Earlier End-of-Life Discussions Linked to Greater Use of Hospice, Less Aggressive Care Near Death

Providing what the American Society of Clinical Oncology (ASCO) has called the “first-of-its-kind evidence that timing of end-of-life care discussions affects decisions about end-of-life care,” a team of North American researchers has found that patients with advanced cancer who had earlier discussions about end-of-life care with their physicians were less likely to receive aggressive measures before death.

“Use of aggressive care was much less frequent when end-of-life discussions took place at any time before the last 30 days of life, and the odds of hospice use were nearly twice as high,” write the authors of a report published in the Journal of Clinical Oncology.

Investigators analyzed data on 1231 patients (male, 62%; non-Hispanic white, 76%) diagnosed between 2003 and 2005 with stage IV lung or colorectal cancer, as part of the national Cancer Care Outcomes Research and Surveillance Consortium, a prospective cohort study based on population and health systems.

OVERALL FINDINGS

• Nearly half (47%) of patients received at least one type of aggressive care, including acute hospital-based care in the last 30 days of life (40%), chemotherapy in the last 14 days of life (16%), and care in the intensive care unit in the last 30 days (9%).
• 58% of patients received hospice care; 15% of patients entered hospice within 7 days of death.
• 88% of patients had end-of-life discussions with their physicians. However, 17% of patients with discussions documented in their medical records did not remember that they took place.
• Among the end-of-life discussions reported in medical records, 39% took place in the last 30 days of life, 40% included the presence of an oncologist, and 63% took place in an inpatient hospital setting.

KEY FINDINGS

• Patients who had end-of-life discussions before the last 30 days of life were less likely to receive chemotherapy (P = .003), acute care (P < .001), or any aggressive care (P < .001) at end of life.
• Compared with discussions that took place within the final 30 days of life, earlier end-of-life discussions were associated with less frequent use of aggressive care (34% [> 90 days before death] to 45% [31-60 days before death] vs 65% [< 30 days before death]).
• Compared with late discussions, earlier end-of-life discussions were associated with increased use of hospice care (77% [> 90 days before death] to 68% [31-60 days before death] vs 49% [< 30 days before death]).

“Others have suggested that end-of-life decision making requires time; most patients need to process the idea that life is nearing its end before they can make decisions about their end-of-life care,” comment the authors. “However, physicians seem to wait until the patient begins deteriorating medically, a strategy that leads to a high incidence of inpatient discussions,” during which patients may be too stressed to make clear decisions or to remember what was said.

Instead, suggest the authors, physicians should consider moving conversations closer to diagnosis and initiating conversations while the patient is doing comparatively well, so the patient has time to plan for more difficult times in the future.

“Conversations about treatment options for advanced cancer are extremely difficult for patients, their families, and their oncologist,” says ASCO president Sandra M. Swain, MD. “But this study underscores a growing body of evidence...
The current Medicare hospice per diem reimbursement structure can put hospices at financial risk when caring for patients with high-cost medical or social needs as they near the end of life. More than three-quarters of the nation’s hospices were found to have at least one enrollment policy restricting access for such patients, according to the results of the first national survey of hospice enrollment policies, published in *Health Affairs*.

“Our results indicate that addressing the financial risk to hospices of caring for patients with high-cost, complex, palliative care needs is likely a key factor to improving access to hospice,” says lead author Melissa Aldridge Carlson, PhD, MBA, assistant professor, Department of Geriatrics and Palliative Medicine, Mount Sinai School of Medicine.

Investigators analyzed survey responses from a random sample of medical directors of U.S. hospices (n = 591) operating from 2008 to 2009 across five census regions. Although the study data are from several years ago, the authors point out that there have been no major Medicare policy changes since then that are likely to affect hospice enrollment policies.

**KEY FINDINGS:**

- 78% of U.S. hospices have at least one enrollment policy that could restrict access to care for patients with potentially high-cost medical care needs.
- Mean number of restrictive enrollment policies per hospice was 2.3 (out of a potential total of 7).
- Prevalence of restrictive policies ranged from 61% (no chemotherapy) to 8% (no tube feeding).
- Smaller hospices and those in the Mountain and Pacific census region reported more limited enrollment policies.
- 29% of hospices had an innovative “open access” policy, offering a full range of palliative care services to patients not yet eligible for hospice. These hospices were significantly less likely to restrict access.
- Many patients with terminal illnesses can benefit from palliative chemotherapy, radiation, or blood transfusions. But some of these treatments can cost more than $10,000 per month, note the authors. The average Medicare hospice reimbursement rate is $140 per day per patient, meaning that some hospices are simply unable to afford to enroll these patients.

