

Quality of Life Matters®

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

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Hospice and Palliative Care Approved As New Subspecialty in Eleven Medical Specialty Areas

Hospice and palliative care medicine has been approved as a new subspecialty by the board of directors of the Accreditation Council for Graduate Medical Education (ACGME), the council announced in June 2006. The council also plans to appoint an advisory committee to develop medical residency program requirements for the new subspecialty.

Hospice and palliative care will be a medical subspecialty in eleven medical practice areas, from internal medicine to otolaryngology (*see sidebar, right, for complete list*).

The ACGME is an independent accrediting organization whose members include the American Board of Medical Specialties, the American Hospital Association, the American Medical Association, the Association of American Medical Colleges, and

the Council of Medical Specialty Societies.

It is hoped that the first certification examination in the subspecialty of hospice and palliative medicine will be offered by the American Board of Medical Specialties in 2008, according to the American Board of Hospice and Palliative Medicine (ABHPM), which has been working to achieve recognition of the subspecialty since 1996.

“The ABHPM has advocated strongly for the view that palliative care is best viewed from the perspective of generalist-level and specialist-level practices,” comments ABHPM chairman Russell K. Portenoy, MD, of Beth Israel Medical Center, New York City.

“The need for this distinction, which parallels the approach to medical practice in other specialties, is apparent to anyone

Medical Specialty Areas:

- Internal medicine
- Family medicine
- Pediatrics
- General surgery
- Anesthesiology
- Emergency medicine
- Radiology
- Physical medicine and rehabilitation
- Psychiatry
- Neurology
- Otolaryngology

who understands the high level of knowledge and skill required to address the multiple domains of human experience within the purview of palliative care, particularly in the setting of advanced illness.”

For more information, visit www.acgme.org or www.abhpm.org.

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Hospice Use Continues to Rise, Yet Median Length of Stay Remains at Two Weeks

Since its establishment in 1983, the Medicare hospice benefit has grown tremendously and is now used by more than three-quarters of a million patients per year.

“This increased use of Medicare’s hospice benefit suggests improved awareness and appreciation of the benefit by physicians, hospitals, patients, and their families,” write the authors of “Report to the Congress: Increasing the Value of Medicare,” presented by the Medicare Payment Advisory Commission (MedPAC) in June 2006.

But while the past several years have seen longer hospice stays for a few, the median length of stay has not budged from two weeks, with 10% of hospice patients enrolled just two days before death. Further, **although the majority of beneficiaries currently enter hospice with noncancer diagnoses, the Medicare payment system remains based upon the six-month-prognosis care model for patients with cancer.**

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Hospice Use Continues to Rise, Yet Median Length of Stay Remains at Two Weeks

Federal Report Urges Update of Medicare to Reflect Changing Population

From Page 1

Charged with the task of advising the U.S. Congress on policy changes needed to increase the value of the Medicare program — to both its beneficiaries and the taxpayers — MedPAC analyzed data from 2000 to 2004 for the current report.

Key data on the Medicare Hospice Benefit include:

- **The number of Medicare hospice users rose by 49%** from 2000 (534,261 beneficiaries) to 2004 (797,117 beneficiaries).
- **Cancer is no longer the primary hospice admission diagnosis.** The proportion of Medicare hospice patients with a principal diagnosis of cancer has fallen to 43% in 2003, from 75% in 1992. The most common noncancer primary diagnoses are neurodegenerative conditions such as dementia, end-stage Alzheimer's disease, and Parkinson's disease, followed by cardiovascular disease.
- **Heavier rates of use do not seem to result in longer lengths of enrollment.** While the length of hospice stay rose among the 90th percentile of users (from 130 days in 2000 to 168 days

in 2004), the median length of enrollment remained at about two weeks. Further, the proportion of beneficiaries enrolled in hospice for less than one week remained at 25% during that same time period.

