# Hospice and Palliative Medicine: New Subspecialty, New Opportunities

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Palliative care is the physical, psychological, social, and spiritual care provided to patients from diagnosis to death or resolution of a life-threatening illness. Hospice care is a comprehensive program of care that is appropriate when patients with chronic, progressive, and eventually fatal illness are determined to have a prognosis of 6 months or fewer. Hospice and palliative medicine has now been recognized by the American Board of Medical Subspecialties as a field with a unique body of knowledge and practice. With 9 other specialty boards, the American Board of Emergency Medicine has cosponsored hospice and palliative medicine as an official subspecialty. As a result, board-certified emergency physicians may now pursue certification in hospice and palliative medicine through either fellowship training or, for a limited time, completing practice track requirements, followed by a written examination in the subspecialty.

As the practice of palliative medicine grows in hospitals, emergency physicians can develop a core of generalist palliative medicine skills for use with adults and children. These would include assessing and communicating prognoses, managing the relief of pain and other distressing symptoms, helping articulate goals of patient care, understanding ethical and legal requirements; and ensuring the provision of culturally appropriate spiritual care in the last hours of living. Front-line emergency physicians possessing these basic palliative medicine skills will be able to work collaboratively with subspecialty physicians who are dually certified in emergency medicine and hospice and palliative medicine. Together, generalist and specialist emergency physicians can advance research, education, and policy in this new field to reach the common goals of high-quality, efficient, evidence-based palliative care in the emergency department. [Ann Emerg Med. 2009;54:94-102.]

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## HOSPICE AND PALLIATIVE MEDICINE: OVERVIEW

Hospice and palliative medicine, a newly designated subspecialty of the American Board of Medical Subspecialties (ABMS), is an advanced-level practice that focuses on the total care of patients with life-threatening illness, whether curable or terminal.<sup>1</sup> Although there is a recognition that palliative care is provided by all clinicians, conferring subspecialty status by ABMS gives palliative medicine a well-defined field of practice with a distinct base of medical science on which graduate medical education training programs can be developed for accreditation by the Accreditation Council of Graduate Medical Education.<sup>2</sup>

*Palliative medicine* is the physician component of the interdisciplinary practice of *palliative care*. Palliative care is the physical, spiritual, and psychosocial care given by multiple disciplines to patients living with life-threatening illness and to their families. Although palliative care is most often discussed in the context of end of life, it is actually appropriate to apply at all

stages of illness. The goal of palliative care is to improve the quality of life through the relief of distressing physical symptoms while also addressing the emotional, social, and spiritual components of suffering. Palliative care can be applied while the patient is receiving disease-modifying therapy, such as intensive care, chemotherapy, or surgery. Palliative care is best practiced as an interdisciplinary team model with physician, nurse, social worker, chaplain, and mental health caregivers working together to formulate and implement a comprehensive treatment plan.<sup>3-5</sup>

When a patient's disease enters its final stage and the patient is perceived to have a prognosis of 6 months or fewer should the disease run its usual course, he or she is eligible for the branch of palliative care known as hospice. Hospice emphasizes that accepting death is a natural part of life and seeks neither to prolong nor hasten death. Hospice pioneered the use of the interdisciplinary model toward the goal of optimizing quality of life while facing a life-ending illness.

The old and now suboptimal model of palliative care suggested that the patient have life-prolonging therapy until there was "nothing else" to try, followed by hospice care. New models of

#### Table. Skills core to the practice of palliative medicine.

A. Emergency Physicians	B. Palliative Medicine Subspecialists
Generalist skills	Generalist skills at an advanced level plus:
1. Assessment of illness	1. Inpatient palliative care (general wards/ICU/hospice/palliative care units,
Trajectory decline	nursing home)
2. Basic formulation of prognosis	<ol><li>Outpatient palliative care (clinic/home hospice/home visits)</li></ol>
3. Difficult communications	3. Interdisciplinary team dynamics
Breaking bad news/death disclosure	4. Psychosocial aspects of care
4. Advance care planning	
5. Family presence during resuscitation	
6. Management of pain/nonpain symptoms	
7. Withdrawal/withholding nonbeneficial	
treatments	
8. Management of the imminently dying	
9. Management of hospice patients/palliative	
care systems referrals	
10. Ethical/legal issues	
11. Spiritual/cultural competency	
12. Management of the dying child	

palliative care suggest that an integrated approach be used, in which life-prolonging therapies are balanced with measures aimed at maximizing quality of life, promoted by strategies of symptom relief and good communication about prognosis and goals of care. When the patient enters the final phase of up to 6 months of life if the disease runs its usual course, hospice care is appropriate.

