Emergency physicians face increasing opportunities for the delivery of palliative care to terminally ill patients presenting to the emergency department (ED) near the end of life. As medical technology enables greater longevity for a growing population of older Americans, “it is essential that all medical professionals know how to help patients negotiate the balance between quantity and quality of life,” write the authors of an article published in *Emergency Medicine Clinics of North America*.

Patients with life-limiting conditions all too frequently present to the ED as death nears, note the authors. Factors associated with increased hospital use by these patients include uncontrolled symptoms, inadequate social support, poor communication, and regional variables, such as higher per-capita number of hospital beds.

“Ultimately, it has been recognized that emergency physicians should have some basic competency in meeting the needs of dying patients,” write the authors. “As emergency physicians, we have the opportunity to both educate patients and their loved ones on how to best accomplish their goals while also enhancing quality of life through the treatment of symptoms.”

Time constraints and limitations on resources can make addressing patient/family end-of-life needs in the ED challenging. Thus, “understanding the factors that families and patients have endorsed as the most important can help physicians prioritize care that best promotes patient-centered goals.”

The authors’ article offers guidance for emergency physicians towards a general understanding of dying trajectories, symptom management for the dying patient presenting to the ED, the bioethical framework that guides end-of-life decision making, and communication strategies helpful in determining the goals of care.

**COMMUNICATION WHEN THE PATIENT IS UNSTABLE**

The paper describes symptoms and signs of imminent death that emergency physicians should familiarize themselves with in order to anticipate the needs of dying patients and offer counseling on the dying process to family members. In determining which treatments to initiate in patients who are “crashing,” a streamlined communication approach is required.

When patients are unstable — i.e., there is an immediate threat to the ABCs (airway, breathing, or circulation) — there are two critical actions emergency physicians should perform before initiating life-sustaining treatment (LST), note the authors. These are the identification of an advance directive, either oral or written, and the determination of the patient’s appropriate decision maker or legal surrogate.

The emergency physician should engage the surrogate decision maker in a discussion to clearly identify the patient’s previously expressed wishes concerning the use of LST, then provide information about the risks and benefits of the procedures, using clear language and avoiding medical jargon.

If there is time, likely functional and cognitive outcomes of invasive LST should be presented in addition to general

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**Quality of Life Matters**

*End-of-life care news & clinical findings for physicians*

**Palliative Care and Hospice Referral Urged as Part of Emergency Medicine Practice**

Vol. 17, Issue 1 May/June/July 2015
survival statistics. Physicians are urged to frame a recommendation against cardiopulmonary resuscitation (CPR) for a dying patient in positive language, explaining that the loved one has a low likelihood of benefit and high risk of harm from the procedure and assuring the family that the focus of care will be to ensure the patient’s comfort.

**COMMUNICATION WHEN THE PATIENT IS STABLE BUT DYING**

A more structured and deliberate approach to discussing goals of care is recommended for patients who are dying, but have no immediate life threats. The responsibility for determining that these patients receive medical care that helps them meet their goals rests frequently with the ED staff.

Because of time constraints in the ED setting, the authors recommend that prior to initiating the goals-of-care discussion, physicians conduct a quick review of the patient’s medical chart, and if possible, telephone the patient’s preferred physician and/or oncologist to confirm an understanding of the medical facts. The authors offer a seven-step approach for conducting the family discussion, with suggested phrases to use and phrasing to avoid, because although well intentioned, some statements have been found to cause the family emotional harm. “[I]t should be clearly stressed that no matter what plan is pursued, patients and families will not be abandoned and will continue to receive high-quality care.” [See sidebar.]

In cases where emotional conflict brings medical decision making to a standstill and the patient will be admitted, it may be advisable to call in a palliative care team or ethics committee, if available, and defer the discussion to the inpatient setting.

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### Breaking Bad News and Determining Goals of Care

1. **Prepare the parties for discussion.** Rather than saying, “We need to talk about your wife’s code status,” emergency physicians can say, “Would it be okay if we all sat down and discussed your wife’s condition, so we can make the best medical plan for her?”

2. **Establish what patients/families know about the illness.** Rather than “Do you understand what is going on with your wife?” physicians can say, “What have the doctors told you about your wife’s illness? How have things been going at home lately?”

3. **Assess readiness and openness to hearing bad and/or surprising news.** “We have some serious news to share about her condition. Is that something you are ready to talk about?”

4. **Deliver the medical information that the patient is dying.** Rather than “There is nothing more we can do,” physicians can say, “I am afraid we have some bad news. Her illness has progressed despite our best efforts to control it. At this point, I think that she is dying. I wish things were different.” Or, “I wish we had better treatments for your wife’s disease.”

