the primary palliative care of emergency medicine so unique is that unlike someone with a progressive disease process, many of our patients have a sudden or drastic change in their health. This results in patients, families, and ED teams having unplanned, difficult, and urgent end-of-life discussions.

Table 9.2 Managing and palliating refractory symptoms in the ED

Symptom	Therapy to consider	Dose	Considerations and tips
Pain	Morphine	2–4 mg q4 h PRN	
	Fentanyl	25–100 mcq PRN	
	Dexamethasone	2–8 mg IV/PO q8 h	
Nausea and vomiting	Ondansetron	4–8 mg IV/PO	
	Haloperidol	0.5–10 mg q1 h PRN	
	Dexamethasone	2–8 mg IV/PO q8 h	
Dyspnea	Morphine	2–4 mg IV or 10 mg PO	
Delirium	Haloperidol	0.5–2 mg Q2 h IV or PO	
Secretions	Atropine sublingual	1% ophthalmic drops, 1–2 drops SL q1–2 h PRN	
	Glycopyrrolate	0.2–0.4 mg IV or SC every 4–8 h PRN	
Constipation	Senna	2 tablets daily	-Every time you prescribe a narcotic you should also prescribe a stool softener
	Colace	1–3 capsules daily	

Quill, Timothy E. *Primer of Palliative Care*. Glenview, IL: American Academy of Hospice and Palliative Medicine, 2010. Print [29]

The delivery of bad news while creating a meaningful goals-of-care conversation with an established patient and their family is challenging and requires a complicated skill set for clinicians to do properly. This task becomes uniquely more challenging in the acute care setting of the ED or the ICU because the physicians, nurses, and palliative care teams often have no prior relationship with that patient or their family. Beyond just giving bad news, the clinical teams in the ED need to quickly transition into assisting the patient and family in making decisions around an urgent progression or de-escalation of care. The following section will describe some tools, suggest language, and describe an organized approach for clinicians in the acute care setting to create meaningful and skilled end-of-life goals of care conversations. These conversations, if executed properly, can create a positive relationship between patient and clinical team and can clearly help guide the patient and family identify their wishes, options, and care goals, regardless of if they are curative, palliative or a combination of both.

Fig. 9.1 Facilitating shared informed decision making to deliver patient centered goal concordant care

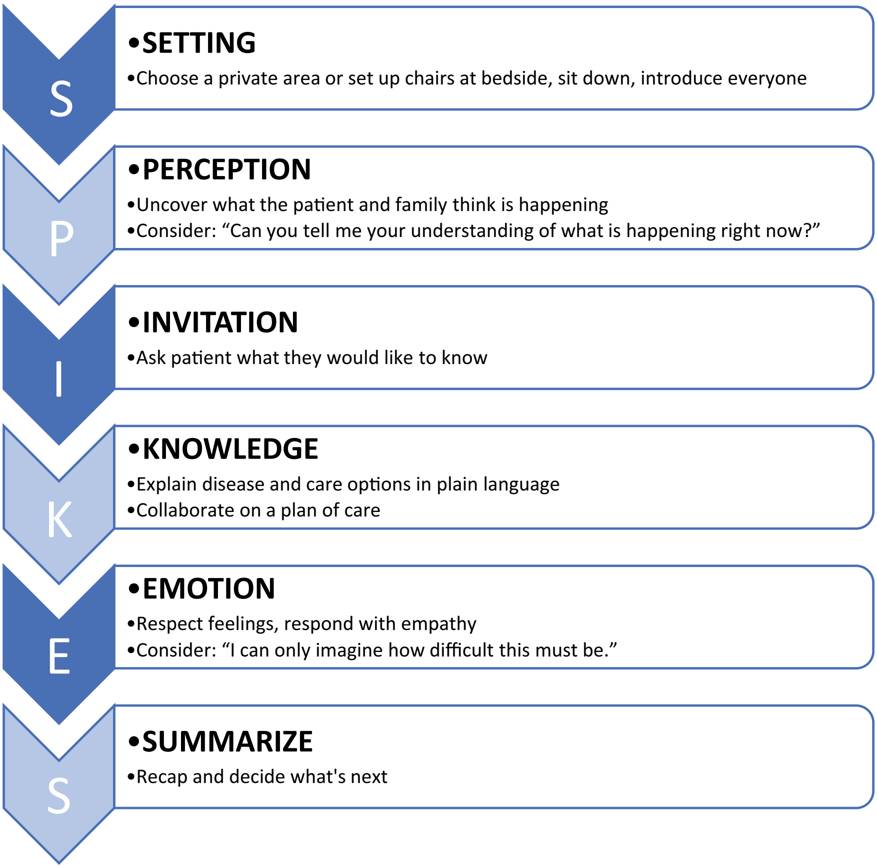
9.8 Importance of Shared Informed Decision Making

Shared decision-making is an essential component of patient-centered health care and the end-of-life discussion. In the palliative medicine arena, this process is focused on clinicians, patients, and their families. With them all working with one another to coordinate end-of-life care decisions and select advance care plans, that balance a patient's personal preferences and values. Both in the acute care setting and out-patient setting, this discussion is centered around thoughtful education and description of care options, which allows informed autonomous decision making by all parties.