In the out-of-hospital or emergency clinical arena, no ideal palliative care models exist.<sup>6</sup> For example, in the out-of-hospital setting in an area with a total coverage area of more than 47 million people, less than 6% of emergency medical systems had protocols in palliative care.<sup>7</sup> Most emergency clinicians do provide primary palliative care by routinely using their best clinical judgment and experience.<sup>8</sup> Like calling for cardiology consultation in acute myocardial infarction, palliative care consultations are appropriate for patients with distressing symptoms and other problems with care in the context of chronic fatal illness.<sup>9</sup> More than 25% of US hospitals have hospital-based palliative care clinical programs, and this number is increasing daily.<sup>10</sup> Early initiation of palliative care services in the emergency department (ED) is an increasing priority for palliative medicine.<sup>11,12</sup> As always, the ED is a first point of access, the front door to everything, including palliative care.

## GENERALIST OR BASIC PALLIATIVE CARE IN THE ED

At the present time, the emergency clinician faces clinical dilemmas in palliative medicine without the benefit of either having mastered a set of educational competencies in palliative care or of having a palliative medicine subspecialist at his or her side. Educators in emergency medicine have not yet comprehensively defined or embraced a core palliative medicine skill set for emergency providers. Although emergency medicine develops a core curriculum in palliative medicine, the National Guidelines for Quality Palliative Care can provide direction to all specialties as they build a cohesive educational curriculum in palliative medicine that addresses core domains across settings.<sup>13</sup> With extrapolations from these guidelines, core domains for palliative care in the ED should include the 12 domains in the Table (A). Specialty palliative care would include these skills and more at a detailed level (Table, B). Application of these basic skills and domains is examined through the framework of a clinical case.

#### CLINICAL CASE

H.M. is a 68-year-old man who presents with stage IV nonsmall cell lung cancer that has been refractory to several lines of chemotherapy and now has severe uncontrolled pain in his right chest wall, a known site of bony invasion of metastases. The patient spends most of the day in bed and is eating and drinking very little. He is taking morphine continuous release of 60 mg every 12 hours and rates his pain in his left chest wall as a 9 of 10. His son accompanies him and says he has become overwhelmed caring for his father. The patient has no written advance directive or advance care plan. He states that he "just wants to go home." What is optimal management in the ED?

Assessment of Illness Trajectory and Decline. New research has suggested that severely ill patients can be assigned to one of 4 predominant illness trajectories: sudden death, cancer, organ failure, or the gradual declining pattern known as frailty.<sup>14</sup> As shown in Figure 1, the patient's ability to provide self-care (function) changes rapidly on the organ failure (eg, heart failure) trajectory or slowly on the frailty trajectory (eg, Parkinson's). The curves indicate the speed at which the illness affects a person's function or performance status. Illness trajectories are derived from analysis of major medical condition in Medicare beneficiaries before death (Figure 1). Using a global illness trajectory for a patient may help the patient, family, and clinical team guide expectations and prognosis, determine appropriate goals for care, and create an effective use of ED, hospital, and community palliative care resources.<sup>15-21</sup>

**Basic Formulation of Prognosis in Common Conditions.** Formulation of prognosis is pivotal in assisting the ED



### **Proposed Trajectories of Dying**

**Figure 1.** Trajectories of dying. Reproduced with permission of Blackwell Publishing (Lunney JR, Lynne J, Hogan C. Profiles of older Medicare decendents. *JAGS*. 2002;50:1108-1112).

