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## AUTHORS:

**Ruth M. Thomson, DO, FACOI, FAAHPM**, Chief Medical Officer, Innovative Care Solutions/Hospice of Dayton, Dayton, OH

**Chirag Rajni Patel, MD**, Medical Director, Innovative Care Solutions, Dayton, OH

## PEER REVIEWER:

**Robert B. Taylor, MD**, Professor Emeritus, Oregon Health & Science University, Portland, OR

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To reveal any potential bias in this publication, and in accordance with Accreditation Council for Continuing Medical Education guidelines, we disclose that Dr. Farel (CME question reviewer) owns stock in Johnson & Johnson. Dr. Stapczynski (editor) owns stock in Pfizer, Johnson & Johnson, AxoGen, Walgreens Boots Alliance Inc., and Bristol Myers Squibb. Ms. Mark's spouse (executive editor) works for a company that creates advertising for Uroplasty. Dr. Schneider (editor), Dr. Wise (editor), Dr. Thomson (author), Dr. Patel (author), Dr. Taylor (peer reviewer), Mr. Landenberger (editorial director), and report no financial relationships with companies related to the field of study covered by this CME activity.

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## Palliative Care Principles for Emergency Providers

*This article is adapted from one that originally appeared in the August 2013 issue of Primary Care Reports.*

Palliative is derived from the Latin *palliare*, which means to cloak. In the world of palliative care, cloak is quite representative of the many supportive functions a palliative care team member can provide for a patient and family.

In September 2006, the American Board of Medical Specialties (ABMS) approved the creation of a subspecialty of Hospice and Palliative Medicine (HPM). Emergency Medicine is one of 10 sponsoring organizations for this sub-board. In June 2006, the Accreditation Council for Graduate Medical Education (ACGME) defined a process to have existing HPM fellowship programs be accredited by ACGME and set a standard that after 2013 only fellowship-trained clinicians would be eligible to sit for the ABMS Board examination. Today, the ACGME Graduate Medical Education Data Resource Book lists 76 ACGME-accredited HPM fellowship programs in the United States. Qualified emergency physicians are eligible for most of these fellowships. In February 2007, the American Osteopathic Association (AOA) Bureau of Osteopathic Specialists approved a Certificate of Added Qualification (CAQ) in hospice and palliative medicine, and the AOA Boards of Family Medicine, Internal Medicine, Neurology & Psychiatry, and Physical Medicine & Rehabilitation added the CAQ in hospice and palliative medicine. Currently, the AOA lists seven approved hospice and palliative care residency programs in the United States.

Even though palliative care is considered a young specialty with only recent acknowledgements by national governing medical boards, the concepts and principles used by palliative care practitioners find their roots in hospice care. The first hospices reported date back to the 11th century, where the incurable were given dedicated treatment.<sup>1</sup> In 1967, nurse, social worker, and physician Dame Cicely Saunders founded the world's first modern hospice, St. Christopher's Hospice, in the United Kingdom. Since its inception, hospice has grown dramatically, and its growth has accelerated in recent years to become a multibillion dollar a year industry. In 2011, an estimated 1.65 million patients received hospice care in

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## EXECUTIVE SUMMARY

- In 2006, the American Board of Medical Specialties approved the creation of a subspecialty of hospice and palliative medicine. These fellowships are open to emergency physicians, many of whom have incorporated palliative medicine into their full time practice.
- Emergency physicians should consider palliative care for patients with complex medical conditions where symptom control is desired. Examples are patients with sickle cell, end stage COPD, CHF, liver disease, and those with advanced diabetes.
- Pain control may be started with acetaminophen or NSAIDs, but frequently opioids are needed. Start treatment for breakthrough pain at 10-20% of the current daily dose of opioids. Repeat after 15-30 minutes if pain persists.
- Treat nausea with standard medications including ondansetron. Haldol is an effective anti-emetic. Dyspnea can be controlled with morphine or benzodiazepines.
- Patients and their families (and readers of this article) are encouraged to discuss their desires around end of life. In the emergency setting, families often just need to be made aware that "now is the time" and that everything has been done.

5300 programs throughout the United States, with 44.6%<sup>2,3</sup> of all deaths in the United States occurring within a hospice program, accounting for a total Medicare expenditure of \$14 billion. To receive hospice services, a patient must be deemed terminally ill by two physicians, with the expected outcome of death within 6 months if the natural course of medical illness is left unaltered.

As medical management of so many illnesses has improved with better therapy and fewer side effects, life expectancy has increased as a result. The AARP Public Policy Institute released a fact sheet detailing expected growth of Medicare beneficiaries. In 2007, 44 million individuals (15% of the U.S. population) were enrolled in Medicare. Enrollment numbers are expected to rise dramatically, projected up to 79 million by 2030 as the baby boomer generation ages.<sup>4</sup> This projected Medicare population is expected to have increasing numbers of chronic conditions that are expected to continue to drive costs higher.<sup>5</sup> As reported in a statistical brief by the Medical Expenditure Panel Survey, 1% of the U.S. population accounted for 28% of total health care expenditures, and 5% of the U.S. population drove more than half of all medical costs.<sup>6</sup>

A report released by the Dartmouth Atlas of Healthcare looking at research from a large-scale, Robert Wood Johnson Foundation-funded study asked patients with serious illness where they would prefer to die at the end of life. A majority of the respondents listed home as their preference; however, 55% actually died in the hospital and the care these individuals desired rarely aligned with the care they received.<sup>7</sup>

A recent poll of Californians showed a large gap between the care patients want and the care received at the end of life. This survey, reported in the *Final Chapter: Californians' Attitudes and Experiences with Death and Dying* and released in February 2012 by the California Healthcare Foundation, finds that nearly 8 out of 10 individuals would prefer to die at home if seriously ill and reports that individuals would want to talk with their doctor about end-of-life care. Of concern, fewer than 1 in 10 individuals reported that they had such a conversation, including just a little more than 1 in 10 (13%) of those 65 years or older. When specifically asked about advance directives, 82% of these individuals corroborated the importance of the documents, but in actuality, fewer than one-fourth had completed them.<sup>8</sup>

Of interest is that physicians more frequently have some type of advance directive, and the majority, regardless of age, do not want aggressive resuscitation. Physicians are more likely to die at home than are the patients they care for.