There is no single way to approach the care of the critically or terminally ill patient. Every individual will have their preferences regarding treatment modalities, testing, and quality of life issues associated with these decisions. It is our role to serve as an educator and advocate for the patient and their wishes. To do this, clinicians must be ready to abandon the historical paternalistic physician- and patient relationship and move towards a shared decision-making model where the clinicians work with the patient to make decisions that best represent their wishes and goals. When done properly, patients will receive care that is goal concordant with their desires on how they want to live and how they want to die. Figure 9.1 illustrates our role to match treatment options to the patient's values and goals.

9.9 The SPIKES Model to Guide Goals of Care Conversation

The SPIKES model for "breaking bad news" is a straightforward and valuable framework to assist clinicians in engaging in and maximizing goals of care conversations. Coming into these encounters with an organized process has been shown to increase the confidence and effectiveness in a clinician's ability to disclose unfavorable information to patients and their families [30]. The SPIKES model uses this mnemonic to help assist clinicians focus on Setting, Perception, Invitation, Knowledge, Emotion, and Summarize, to guide these challenging conversations. Figure 9.2 highlights the SPIKE model and details suggested language and take away points from each step.



- **SETTING**
  - Choose a private area or set up chairs at bedside, sit down, introduce everyone
- **PERCEPTION**
  - Uncover what the patient and family think is happening
  - Consider: “Can you tell me your understanding of what is happening right now?”
- **INVITATION**
  - Ask patient what they would like to know
- **KNOWLEDGE**
  - Explain disease and care options in plain language
  - Collaborate on a plan of care
- **EMOTION**
  - Respect feelings, respond with empathy
  - Consider: “I can only imagine how difficult this must be.”
- **SUMMARIZE**
  - Recap and decide what's next

Fig. 9.2 Highlights how to use the SPIKE model and suggests language to help guide goals of care conversations

9.10 Proper and Organized Introductions

The first step in every patient and family encounter around delivering bad news in the ED is to assemble your team and get the family together in a quiet and private area. Historically this has been at the patient bedside, or in designated family room areas in the ED, but in the COVID era this has become more challenging. Setting is very important and should be prioritized around being private, quiet and with seating so that everyone can comfortably sit down to talk. Having a nurse, chaplain, or patient representative with you during these discussions can provide invaluable support. After family is gathered in the private area and your team is ready to go talk with them, it is an absolute priority that you verify the patient’s name and then verify that the individuals in the room are truly the family of the patient you are discussing. Although rare, it is not uncommon to assemble the wrong family and then begin discussions that do not pertain to them. This is incredibly distressing to anyone involved and obviously embarrassing. Making sure you take a pause to review patient's name, any family listed in the chart, and gather contact information. Introduce yourself and your team and then ask, "who do we have in the room and what is your relationship to Mr. Joseph Smith?"

9.11 Advance Directives and Durable Power of Attorneys

It is important early in the discussion to identify who in the room is the Durable Power of Attorney or the de facto decision maker for the patient. Our hope is that this person has a clear understanding of the previously expressed wishes of the patient. Frequently when presented with an overwhelming and life-threatening condition, our default as humans who care for someone is wanting to essentially do anything and everything to keep that person we care about alive as long as possible. As skilled clinicians though, we must frame our goals of care discussions in simple, straight, and concise terms to provide a clear path. It is important not to overload the patient and family with information and options. The emergency department is the right place to initiate this conversation with the patient and power of attorney when presented with a life-altering diagnosis. Holding these conversations as early as possible and addressing the patient and families' questions, fears, and hopes can help assist future treatment teams as they present more data and options along the course of the hospitalization.

9.12 Really Listening to the Family

The art of listening is key during moments like this. Medical literature unfortunately describes physicians and clinicians as poor listeners who rarely can keep silent without interrupting patients and family for more than 11 seconds [31]. This must be one of those moments where we sit back and listen. Use open body language, affirmations like nodding your head, and looking people in their eyes when you are listening and speaking. To connect with a family or patient in moments like this, they must feel like they are being heard.