- **Hospice use remains higher among decedents in managed care plans** (38% in 2004; 30% in 2000) than in those in fee-for-service plans (30% in 2004; 20% in 2000).
- **The number of hospice agencies participating in the Medicare program rose by 26%** from 2001 to 2005. The largest growth was seen in the category of freestanding hospices, which increased from 949 to 1615.
- **Growth in the use of hospice care among residents of nursing homes has been substantial.** Although Medicare data do not currently track hospice use by nursing home setting, the data most recently available (1999) to the commission suggest that at least 45% of hospice patients reside in nursing homes.

“The [Medicare hospice] payment system was developed from a demonstration project that analyzed the costs of hospice

Most Common Hospice Noncancer Diagnoses

- Neurodegenerative diseases such as dementia, end-stage Alzheimer's disease, and Parkinson's disease
- Cardiovascular disease

care for patients with terminal cancer diagnoses who lived in the community,” notes the report. “Nursing home patients were not included...As the number of users has grown, the population of hospice patients has become more diverse.

“Growth in the benefit, changes to the hospice population, and changes in the delivery of care over time underscore the need to evaluate Medicare's hospice payment system...to assess what the program is buying and whether it is paying adequately for all patients.”

A section containing statistical charts and tables on hospice use is included in MedPAC's “A Data Book: Healthcare Spending and the Medicare Program,” also published in June 2006.

For more information, visit www.medpac.gov.

VA Research Service ‘Spotlights’ End-of-Life Care

The research program of the federal Department of Veterans Affairs (VA) tasked with identifying and funding high-priority efforts to improve the quality and effectiveness of health care for veterans and the nation has focused its attention on end-of-life care.

The VA's Health Services Research and Development Service highlighted end-of-

life care in its June 2006 edition of “Health Spotlight,” its monthly online report on health care topics deemed of national importance. Other topics recently examined include medication safety, depression, and women's health care.

After a brief description of hospice and end-of-life care, the June entry provides a summary of advances made in the VA

health system toward a more comprehensive and coordinated delivery of end-of-life care, recent and ongoing VA-sponsored research in the field, and factors for clinicians to consider when caring for dying patients who are veterans.

For more information, follow the links to “News” and “Health Spotlight” at www.hsrdr.research.va.gov.

Palliative Care Teams May Help Hospitalized Patients to Die Where They Wish

Discharge planning coordinated by an inpatient palliative care team has been found to allow nearly two-thirds of seriously ill patients to be successfully discharged into the community, even when death occurs within two weeks, Oregon researchers report.

“Hospital-based palliative care teams can play an important and unique role in discharge planning — allowing even patients very near death to leave the hospital if they wish — by ensuring that the right equipment and resources are in place, and preparing patients and family members for life and death away from the hospital,” write the authors of a report published in the *Journal of Palliative Medicine*.

Investigators followed 292 consecutive adult patients (mean age, 60.3 years; cancer diagnosis, 26%) referred for palliative care consults at the Oregon Health & Science University (OHSU), Portland, between October 2003 and September 2004. Mean length of hospital stay was 20 days, with 67.8% of patients having spent time in the intensive care unit.

Nearly two-thirds (62.7%) of the patients survived to be discharged, either to a nursing home (20%), inpatient hospice (26%), or their home (54%). Of those discharged home, 79% were under hospice care.

Key findings include:

- Only 4.7% of patients discharged alive following palliative care consult ultimately died in the hospital.
- Only 10% of discharged patients were readmitted to the hospital within 30 days.
- 38.3% of patients died within 2 weeks of discharge, 32.2% died between 2 weeks and 6 months, and 25.1% were alive at 6 months.
- Of the 38.3% of discharged patients who died within 2 weeks, 48.6% were in an inpatient hospice, 27.1% died at home, and 18.6% died in a nursing home.

“While the readmission rate is undoubtedly lower because so many patients died, these patients were also presumably sick enough to warrant readmission if they desired it,” comment the authors. **“The very low rate of ‘death in an acute care hospi-**

tal’ could indicate that most of these patients did not wish to die in the hospital and therefore the decision to discharge them from OHSU was sound.”