clinicians, patients, and decisionmakers in setting goals of care and appropriate clinical expectations. For example, there are good data to guide recommendations for inhospital resuscitation in malignant and nonmalignant conditions<sup>22-24</sup> and for use in estimation prognosis in cancer,<sup>25</sup> chronic obstructive pulmonary disease,<sup>26</sup> heart failure,<sup>27</sup> liver failure,<sup>28</sup> dementia,<sup>29</sup> and HIV.<sup>30</sup> Formulation of prognosis does not necessarily mandate the need to communicate the prognosis but can greatly assist the emergency clinician in framing recommendations for lifesustaining therapies, assessing dispositions, and preparing patients and families for what to expect. Although not ideal, communication of prognosis not previously discussed by primary care clinicians may need to occur in the ED. Evidencebased prognostic instruments provide confirmation that both symptom distress and performance status, the ability to provide self-care, are powerful predictors of a patient's poor prognosis.<sup>31</sup>

**Difficult Communications/Breaking Bad News.** Difficult communications include telling about failed resuscitations (death disclosure) or the diagnosis of an incurable disease (such as metastatic lung cancer), negotiating realistic goals of care, or recommending the withdrawal or withholding of nonbeneficial therapies. These are all crucial aspects of practice in the ED. The delivery of accurate information about the disease and its

prognosis, even if considered distressing for patients and families, is essential in developing realistic goals and expectations.<sup>32</sup>

Advance Care Planning. Comfort and skill with advance care planning are difficult to manage and master in the crisis setting of the ED. Although studies reveal that aggressive resuscitative efforts are not desired by all patients and families<sup>33,34</sup> only 8% to 24% of adults surveyed in the ED have completed an advance directive.<sup>35-37</sup> Even fewer present to the ED with a document.<sup>38</sup> To complicate matters further, even when an advance directive exists, if the patient still has decisional capacity, ED assessment of the patient's current wishes is still important.<sup>39</sup> Patient/family views may change over time, especially during the course of an acute illness, as well as potential confusion about what "comfort care" might mean.<sup>40</sup> As a result, emergency clinicians are often faced with the responsibility of discussing with patients or their surrogate decisionmakers at the bedside the value and appropriateness of aggressive interventions, such as cardiopulmonary resuscitation, when the discussion about their use becomes unavoidable.

*Family Presence During Resuscitation.* Emergency physicians should be familiar with procedures for allowing families to view resuscitation and support this practice when a

system is in place to allow this option.<sup>41,42</sup> Allowing family members to be present at the resuscitation of their loved one, referred to as family-witnessed resuscitation, has been formally endorsed by the Emergency Nurses Association.<sup>43</sup> Family presence may serve to allay guilt during their bereavement period and may be an important part of a healthy grieving process.<sup>44-47</sup> Despite endorsement by emergency nurses, physicians generally fear litigation, trauma to onlookers, or interference in resuscitation. Data show that such fears are unwarranted.<sup>48-59</sup>

*Management of Pain and Nonpain Symptoms.* The relief of distressing symptoms is required to improve the patient's quality of life. Unrelieved symptoms also can preclude the possibility of addressing psychological, social, and spiritual suffering and can interfere with the business of completing a life.

Pain relief is thus a central obligation of physicians treating patients at the end of life.<sup>60-62</sup> Unfortunately, nearly 50% of patients experience significant pain at the end of life,<sup>63</sup> giving all physicians an opportunity to greatly influence the patient's quality of life.

Thus, skills to manage acute and chronic pain are essential. A fund of knowledge in opioid pharmacology, including the dosing and pharmacokinetics in both opioid-naive and opioid-tolerant patients, allows for an evidence-based approach to pain care and helps mediate and allay ethical or legal dilemmas, particularly concerning the fears of respiratory depression. Though widely feared, respiratory depression is in fact a rare occurrence when medications are dosed appropriately.<sup>64</sup> Pharmacologically based approaches are also required to manage distressing nonpain symptoms such as dyspnea, nausea/vomiting, and delirium.

