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Quality of Life Matters®
End-of-life care news & clinical findings for physicians

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National Study Finds Further Evidence That Hospice Use Does 'Not Compromise Survival'

Bolstering other recent findings that hospice care does not shorten — and may even prolong — survival among patients with cancer, an international team of researchers reports that Medicare hospice patients have a slight survival advantage over their nonhospice counterparts. Further, aggressive care delivered late in the illness is more likely merely to shorten hospice stay than to extend life.

> "Appropriate timing of referral to hospice gives terminally ill cancer patients and their families more time and opportunity to benefit from palliative services and avoid futile interventions. Concern about hastening death should not be a barrier to hospice care."
>
> — *Saito et al,* Journal of Palliative Medicine

"Despite a significant relationship between aggressive care at the end of life and no or only short-term hospice stay, hospice patients were found to have comparable or even longer survival compared to nonhospice patients, based on three different statistical approaches," write the authors of a report published in the Journal of Palliative Medicine.

The team conducted multiple analyses of data on Medicare patients (n = 7879) who survived for at least three months following diagnosis of non-small-cell lung cancer between 1991 and 1999. Patients were divided into matched "hospice" and "nonhospice" groups, with the hospice group further divided according to length of stay: "short term" (≤ 3 days in hospice) or "longer term" (≥ 4 days in hospice).

Indicators of "aggressive care" near the end of life included: a new chemotherapy regimen begun less than 30 days before death; receiving a last dose of chemotherapy within 14 days of death; more than one emergency department visit or hospital admission in the last month of life; or being hospitalized for longer than 14 days in the final month.

KEY FINDINGS:

- Survival was found to favor hospice patients relative to nonhospice patients by 5.0% at one year following diagnosis (25.7%, hospice patients vs 20.7%, nonhospice) and by 1.4% at two years post-diagnosis (6.9% vs 5.5%).
- Longer-term hospice patients had longer survival than nonhospice patients (hazard ratio [HR], 0.87; 95% confidence interval [CI], 0.83 to 0.91; p = 0.0001).
- Short-term hospice patients had a similar, although slight, survival advantage compared with patients in the nonhospice group (HR, 0.94; 95% CI, 0.83 to 1.05; p = 0.26).
- Hospice patients with short-term admissions were more likely to be male, urban dwellers, and to have received aggressive care near the end of life.

OVERALL:

- 47.9% of all patients received hospice care.

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Achieving Equitable Access to Quality Hospice and Palliative Care: We're at the 'Tipping Point,' Declares Expert

Caring for the sickest Medicare beneficiaries — the 10% with serious illness or multiple chronic conditions — accounts for 57% of the total program spending, yet studies demonstrate that these patients and their families are receiving health care of inadequate quality. The dual goals of cutting expenditures and delivering the care that patients need and desire can be achieved by strengthening access to quality palliative care and hospice.

That is according to an article published in the September issue of The Milbank Quarterly, a peer-reviewed, multidisciplinary journal of population health and health policy. The article reviews the benefits of palliative care and the barriers to its delivery, and suggests policy approaches for standardizing access to high-quality care.

"Palliative care and hospice services improve patient-centered outcomes such as pain, depression, and other symptoms; patient and family satisfaction; and the receipt of care in the place that the patient chooses," writes author Diane E. Meier, MD, professor of geriatrics and palliative medicine at the Mount Sinai School of Medicine, New York City.

"By helping patients get the care they need to avoid unnecessary emergency department and hospital stays and shifting the locus of care to the home or community, palliative care and hospice reduce health care spending for America's sickest and most costly patient populations."