As part of its discharge planning, the OHSU palliative service team:

- Helps to arrange meetings to clarify prognosis and goals of care among patients, family, and clinicians
- Assesses family resources
- Recommends a suitable discharge location
- Ensures continuity of pain and symptom management
- Provides anticipatory guidance
- Ensures appropriate follow up

Care of terminally ill patients in Oregon differs in several ways from care in other states, the authors caution. This is not simply because Oregon has legalized physician-assisted suicide (although it is estimated that fewer than 0.1% of decedents have utilized the option). Oregon also has a high rate of advance directive completion — due in part to the Physician Orders for Life-Sustaining Treatment (POLST) program, developed by OHSU and widely used by physicians throughout the state.

In addition, Oregon has among the highest rates of hospice referral in the nation and a network of well-established hospice services and home hospice programs.

“Many patients in this study could not have been discharged without the rapid response of skilled hospice programs who were willing and capable of managing complex patients, who enrolled patients on weekends, and who followed patients in nursing homes,” comment the authors.

Source: “Survival, Mortality, and Location of Death for Patients Seen by a Hospital-Based Palliative Care Team,” Journal of Palliative Medicine; August 2006; 9(4):903-911. Fromme EK, Bascom PB, Smith MD, Tolle SW, Hanson L, Hickam DH, Osborne ML; Division of Hematology and Medical Oncology, Division of General Medicine and Geriatrics, Division of Pulmonary and Critical Care Medicine, Department of Medicine, and School of Nursing, Oregon Health and Science University, Portland, Oregon.

Key Elements of Palliative Care Consultation

- Pain and symptom assessment and management
- Communication of prognosis and identification of the goals of care
- Assessment of the patient’s support system; attention to information and emotional needs
- Assessment of discharge planning issues and active ensuring of successful discharge
- Terminal care for patients perceived to be actively dying

— Adapted from Fromme, et al, *Journal of Palliative Medicine*

COPD Patients Have Unmet Palliative Care Needs

Mortality from chronic obstructive pulmonary disease (COPD) — the fourth leading cause of death in the U.S. — continues to rise. Yet, when compared with patients with lung cancer, COPD patients nearing the end of their lives receive more aggressive care, with more frequent admissions to intensive care units (ICUs), longer ICU stays, and fewer palliative medications.

That is according to a study published in a recent issue of the *Archives of Internal Medicine*. “Our results suggest that compared with patients with lung cancer, patients with COPD received care that was more consistent with prolongation of life than palliation of symptoms during their last 6 months of life,” the authors write.

Researchers examined health care use in the last 6 months of life for 1490 COPD patients and 459 lung cancer patients provided for by the federal Department of Veterans Affairs (VA) health care system, where COPD and lung cancer are found more commonly than in the nation’s general population.

Findings include:

- In the last 6 months of life, COPD patients were twice as likely to be admitted to an ICU and had five times the odds of remaining there for 2 weeks or longer, compared with lung cancer patients.
- ICU use in the last 6 months of life was found to vary geographically among COPD patients, but not among cancer patients.
- COPD patients were 50% less likely to receive outpatient prescriptions for opiates and 65% less likely to be pre-

scribed benzodiazepines than were patients with cancer.

“Patients with COPD have been demonstrated to have similar degrees of severe pain and depression and worse dyspnea, functional status, and anxiety, compared with patients with lung cancer,” write the authors. “Our finding that patients with COPD received less palliative medications raises concern about unmet palliative care needs.

“These discrepancies suggest that physicians may be deciding to provide palliative services based more on general characterizations of disease (i.e., ‘malignant’ vs ‘benign’) rather than more specific characteristics, such as severity of symptoms or quality of life,” they write.

In addition, previous research has shown that patients with COPD are less likely to be invited to discuss advance care planning, have a greater need for education about their disease prognosis — including the dying process — and that instead of receiving care based on long-term goals, they tend to receive care that is a reaction to acute exacerbations.

“Our findings, in the setting of prior research, imply that to ensure that clinicians provide care consistent with patient wishes, discussions between patients, families, and health care providers should occur prior to an acute deterioration in clinical status.”