There may be several reasons for this disparity. However, as every emergency provider knows, few patients come with any type of advance directive. And those who do are often still brought to the ED even though they are clearly in the final stages of death. Based on the very high survival of patients who receive CPR on TV, where the majority of patients go home with good functionality, families may override the patient's wishes. At times, families agree with withholding treatment at the final stage of life, but fail to recognize it is the final stage.

As reported by the Center to Advance Palliative Care (CAPC) 2011 public

opinion report, once patients and families understood the definition of palliative care, with language that best fit its principles and mission, the majority of polled individuals endorsed that if they had serious illness they would want access to palliative care.<sup>9</sup> Certainly patients at the end of their life's journey should receive and have access to all measures of hospice and palliative care, to assure comfort, dignity, and quality of life until death. But one could argue that suffering is not only perceived for those who fit Medicare's defined end-of-life window; in fact, suffering is something patients with serious illness and their families battle every day. Research proves that patients want access to symptom management, clarity and alignment of their goals of care, and total support not only for themselves but also for their families. This is where palliative care and its principles can be effectively used to satisfy this need.<sup>9</sup>

### What Is Palliative Care?

One of the greatest challenges palliative medicine practitioners face is explaining to patients, families, health care administrators, and other health care workers what they really do. This point was proven by the CAPC public opinion strategies report. Interpretation of what palliative medicine is or does is often defined by an individual's perceived understanding of what he/she feels. This survey polled 800 registered users (300 of these members were seniors  $\geq$  65 years of age) via telephone and asked, "How knowledgeable, if at all, are you about palliative care?"<sup>9</sup>

The report illustrated that palliative care is poorly understood. Seventy-eight percent of individuals who answered the

survey said they were not at all knowledgeable. A more concerning finding is that physicians commonly equate palliative care to hospice or end-of-life care. A limitation of this report is that only eight physicians were polled, but those who were questioned were very resistant to believe that palliative care is nothing more than hospice care or end-of-life care. These physicians believed strongly that patients who receive palliative care should have comfort, symptom management, and maintenance of dignity at the end of life. One individual mentioned support of family, but again, directed toward the end of the continuum of care.

The language used to define palliative care makes a meaningful difference in what is perceived by patients and families. Simply using the word serious vs advanced to define the status of an illness was shown to have less negative emotion, and the medical care that would be needed was less connected to terminal care for individuals who were polled.

Many national and global health care governing organizations have reported definitions and support for palliative care. The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>10</sup>

“Palliative care is patient- and family-centered care that focuses on effective management of pain and other distressing symptoms, while incorporating psychological and spiritual care according to patient/family needs, values, beliefs, and culture(s). The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of disease or the need for other therapies. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care.”<sup>11</sup>

The CAPC updated the language in its definition after public opinion research showed a significant positive impact of this definition. “Palliative care is the specialized medical care for people with serious illness. This type of care is focused

on providing patients with relief from the symptoms of pain and stress of a serious illness — whatever the diagnosis. The goal is to improve the quality of life of both the patient and family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.”<sup>9</sup>

Patients and their families (and readers of this article) are encouraged to discuss their desires around end of life. In the emergency setting, families often just need to be made aware that “now is the time” and that everything has been done.

In gist, palliative care can be accessed at any stage of serious illness, using a multidisciplinary team of health care professionals looking at aspects of a patient’s care including input from family at every level. The team works collaboratively with the primary medical team to maximize symptom control, improve quality of life, and support patients and families.

## Where Can I Find Palliative Care?

The nation’s hospitals are still the most prevalent site for palliative medicine delivery. Since 2000, the number of palliative care programs within hospital systems has grown by 148.5%, and as of 2011, 65.7% of U.S. hospitals reported having palliative care programs.<sup>12,13</sup> Since hospitals are the site for the most acutely ill patients, a frequent site of death, and a place where fragmented communication to patients and families is common, it is not surprising that hospital palliative care programs have grown so rapidly.

Many emergency physicians have developed palliative care practices based in the ED. Such programs have been successful in reducing hospitalizations and reducing the use of intensive care. The American College of Emergency Physicians has a Palliative Care Section with many free resources, including case studies of successful emergency-based palliative care programs.

## Gaps in the Continuum of Care

With Medicare’s new focus on the

patient experience, looking at pain and other symptom scores linking reimbursement to outcomes as a part of the Affordable Care Act,<sup>14,15</sup> hospitals remain a necessary site for palliative care delivery. It has been argued and proven that earlier palliative care intervention improves quality of life, and palliative care even improved length of life for patients with metastatic non-small cell lung cancer.<sup>16</sup>

Palliative care should ideally be involved long before a patient arrives in the ED. Should they be involved, it is helpful to contact them as they are likely to understand the wishes of the patient. They can be very helpful interacting with the family. However, palliative care may not be involved, they may not even be present in most hospitals. Like many resources, they may keep “regular” hours.