PALLIATIVE CARE AND HOSPICE TEAMS: DELIVERING HIGH-QUALITY CARE

Much of the strength of palliative care services lies in their coordinated, patient-centered, multidisciplinary approach. Palliative care and hospice teams improve quality of care by:

- Identifying and rapidly treating distressing symptoms that are shown to increase medical complications and hospitalization
- Planning for safe transitions from acute care to more supportive settings, such as home health care, home or inpatient hospice, or nursing home care with hospice
- Avoiding nonbeneficial or harmful tests, procedures, or specialty consultations
- Meeting often with patients and families to establish realistic goals, leading to better-informed decision making, clarity of the care plan, and consistent follow-through
- Easing the burden experienced by families and increasing satisfaction by supporting families in routine care, in crisis, and in bereavement

Policy Focus for Improving Access to Quality Palliative Care

- **Enhance** the medical and nursing workforce with expertise in palliative care
- **Invest** in the field's research evidence base
- **Increase** availability of services in hospitals and nursing homes

— Meier, *The Milbank Quarterly*

COST SAVINGS OF PALLIATIVE CARE AND HOSPICE

Recent data show that the average per-patient, per-admission, net cost saved by using hospital palliative care consultation is $2659, which translates into an estimated $1.2 billion saved per year by the programs currently established at more than 60% of U.S. hospitals. Meier points out that this figure could increase to $4 billion saved, if appropriate hospital palliative care services were expanded to meet the needs of most patients who are currently discharged with serious and complex chronic illness without benefit of these services.

Hospice care, currently provided to over 1.5 million patients yearly, has been shown to reduce total health care costs by an estimated $2300 per Medicare beneficiary, with an average annual savings of more than $3.5 billion per year. When patients disenroll from hospice, their medical costs are nearly five times higher than for those who remain in hospice care, Meier points out.

The United States is unique in its categorization of palliative care into two distinct types, notes Meier, in that it labels "palliative care" as needs-based, with no prognostic restriction, and "hospice" as palliative care that is restricted to patients with a prognosis of living six months or less.

The relatively new field of palliative care outside of hospice has been created largely by private sector contribu-

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National Study Finds Further Evidence That Hospice Use Does 'Not Compromise Survival'

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- 92.6% of the hospice patients died under hospice care, while only 2.8% died in a hospital.
- In contrast, 39.7% of nonhospice patients died in an acute care setting.
- Hospice patients were older, more likely to be non-Hispanic white and female, and more likely to live in urban areas with high hospice availability.

"[R]egional availability of hospice was associated with any hospice use, but not with length of hospice stay," the authors point out. "Instead, experiencing aggressive end-of-life care was more predictive of shorter duration of hospice use."

Despite the results of recent studies showing that hospice care does not hasten death, there is a current trend in this country toward increasingly aggressive care among cancer patients nearing death, the authors point out. "Advances in medical technologies and a perception that patients favor receiving aggressive care even very near death for small expected benefits may reduce the number of patients referred to hospice," they suggest.

Nevertheless, the authors state firmly in their conclusion, "[the] use of hospice and length of hospice stay for Medicare patients with advanced non-small-cell lung cancer did not compromise survival."

Source: "Hospice Care and Survival among Elderly Patients with Lung Cancer," Journal of Palliative Medicine; *August 2011; 14(8):929-939. Saito AM, Landrum MB, Neville BA, Ayanian JZ, Weeks JC, Earle CC; Laboratory of Clinical, Epidemiological, and Health Services Research, Clinical Research Center, National Hospital Organization Nagoya Medical Center, Aichi, Japan; Department of Health Care Policy, Harvard Medical School, Boston; Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute, Boston; Division of General Medicine, Brigham and Women's Hospital, Boston; Cancer Care Ontario, Ontario Institute for Cancer Research, and the Institute for Clinical Evaluative Sciences, Toronto.*

Achieving Equitable Access to Quality Hospice and Palliative Care: We're at the 'Tipping Point,' Declares Expert

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tions and initiatives from major professional organizations. Meanwhile, the growth in federally mandated hospice programs has resulted in a national workforce that is already trained and experienced in caring for this high-need population. Meier suggests combining the strengths of these services.

"Linking palliative care and hospice teams to implementing new delivery models may increase the likelihood of their achieving their quality and health care value objective," suggests Meier. "The combined and sustained commitment of both the private and the public sectors will be necessary to bring the palliative care innovation to scale in the United States."