9.13 Asking Open Ended Questions

One challenge in the emergency room is that we are highly decision-oriented, looking for affirmation to continue or discontinue critical care resuscitation. Our instinct and training are to be direct and get right to the most important questions we need to be answered. In this situation, this instinct is likely a hinderance and will often create misguided conversations and decisions. Table 9.3 is a series of phrases that clinicians should avoid in the acute care setting when having goals of care discussions. Alternative phrases that allow for more meaningful open-ended discussion and sharing of patient and family wishes are listed for consideration [32].

Table 9.3 Reframing sentences

Reframing sentences	
"Do you want us to do everything?"	"Your mother/father is very sick right now, what would be most important for them right now?"
"Do you want us to resuscitate your mother/father?"	"It sounds like from how you're describing your mother/father, they would want a natural death"
"I'm sorry there's nothing more we can do"	I wish I could change what is happening here, but there is so much we can do moving forward to support her and you throughout this process

(Quill, JAMA 2000) [32]

9.14 How to Help Patients and Families Make Decisions to Progress Care

The ABCD approach outlined by the EPEC-EM curriculum is an excellent resource to help patients, families, and clinical teams stay focused when addressing goals of care conversations [15]. Keeping your discussion organized and simple allows the patient and family to feel more in control of the situation. The ABCD approach is outlined below:

A. Is there an **Advance** care plan regarding life-sustaining intervention wishes?
B. Can we make the patient feel **Better**?
C. Are there **Caregivers** to consider?
D. Does the patient have **Decision-making capacity** and, if not, has a surrogate been identified?

9.15 De-escalation of Care and the Terminal Wean

When patients and families decide not to advance care, it is our job in this situation to walk them through the hospice and palliative care options available to them. The first decision to consider includes maintaining the patient's current level of care with no further escalation. This choice essentially keeps all care that is actively occurring in place, but no additional escalation of care would occur, and very clear advance directives are defined around CPR, intubation, vasopressors, and other life support measures. Often patients and families will ask for withdrawal of care and an emphasis on comfort measures only. This too needs detailed advance directive charting and updates, but, in the ED or ICU may lead to withdrawal of care consistent with a terminal extubation or wean.

Terminal wean is a term that describes the withdrawal of advanced life support measures in critically ill patients. This often includes discontinuation of vasopressor or antiarrhythmic agents which are supporting blood pressures and preventing arrhythmia. This also can include the discontinuation of ventilatory support and extubation. These patients are often critically ill, and the discontinuation of this care will result in rapid decompensation and death. It is impossible to truly predict how long a patient will survive after withdrawal of care. If we tell the family minutes to hours the patient lives for days, if we say days they live only for minutes to hours. It is best, to advise the patient and family that after withdrawal of care the emphasis will be on comfort measures to avoid pain, anxiety, and prolonged suffering. This can be supported using low to moderate dose opiates like Fentanyl or Morphine as well as low dose sedatives like Versed or Ativan.

Terminal extubations should be carefully planned, families need to be advised that patients can die quickly without ventilatory support. Extubation should be performed without family at bedside, airway should be suctioned afterwards, and face cleaned. Applying a nasal cannula or non-rebreather mask as well as predosing with morphine can help prevent some of the hypoxic respiratory distress that ensues and should be used as part of post-extubation comfort measures. The monitors and the alarms in the room should be turned off and observed from telemetry areas so families don’t have to be distracted by these readings. Any opportunity to coordinate family, chaplains, or other important spiritual figures for the patient should be maximized.

It is OK if the patient and family are not ready to embrace palliative care discussions or advance care planning. Never take it personally.

You may encounter that the patient or family members are resistant to approaching the topic of initiating a palliative care or hospice consult during their hospitalization. This may be their third time being admitted for a COPD exacerbation and they have been experiencing significant functional decline since their first admission. Sometimes it is hard for us as clinicians to understand the why behind what the patient and/or family is resistant to discuss. Frequently, there are underlying stories as to why. They may be holding out for a special day such as a birthday, anniversary, or a wedding. Other times, it can be that they feel bad about not being the son, daughter, mother, father they thought they should be and hope in this time-restrained period that they can make up for it. Whatever the reasoning is, we need to merely plant the seeds of options available to them and be present at the moment to lend an ear. Just listening to stories about the patient and their life as the family member sits with them can be so meaningful and sometimes helps family come to the realization that not prolonging the inevitable is what their loved one would truly want.