5. **Respond to emotions.** Rather than “I am so sorry,” physicians can say, “This must be hard to hear,” or “I can only imagine how scary this must be.”

6. **Establish goals of care.** Rather than “Would she want to be resuscitated?” or “Does she want everything done?” physicians can say, “Knowing that time is short, what would your wife say is most important to her? What are your hopes for her when you look into the future? Are there any particular worries you have when you look into the future?”

7. **Recommend a medical plan, and summarize.** Rather than “Let’s just keep her comfortable,” physicians can say, “Based on what you have told me, I recommend that we refocus our efforts on maximizing her comfort. We will aggressively manage her symptoms. We will make sure we use all our resources to support her and all of you through her dying process. We will allow her to have a natural, peaceful death and will not artificially prolong her dying process.”

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### HOSPICE REFERRAL

“When and where available, involvement of palliative care and/or hospice services is recommended to ensure that dying patients receive high-quality end-of-life care,” write the authors. Palliative medicine is a relatively new specialty, focused on improving the quality of life of patients with serious illness, while hospice is palliative care delivered to patients with a prognosis of six months or less who have chosen to forgo curative attempts. For dying patients in the ED, the distinction is moot.

“Initiating a palliative care consult may be one of the most important steps the emergency physician can take in improving the overall care of patients at the end of life,” the authors state. “These specialists can be particularly helpful at ensuring dying patients’ transition from the ED to an appropriate care setting.”

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Continued on Page 3
Reports of Pain, Depression in the Last Year of Life Increasing, National Survey Finds

While use of hospice care has doubled nationwide, many more patients could benefit

Despite nationwide efforts to improve end-of-life care, palliative care and hospice services may not be reaching many terminally ill patients who might benefit from them. Between 1998 and 2010, reports by family members of pain and other distressing symptoms experienced by their loved ones in the year before death rose significantly, according to a report published in Annals of Internal Medicine.

“It is particularly concerning that proxy reports of pain have increased, because pain is among the most visible and well-studied aspects of the end-of-life experience, has received policy attention, and significantly affects health-related quality of life,” write the authors.

Since 1997, when the Institute of Medicine issued its landmark report calling for better care of dying Americans, efforts to improve care have yielded an increase in the number of hospice facilities and hospital palliative care services. The number of Americans receiving hospice care doubled between 2000 and 2009, note the authors, but serious gaps in the delivery of this important care remain.

“Proxy reports of worsening symptom prevalence raise concerns about shortcomings in end-of-life care, despite increasing national attention and resources devoted to it,” observe the authors. “Indeed, recent studies of health care performance suggest that persistent gaps remain in addressing symptoms near the end of life.”

Investigators analyzed data from the Health and Retirement Study, a nationally representative longitudinal survey of community-dwelling adults aged 51 years or older. Participants (n = 7204) were interviewed every two years from 1998 to 2010 or death (mean age at death, 79.1 years), after which a proxy most familiar with the decedent provided an interview about that person’s end-of-life experience.

The team evaluated the prevalence of each of eight symptoms in the last year of life, both over time for all decedents and across subgroups by diagnosis category: cancer (22%); congestive heart failure or chronic lung disease (33%); frailty, which included death in a nursing home, diagnosis of memory impairment, or hip fracture in the last two years of life (16%); and sudden death; i.e., death within one day of receiving a terminal diagnosis (16%).

**KEY FINDINGS**

- Over the course of the study, reports of pain increased by 11.9% (95% confidence interval [CI], 3.1% to 21.4%), from 54.3% to 60.8%.
- Prevalence of depression increased by 26.6% (95% CI, 14.5% to 40.1%), from 45% to 57%.
- Periodic confusion rose by 31.3% (95% CI, 18.6% to 45.1%), from 41.1% to 53.9%.
- Individual symptoms increased among patients in all diagnosis categories except cancer, which showed no significant trends in any symptom.

“It is encouraging...that trends in the prevalence and severity of cancer pain may have stabilized,” comment the authors. “This should be monitored, in the face of growing public concern about prescription opioid abuse, which may create resistance to opioid use from clinicians and patients in otherwise appropriate scenarios.”

**FACTORS RELATED TO HIGH SYMPTOM PREVALENCE**

- Higher rates of aggressive care. The intensity of treatment for patients nearing the end of life has been increasing in recent years, note the authors, as has the rate of adverse transitions among this population.

“Hospice is often ‘tacked on’ to this more intense late-life care: although hospice use doubled from 2000 to 2009, the median stay is less than three weeks,” they point out.