Meanwhile, Meier suggests that organizations and clinicians can help increase public awareness and access to palliative care and hospice services by directing consumers, employees, and patients to such websites as palliativedoctors.org and getpalliativecare.org, developed by the American Academy of Hospice and Palliative Medicine and the Center to Advance Palliative Care, respectively.

"Ensuring access to high-quality palliative care for all Americans who might benefit requires that providers be trained to deliver this kind of care; that an evidence base exists to ensure quality; that health care organizations have the capacity to provide palliative care; and that the public understands what palliative care and hospice are and demand such care from their clinician," declares Meier.

"We have come a long way toward achieving these goals, and ensuring that palliative care is reliably available to America's sickest and most vulnerable patients and their families is now at a tipping point."

Source: "Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care," The Milbank Quarterly; *September 2011; 89(3):343-380. DOI: 10.1111/j.1468-0009.2011.00632.x. Meier DE; Department of Geriatrics and Palliative Medicine, Mount Sinai School of Medicine, New York City.*

RESEARCH MONITOR

When Patients Have Multiple Comorbidities: The Challenges of End-of-Life Discussions without One Clear Terminal Diagnosis

Prognostic uncertainty and lack of good communication tools are two major barriers to conducting effective end-of-life (EOL) conversations for timely referral to palliative and/or hospice care. When elderly patients have a variety of chronic diseases, deciding when and how to conduct such conversations may be uniquely challenging, according to a report published in the American Journal of Hospice & Palliative Medicine.

"These difficulties may be magnified in patients with multimorbid medical conditions — often characterized as 'debility, unspecified' — where both the timing and content of conversations about EOL issues may pose difficulties for providers," write the authors. "For these patients, there is no single, clear 'terminal' diagnosis that precipitates the transition to EOL care, nor is there often a sentinel event that signals a marked and clear decline."

A review of the literature finds that there are knowledge gaps regarding what prognostic tools or communication scripts might assist physicians with predictive accuracy and timing of discussions for multimorbid patients, the authors point out.

Many of these patients exhibit debility, frailty, or failure to thrive, yet none of these diagnoses clearly indicates a terminal condition. Nevertheless, "these patients are dying, and ensuring appropriate EOL care planning requires that both health care providers and patients and their families address this fact," they note.

PHYSICIAN EXPERIENCES: A QUALITATIVE STUDY

The team analyzed qualitative data gathered from focus groups consisting of a total of 32 attending or resident physicians (mean age, 37.8 years; female, 59.4%) in family, internal, or geriatric medicine at a Midwestern academic medical center. While less than half had participated in EOL discussions with a patient with multiple morbidities in a clinical setting, more than 80% had engaged in such discussions in private life.

Participants overwhelmingly reported that EOL discussions are more challenging with multimorbid patients. Physicians believed that a terminal diagnosis such as cancer was easier and less time-consuming for physicians to explain, easier for patients/families to understand and accept, and thus it was easier to reach a consensus regarding prognosis and a plan of care.

"Cancer appears to be a special case, in that patients and families seem to understand that cancer is often terminal, while on the other hand, patients and families seem to believe that other diseases with comparable life expectancies (e.g., heart failure or renal disease) can be treated or cured," the authors point out.

Another important difference is that "with a clear, terminal diagnosis, providers and patients focus on the diagnosis itself, whereas with multiple comorbidities, the focus tends to be more on the quality of life of the patient," the authors add.

TIMING THE EOL DISCUSSION WITH MULTIMORBID PATIENTS

Physicians in the study reported a number of physical cues they use to prompt discussions, such as health status, frequency of visits, efficacy of treatment, decreased functional status, or age. "Participants were unaware of the existence of prognostic tools to aid them in estimating a multimorbid patient's prognosis, but were interested in learning more."