The benefit of providing integrated palliative care across the entire continuum of care — specifically for high-risk, late-stage, chronically ill patients — is seen clearly by the Advanced Illness Management (AIM®) program offered by Sutter Health in northern California. This systems-based model of palliative care delivery has shown an increased use of hospice care after properly aligning patient/family goals using advance directives and medical/physician orders for life-sustaining treatment documents (MOLST/POLST). Data also showed less ambulatory care and inpatient usage by patients enrolled in the AIM® program. For patients who survived more than 90 days after enrollment, data showed a 54% decline in hospitalization compared to the 90-day interval period prior to AIM® enrollment. ICU days and length of stay on subsequent hospitalizations both were reduced. Visits to physicians’ offices also declined, with a small uptick in physician telephone calls.<sup>17</sup> These accomplishments were achieved with improved patient, family, and physician satisfaction when measured.<sup>18</sup>

## Isn’t Palliative Care Really the Responsibility of the Primary Care Physician?

The answer, of course, is yes. However, when the system fails, emergency care must fill in the gap. Primary care physicians lack the time, and often the knowledge, to provide this level of care. Many

**Table 1. Benefits of Palliative Care**

- Improved patient and family understanding of illness
- Clarification of treatment goals
- Assistance with complex medical decision making
- Improved early symptom recognition and expert management
- Supportive services using interdisciplinary team model to deliver targeted and efficient care (incorporating all eight domains that cause suffering)
- Family support
- Grief support
- Transitional care
- Survivorship
- Reduced hospitalizations/ED visits
- Improved coordination of care

no longer care for their own patients within the hospital, fragmenting care for the most vulnerable patients. While many suggest that primary care physicians do not provide palliative care or have end of life discussions because there is no reimbursement, that is a harder argument for emergency providers to understand, as many are required to provide free care.

A recent paper<sup>19</sup> corroborates the importance of the primary care physician's role in today's fragmented health care delivery system. A perception illuminated in this discussion was that many primary care physicians are not on the front lines when it comes to end-of-life care. Often, a letter of condolence or a death summary is sent from the end-of-life responsible care party confirming the death of a patient. As the prevalence of the site of death has moved from home to institutions, it is easy to see why primary care physicians feel less engaged in participating in end-of-life discussion with patients and their families.

Primary care physicians hold extreme value in helping patients and families transition during critical phases in their clinical life.<sup>19</sup> No one is better suited to discuss patient goals, desires, and quality-of-life outcomes than the physician who best knows and has the trust of that patient and his/her family.

Emergency physicians can use some palliative care principles, such as improving symptom assessment and management; using patient and family goals vs problem-focused care as the directive; learning improved understanding of prognosis; delivering this message with compassion and empathy; and recognizing that spiritual, psychosocial, and

cultural elements play a relevant role in creating suffering in patients with serious illness.

### Benefits of Implementing Palliative Care Principles

The benefits of using palliative care principles in emergency practices are clear. (See Table 1.) Implementing a structured approach to define what factors make up the characteristics of a patient and his/her family in the context of understanding specific domains of concern to individuals facing serious and possibly life-limiting illness can help assure focus remains on what is relevant to that patient and his or her family.

Physicians can use patient and family characteristics — including demographics, culture, personal views, beliefs, and values — to identify areas that can cause suffering for patients with serious illness and their families.<sup>20</sup>

### Identifying Patients for Palliative Care

Palliative care can be delivered to any patient of any age with a serious, potentially life-limiting or life-threatening illness. Disease can be in any organ system. Table 2 lists examples of conditions that could lead to palliative care intervention. Any patient with serious illness for whom recovery back to normal function is routine and expected would not be included in this defined population.<sup>21</sup>

Certain characteristics of patients with serious illness can help define their eligibility for palliative care. Research shows that individuals with multiple hospitalizations, especially with less interval time between, are at risk of decline and possibly may need palliative care.<sup>21</sup> Other

functional or clinical changes — such as weight loss, decrease in functional status, more dependence on others for activity of daily living support, and refractory symptoms despite medical intervention — can further reinforce to the clinical team that there could be unmet palliative care needs for this patient and/or his/her family. Another clarifying question to ask with every palliative care encounter is, “Would you be surprised if this patient died within 12 months?” This “surprise” question has proven to be remarkably valid in predicting poor outcomes.<sup>22-24</sup>

Using symptom assessment scales also can identify symptom risk, incorporating not just physical, but psychological and spiritual distress as well. NCCN has established guidelines for distress management using a thermometer linked to practical problems as well as physical problems.<sup>25</sup> The National Palliative Care Research Center has multiple screening tools available for use, including pain and symptom management, functional status, psychosocial care, caregiver assessment, and quality-of-life measuring tools.<sup>26</sup>

### Models of Palliative Care Delivery

As health care continues to become more complex and fragmented, a reasonable option would be to defer implementing palliative care to specialists.

As previously stated, the number of Medicare beneficiaries is expected to significantly increase and that many will be living with multiple chronic conditions. With the described workforce shortages for palliative care personnel and increasing growth of at-risk populations, understanding and implementing basic palliative care principles by emergency physicians makes theoretical sense.<sup>27</sup>

While many of the principles of palliative care can be learned without formal fellowship training, a recent article delineated those who should be referred to palliative care specialists.<sup>27</sup> (See Table 3.)

Individual specialties and institutions should develop expectations with prescribed outcomes for basic palliative care skills and screening tools to guide specialty palliative care consultations.<sup>27</sup>

Emergency physicians who have access to palliative medicine experts in community specialty programs or tertiary academic centers can rely on these

experts as valuable resources to assist with complicated symptom management and palliative care needs.

## Palliative Care Components

**Symptom Management.** Symptom management encompasses addressing pain and other distressing physical and/or psychosocial symptoms or medical problems patients experience as a result of their advanced illness. In a 2004 study, Paice et al performed a retrospective chart review of all adult patients who died in the hospital setting over a 6-month period in the ICU, oncology, and medical unit settings. Of 213 patients who met inclusion criteria, 195 were included in the final analysis. They noted that most of the patients in this population experienced one or more distressing symptoms: pulmonary congestion (92%), confusion (86%), fever (78%), dyspnea (78%), pain (77%), fatigue (42%), sedation (36%), constipation (32%), agitation (32%), and decubitus ulcers (26%).<sup>28</sup> This symptom analysis provides a fairly complete list of the typical distressing symptoms patients experience in their last few days to weeks of life. Other common symptoms warranting palliation include nausea, vomiting, anxiety, depression, and anorexia.