In addition, some patients may require more labor-intensive care, such as tube feeding or intravenous nutrition, or more frequent and intensive home visits when there is no informal caregiver in the home, for example. “Because the per diem hospice reimbursement rate is not adjusted for the cost or intensity of care, hospices have financial incentives to not enroll these potentially high-cost patients,” observe the authors.

“Hospice care is an ideal model of health care reform,” observes Aldridge Carlson, and is consistent with currently desirable health care reform goals.

**THE HOSPICE MODEL OF CARE:**

- Provides a patient-centered approach to care
- Delivers care through a multidisciplinary team
- Coordinates care across settings

**Recommendations for Expanding Access to Hospice**

- Increase the Medicare hospice per diem rate for patients with complex needs.
- Relax the hospice eligibility criteria that currently create an “artificial dichotomy” between curative and palliative treatments.
- Create partnerships between smaller hospices and hospital-based palliative care programs.
- Encourage innovations such as the open-access enrollment policy.

— Adapted from Aldridge Carlson et al, *Health Affairs*

The authors call for a reform of the Medicare reimbursement rates, as well as reform of hospice eligibility requirements. “Specifically, if the hospice per diem reimbursement were increased for patients with high-cost needs, such patients would not be as financially risky for hospices to enroll, and enrollment policies might become less restrictive,” they suggest.

“Findings from this study may be central to unraveling the puzzle of concurrent expansion of the hospice industry with persistent unmet need for hospice care,” comment the authors. For now, “it is important for referring physicians to be aware that there is extensive variation in hospice enrollment policies.”

Source: “Hospices’ Enrollment Policies May Contribute to Underuse of Hospice Care in the United States,” *Health Affairs*; December 2012; 31(12):2690-2698. Aldridge Carlson MD, Barry CL, Cherlin EJ, McCorkle R, Bradley EH; Department of Geriatrics and Palliative Medicine, Mount Sinai School of Medicine, New York City; Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore; Yale University School of Public Health, New Haven, Connecticut.
Record Number of Americans Received Hospice Services in 2011, but Trend Toward Shorter Lengths of Service Continues

An estimated 1.65 million patients received care from one of the nation’s more than 5,300 hospice programs in 2011, according to an annual report released in November by the National Hospice and Palliative Care Organization (NHPCO). Yet, more than one-third of these patients received hospice’s specialized end-of-life services for seven days or less.

“We continue to see more dying Americans opting for hospice care at the end of their lives, yet far too many receive care for a week or less,” says J. Donald Schumacher, PsyD, NHPCO president and CEO. “We need to reach patients earlier in the course of their illness to ensure they receive the full benefits that hospice and palliative care can offer.”

The NHPCO publication, entitled “Facts and Figures: Hospice Care in America,” reports that 44.6% of all U.S. deaths occurred under the care of a hospice program in 2011, up from 41.9% in 2010 and just under 40% in 2009.

**KEY FINDINGS INCLUDE:**

- 35.7% of hospice patients died or were discharged within seven days of enrollment, up from 35.3% in 2010 and 34.4% in 2009.
- About half (50.1%) died or were discharged within 14 days of enrollment, an increase from 49.4% in 2010 and 48.4% in 2009.
- The median length of service in 2011 was 19.1 days, a decrease from 19.7 days in 2010 and 21.2 days in 2009.
- In contrast, the percentage of patients remaining under hospice care for longer than 180 days decreased slightly, from 11.8% in 2010 to 11.4% in 2011.

“Primary non-cancer admitting diagnoses in 2011 included:
- Dementia, 12.5%
- Heart disease, 11.4%
- Lung disease, 8.5%
- Stroke or coma, 4.1%
- Kidney disease, 2.7%
- Liver disease, 2.1%
- Debility unspecified, 13.9%”

The NHPCO states that it continues to stress the importance of having health care providers of patients with serious or life-limiting illness discuss the options of hospice and palliative care early enough for patients and their families to be aware of and receive the full benefits of expert end-of-life care.

“There’s a common misconception that hospice care is giving up,” observes Schumacher. “Nothing could be farther from the truth. Hospice provides high-quality medical care and services from an interdisciplinary team of professionals and trained volunteers that maximizes quality of life and makes the wishes of the patient a priority.”

For more information, visit www.nhpco.org.

Earlier End-of Life Discussions (from page 1)

that the earlier these conversations take place, the better, because they have a real impact on a patient’s quality of life in their final days.”