Social cues that can prompt EOL conversations included the establishment of a rapport with the patient, statements of patient readiness, patient remarks about quality of life, or even the physician's own self-perceived readiness to initiate such a discussion.

APPROACHES TO DISCUSSION

Participants identified three types of approaches to discussing EOL care with patients with multiple comorbidities:

In the direct approach, the physician introduces the topic after assessing the patient's readiness and receptiveness. Although difficult, this physician-driven approach may be needed when families hesitate because of feelings of guilt.

The second method, the indirect approach, was considered to be more effective. The physician encourages the patient/family to broach the topic, by using an open-ended question such as asking how they think the patient is doing.

The third option is the collaborative approach, in which the physician calls for a structured family meeting, provides information for all involved to discuss, then ends the meeting by making sure clear decisions have been agreed upon.

"[F]uture research is needed to determine ways to overcome both the real and perceived barriers to having EOL conversations with older patients with multiple comorbidities and their families," conclude the authors. "Facilitating effective communication and optimal times for this patient population may better respect patient autonomy, improve overall quality of life, and enhance provider-patient relationships."

Source: "Assessing Challenges in End-of-Life Conversations with Elderly Patients with Multiple Morbidities," American Journal of Hospice & Palliative Medicine; *Epub ahead of print, August 25, 2011; DOI; 10.1177/1049909111418778. Schonfeld TL, Stevens EA, Lampman MM, Lyons WL; Bioethics Program, Center for Ethics, and Department of Medicine, School of Medicine, Emory University, Atlanta, Georgia; Department of Health Management and Policy, University of Iowa, Iowa City; and Department of Internal Medicine, College of Medicine, University of Nebraska Medical Center, Omaha.*

RESEARCH MONITOR

Timely Receipt of Hospice Services Yields Higher Family Perceptions of Quality of Nursing Home Death among Dementia Patients

Family members of nursing home residents with dementia who died while under hospice care were twice as likely as those whose loved ones did not receive hospice to give high ratings for the quality of care received, researchers have found. Further, ratings of care were even higher when families believed that hospice services were instituted in a timely manner.

"This is the first study that provides evidence that the provision of hospice services, especially when they are initiated 'at the right time' for persons with dementia, improve family members' perceptions of the quality of care," write the authors of a report published in the Journal of the American Geriatrics Society.

Since the goals of hospice care are "effective symptom management and maximization of quality of life, hospice services should be of significant benefit to nursing home residents, yet little research has examined the effectiveness of hospice services for persons dying of dementia," the authors maintain.

Investigators compared responses regarding the quality of care and quality of dying reported by 538 bereaved family members of hospice and nonhospice nursing home decedents who had dementia as the listed cause of death. Results were further stratified based on whether family members felt their loved ones had received hospice services "too late" or "at the right time." The mortality follow-back survey was conducted between 2007 and 2009 in five states (AL, FL, MA, MN, and TX).

KEY FINDINGS:

- Overall, 73.2% of dementia patients died in the nursing home.
- Family members of those receiving hospice care were 51% less likely to report unmet needs and concerns with quality of care than were respondents whose loved ones were not in hospice (adjusted odds ratio [AOR], 0.49; 95% confidence interval [CI], 0.33 to 0.74).
- Compared with respondents whose loved ones died without hospice care, family members of hospice patients were twice as likely to give high ratings for the

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New Accreditation Standards from the American College of Surgeons Focus on Patient-Centered Approach to Hospice and Palliative Care

A patient-centered approach to cancer care is now a required part of the accreditation standards set for hospital cancer programs by the Commission on Cancer of the American College of Surgeons (ACS), which just released its new manual entitled, "Cancer Program Standards 2012: Ensuring Patient-Centered Care."

"The changing landscape of cancer patient care motivated us to develop new standards to directly address patient concerns," says commission chair Stephen B. Edge, MD, professor of surgery at the School of Medicine and Biomedical Sciences, State University of New York at Buffalo. "These standards enhance the focus of care so that it is much more than a defined structure of clinical treatment."