While certainly, the flow of your emergency department is important to manage, pausing to ask, “Tell me about them”, while you take a moment to sit in the room, will usually allow the patient and their family to know that you and your team genuinely care for them. Sometimes it’s moments as simple as this that will turn conversations from life-sustaining treatments to discussions about how their loved ones lived, as well as the caregivers’ own fears about their loved one suffering, or how their loved one’s death may look. Non-verbal cues to show your interest in the patient can even be as simple as finding them an extra pillow or blanket and making the patient more comfortable without saying anything in the room.

Both verbal and non-verbal interaction with the patient and family can help open conversation.

9.16 Moving Palliative Care Discussions and End-of-Life Care Options Earlier in the Continuum of Hospital Death. It needs to start in the ED

Some of the most significant innovations in critical care medicine over the last 30 years have involved proactively moving screening, assessment, and management earlier into a critically ill patient's clinical course. The evolution of sepsis care is one of the best examples. Historically definitive sepsis identification, resuscitation, and source control were coordinated in the ICU. In the early 2000s, it was proactively moved into the spectrum of emergency medicine. In this setting, ED teams were asked to provide earlier sepsis screening, identification, antibiotics, fluid resuscitation, and goal-directed resuscitation, which ultimately created dramatic improvements in patient outcomes [33–35]. Similar for admitted patients, the advent of hospital-based rapid response or medical emergency teams, changed the incidence of inpatient mortality [36]. The old paradigm would often manage decompensating patients on the floor, to the point of severe clinical demise, prior to activating necessary support resources needed to change the medical trajectory of a patient's illness. The presence of rapid response teams, empowered nurses, and other clinicians to screen for decompensation and ask for help earlier, which directly allowed patients to receive time-sensitive care more promptly to improve outcomes. In the same way, the specialized palliative medicine community needs to embrace EM leadership to continue to develop novel solutions on how to improve early engagement regarding end-of-life discussions and improve access to palliative care specialists earlier in the continuum of death.

Unfortunately, every ED across the nation has varying access to specialized palliative teams and primary palliative care education [11, 16, 37]. Some hospital systems have well-organized and intricate protocols and policies that facilitate early engagement of palliative care resources, many do not [11, 16, 37]. The variance of primary palliative care practices fluctuates within a single ED from shift to shift depending on who the clinical team is that day, and this variation obviously continues across our country's very diverse ED network. The challenge over the next 10 years will be to homogenize these resources and processes, transitioning EDs away from heterogenous and variable practice. Creating best practice guidelines as outlined by ACEP in 2021 is a great start [11]. EDs and health systems will need to identify and reward EM palliative champions who will serve to foster improved primary palliative care in their own departments locally. This will require direct and proactive collaboration with local specialized palliative care team members. Health systems need to mobilize much-needed, chaplain, social work and case manager support services to ED teams and their patients and families who may benefit from early palliative care referrals and home health care needs.

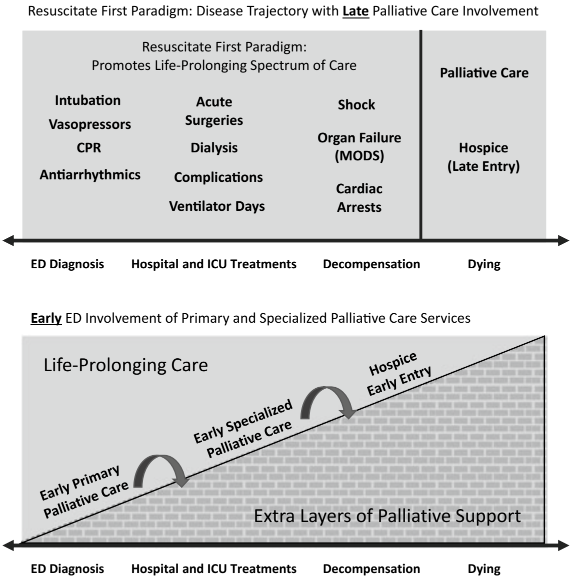


Fig. 9.3 Reconceptualizing palliative care as a continuum of support and emphasizing the benefit of early goal-directed end of life care (based on figure by Wang et al. [8])

EDs will continue to see a larger portion of patients dealing with terminal and chronic illness that may benefit from early evaluation of palliative care needs. Because of this, EM is positioned to take the lead on triaging these patients and then proactively becoming a palliative care hub helping patients link to the resources that would most benefit them. At the minimum, the ED can initiate skilled goals of care discussions with patients and their families, and fully address their advance directives, and some advance care planning needs. The ability of the ED to focus on the palliation of primary symptoms, and then proactively avoid hospitalizations, is another opportunity to reduce suffering and avoid unwanted hospital-based deaths. Early referral to palliative and hospice services will benefit patients, families, and health systems manage resources, and provide truly goal-concordant care for patients through their continuum of illness [8]. When primary palliative care resources are layered on top of traditional life-prolonging curative care, we see a significant increase in patients' receiving goal-concordant care, and the effects of this paradigm change are described in Fig. 9.3.