Continued on Page 5
Hospice Entry Prompts Life-Closure Decision Making Important to Patients and Families

The dying process is a distinct stage of the human life cycle, and patients who enroll in hospice discover with their families the opportunity to confront their new reality openly and to make choices that create a meaningful phase of life with the time they have left, according to a report published in *Palliative and Supportive Care*, an international journal of palliative medicine published by the Cambridge University Press.

“The decision to enroll in hospice was a critical juncture on the trajectory of a terminal illness that allowed patients and their families an opportunity to consider subsequent tasks that were important for life closure,” write the authors. “Both the shift in participants’ perceptions and the care being offered opened the door to a new developmental life phase.”

Based on their findings, the authors emphasize the importance of the timely mentioning of hospice to seriously ill patients, so that they and their families have the chance to create a satisfying life closure.

“It is important for clinicians to recognize that well-timed encouragement to consider and explore the use of hospice services, although it may indeed diminish hope for cure or recovery, simultaneously offers an opportunity to engage with important and time-sensitive developmental tasks,” they state.

Researchers analyzed a subset of data from a larger project examining factors that prompt patients to consider enrolling in hospice. For the qualitative study, face-to-face interviews were conducted with newly enrolled hospice patients aged ≥ 65 years (n = 35) and their caregivers (n = 45) from 53 families cared for by one of two participating hospice facilities.

Whenever possible, joint interviews were conducted with both patients and caregivers. Mean age of the patients was 80.3 years, 53% had a diagnosis of cancer, 58% were male, and all were Caucasian.

Five types of decisions were found to be most frequently made by patients and their caregivers as they entered this new phase of life together. The report includes both descriptions and samples in the participants’ own words of how entering hospice prompted them to make further, real-time choices on issues newly central to their lives.

**TYPES OF POST-ENROLLMENT DECISIONS**

**1. Activated/reactivated advance care planning (ACP).** Upon entering hospice, patients are routinely asked about the existence of advance directives, and their preferences for end-stage care are explored. Hospice enrollment and the team’s involvement address the patient’s/family’s need to consider contingency decisions and to make end-of-life choices in real time.

Participants experienced a greater understanding of what symptoms to expect, a renewed and sharpened focus on their options for care and on how to reach agreement with one another on decisions. “There is a substantive difference between completing a form with ideas about future needs of a future self and the need to make real-time choices,” the authors note.

Both patients and families were grateful for the education and support provided by the hospice team. Patient: “I knew I had cancer but I didn’t know what was going to happen to me. Was I going to become impossible. The open acknowledgement of approaching death was a catalyst for clarifying where the person wanted to be when he or she was actively dying, and whether this would be possible. Most participants preferred a home death and did not want to be hospitalized, but a stay at an inpatient hospice unit was considered to be the best compromise, if remaining at home became impossible.

“Continuous hospice home care in the last week of life is less likely to occur when patients have short hospice stays.”

**2. Surrogate decision making.** Caregivers began to make both informal and formal decisions for the dying person. Informally, family members took increasingly greater charge of everyday care as the patient’s condition declined. Formally, caregivers began to speak for the patient, making decisions on his or her behalf about type of care and medical procedures.

“Surrogate decision making can occur suddenly following rapid change, or slowly and gradually over time,” write the authors. “In both cases, deciding on behalf of another is a central part of caregiving for someone who is nearing the end of life.”

**3. Meaning-making.** Hospice enrollment triggered awareness that there were time-limited opportunities for creating special memories, having important conversations, and attending special events. Participants expressed sincere appreciation for the time they had to spend together. One caregiver explained: “When her time finally comes, at least I’ll know that she had good quality of life — the best that I could do for her. I take her places still, even though she doesn’t want to get out and walk around.”

**4. Location of death decisions.** The open acknowledgement of approaching death was a catalyst for clarifying where the person wanted to be when he or she was actively dying, and whether this would be possible. Most participants preferred a home death and did not want to be hospitalized, but a stay at an inpatient hospice unit was considered to be the best compromise, if remaining at home became impossible.

“Continuous hospice home care in the last week of life is less likely to occur when patients have short hospice stays.”

*Continued on Page 6*
Study Findings May Help Physicians Understand Role of Families in Treatment Decisions for Cancer Patients

How likely certain cancer patients are to wish their families to be involved in their medical decision making is not well known, according to the authors of a study published in Cancer, a journal of the American Cancer Society. Their findings offer insights that may assist physicians in understanding patient preferences and improving patient participation in discussions of treatment options.