While ensuring that key elements of quality cancer care are provided to every patient treated at one of their accredited facilities throughout the diagnosis and treatment process, the updated standards emphasize the importance of a supportive, patient-centered approach to care.

ACCREDITED PROGRAMS ARE REQUIRED TO OFFER:

- Screening for psychosocial distress and access to support for patients and families
- Care for cancer-related pain
- A patient navigation process to help coordinate multidisciplinary care and facilitate timely access to quality medical and psychosocial care
- Palliative care (either on-site or by referral to other locations, including community-based resources)
- Access to hospice care when prognosis is limited and when "death would not be surprising"

"Cancer care over the last 50 years has evolved from its primary focus on local disease to a sophisticated, multidisciplinary approach...," states the manual. "Unfortunately, there remains substantial evidence that many people with cancer do not receive the benefits of high quality care that are now possible. Meeting these standards is the obligation of all who provide cancer care."

The multidisciplinary commission is a consortium of 47 professional organizations that establishes cancer care standards and monitors quality at the more than 1500 hospitals it accredits. According to the ACS, these institutions represent more than 70% of all new cancer cases diagnosed annually.

For more information, visit ***www.facs.org/cancer/coc/programstandards2012.html.***

RESEARCH MONITOR

Informing Patients of Impending Death Linked to Improved End-of-Life Care, with No Increase in Pain or Anxiety

Being informed of the imminence of death does not lead to more unrelieved symptoms among cancer patients during the last week of life, but rather appears to increase the probability that patients will receive needed symptom control and die in the location of their choice, a team of Swedish researchers has found.

"Providing information of imminent death to a patient with cancer at the end of life does not seem to increase pain or anxiety, but it does seem to be associated with improved care and to increase the likelihood of fulfilling the principles of a good death," write the authors of a report published in the Journal of Clinical Oncology.

The team analyzed data collected on all cancer deaths between 2006 and 2008 from the Swedish Register for Palliative Care. This national quality register is an online questionnaire based on the 11 principles of a good death as defined by the British Geriatrics Society, and is completed by the physician and/or nurse who cared for the patient during the last week of life.

During the study period, 13,818 patients who died of advanced cancer had documentation regarding the imminence of their expected deaths and whether or not they had been so informed. Since only 9% of patients had not been informed, researchers compared two matched groups (informed vs uninformed) consisting of 1191 patients in each group.

KEY FINDINGS:

- Significantly more patients in the informed group than in the uninformed group died in their preferred location (70% vs 39%).
- Patients in the informed group were more likely to have parenteral as-needed prescriptions, and to have their family members informed and offered bereavement support.
- Registered symptoms (pain, anxiety, confusion, nausea, dyspnea, and respiratory tract secretions) were reported as being relieved in 80% to 96% of all patients. There were no significant differences between the two groups, except for confusion, which had a slightly higher rate of relief among informed patients.
- Staff knowledge of the patient's preferred place of death was significantly higher among informed patients than among those who were uninformed (75% vs 41%).

"To give information about imminent death is a conscious act that involves awareness of the fact that the patient is dying, an awareness that also implies preparedness of the health care professional," comment the authors. "Such preparedness should increase the probability of a more proactive approach with respect to prescribing palliative drugs and addressing patient and family wishes and needs during the last days of life (i.e., a concept of total care)."

Source: "Information of Imminent Death or Not: Does It Make a Difference?" Journal of Clinical Oncology; *Epub ahead of print, September 12, 2011; DOI: 10.1200/JCO.2011.34.6247. Lundquist G, Rasmussen BH, Axelsson B; Umeå University and Umeå Hospice, Umeå; Center of Clinical Research, County Council of Dalarna, Falun; and Östersund Hospital, Östersund, Sweden.*

Timely Receipt of Hospice Services Yields Higher Family Perceptions of Quality of Nursing Home Death among Dementia Patients

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quality of care (AOR, 2.0; 95% CI, 1.53 to 2.72).