9.17 COVID-19 and Its Impact on Health Systems, ED, and Palliative Care

As we face sequential waves and new variants of COVID-19 in our nation, our healthcare system continues to be stretched to the very edge of its limits. Health care providers are facing significant physical, emotional, and spiritual strain as resources become more limited [38, 39]. On May 13th, 2022, one million Americans had died from COVID and over 6 million deaths worldwide [40]. The

American healthcare system, and the EDs specifically, are feeling significant pressures related to reduced ED and ICU capacity secondary to a severe national nursing and ancillary staffing crisis [41]. These deficiencies affect all staffing including technicians, respiratory therapists, social workers, and even other downstream palliative care teams [41]. Waiting room times in the ED are at an all-time high, with patients either leaving without completion of services or decompensating abruptly in the ED lobby waiting to be seen [42]. During such volatile times, we continue to see patient and family-directed aggression towards healthcare workers. The incidents of both physical and emotional injuries suffered by health care professionals during these encounters are sadly on the rise [38, 39].

As the pandemic spread and visitor restrictions started to be enacted across the nation, we found ourselves having to transition to phone or video conferencing. In fact, early in the pandemic, the majority of hospitals completely eliminated any visitors in the emergency departments as well as the ICUs, unless the patient was actively dying. Even during that period, the family often would only be able only to look into the room and were unable to hold their loved ones hands or be at their side. Though visitor restrictions have now been softened, families continue to have less access to patients in the ED and ICU than before the pandemic started. Our traditional in-person ways of communicating with and supporting patients and their families during this time have dramatically changed medicine. Being able to sit face-to-face with the patient and family was the cornerstone of the “goals of care conversation”. It allowed us to use non-verbal cues when discussing their care process. It allowed a more collaborative approach to the treatment plan and offered numerous chances to clarify the trajectory of care. This transition period has been and will continue to be, challenging for many. Clinicians will be required to focus on delivering clear and concise summations of what was happening during the ED stay, as well as next steps or interventions, and even potential pitfalls along the way. In the future ED teams will be frequently asked to make multiple phone calls to family members and will need to be proactive in keeping families involved in patient care.

9.18 Embracing the Future of Telemedicine in Palliative Care

Innovations often thrive in troubling times and the use of virtual telemedicine platforms and processes have grown exponentially since the onset of COVID [43]. We are seeing significant increases in patients using telemedicine with both primary care and specialty physicians for ED follow-up visits [43]. Behavioral health, too, as a specialty is utilizing virtual tele-psychiatry and mobilizing social workers virtually to reach more patients in need of care that were previously vulnerable due to lack of resources or geographic locations [44]. Across the country, we are seeing Emergency Medical Services (EMS) starting to utilize telemedicine in the form of well-developed mobile integrated health teams as well and community paramedicine programs [45]. A real opportunity exists for prehospital teams to join the many layers of available outpatient palliative support services and assist in the delivery of palliative care under physician guidance [45]. The Prehospital Providers Perspective on Palliative and Hospice Care Course is an innovative, free, three-hour educational program that is beginning to support and develop this opportunity and another example of innovation [46].

The palliative care and hospice specialty has already started to embrace these platforms. With palliative and hospice resources in some areas of the country being scarce, these virtual medical tools can help fill gaps where there is a deficit of trained workers to provide specialized palliative care [47]. Skilled palliative care specialists can now provide telemedicine services to other hospitals, skilled nursing facilities, Long-Term Acute Care Hospitals (LTACHs), as well as coordinate home visits. It is time to invest resources into coordinating systems that allow for urgent tele-medicine consultations between specialty palliative teams and the ED. The technology, platforms, patients, and need, are there for the ED and specialty palliative care to partner up to create a higher level of services than are currently being provided. Maximizing tele-medicine offers great potential to deliver both increased quantity and quality of palliative care services to patients who previously would not have been able to receive them.

9.19 Embracing Opportunities for Primary Palliative Care in the ED and Acute Care Setting

As EM continues to evolve, it is essential that the palliative care community and its leaders, continue to embrace and foster relationships with their ED partners. Working together, these two specialties can further develop much-needed awareness, education, processes, and protocols, that will foster primary and specialized palliative care services being initiated more often from the ED. When this happens, we will see a profound shift of unwanted and resource-consuming care, move away from acute critical care encounters. Instead, we will see more focused, goal-directed, and goal concordant end-of-life care being initiated earlier in the continuum of death. Bringing specialized medical and surgical services to the ED and patient bedside is not novel. Interventional cardiologists, trauma teams, and surgical specialists, are regularly activated to provide emergent care for cardiac, traumatic, and surgical emergencies. In collaboration, EM physicians and palliative care specialists, in combination, have an opportunity to fill a similar gap for the terminally ill. Patients and their families facing acute critical illness, and the looming possibility of a “goal-discordant death”, need the expertise of both a trained EM team, and palliative specialists. The ability to initiate essential goals of care discussions and then coordinate end-of-life care resources for patients much earlier in the continuum of terminal illness can play a dramatic role in improving both their quality and quantity of life (Table 9.4).