In 2009, the NCCN released Palliative Care Clinical Practice Guidelines in Oncology, which addresses pain, dyspnea, anorexia/cachexia, nausea/vomiting, constipation, malignant bowel obstruction, delirium, as well as advance care planning and post-death support.<sup>29</sup> Although the guidelines are intended for oncology patients, they are applicable to patients with noncancer advanced illness. The guidelines also embrace the spirit of palliative care by addressing symptoms and needs early in the disease course rather than only focusing on end-of-life. This is accomplished by categorizing palliative interventions based on projected prognosis into years, years to months, months to weeks, and weeks to days.<sup>29</sup>

**Pain.** It is important to recognize that most patients with any serious illness will experience at least some degree of pain during the course of their disease. Pain may be directly related to the advanced illness itself, the dying process at end-of-life, or unrelated, in the form of chronic pain as a comorbid condition. Regardless

## Table 2. Patients Appropriate for Palliative Care

### Defining the Population

- Advanced cancer, especially with symptom burden
- Progressive illness
  - Pulmonary disorders
    - Few conditions, but not limited to: oxygen-dependent chronic obstructive pulmonary disease, cystic fibrosis, pulmonary fibrosis, pulmonary hypertension
  - Advanced renal disease
    - Contemplating renal replacement therapy
  - Advanced cardiac disease
    - Out-of-hospital cardiac arrest
    - Contemplating medical cardiac support (LVAD)
    - Consideration of continuously infused inotropic support
  - End-stage AIDS
  - Liver disease
    - Cirrhosis
  - Neurologic disorders
    - Few conditions, but not limited to: dementia, neuromuscular disease, organ brain disease, amyotrophic lateral sclerosis, multiple sclerosis, cerebrovascular accident
- Death imminent
  - Multi-organ system failure, sepsis, major trauma
- Limited social support
- No advanced care planning discussion or document
  - Goals of care conflict
- Consideration of artificial nutrition and hydration

of cause, relief of suffering from pain for patients with advanced illness is globally considered a patient right. The Joint Commission released pain management standards in 2001 that resulted in the designation of assessing pain as “the fifth vital sign.” The standards require that assessment and treatment of pain is a patient’s right, pain should be assessed at every initial encounter and reassessed periodically as clinically appropriate, and pain management education should be available for all patients suffering from pain and their families.<sup>30</sup> Despite the Joint Commission standards and incorporation of pain as the fifth vital sign, improvement of pain management has been questioned. The results of a small VA comparison study by Mularski et al showed no difference in management of pain before and after implementation of eliciting and documenting pain as the fifth vital sign.<sup>31</sup> All clinicians are responsible for continuing to strive to make an impact on relief of suffering from pain related to advanced illness. Assessment and routine reassessment of pain control is critical to achieving good outcomes in

pain management.

The basis of modern pain management is built on the World Health Organization stepladder, first described in 1986. The pain ladder recommends a systematic approach of matching the strength of analgesics to the level of pain, titrating analgesics in a stepwise manner in response to uncontrolled pain, administering analgesics around-the-clock rather than as needed, and utilizing adjunct medications to aid in pain relief.<sup>32</sup>

Many ED patients complain of severe pain; however, it is important to address mild to moderate pain in patients with cancer and advanced noncancer conditions. Providers should ask about mild pain and, when present, treat it. Typical nonopioid analgesics include acetaminophen, ibuprofen, and other nonsteroidal anti-inflammatory drugs (NSAIDs). These are most effective for mild pain, particularly nonmalignant pain. Acetaminophen is a good initial choice for pain relief in the elderly who are struggling with advanced noncancer illness, since their source of pain is often musculoskeletal related to osteoarthritis

**Table 3. Defining Specialty Palliative Care**

**Basic vs Specialty-level Palliative Care Skill Set**

- Primary palliative care
  - Identification of symptoms/suffering
  - Basic management of pain and symptoms
  - Basic management of depression and anxiety
  - Basic discussions about:
    - Prognosis
    - Goals of treatment
    - Suffering
    - Code status
- Specialty-level palliative care
  - Management of refractory symptoms
  - Management of complex depression, anxiety, grief, and existential distress
  - Assistance with conflict resolution regarding goals or methods of treatment
    - Within families
    - Between staff and families
    - Treatment teams
  - Assistance in addressing cases of near futility

Adapted from: Quill TE, Abernethy AP. *N Engl J Med* 2013;368:1173-1175.

and may be compounded by decreased mobility. For ongoing pain, acetaminophen is most effective if it is administered on a routine schedule, being mindful not to exceed 3 g in 24 hours for geriatric patients and exercising caution in patients with hepatic or kidney disease. NSAIDs can be helpful for mild malignant or nonmalignant bone pain. In the palliative care patient population, NSAIDs are most commonly used as adjuvants to opioids for bone pain relief. Caution should be used when prescribing NSAIDs to geriatric patients and patients with renal, hepatic, hematologic, and cardiovascular disease, and a history of GI bleeding. Consideration should be given to prescribe GI prophylaxis for prolonged NSAID administration or concomitant steroid use.

Opioid/nonopioid combination medications are very commonly prescribed in all areas of pain management. In the palliative care setting, they are most effective for mild-to-moderate pain. If utilized as the sole medication for ongoing pain, they are most effective if prescribed on a routine schedule. If they are prescribed as short-acting therapy for breakthrough pain in addition to a long-acting opioid, as-needed dosing is appropriate. Clinicians must remember to exercise the same caution with these combination

medications as with acetaminophen and ibuprofen alone.