Withdrawing and withholding nonbeneficial treatments. When more information is obtained about end-of-life wishes, such as that found in an advance directive or in a subsequent discussion with the patient or surrogate, aggressive therapies aimed at life extension may be withheld or withdrawn and comfort-based strategies, such as pain relief and sedation, provided instead. In some clinical scenarios, the emergency physician may need to take the lead in initiating discussions about the desirability of life-sustaining treatment when the death is inevitable regardless of treatments used. The emergency physician can educate, assist in deliberation, and make clinical recommendations about the treatment plan according to the specific goals of care. In particular, emergency clinicians should be familiar with commonly accepted evidence-based procedures in palliative medicine for ventilator withdrawal<sup>65</sup> and should be able to provide advice on the pros and cons of artificial nutrition and hydration at the end of life.<sup>66-68</sup>

*Management of the imminently dying.* Care of patients with imminent death, where comfort measures are used as the disease advances to completion, is likely to be a more difficult area for emergency clinicians because the habitual response is to resuscitate. Recognition of natural dying and death and

explaining to families what to expect when death is imminent are crucial to lessening the suffering of the patient and family. It may also help avoid doubts about aggressive interventions once the decision has been made to forgo these efforts. Natural death from chronic incurable illness is characterized by changes in neurologic, respiratory, circulatory, and muscular function, resulting in laboratory and vital sign abnormalities that culminate in low blood pressure, slow breathing, and apnea.<sup>69</sup> Patients and their families should be encouraged to comfort one another during this process, by the presence and guidance of the multidisciplinary team in the ED, including physicians and nurses, but especially by the chaplain and social worker.

*Knowledge of Hospice and Palliative Care Systems.* Clinicians can be more effective if they become familiar with criteria for the appropriate referral of patients to hospital- or outpatient-based palliative care services,<sup>70</sup> including a familiarity with Medicare guidelines for hospice care.<sup>71</sup> Such recommendations for care should be based on a number of factors, including patient and family preference, ability to function, severity of symptoms, and nutrition/hydration status.<sup>72</sup> Some patients may be directly admitted to hospice or palliative care inpatient services or discharged home with a hospice referral. In hospitals with palliative care consultation services for the ED, consider seeking a palliative care a patient is eligible for hospice and how to best access this benefit for them.<sup>73</sup>

*Ethical and Legal Issues.* Patients who have decisionmaking capacity have the right to consent to or refuse any and all recommended medical treatments. Patients who do not have decisionmaking capacity may have their right to accept or refuse treatment asserted on their behalf by those with legal authority to do so, such as an agent of a durable power of attorney for healthcare, or a legally recognized surrogate, for example a guardian or family member.<sup>74,75</sup> Withdrawing and withholding treatments are regarded as ethically and legally equivalent.<sup>76-78</sup>

State law may govern the level of evidence required (eg, preponderance of the evidence or clear and convincing evidence) to be able to act on behalf of a patient who currently lacks decisionmaking capability. Evidence may be written, such as that expressed in a living will or in a power of attorney for health care document, or other evidence, such as conversations with physicians or family.<sup>79</sup> Ultimately, decisions concerning end-of-life care should be discussed with family and friends, and the expressed wishes of the patient when he or she is able to make decisions should take precedence. Emergency physicians should be familiar with these standards so that, if end-of-lifecare discussions need to take place while caring for the patient in the ED, they can serve as knowledgeable participants. There is significant ethical and legal controversy concerning requests by family for treatments that may not improve the patient's quality of life (eg, request for dialysis in a patient in persistent vegetative state). However, despite the legal requirements under

the Emergency Medical Treatment and Active Labor Act to treat or stabilize patients with life-threatening illnesses, there is no ethical or legal requirement to institute measures that would not be medically beneficial.<sup>80</sup>

Since death may occur during appropriate palliative treatment, the ethical principle of the "double effect" becomes relevant. It permits the unavoidable shortening of a patient's life in the context of medical or surgical therapy, provided that hastening death is not the intent of the caregiver or goal of the procedure. Ethicists and courts have recognized this potential double effect—treatment aimed at cure or comfort may also unintentionally hasten a patient's death—as ethically and legally appropriate.<sup>81,82</sup>