Table 9.4 Glossary of important primary palliative care terms

Primary palliative care	In the context of end-of-life care, a primary palliative care provider is the principal medical, nursing, or allied health professional, who undertakes the clinical management and care coordination including palliative assessment, triage, referral, and assisting patients and families to establish appropriate goals of care
Specialist palliative care	A *specialist palliative care provider* is a medical, nursing, or allied health professional, that have the specialist knowledge, skills, and expertise in the care of people living with an eventually fatal condition and their families Specialist palliative care services work in three key ways; providing direct care to referred patients with complex needs, providing consultation-based services to patients being cared for by primary care providers, providing support to end-of-life care services
Hospice	Hospice refers to a "program" that gives special care to people who are near the end of life, with an estimated prognosis of less than 6 months, and have stopped treatment to cure or control their disease. Hospice offers physical, emotional, social, and spiritual support for patients and their families. The main goal of hospice care is to control pain and other symptoms of illness so patients can be as comfortable and alert as possible. It is usually given at home, but may also be given in a hospice center, hospital, or nursing home
Illness trajectories	Distinct illness trajectories have been described at the end of life for frailty, dementia, cancer, and organ failure. These trajectories can provide a framework for addressing patient and family expectations of what will happen regarding their health
Advance care planning	A process to help the patient plan medical care in advance, so that if they become too unwell to make decisions, their wishes can still be respected by the healthcare team and the family. An important part of the plan is identifying a substitute decision maker, one who is able to adhere to the patient's values and wishes, in the event that the patient becomes unwell and is no longer able to speak or properly communicate their wishes

(continued)

Table 9.4 (continued)

Advance directives	A legal document that states a person's wishes about receiving medical care if that person is no longer able to make medical decisions because of a serious illness or injury. There are different types of advance directives, including a living will, durable power of attorney (DPA) for healthcare, and do not resuscitate (DNR) orders. In the United States, the laws for advance directives may be different for each state, and each state may allow only certain types of advance directives
Terminal wean	The gradual withdrawal of mechanical ventilation from a patient who is not expected to survive without respiratory support
Physician order for list sustaining treatment (POLST	POLST is a document that states a person's end-of-life wishes and may include a "Do Not Resuscitate" (DNR) order, instructions about artificial nutrition, antibiotics, and other medical interventions. While an advance care directive is usually meant for a hospital, POLST is designed to instruct emergency personnel on what actions to take while the patient is still at home

Definitions adapted from Pallipedia: https://pallipedia.org The Free Online Palliative Care Dictionary [48] and the National Cancer Institute's Dictionary of Cancer Terms: https://www.cancer.gov/publications/dictionaries/cancer-terms/ [49]

References

1. Cairns C, Kang K, Santo L (2018) National hospital ambulatory medical care survey: 2018 emergency department summary tables. https://www.cdc.gov/nchs/data/nhamcs/web_tables/2018_ed_web_tables-508.pdf
2. Pitts SR, Niska RW, Xu J, Burt CW (2008) National hospital ambulatory medical care survey: 2006 emergency department summary. Natl Health Stat Rep 7:1–38
3. Smith AK, McCarthy E, Weber E, et al (2012) Half of older Americans seen in emergency department in last month of life; most admitted to hospital, and many die there [published correction appears in Health Aff (Millwood) 31(7):1650]. Health Aff (Millwood) 31(6):1277–1285. https://doi.org/10.1377/hlthaff.2011.0922
4. Albert M, McCaig LF, Ashman JJ (2013) Emergency department visits by persons aged 65 and over: United States, 2009–2010. NCHS Data Brief 130:1–8
5. Suter RE (2012) Emergency medicine in the United States: a systemic review. World J Emerg Med 3(1):5–10. https://doi.org/10.5847/wjem.j.issn.1920-8642.2012.01.001
6. Lamba S (2009) Early goal-directed palliative therapy in the emergency department: a step to move palliative care upstream. J Palliat Med 12(9):767. https://doi.org/10.1089/jpm.2009.0111
7. Grudzen CR, Stone SC, Morrison RS (2011) The palliative care model for emergency department patients with advanced illness. J Palliat Med 14(8):945–50. https://doi.org/10.1089/jpm.2011.0011. Epub 2011 Jul 18. PMID: 21767164; PMCID: PMC3180760
8. Wang DH (2017) Beyond code status: palliative care begins in the emergency department. Ann Emerg Med 69(4):437–443. https://doi.org/10.1016/j.annemergmed.2016.10.027. Epub 2017