Pure opioids are most appropriate for moderate-to-severe pain. Emergency physicians often see patients with advanced disease whose current pain regimen has failed. ClinCalc.com is a great resource for converting oral to intravenous doses and determining equivalent doses between opioids. Breakthrough pain should be treated by first determining the patient's current daily dose of opioids and administering 10-20% of that. Patients should be reassessed in 15-30 minutes and additional medication given if pain persists.

If the patient is going to be discharged either to home or to a facility, continued pain treatment should be ordered. As-needed dosing is appropriate if prescribed for breakthrough pain in addition to a long-acting opioid. Commonly prescribed immediate-release opioids include oxycodone, morphine, and hydro-morphone. Sustained-release opioid choices include oxycodone CR, morphine ER, and fentanyl patch. Unfortunately, when managing ongoing pain in the palliative care patient population with long-acting opioids, most patients will still experience breakthrough pain at least some of the time; therefore, clinicians should always prescribe a short-acting

opioid as needed for rescue dosing.

Possessing unique pharmacokinetics, methadone exhibits both short-acting and long-acting properties. In addition to binding to the  $\mu$ -opioid receptor, methadone also blocks the NMDA receptor, resulting in effectiveness in managing somatic or visceral pain and neuropathic pain. Because of its long and highly variable half life and multiple drug-drug interactions, methadone is best reserved to be prescribed by clinicians with a good working knowledge of the potential implications of its pharmacokinetics and experience with the drug. Specialists trained in pain management or hospice and palliative medicine can serve as a resource to clinicians without experience prescribing methadone.

For patients with renal failure, it is best to avoid morphine because of the potential for its active metabolite, morphine 6-glucuronide, to accumulate, resulting in undesirable side effects including sedation and respiratory depression.<sup>33</sup>

Adult patients with sickle cell can be very challenging in the ED. The best treatment plan is established as an individualized protocol, created by the outpatient physician and the patient. When such protocols do not exist, NHLBI guidelines ([nhlbi.nih.gov](http://nhlbi.nih.gov)) provide clear guidance for initial and subsequent care. There are also extensive resources at [sickleemergency.duke.edu](http://sickleemergency.duke.edu).

Constipation is one of the most common side effects of chronic opioid administration. Opioids exert this effect in the gut by binding to  $\mu$ -opioid receptors in the enteric nervous system, resulting inhibition of both excitatory and inhibitory neurotransmitters and leading to peristalsis interruption and decreased mucosal secretion.<sup>34</sup> It is a routine recommendation to prescribe a bowel regimen for all patients newly initiated on routine dosing of an opioid. Nausea and vomiting is another common GI side effect thought to be caused by the same mechanism of action as constipation. Proactive treatment of opioid-induced nausea and vomiting by concomitant administration of an antiemetic can be effective to allay this distressing symptom. Oral methyl-naltrexone can be used to treat constipation. Most patients will develop tolerance to the side effect of nausea

and vomiting after a few days of opioid administration, but tolerance to the side effect of constipation rarely develops and thus must be continually addressed.

Many clinicians have an ever-present concern for opioid-induced respiratory depression. Opioid respiratory depression is defined as a decrease in effective ventilation following opioid administration. Multiple factors weigh into the potential for opioid-induced respiratory depression including dose, formulation, duration of therapy, and other medications being taken. It is important to recognize that sedation precedes respiratory depression and can be used as a predictor of the potential for respiratory depression. However, clinicians must guard against overreacting to sedation, since sedation is a commonly expected side effect of opioids, especially with the first 24–48 hours of initial therapy or dose titration. Individual factors for increased risk of respiratory depression include advanced age, obesity, sleep apnea, and end organ dysfunction.<sup>35</sup> If sedation progresses to hypoventilation and impending respiratory depression, consideration should be given to administration of naloxone. Judicious dosing is imperative for patients on chronic opioids to avoid the dramatic distressing effects of acute opioid withdrawal. Recommended dosing of naloxone can be easily remembered by repeating a rhyme coined by one of our colleagues, “1 in 9, 1 at a time” — diluting 1 ampule of naloxone in 9 mL of saline and administer 1 mL via the parenteral route every 1–2 minutes until the respiratory rate increases and the level of sedation lightens. The goal is not full alertness. Naloxone administration may need to be repeated or continuous infusion may be necessary to reverse significant sedation secondary to long-acting opioids, especially transdermal fentanyl and methadone.

There is growing interest in providing naloxone to patients and patients’ families who receive opioids. Since naloxone can be administered SQ and intranasal, as well as IV, administration is easily taught. Auto-injectors similar to those used for epinephrine are available.

The *principle of double effect* is commonly applied at end of life, explaining that comfort medications at doses necessary to control pain and ease suffering at

end of life may potentially hasten death; this care is morally justified as long as the intent is not meant to cause harm or hasten death.

**Nausea and Vomiting.** Nausea and vomiting is another common distressing symptom patients with serious illness may experience over the course of their disease trajectory. A variety of mechanisms contribute to nausea and vomiting in advanced illness, including treatment-related (i.e., chemotherapy and radiation), GI dysmotility, bowel and gastric outlet obstruction, CNS disease, metabolic, and psychogenic. Treatment aimed at relieving nausea and vomiting should be guided by the underlying cause.<sup>36</sup>

Standard antiemetic therapy includes the dopamine antagonists promethazine and prochlorperazine. Many clinicians are not aware that haloperidol is also a dopamine antagonist and, thus, when used off-label is an effective antiemetic. In fact, haloperidol is a very potent dopamine type-2 receptor antagonist and exhibits an antiemetic effect, even at low doses of 0.5–1.0 mg. Sedation can be a side effect at higher doses. Extrapyramidal side effects typically are not seen unless prescribed in high doses over a prolonged time frame. Metoclopramide is also a dopamine receptor antagonist and exerts its effect by increasing peristalsis. Caution must be exercised in patients with complete bowel obstruction because the increased peristalsis effect may result in the negative result of increased colicky abdominal pain and can increase the risk of catastrophic intestinal perforation. Metoclopramide can be used in partial bowel obstruction, but can have the potential negative side effect of increasing colicky abdominal pain.