“Our study suggests that not all patients wish to include family in the same way,” says lead author Gabriella Hobbs, MD, of the Department of Medical Oncology, Harvard Medical School, Boston. “By raising awareness of these preferences, we hope that physicians will be aware of these variations and elicit their patients’ preferences on how they wish to include — or not to include — families in decision making.”

The majority of cancer patients do involve their families in their treatment decisions, at least to some degree, the study found, and about half share the decision making equally, but more than one-quarter of patients say they have little or no input from their families.

“Understanding how patients vary in their inclusion of family members in decisions — by ethnicity, language spoken, marital status, sex, age, insurance status, and veteran status — may help physicians to better assess their patients’ preferences for engaging family members in decisions,” says Hobbs. “As we move to more patient-centered models of care, such assessments may help doctors personalize the care they offer their patients.”

Investigators surveyed a large, population-based cohort of 5284 adult patients newly diagnosed with lung or colorectal cancer (male, 53%; non-Hispanic white, 70%). Data were collected as part of the national CanCORS (Cancer Care Outcomes Research and Surveillance) Consortium, which enrolled patients between 2003 and 2005 from five geographic areas of the country, 15 Veterans Affairs medical centers, and five large health maintenance organizations.

Based on patient responses, treatment decisions were categorized as: having little family input; having some family input; being equally shared between the patient and family; or being family-controlled (decisions were made by the family after considering the patient’s opinion, or were made by the family with little or no input from the patient).

Among those patients whose families did not control their treatment decisions:

- 49.4% reported equally sharing decisions with family.
- 22.1% reported some family input.
- 28.5% said there was little or no input from their families.

After adjustment, non-English-speaking Asian patients (59.8%) and Spanish-speaking Hispanic patients (56.5%) were more likely than English-speaking Hispanics (48.0%) or non-Hispanic whites (47.6%) to report equally shared decisions. Patients who were married, female, older, or insured were more likely than their counterparts to share decision making equally (all, P < .001). Military veterans...
Hospice Entry Prompts Life-Closure Decision Making (from page 4)

comment the authors. Patients with stays of under 14 days have been found to have a greater likelihood of dying in an inpatient hospice bed.

5. Final acts. Hospice enrollment set the stage for making final arrangements. Participants engaged in decisions about wills, funeral arrangements, and leaving a legacy for their children. “Participants expressed both satisfaction and relief at being able to complete these tasks,” write the authors.

“With short [hospice] stays, there is not time to address the decisions presented here,” the authors point out. “Focusing on these tasks and continuing to be challenged with decisions strengthens personhood, identity, and control of one’s life. Benefits accrue to both patient and family during the dying phase, and continue for family members by easing their transition to their own next life phase following loss.”

**TRANSITION TO HOSPICE CAN BE MORE DIFFICULT WHEN:**
- Fears of helplessness and abandonment are not addressed beforehand.
- The transition occurs too rapidly for the patient to have time to come to terms with it.
- Lack of previous information about the nature of hospice/palliative care exacerbates fear or reluctance.

“These findings add to the growing knowledge about how people die in the family context, extending awareness about how both individuals and families continue to grow and change, both individually and together, during the final stage of life,” conclude the authors. They suggest further research, particularly among racially and ethnically diverse populations.


Role of Families in Treatment Decisions for Cancer Patients (from page 5)

(36.6%) were the least likely to share decision making with their families (P < .001).

**FAMILY-CONTROLLED DECISIONS**
- Only 1.5% of patients reported that their treatment decisions were family-controlled.
- Of these, Chinese-speaking Asians (12.8%) were significantly more likely than white patients (1.3%) to report family-controlled decisions (adjusted odds ratio [OR], 7.41; 95% confidence interval [CI], 4.93 to 11.40).
- English-speaking Asians were also more likely than white patients to report family-controlled decisions (OR, 1.93; 95% CI, 1.17 to 3.16).
- Other patient characteristics associated with a higher likelihood of family-controlled decisions included age > 81 years vs age 21 to 56 years (OR, 1.82; 95% CI, 1.25 to 2.65), a diagnosis of depression (OR, 1.91; 95% CI, 1.46 to 2.51), and patient preference for physician-driven decisions (OR, 3.06; 95% CI, 2.23 to 4.21).

“Family members appear to play an important role in decisions regarding care for many patients with cancer,” comment the authors. “Certain groups, such as non-English-speaking Hispanic or Asian individuals, rely significantly on family, and for these groups it is important that physicians respect and make efforts to integrate family members into decision making.”