Jan 26 PMID: 28131488

9. George N, Bowman J, Aaronson E, Ouchi K (2020) Past, present, and future of palliative care in emergency medicine in the USA. Acute Med Surg 7(1):e497. https://doi.org/10.1002/ams2.497.PMID:32395248;PMCID:PMC7204801
10. Schafer K (2018) EMRA fellowship guide: opportunities for emergency physicians, 2nd edn. https://www.emra.org/books/fellowship-guide-book/i-title/. Accessed 15 June 2022
11. American College of Emergency Physicians (2013) ACEP announces list of tests as part of choosing wisely campaign. https://www.acep.org/administration/quality/acep-announces-list-of-tests-as-part-of-choosing-wisely-campaign. Accessed 15 June 2022
12. NIH State-of-the-Science Conference Statement on improving end-of-life care. NIH Consens State Sci Statements 21(3):1–26 (2004)
13. American College of Emergency Physicians (2008) Ethical issues at the end of life. Ann Emerg Med 52(5):592. https://doi.org/10.1016/j.annemergmed.2008.07.035
14. Grudzen CR, Stone SC, Morrison RS (2011) The palliative care model for emergency department patients with advanced illness. J Palliat Med 14(8):945–950. https://doi.org/10.1089/jpm.2011.0011
15. Education in Palliative and End of Life Care (EPEC) (2010) https://www.bioethics.northwestern.edu/programs/epec/curricula/emergency.html. Accessed 15 June 2022
16. Improving Palliative Care in Emergency Medicine (2011) http://www.capc.org/ipal/ipal-em. Accessed 15 June 2022
17. Loffredo AJ, Chan GK, Wang DH et al (2021) United States best practice guidelines for primary palliative care in the emergency department. Ann Emerg Med 78(5):658–669. https://doi.org/10.1016/j.annemergmed.2021.05.021
18. Boland JW, Brown MEL, Duenas A, Finn GM, Gibbins J (2020) How effective is undergraduate palliative care teaching for medical students? A systematic literature review. BMJ Open 10(9):e036458. https://doi.org/10.1136/bmjopen-2019-036458
19. Pieters J, Dolmans DHJM, van den Beuken-van Everdingen MHJ, Warmenhoven FC, Westen JH, Verstegen DML (2020) A national, palliative care competency framework for undergraduate medical curricula. Int J Environ Res Public Health 17(7):2396. https://doi.org/10.3390/ijerph17072396
20. Ferrell B, Buller H, Paice J, Anderson W, Donesky D (2019) End-of-Life nursing and education consortium communication curriculum for interdisciplinary palliative care teams. J Palliat Med 22(9):1082–1091. https://doi.org/10.1089/jpm.2018.0645
21. Fast Facts and Concepts. Palliative Care network of Wisconsin. https://www.mypcnow.org/fast-facts/. Accessed 15 June 2022
22. Back AAR, Edwards K, Tulsky J, VitalTalk (2018). vitaltalk.org. Accessed 15 June 2022
23. End-of-Life Nursing Education Consortium (n.d.) American Association of Colleges of Nursing, 2020. https://www.aacnnursing.org/ELNEC. Accessed 15 June 2022
24. Compassion and choices: dementia values and priority tools. https://compassionandchoices.org/end-of-life-planning/assess/dementia-values-priorities-tool. Accessed 15 June 2022
25. Lamba S, Pound A, Rella JG, Compton S (2012) Emergency medicine resident education in palliative care: a needs assessment. J Palliat Med 15(5):516–520. https://doi.org/10.1089/jpm.2011.0457
26. Kraus CK, Greenberg MR, Ray DE, Dy SM (2016) Palliative care education in emergency medicine residency training: a survey of program directors, associate program directors, and assistant program directors. J Pain Symptom Manag 51(5):898–906. https://doi.org/10.1016/j.jpainsymman.2015.12.334
27. Shoenberger J, Lamba S, Goett R, et al (2018) Development of hospice and palliative medicine knowledge and skills for emergency medicine residents: using the accreditation council for graduate medical education milestone framework. AEM Educ Train 2(2):130–145. https://doi.org/10.1002/aet2.10088
28. Moroni M, Zocchi D, Bolognesi D et al (2014) The ‘surprise’ question in advanced cancer patients: a prospective study among general practitioners. Palliat Med 28(7):959–964. https://doi.org/10.1177/0269216314526273