The 5-hydroxytryptamine receptor antagonists, such as ondansetron and granisetron, have gained popularity in mainstream management of nausea and vomiting, likely related to their favorable side effect profile. However, they are only FDA-labeled to treat postoperative and chemotherapy- or radiation-induced nausea and vomiting. Also, even though generics are available globally, cost is still an issue and should be considered in palliative use.

Corticosteroids, particularly dexamethasone, remain the crux of treatment for nausea and vomiting secondary to

increased intracranial pressure or meningeal irritation from CNS disease. Liberal dosing is usually required to achieve an anti-nausea effect, generally 4–8 mg, 3–4 times per day. Dexamethasone also may be effective for nausea and vomiting related to malignant bowel or gastric outlet obstruction by decreasing inflammation and peritumoral edema.

An additional antiemetic consideration is the use of benzodiazepines, particularly lorazepam, for anticipatory nausea and vomiting as well as for patients with a significant psychogenic component to their symptoms.

Clinicians should always seek to define the etiology of nausea and vomiting and address contributing or concomitant medical conditions. Treating dehydration by administration of parenteral hydration solutions may act in conjunction with medication therapy to improve nausea and vomiting. Identifying and treating underlying metabolic disturbances, such as hypercalcemia, may have a significant positive impact on symptom control. Adequately assessing for and treating constipation also can positively impact symptom control.

**Dyspnea.** One of the most difficult to manage symptoms in serious illness is dyspnea, which is defined by the American Thoracic Society as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, social, and environmental factors.” Dyspnea remains a widespread symptom experienced by patients with serious illness. A study reported that in cancer patients, 21–78% of patients experienced dyspnea days or weeks before death, with increased prevalence in the last 6 weeks of life.<sup>37</sup> This symptom is not limited to cancer patients, with multiple studies proving that individuals with advanced chronic obstructive pulmonary disease,<sup>38</sup> cardiac<sup>39</sup> or neurologic disorders,<sup>40,41</sup> or HIV/AIDS<sup>42</sup> also face debilitating dyspnea at the end of life.

Dyspnea has a biochemical etiology, but a key regulatory component on how debilitating it can become is moderated by a person’s sensory cortex. Using traditional dyspnea medical management may not be effective if a person’s emotional

state is altering his/her coping ability. This is where gentle sedatives, counseling, distraction therapy, spiritual or psychosocial support, or other input from multidisciplinary team members can be effective in moderating the effect of this disabling symptom in patients.

The key strategy in managing this symptom is that it is always acceptable and desirable to use standard therapy to treat or reverse the underlying cause if possible. However, if an individual has failed dyspnea management while maximizing traditional therapy, consideration of opioid use is reasonable. Opioids have been used to treat dyspnea for centuries; however, their exact mechanism of action is unclear. One thought is that opioids decrease the perception of dyspnea centrally, at the sensory cortex. Other data show increased pulmonary artery dilation facilitating blood flow to the lungs post opioid administration.<sup>43-45</sup> With the respiratory sedation risk, many clinicians feel when initiating opioids in a patient with compromised respiratory status, one can be easily convinced that opioids are not being used with any regularity for patients with dyspnea with serious, life-limiting illness unless they are enrolled in hospice care. The risk for respiratory depression and failure is nominal when opioids are used at the lowest therapeutic dose for dyspnea control. If opioids are used to manage dyspnea, dosing must be tailored to the individual patient's clinical situation, taking into account their comorbidities, contraindications, and history of opioid use.

Maximizing non-pharmacologic measures remains valuable. Providing adequate air circulation around patients with dyspnea, with a fan for example, has proven benefit in reducing anxiety and the patient's sense of breathlessness.<sup>46</sup> Intensity of a patient's dyspnea is magnified by life experiences, surrounding environment, culture, and psychological and spiritual distress.<sup>36</sup> Understanding why a patient is short of breath and being aware of his or her life story and family/support structure can be instrumental in finding the most efficient way to help find relief.

**Life Planning.** The SUPPORT study demonstrated that end-of-life preferences often are not honored.<sup>15</sup> A 2011 prospective study by Nicholas et al examined regional variations in the relationship

between advance directives, Medicare expenditures at end of life, and treatments received for Medicare beneficiaries between 1998 and 2007. The premise was that many patients do not want aggressive interventions at the end of life; however, often these wishes go undocumented and thus do not impact the end-of-life plan of care. Data showed that Medicare beneficiaries receiving care in regions of the country with high end-of-life care expenditures spent fewer health care dollars, died less often in the hospital setting, and exercised the Medicare hospice benefit more often if they had documented advance directives in place indicating the wish to avoid aggressive care at end-of-life.<sup>47</sup>

Eliciting patient input and honoring patients' wishes are principles most clinicians strive to accomplish in the day-to-day care they provide. Often, clinicians fear that eliciting patient input and wishes may drive health care spending upward; however, as demonstrated in the study referenced above, the contrary may actually be true. Clinicians also may worry that conversations about patient preferences at end of life may be perceived as negative by patients and their families; however, again, the contrary actually may be true. A 2012 study in *Chest* examined the perceptions of patients with COPD following discussions about end-of-life care. Although the number of patients (14.6%) who reported having had discussions with their physicians about end-of-life wishes was small, those who had discussions were significantly more likely to rate their satisfaction as "the best care imaginable."<sup>48</sup>