*Spiritual and cultural considerations.* Emergency physicians encounter spiritual and cultural issues frequently in the ED but may not address them directly. Chaplains and social workers play a key role in the provision of these services. Regardless of the ethical beliefs of the physician, a supportive environment, including religious, cultural, and social practices, serves an important function at the end of life. Spiritual, religious, and cultural beliefs about death and dying vary widely.<sup>83</sup> Thus, it is important that providers whenever possible permit the expression of a variety of experiences rather than focusing only narrowly on medical issues.<sup>84-87</sup>

*Management of the dying child.* Pediatric palliative care and death in the ED are particularly challenging for families and health care providers.<sup>88</sup> A multidisciplinary approach should include effective communication, empathy, allowing family presence, allowing a physical memento (such as a lock of hair or handprint), and follow-up communications.<sup>89-98</sup> Specific to pediatrics, the majority of parents indicate that they would prefer to be present during procedures performed on their child. Moreover, most parents are more willing to be present during less invasive procedures.<sup>99,100</sup> A recent statement from the National Consensus Conference on Family Presence During Pediatric Cardiopulmonary Resuscitation and Procedures recommends that family presence be considered during such procedures and that education and research about family presence be supported.<sup>101</sup>

**Training opportunities in palliative care.** To assist in providing training opportunities for basic palliative care skills for emergency care providers, the National Cancer Institute of the National Institutes of Health has sponsored the Education in Palliative and End of Life Care–Emergency Medicine (EPEC-EM) Project. Developed especially for emergency physicians, nurses, out-of-hospital providers, chaplains, and social workers interested in learning and teaching core skills in palliative care for use in the ED, the project is an evolving resource that seeks to create and disseminate a palliative medicine curriculum. It has been developed by and for use by emergency educators and clinical providers across disciplines. Its focus is on providing clinicians with palliative care skills tailored for use in the ED, with the vision to enhance education, improve clinical practice, and positively affect patient outcomes and ED practice norms.<sup>102</sup>

#### CLINICAL CASE CONCLUSION

The case of H.M. can now be appropriately managed with the key precepts listed above. Using the cancer trajectory for the patient and observing that the patient is now bed bound, the emergency physician realizes that the patient now has just weeks to months to live. A candid discussion with his oncologist confirms this, and the oncologist reluctantly admits to the emergency physician that, given the patient's functional or performance status, he has nothing more to offer him in the way of cancer-directed therapy. The emergency physician discusses the possible goals of care with the patient's son, his surrogate decisionmaker. He finds that the patient is a widower, having lost his wife to a stroke in the past year. The son indicates that his father has expressed that he is tired of fighting and just wants to be comfortable. A conversion based on his current oral opioid dose indicates that a bolus of 10 mg of morphine will ease his pain, and his pain score subsequently decreases to a 3 of 10 after intravenous administration of morphine sulphate. A palliative care consultation is called, and that team arranges for admission to inpatient hospice, with a goal of discharging him to home hospice as soon as his symptoms are well controlled. A Do Not Attempt Resuscitation order is entered by the emergency physician after discussion with the palliative care team. An ICU consultation that was planned is no longer necessary. H.M. is discharged from inpatient hospice 3 days after admission. He dies in home hospice 3 weeks later, accompanied by his family, free of pain and at peace.

#### A NEW OPPORTUNITY FOR EMERGENCY PHYSICIANS: THE SUBSPECIALTY PRACTICE OF PALLIATIVE MEDICINE

Emergency clinicians will struggle during the next decade on the optimal skill set and model to provide the best palliative care in the ED setting.<sup>103</sup> Currently, emergency physicians with a strong desire to deepen their expertise in palliative care may wish to pursue a career in subspecialty palliative medicine practice. Requisite to successful practice is a willingness to accept death as a normal part of life and move beyond the now obsolete belief that death means failure. Embracing the concept of the "good death" entails understanding that an interdisciplinary team approach is necessary to achieve this goal. Only such a team can address on a deep level the physical, spiritual, psychological, and social aspects of care. Hence, emergency physicians who seek palliative medicine specialty training will gain both a deeper knowledge and skill level in the 12 core domains of the National Consensus Guidelines. Understanding these core competencies in hospice and palliative medicine also serves as a guide for emergency physicians to the advanced practice of palliative medicine<sup>104</sup> and indicates the topics likely to be covered in detail during fellowship training or practice track experience.