- Among family members who reported that hospice services were timely, the likelihood of high ratings for quality of care was even greater (AOR, 2.30; 95% CI, 1.69 to 3.13).
- Quality of death was more likely to be rated highly by respondents whose loved ones died under hospice care (AOR, 1.68; 95% CI, 1.11 to 2.56).

"Hospice services were associated with fewer unmet needs, fewer reported concerns with the quality of care, and higher family ratings of the quality of care," write the authors. "Additionally, family members reported that decedents who received hospice services had better quality of dying than those who did not receive hospice services."

Although few survey respondents reported that residents were referred to hospice services too late (n = 33), the "findings show that time of referral to hospice services is related to perceived quality of care," note the authors. "Therefore, it is not only receipt of hospice services, but also whether the family member believes that they received hospice services in a timely manner that is an important quality concern."

Source: "Does Hospice Improve Quality of Care for Persons Dying from Dementia?" Journal of the American Geriatrics Society; *August 2011; 59(8):1531-1536. Teno JM, Gozalo PL, Lee IC, Kuo S, Spence C, Connor SR, Casarett DJ; Department of Community Health, Warren Alpert School of Medicine, Brown University, Providence, Rhode Island; National Hospice and Palliative Care Organization, Alexandria, Virginia; Worldwide Palliative Care Alliance, London, United Kingdom; and Division of Geriatrics, School of Medicine, Department of Medicine, University of Pennsylvania, Philadelphia.*

CLINICIAN RESOURCES

Approach to Addressing Cultural Beliefs and Preferences

Misunderstandings can arise in communication about serious illness and palliative care due to patients' particular cultural beliefs held regarding the end of life. A recent monograph from EPERC (End-of-Life/Palliative Education Resource Center) outlines approaches for avoiding miscommunication with these patients and their families.

University of Pittsburgh Medical Center experts offer the following suggestions in EPERC's Fast Facts and Concepts #216:

- Determine the patient's information preferences, how and whether he or she wants medical information shared, and with whom. "Some people want to know everything about their medical condition, while others do not. How much would you like to know?" Identify the patient's main contacts, and how they choose to be informed. "Would you like me to talk to your family alone, or would you like to be present?"
- Respectfully explore the patient and family's heritage and cultural values, using open-ended questions. "Is there anything about how you and your family view serious illness that would be helpful for me to know?" If discussing death is acceptable, ask if there are concerns about dying. "Are there things that are important to you that I should know about?"
- Communicate specific customs the patient wishes to be followed to the care team. The clinician may need to advocate for the patient to ensure — particularly in a hospital setting — that these will be honored. "Are there specific practices that you would like to have in the hospital or at home? Are there aspects of medical care that you wish to forgo or have withheld because of your cultural beliefs?"
- Identify the decision-making structure, and whether it includes the family and/or a community leader. "Do you prefer to make medical decisions about tests and treatments yourself, or would you prefer that others in your family or community make them for you?"
- Confirm the patient's understanding by asking him or her to summarize what both of you have said. "Can you tell me, in your own words, what you have heard from me and what is the most important to you about what I have said?"
- Utilize the services of a medical interpreter, if there is a serious language barrier.
- Determine whether the patient is open to receiving care in his or her home when referring to hospice. This is important since most hospice care is delivered in the home and some patients may be resistant to accepting help in the home from health care professionals outside their cultural community.

Source: "Asking about Cultural Beliefs in Palliative Care," Fast Facts and Concepts #216. Lum H, Arnold R; University of Pittsburgh Medical Center, Pittsburgh. Available at: www.eperc.mcw.edu/fastfact/ff_216.htm.

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 (EPERC)

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
Caring Connections: 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/palliativecare.htm
Medical College of Wisconsin
Palliative Care Center

www.painpolicy.wisc.edu
University of Wisconsin Pain
and Policy Studies Group

www.capc.org
Center to Advance Palliative Care

www.stoppain.org
Pain Medicine & Palliative Care,
Beth Israel Medical Center

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