Source: “Differences in Health Care Utilization at the End of Life among Patients with Chronic Obstructive Pulmonary Disease and Patients with Lung Cancer,” Archives of Internal Medicine; February 13, 2006; 166(3):326-331. Au DH, Udris EM, Fihn SD, McDonnell MB, Curtis JR; Health Services Research and Development, VA Puget Sound Health Care System, Seattle, Washington; Department of Medicine, University of Washington, Seattle.

Experts Speak to Wide Range of Reforms Needed in End-of-Life Care

For the final issue in its eight-year series of influential policy briefs on end-of-life care, the Center for Practical Bioethics (CPB) asked three dozen experts what they would recommend to ensure “quality care for most Americans” in the foreseeable future.

“The Way Forward: Thirty-Five Leaders Map the Future of Reform,” celebrates the milestones reached in caring for patients at the end of life, then turns its attention to the challenges looming on the horizon and what might be done about them. The May 2006 brief is issue 25 in the series “State Initiatives in End-of-Life Care,” published jointly since 1998 by CPB and the Robert Wood Johnson Foundation.

Recommendations for end-of-life care reform, as identified by leading experts, include:

HOSPICE

Make Hospice an Integral Part of Comprehensive Care:

“Hospice care must be an expectation of consumers and the health care system, just like trauma centers are.” — *Charles von Gunten, MD, PhD, director, Center for Palliative Studies, San Diego Hospice & Palliative Care, San Diego, CA*

SPIRITUAL NEEDS

Address Spiritual Needs: “The real challenge for the near term is to find effective ways to teach practitioners to use nonpharmacological treatments — psychological, psychoso-

Continued on Page 5

Nutrition in End-of-Life Care: ‘Can’ Vs ‘Should’

The goals of nutrition support are generally focused on promoting improved health states. For patients nearing the end of life, nutrition support can be appropriate — not simply because it is technologically possible — but when it has the potential to relieve pain and suffering.

That is according to a review published in *Nutrition in Clinical Practice*, a journal of the American Society for Parenteral and Enteral Nutrition.

“Healthcare providers must be aware of the ‘technological imperative’ that unfortunately exists today: We *can* do something; therefore, we *should* do something. This imperative is neither morally correct nor ethically sound,” write the authors. “It is our responsibility to change the question from ‘what *can* be done?’ to ‘what *should* be done?’”

What should be done, assert the authors, is to base the decision to provide nutrition support for patients with life-limiting illness on the best interests of the patients and the goals that are achievable. The article offers a discussion of current literature on the role of the intervention in hospice and palliative care.

The decision to provide nutrition support during palliative and end-of-life care must be weighed against:

- The goals of therapy
- Benefits vs burden, as perceived by the patient
- The patient’s subjective assessment of quality of life

The term *quality of life* has no fixed meaning, note the authors; it can be defined differently by different patients, and the patient’s definition is likely to differ from that of the clinician. Thus, the patient’s assessment of his or her personal quality of life (or the assessment of the surrogate) must be monitored over time.

“Health care providers can offer great comfort to patients and families by helping the patient articulate how she or he defines quality of life, and by encouraging the patient to establish short-term, achievable goals.”

The article includes a discussion of contraindications for artificial nutrition, a table listing common benefits and burdens associated with nutrition support, and a list of criteria clinicians can use to determine

when a trial of parenteral nutrition may be indicated.

Effective management of symptoms that interfere with nutrient intake is imperative prior to consideration of specialized nutrition support, the authors point out. Such symptoms include: depression, bowel obstruction, dyspnea, nausea, vomiting, and pain. “The most important palliative intervention is meticulous pain management,” they state.

Because nutrition support should be used to contribute to the relief of pain and suffering, they add, its withdrawal should never justify the discontinuation of other comfort support.

“The opportunity to assist patients and their families during a terminal illness is one of the most important obligations of health care providers, and allows us to help patients in a very intimate way in one of the most important times of their lives.”