The standard "menu" of advance directives includes the living will, health care power of attorney, and DNR order, all of which are independent legal documents. The living will documents a patient's wishes for care at end of life as it pertains to life-sustaining measures including artificial hydration and nutrition (AHN). The living will essentially serves as the patient's "insurance policy" that their end-of-life wishes are documented and honored. The health care power of attorney, also known as durable power of attorney or health care proxy, designates a person or persons to carry out the patient's health-related wishes if they are

unable to do so themselves. Lay people often mistake a power of attorney for financial matters as also granting health care decision-making capacity; however, these are two unique documents addressing two different areas of decisional authority. Unlike the former, which is executed by the patient, the DNR is a physician or clinician order addressing cardiopulmonary resuscitation wishes in the event of cardiac and/or pulmonary arrest. Many states have now enacted MOLST/POLST, which address resuscitation wishes as well as more specific wishes such as AHN, cardiac drips, and antibiotic therapy. While the POLST form is a great step forward, in its current form, it does allow the patient to select a medically challenging scenario, such as intubation without ventilator or ventilator without intubation.

## Communication

Assisting patients with advance directives is a duty all clinicians should embrace. However, advance directives may have little meaning if the patient and family have not had discussions about the patient's wishes, hopes, fears, values, definition of quality of life, and life goals. Too often, the health care power of attorney may feel conflicted about critical decisions because they never had clear detailed discussions about what their loved one really wants at end of life. Establishing goals of care and aligning those goals with the patient's care plan is the "bread and butter" of good care.

The "ask, tell, ask" method of communication is well documented<sup>49,50</sup> and suitable for this type of communication. This strategy begins by eliciting the patients' understanding of their situation and allowing the clinician to assess knowledge base, educational level, emotional state, and any misperceptions. The next step is to deliver the information in a clear, concise, understandable manner — typically divulging important information in bite-sized morsels to allow time for patients to process what they are hearing. The last step is to inquire about the patients' understanding of the information and, if needed, ask them to restate what was said to assess their understanding.

EPEC defines a seven-step protocol for having a successful goals-of-care discussion with patients and their family

unit.<sup>68</sup> This model, discussed below, incorporates the “ask, tell, ask” strategy.

Beginning these discussions with patients and their family units is not easy. Implementing a structured process for delivering “bad” news will assist in assuring this conversation will hold value and meaning to patients. This is an emotional discussion. This is one of the most important discussions patients and families will ever have, so the deliverer of this message must be prepared and organized. It is important to set the stage with a proper venue, for example, selecting a large enough room in advance to accommodate the family, treatment team, and patient. It is important not to make the family feel rushed, so the clinician should sit down and talk directly with them. Clinicians should always introduce, by name and role, themselves and any other team members participating in the meeting and describe what goals the meeting hopes to accomplish.

It is relevant to assess what the patient and family know about the illness. This initial “ask” step helps reemphasize to the patients and family that their understanding of their disease process has value and is important to the treatment team. It is important to define what the patient and family wants to know about the disease and prognosis and to define their hopes and goals.

The next step is “tell.” It is imperative to disclose this information to the patient and family in straightforward, understandable language with sincere honesty. It is important to suggest realistic goals as a medical expert, and to remain patient while working through unrealistic expectations. If emotions arise, it is important to recognize and acknowledge them in an empathic way, but attempt to remain focused.<sup>51</sup>

The final “ask” comes after development of the plan of care and summary review. Ask if there are any questions, define next steps and a follow-up plan, and lastly ask the patient and family for buy in, for example, “Does this plan of care that we developed together suit your needs and goals, and is it one you would be willing to follow?”

Some patients will come to the ED having established their wishes. Families and patients may not recognize the severity of their current condition.

Families may ask for “everything to be done.” It may fall to the emergency provider to inform them that we already have done everything. Families may know what the patient wants “when the time comes” but need to be told now is that time. Once the ED care plan changes from life salvage to comfort care, adjustments may be necessary. Patients and their families should be offered private settings, rules about family visitors need to be removed, and support from clergy, social work, and others encouraged.

## Prognosis

All experienced clinicians recognize that prognostication is far from an exact science. Some diseases, such as advanced cancer, may be more predictable than others, such a cardiac or pulmonary disease. Depending on the specific disease, various criteria may be used to help with prognostication, the details of which are outside of the scope of this article. Several interesting articles discuss perspectives on the overarching issue of addressing mortality. One 2011 perspective article attempts to address the value of discussing overall prognosis in the elderly patient population.<sup>52</sup> Given that life expectancy decreases with age, the authors cite the paradox that most clinicians do not discuss prognosis with elderly patients unless they have a serious illness. They suggest a change in practice standards to include offering to routinely discuss prognosis with all elderly patients with a projected life expectancy of 10 years or less or by age 85, whichever comes first. One of the many initiatives in this area is The Conversation Project ([theconversationproject.org](http://theconversationproject.org)), which provides resources for initiating and documenting a patient’s wishes around end of life. This resource was highlighted in a recent PBS special. It is hoped that each of the readers of this article will have a conversation with any of their elderly relatives, and more importantly with their families about their own wishes.

## Hospice Care

All hospice care is palliative care, but not all palliative care is hospice care. Hospice is a Medicare benefit that can be elected as a choice by all Medicare beneficiaries who meet

eligibility criteria. The crux of eligibility is that the patient has a terminal illness with a projected life expectancy of  $\leq 6$  months if the disease runs its natural course. Given the understanding that prognostication is not an exact science, this 6-month projection should be based on the clinician’s best estimate considering the natural history of the specific terminal disease in context with the individual patient’s clinical condition and comorbid medical conditions. Many patients outlive this 6-month window and still remain eligible for hospice care based on continued decline, albeit at a slower trajectory than 6 months. Hospice programs and hospice and palliative medicine specialists are the experts in eligibility and should be utilized by clinicians as a resource if eligibility is unclear. Rather than choosing to postpone or not refer a patient who may benefit from the care and support hospice offers, clinicians should make the referral and collaborate with the hospice program to help determine eligibility. Even if patients are determined not to be eligible for hospice, they likely would be appropriate for palliative care interventions and they may be eligible for home health services until they reach a point in their illness that they do become hospice eligible.