Figure 2. Pathway to Palliative Care Board certification.<sup>106</sup>

Emergency physicians in academic positions who pursue subspecialty certification will be leaders in palliative educational, research, and quality initiatives for emergency care. Similar to emergency physicians who pursue careers in toxicology, palliative emergency medicine faculty would be expected to teach residents, faculty, and staff. In partnership with residency program leadership, they will refine and optimize curricula and teaching models to suit emergency clinician education in palliative medicine.

The model for practice of an integrated clinical career of palliative medicine and emergency practice is in evolution. Palliative medicine subspecialty physicians most often serve as hospice medical directors or hospital-based consultants. Shift work lends itself well to pursuing these career options as one accommodates schedules to meet inpatient palliative care team obligations or hospice responsibilities. In academic and private practice, these physicians can serve as important liaisons to the inpatient and community hospice partnerships.

#### EMERGENCY PHYSICIANS' PATHWAYS TO PALLIATIVE MEDICINE SUBSPECIALTY BOARD CERTIFICATION

Before the recognition by the American Board of Medical Specialties, the non-ABMS American Board of Palliative Medicine specified criteria for board certification and administered the qualifying examination. With the approval of subspecialty status by the ABMS, all currently certified hospice and palliative medicine diplomates will be eligible to take the new Hospice and Palliative Medicine Certification examination. It is estimated that there are more than 1,500 physicians in the United States, including 22 emergency physicians, certified in hospice and palliative medicine by the previous non-ABMS board with more to be certified with the 2008 exam.<sup>105</sup> This non-ABMS board will be dissolved.

Physicians who have not previously been certified may become eligible for certification examination by one of 2 pathways: an Accreditation Council for Graduate Medical Education-approved fellowship or a practice track ("grandfathering") process open until 2012. For the practice track, clinicians must (1) have at least 800 hours of clinical involvement in subspecialty-level practice of hospice and palliative medicine, (2) have at least 100 hours of interdisciplinary team participation during a minimum of 24 months with a hospice and palliative care team, and (3) participate in the active care of at least 50 terminally ill patients (25 for pediatrics). An interdisciplinary team must have the regular membership of a physician, nurse, and at least 1 other professional from a psychosocial discipline. The team must provide active clinical care, hold regular meetings, and operate in the context in which a substantial number of the team's patients are near the end of life<sup>106</sup> (Figure 2). Such interdisciplinary teams need to be involved in active bedside clinical care. As a condition of certification, ABEM diplomates must maintain active emergency medicine board certification. Accreditation Council for Graduate Medical Education fellowship training is ideal and should be pursued whenever possible.<sup>107</sup> Fellowship training may be impractical for emergency clinicians in clinical practice, and for this potentially large group of candidates, partnership with an established hospital-based palliative care team or hospice team is the most effective route to gain the specified clinical experience.

#### CONCLUSION

Emergency clinicians provide palliative care to patients in their daily practice and have done so since the inception of the specialty. Building on this component of emergency practice, the new subspecialty of palliative medicine has opened to emergency physicians. Whether one pursues specialization or not, all emergency clinicians can use the growing body of knowledge of palliative medicine in their bedside ED practice. Education of current core faculty responsible for postgraduate training is a first step. The authors hope that the incorporation of evidence-based palliative medicine skills in emergency medicine residency training will ensure quality practice in our EDs for all patients. Emergency physicians who pursue palliative medicine subspecialty training will provide the educators and researchers needed to build the field of EDcentered palliative medicine.

The rewards of a honed set of palliative medicine skills for emergency clinicians come when goals of care are properly identified and supported, when pain or other symptoms are relieved, when a death disclosure goes well, and when a child or adult dies in the ED with dignity and comfort. It is hoped that generalist skills in hospice and palliative medicine will improve across all specialties, with benefits to patients, staff, medical students, residents and faculty, and hospital systems. The vision is to achieve high-quality care from initial diagnosis to ultimate resolution for all patients and families who present to the ED and face life-threatening illness. With its emphasis on improved communication, quality of life, patient satisfaction, and the appropriate and coordinated use of scarce health care resources, the advent of palliative medicine could not be timelier.

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