29. Quill TE (2010) Primer of palliative care. American Academy of Hospice and Palliative Medicine, Glenview, IL (Print)
30. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP (2000) SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 5(4):302–311. https://doi.org/10.1634/theoncologist.5-4-302
31. Singh Ospina N, Phillips KA, Rodriguez-Gutierrez R et al (2019) Eliciting the patient's agenda—secondary analysis of recorded clinical encounters. J Gen Intern Med 34(1):36–40. https://doi.org/10.1007/s11606-018-4540-5
32. Quill TE (2000) Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". JAMA 284(19):2502–2507. https://doi.org/10.1001/jama.284.19.2502. PMID: 11074781
33. Rivers E, Nguyen B, Havstad S et al (2001) Early goal-directed therapy in the treatment of severe sepsis and septic shock. N Engl J Med 345(19):1368–1377. https://doi.org/10.1056/NEJMoa010307
34. Cannon CM, Holthaus CV, Zubrow MT et al (2013) The GENESIS project (GENeralized early sepsis intervention strategies): a multicenter quality improvement collaborative. J Intensive Care Med 28(6):355–368. https://doi.org/10.1177/0885066612453025
35. Levy MM, Evans LE, Rhodes A (2018) The surviving sepsis campaign bundle: 2018 update. Intensive Care Med 44(6):925–928. https://doi.org/10.1007/s00134-018-5085-0
36. Maharaj R, Raffaele I, Wendon J (2015) Rapid response systems: a systematic review and meta-analysis. Crit Care 19(1):254. https://doi.org/10.1186/s13054-015-0973-y
37. Weil J, Weiland TJ, Lane H, Jelinek GA, Boughey M, Marck CH, Philip J (2015) What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department. Palliat Med 29(4):293–301. https://doi.org/10.1177/0269216314560801. PMID: 25634627
38. Shreffler J, Petrey J, Huecker M (2020) The impact of COVID-19 on healthcare worker wellness: a scoping review. West J Emerg Med 21(5):1059–1066. https://doi.org/10.5811/westjem.2020.7.48684
39. Howell BAM (2021) Battling burnout at the frontlines of health care amid COVID-19. AACN Adv Crit Care 32(2):195–203. https://doi.org/10.4037/aacnacc2021454
40. Johns Hopkins University of Medicine, Coronovirus Resource Center. https://coronavirus.jhu.edu/map.html. Accessed 15 June 2022
41. Bhandari N, Batra K, Upadhyay S, Cochran C (2021) Impact of COVID-19 on Healthcare labor market in the United States: lower paid workers experienced higher vulnerability and slower recovery. Int J Environ Res Public Health. 18(8):3894. https://doi.org/10.3390/ijerph18083894
42. Gabor D (2022) Emergency department overcrowding: the canary in the coal mine. NEJM Catal. https://doi.org/10.1056/CAT.21.0217. Accessed 15 June 2022
43. The Harris Poll (2020, April). Telehealth: the coming "new normal" for healthcare. https://theharrispoll.com/telehealth-new-normal-healthcare. Accessed 16 April 2021
44. Abraham A, Jithesh A, Doraiswamy S, Al-Khawaga N, Mamtani R, Cheema S (2021) Telemental health use in the COVID-19 pandemic: a scoping review and evidence gap mapping. Front Psychiatry 12:748069. https://doi.org/10.3389/fpsyt.2021.748069
45. Gregg A, Tutek J, Leatherwood MD et al (2019) Systematic review of community paramedicine and EMS mobile integrated health care interventions in the United States. Popul Health Manag 22(3):213–222. https://doi.org/10.1089/pop.2018.0114
46. The Prehospital Perspective in Palliative and Hospital Care Course. https://frontend.prodigyems.com/login?redirect-to=%2Fclass%2FFB016EB9-0474-426E-B7F3-C1E3F3FF2A1D. Accessed 15 June 2022
47. Salvador Vergès À, Cusí Sánchez MV, Bossio Grigera P, et al (2021) Determinants in stakeholder opinions about telemedicine in palliative care: a scoping review [published online ahead of print, 2021 Dec 6]. Telemed J E Health. https://doi.org/10.1089/tmj.2021.0441
48. Pallipedia. https://pallipedia.org The Free Online Palliative Care Dictionary. Accessed 15 June 2022

49. National Cancer Institute's Dictionary of Cancer Terms. https://www.cancer.gov/publications/dictionaries/cancer-terms/. Accessed 15 June 2022