Emergency providers often admit patients with chronic conditions and at the end of life when families are not comfortable or unable to provide home care. Some of these patients could be cared for at home, but even when home care is established, organizing new services in the off hours or on weekends is almost impossible. Some large home health/hospice providers now have 24/7 availability that can provide services around the clock within the patient’s home.

## Educational Resources

It has only been over the last few years that medical schools and residency programs in the United States have begun to incorporate hospice and palliative medicine principles into their education curriculum. This type of education is increasing, but there are still gaps for which clinicians must seek resources to fill.

As mentioned earlier, the American

College of Emergency Physicians has many excellent resources for palliative care. Fellowships for emergency physicians exist. Other resources include EPEC, ELNEC, CAPC, and AAHPM. A good information resource for patients and families is [www.getpalliativecare.org](http://www.getpalliativecare.org).

## Palliative Care and Health Care Reform

Many changes have been proposed or implemented since the passage of the Patient Protection and Affordable Care Act (PPACA) in 2010. Included in the PPACA, hospital admission recidivism is a current focus of Medicare with potential penalties enacted for readmission within 30 days for acute myocardial infarction, pneumonia, and congestive heart failure. Under the PPACA, Medicare is also focusing on quality, outcomes, and patient satisfaction and includes Hospital Consumer Assessment of Healthcare Providers and Systems as one of the measures used to calculate value-based incentive payments to hospitals. Utilizing palliative care principles potentially can impact both of these areas in a positive way. Documentation of advance directives, meaningful goals of care conversions, hospice referral when appropriate, and diligent symptom management have the potential to decrease hospital readmissions. Honest, empathetic, patient-centered communication can improve patient satisfaction.

## Conclusion

Palliative care, especially when implemented early, has proven benefits that are well documented by research. If palliative care principles are implemented, they have value, improve outcomes, and make a meaningful difference in the experience patients and their families face when battling serious illness. Many national organizations have endorsed and acknowledged the benefit of palliative care, which has created the momentum to improve access to its principles earlier in the disease trajectory. Evidence is clear that patients and families desire palliative care. Where early access to palliative care is available, research has proven value from both the patient experience and the treatment delivery team perspective. Specialty palliative care is still limited, especially in the outpatient setting, and

will likely remain strained for the foreseeable future. Palliative care leaders continue to evaluate different models of ambulatory palliative care, but no single model currently stands out. In our current health care landscape, basic palliative care in the emergency setting has value and is appreciated by patients and families. Emergency clinicians can reduce suffering and improve the quality of life of their patients and families. Palliative care can have a real impact, both clinically and financially, on patient care in the United States, particularly as it pertains to our rapidly growing Medicare population.

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## CME Questions

1. Which of the following would **not** be eligible for palliative care?
  - A. patient considering artificial nutrition/hydration
  - B. patient with advanced oxygen-dependent pulmonary fibrosis where family conflict exists regarding code status
  - C. a 90-year-old in good health, admitted for community-acquired pneumonia, first hospitalization in 5 years
  - D. metastatic lung cancer patient in active treatment admitted for neutropenic fever
2. Which is **not** an element in the definition of palliative care?
  - A. only available to those who are terminally ill with 6 months or less of expected life
  - B. works collaboratively with the primary medical team
  - C. goal is to reduce suffering and improve quality of life
  - D. better implemented at the start of serious illness vs later in the continuum
3. Which of the following antiemetics is **not** a dopamine receptor antagonist?
  - A. metoclopramide
  - B. haloperidol
  - C. ondansetron
  - D. prochlorperazine
4. Which of the following is **not** considered an advance directive for health care?
  - A. do not resuscitate order
  - B. living will
  - C. durable power of attorney
  - D. power of attorney
5. A patient presents with nausea related to opioid use for metastatic breast cancer. The pain is controlled. All of the following are appropriate **except**:
  - A. ondansetron
  - B. Haldol
  - C. reduce opioid dose
  - D. metoclopramide
6. A patient has end stage metastatic breast cancer with severe pain. She has been taking 12 mg of oral dilaudid every 3 hours around the clock. The equianalgesic effect of 4 mg oral dilaudid is 1 mg IV. How much IV dilaudid should be given as an initial dose in the ED?
  - A. 2.5 mg
  - B. 1 mg
  - C. 1.5 mg
  - D. 10 mg
7. A patient with sickle cell is being discharged on a large dose of opioids. The nurse also suggests giving a prescription for naloxone. Which of the following is true?
  - A. Naloxone is a schedule I drug and can only be prescribed by addiction physicians.
  - B. Naloxone can only be administered through an IV and the patient is a hard stick.
  - C. The patient might be a good candidate for self-administered naloxone.
  - D. Naloxone is contraindicated in sickle cell.
8. An 89-year-old female presents with painless hematuria. She is bed-ridden secondary to a stroke and complains of mild to moderate pain in her hips and back when the review of systems is discussed. Which of the following is best for this patient?
  - A. Start the patient on acetaminophen.
  - B. Start the patient on oxycodone.
  - C. Tell the patient to call her primary care provider.
  - D. Admit the patient to palliative care.
9. Which of the following individuals should **not** discuss their end-of-life wishes?
  - A. an 88-year-old female with severe COPD
  - B. a 90-year-old male in good health
  - C. a 35-year-old emergency provider
  - D. none of the above
10. Which of the following is **false**?
  - A. Most patients want to die at home.
  - B. Most patients die in the hospital.
  - C. Physicians with chronic disease tend to die at home.
  - D. The majority of patients have an advance directive.

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