Source: “Bridging the Continuum: Nutrition Support in Palliative and Hospice Care,” Nutrition in Clinical Practice; April 2006; 21(2):134-141. Fuhrman MP, Herrmann VM; Coram, Inc., Ballwin, Missouri; and Center for Breast Care, Memorial Health University Hospital/Anderson Cancer Institute, Savannah, Georgia.

Experts Speak (from Page 4)

cial, and spiritual interventions — and provide ways to integrate them into medical approaches.” — *Richard Payne, MD, director, Institute on Care at the End of Life, Duke Divinity School, Durham, NC*

“We must realize that dying is a spiritual process with medical implications, not a medical process with spiritual implications.” — *Gwendolyn London, DMin, former executive director, the DC Partnership to Improve End-of-Life Care*

PAIN MEDICATION

Improve the Regulatory Climate Surrounding Pain Medication Prescribing: “Far too many people still die in pain. This is morally unacceptable. Pain relief is a right, not a privilege.” — *June Dahl, PhD, professor of pharmacology, Uni-*

versity of Wisconsin School of Medicine and Public Health, Madison, WI

ADVANCE CARE PLANNING

Update Advance Care Planning Documentation to Reflect Changes in Patient Preferences and Shifts in Settings: “Everybody approaches or avoids the issue of dying in different ways, so you want to make the system friendly and supportive of elucidating patient desires in any way you can...Older living will forms will fade and be replaced by conversational approaches that help to develop people’s thinking on a continuing basis.” — *Charles Sabatino, JD, director, Commission on Law and Aging, the American Bar Association*

All 25 issues of “State Initiatives in End-of-Life Care” are freely available online. Select “Resources” on the CPB website at www.practicalbioethics.org.

CLINICIAN RESOURCES

Physicians Offered Framework for Discontinuing Medications in Elderly Patients

Although guidelines exist for identifying inappropriate medications to be avoided in patients late in life, there is a dearth of information to guide physicians in the withholding or discontinuation of no longer effective but otherwise recommended medications in these patients.

That is according to a team of University of Chicago physicians, whose model for medication decision making was published in a recent issue of the *Archives of Internal Medicine*.

“Our framework was designed to help patients and physicians decide when to stop taking even safe and effective drugs in situations that are often radically different from those in which the medications were started,” says geriatrician and lead author Holly M. Holmes, MD, instructor of medicine at the university.

“We wanted to provide a road map that would steer people away from the prescribing cascade that is common for patients late in life,” continues Holmes, “and guide them past the barriers that prevent removal of treatments that may no longer be effective.”

To the usual consideration of drug risk vs benefit, **the guidelines presented by Holmes and colleagues add four components: remaining life expectancy, time until benefit, goals of care, and treatment targets.** Use of the model is illustrated in the article by case scenarios.

Physicians can:

- Calculate the patient’s **remaining life expectancy**, based on actuarial tables (an example is included in the article), modified by comorbidities and patient history.
- Consider the **time until treatment benefit** will be achieved. Patients with less than two years to live are not likely to benefit from angiotensin-converting enzyme inhibitors or statins, for example, whereas analgesics for symptom relief “would continue to benefit

all patients, including (or especially) those close to death.”

- Determine the **goals of care** with the patient and family, moving through prevention, treatment, and/or palliation. “Goals of care can be challenging, but may be the component of the prescribing process over which physicians have the most influence,” comment the authors.
- Define the **treatment targets** that match with the goals of care. Examples include: prevention of morbidity and mortality, treatment of acute illness, maintenance of current function, and palliation of symptoms.

Stopping medications in elderly patients may make clinical sense, warn the authors, but can nevertheless be challenging for both physicians and patients. Physicians — who tend to have “clinical inertia with regard to prescribing” — are commonly encouraged to increase medications to reach disease-specific targets regardless of the patient’s age, while patients are admonished to adhere to their prescription regimens.

However, physicians may overestimate patients’ discomfort with discontinuing the use of medicines, note the authors, particularly in light of the frequently unpleasant side effects of some drugs and the expense of paying for multiple prescriptions.