In 2013, the Institute of Medicine issued a report urging improvement in the quality of cancer care in the U.S. “Care often is not patient-centered, and many patients do not receive palliative care,” stated the report. Entitled “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis,” it called for a health care system that engages patients in their care and supports informed decision making consistent with patient values from diagnosis through the terminal phase of illness.

“[I]t may be helpful for physicians to elicit patient’s preferences concerning the involvement of their family in treatment decisions,” observe the authors. “For patients who desire family involvement, engaging families may help to achieve the Institute of Medicine’s key goal of a delivery system with truly engaged patients.”


Source: “The Role of Families in Decisions Regarding Cancer Treatments,” Cancer; Epub ahead of print, February 23, 2015; DOI: 10.1002/cncr.29064. Hobbs GS, Landrum MB, et al; Department of Medical Oncology; and Department of Health Care Policy, Harvard Medical School, Boston; Massachusetts General Hospital, Boston; Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, Maryland; Departments of Health Policy and Management, and Cancer Prevention and Control Research, Jonsson Comprehensive Cancer Center, University of California, Los Angeles; Division of Hematology-Oncology, Department of Medicine, David Geffen School of Medicine University of California, Los Angeles; Health Services Research, Mayo Clinic, Rochester, Minnesota; Fielding School of Public Health, Los Angeles.
Addressing Common Patient Misunderstandings of Hospice

Because a lack of understanding of the nature of hospice care and how it can benefit themselves and their families can be a barrier to patients’ timely enrollment, physicians may want to ensure that their seriously ill patients are not subject to common misapprehensions about this supportive, multidisciplinary service.

“People are naturally reluctant to study what hospice care is until they are in need of hospice services,” writes Forbes contributor Jacob Edward, founder and manager of Senior Planning in Phoenix, AZ, a service helping older individuals make choices about long-term care. In his article on the Forbes website, Edward debunks several commonly held myths about hospice.

**COMMON MISCONCEPTIONS ABOUT HOSPICE:**

- **Myth:** Hospice places a time limit on hospice stays and hastens death.
  **Truth:** Patients and families can receive care for an unlimited amount of time, depending on the course of the illness. Medicare hospice is provided in two 90-day benefit periods, followed by an unlimited number of 60-day periods. “The reason many patients receive hospice care for only short periods of time is because many people who could benefit are not referred,” writes Edward.

  Hospice does not hasten death; rather, it supports patients in living their lives fully, completely, and without pain until the end of their lives. Research has found that with timely enrollment, some patients live even longer than expected “because the reduction of stress and increase of comfort can benefit health in a very positive way.”

- **Myth:** People must go to a hospice center to receive care.
  **Truth:** Hospice care is delivered wherever the patient wants to be, usually in their own home, the home of a family member, or in a licensed facility. “First and foremost, hospice care is a philosophy on death and dying, rather than a physical place,” states Edward. “If patients choose to remain in their homes, hospice services are still available 24/7.”

- **Myth:** Once enrolled in a hospice program, there’s no turning back.
  **Truth:** Patients can opt out of hospice at any time for any reason. If they wish to return in the future, they can be re-certified and resume care beginning with a new 60-day benefit.

  “There is nothing wrong with anticipating and preparing for death,” writes Edward. “This gives people closure not only in their own lives, but also in the lives of those around them.”

Physicians whose patients wish to know more about the Medicare hospice benefit can direct them to the official 20-page booklet available online from the Centers for Medicare and Medicaid Services (CMS). Entitled “Medicare Hospice Benefits,” the booklet can be downloaded and printed free of charge. The booklet explains who is eligible for hospice, what services are provided, how to find a hospice program, and where to find more information, including a list of hospice organizations in all U.S. states and territories.

End-of-Life Care Meetings for Clinicians

34th Annual Scientific Meeting of the American Pain Society. May 13–16, 2015, Palm Springs, CA. Phone: 847-375-4715; Email: info@americanpainsociety.org; Website: www.americanpainsociety.org/annual-meeting/overview


Palliative Medicine and End-of-Life Care: 2015 Update Including Related Topics in Neurology. August 21–31, 2015, 10-night Eastern Mediterranean cruise conference, round-trip from Rome, Italy. Topics include: Palliative Care and Hospice — relationship and differences; Advanced Care Directives/Advanced Care Protocols — prognostic uncertainty and tools for family and patient conversations; and much more. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: www.continuingeducation.net


National Hospice and Palliative Care Organization 16th Clinical Team Conference and Pediatric Intensive. October 15–17, 2015, Gaylord Texan Resort and Convention Center, Grapevine, TX. Website: www.nhpco.org

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