“Most drug studies tell you how to treat the chart, how to treat the numbers,” says co-author G. Caleb Alexander, MD, assistant professor of medicine at the University of Chicago, “but they don’t always help you treat the patient. We set out to fill some of those gaps.”

The authors conclude, “We believe that a framework such as the model we propose may help guide decisions about the use of medications that are more concordant with the possible benefits of medications in the context of patients’ life expectancies and goals of care.”

Source: “Reconsidering Medication Appropriateness for Patients Late in Life,” *Archives of Internal Medicine*; March 27, 2006; 166(6):605-609. Holmes HM, Hayley DC, Alexander GC, Sachs GA; Department of Medicine, University of Chicago, Chicago.

“Medication discontinuation, when done right, can decrease costs, simplify prescription regimens, decrease adverse drug events, and focus therapy for maximum benefit.”

— Alexander

“Evidence-based medicine has changed the way physicians practice, but it seems to have had tunnel vision when it comes to withdrawing drugs. The discontinuation of medications is a neglected science.”

— Holmes

— *Archives of Internal Medicine*

CLINICIAN RESOURCES

Oncotalk: Improving Oncologists' Communication Skills

———— www.oncotalk.info ————

Good communication is consistently identified by patients and families as one of the most important elements of quality end-of-life care. But misconceptions about improving communication skills and a lack of supervised training — particularly among oncologists — prevent many physicians from honing these needed skills.

“Discussing patients’ difficulties with the emotional aspects of their disease and the possibility of death had become a disruption to my own delicate balance of time and emotional energy,” writes oncology fellow Lanie K. Francis, MD, in the July 1, 2006, issue of the *Journal of Clinical Oncology*. “I increasingly understood how physicians learned to compartmentalize the job of taking care of cancer patients and focus only on the treatment.”

Lanie decided to participate in the Oncotalk program, a four-day intensive retreat designed to build communication skills through lectures, discussions, and experience. Physicians practice talking with trained actors, who stay in the roles of patients throughout the course of an illness, from first disclosure of bad news to discussion of impending death.

The role-playing scenario allows physicians to make mistakes, reword their thoughts, and receive feedback from teachers and peers. “It’s one thing to know what you have to say and another thing to say it,” says Oncotalk principal investigator Anthony Back, MD, associate professor of medicine at the University of Washington, Seattle. “So our goal is to have the fellows become aware of the ways they avoid conversations, and to help them learn new behaviors.”

The Oncotalk program maintains a website offering brief guides to the communication topics and tasks addressed during the workshop retreat. These are organized into eight learning modules in PDF format. Each module includes background information, practical steps, references, and “pearls and pitfalls,” although the emphasis is on actively following the principles, rather than avoiding the pitfalls.

Learning module titles include:

1. Fundamental Communication Skills
2. Giving Bad News
3. Managing Transitions to Palliative Care When Chemotherapy is Failing
4. Talking about Advance Care Plans and Do-Not-Resuscitate Orders
5. Discussing Treatment Options and Informed Consent
6. Conducting a Family Conference
7. Handling Requests for Therapies That You Feel Are Futile
8. Cultivating Your Communication Skills

“I learned that what I always perceived as the emotionally draining aspects of oncology — getting close to patients to care and feel for them — were rewarding, renewing, and ultimately energizing,” concludes Francis, who is with the department of medicine, division of hematology/oncology, University of Pittsburgh Cancer Institute, Pittsburgh.

Oncotalk is funded by the National Cancer Institute and based at the University of Washington, Seattle. The quotations from Back appeared in the Winter 2006 issue of *UW Medicine*, a publication of the university’s School of Medicine.

For more information, visit www.oncotalk.info.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPEC)

www.epec.net

The EPEC Project (Education in Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.caringinfo.org

National consumer engagement initiative to improve end-of-life care

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/pallmed/

Medical College of Wisconsin Palliative Care Center

www.medsch.wisc.edu/painpolicy/

University of Wisconsin Pain and Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

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