Receiving less aggressive care at the end of life is associated with:
- Better quality of life, with a greater focus on symptom management
- A higher likelihood of receiving care at home
- Lower risk of depression among bereaved caregivers

“Given the many arguments for less aggressive end-of-life care, earlier discussions have the potential to change the way end-of-life care is delivered for patients with advanced cancer and help to assure that care is consistent with patients’ preferences,” the authors conclude.

*Source: “Associations between End-of-Life Discussion Characteristics and Care Received near Death: A Prospective Cohort Study,”* Journal of Clinical Oncology; Epub ahead of print, November 13, 2012; DOI: 10.1200/JCO.2012.43.6055. Mack JW, Cronin A, Keating NL, Taback N, Huskamp HA, Malin JL, Earle CC, Weeks JC; Dana-Farber Cancer Institute; Boston Children’s Hospital; and Harvard Medical School, Boston; Greater Los Angeles Veterans Administration Health Care System and University of California at Los Angeles, Los Angeles; and Ontario Institute for Cancer Research, Toronto, Ontario.
Primary Care Physicians Much More Likely Than Specialists to Make End-of-Life Care Referrals

Physician comfort discussing end-of-life care plans strongly linked to higher referral rate

Family and/or internal medicine physicians are nine times more likely than specialists or emergency medicine physicians to refer their patients with life-limiting illness to hospice and palliative care, a team of California researchers reports in the American Journal of Managed Care. Further, those physicians who are comfortable discussing end-of-life care are seven times more likely than their counterparts to make single — and frequent — referrals, the investigators have found.

“Research on end-of-life referrals has tended to focus on patient-level characteristics rather than physician factors,” write the authors. “We identified physician comfort [with end-of-life discussions] as a factor associated with physician referral of end-of-life patients to hospice and home-based palliative care.”

Investigators examined the 2009 survey responses of a sample of 545 managed care physicians (mean age, 47 years; male, 66%) who had treated a patient in their office within six months of the patient’s death from a chronic condition. All participants were from the Southern California region of a national, nonprofit health maintenance organization (HMO) that provides both hospice and home-based palliative care.

**PHYSICIAN DATA**

- Most respondents (69.1%) were born in the U.S.
- Area of practice was most commonly a specialty (46.2%) or family/ internal medicine (45.6%).
- Specialty areas included surgery (24.3%), oncology (11.7%), and psychiatry (11.3%), among 26 reported specialties.
- Most respondents (83.2%) reported having made at least one end-of-life care referral in the past year, and 80.4% reported feeling comfortable conducting end-of-life discussions with terminally ill patients.
- About half (50.5%) had made four or more end-of-life care referrals in the past year.

**KEY FINDINGS**

- Family/internal medicine physicians were nearly nine times more likely to make end-of-life referrals (95% confidence interval [CI], 3.88 to 19.43), compared with specialists and emergency care physicians.
- Physicians who reported feeling comfortable conducting end-of-life care discussions were nearly seven times more likely to refer patients (95% CI, 3.47 to 12.75) than those who were uncomfortable discussing end-of-life care plans.
- Younger age was a significant predictor of end-of-life care referral: with every one-year decrease in age, physicians were 5% more likely to refer (95% CI, 0.911 to 0.985).
- No significant association was found with other demographic variables, or with the physician’s personal/family experience with hospice.

**FREQUENT REFERRALS**

- Physicians comfortable discussing end-of-life care were five times more likely to make frequent referrals (95% CI, 2.96 to 9.69), compared with those who reported discomfort.
- Family/internal medicine physicians were twice as likely to refer frequently (95% CI, 1.126 to 2.90), compared with specialists and emergency medicine physicians.
- Demographic variables were not significant predictors of frequent referrals, nor was the physician’s personal or family experience with end-of-life care.

These findings support recent efforts to reduce at least one physician-level barrier to end-of-life referrals by increasing physician comfort with end-of-life conversations, note the authors. Targeted strategies could include group discussions of case studies, role-playing with colleagues, and web-based learning modules and mentoring.

“Increased focus on training specialists who work with end-of-life patients is also needed to help them see end-of-life referrals as part of their practice and not solely a task for primary care,” comment the authors.

**SUGGESTIONS FOR MEDICAL SOCIETIES**

The authors suggest that professional medical societies can:

- Recognize the importance of end-of-life communication skills and knowledge.
- Establish a clear stance on end-of-life care delivery.
- Normalize the behavior endorsed by the specialty.
- Keep physicians apprised of end-of-life care options, knowledge, and referral protocol.

“This study points the way for improving end-of-life care, and suggests that more research is needed to build a strong knowledge base in this area,” they conclude.

Terminally ill patients residing in nursing homes with a greater tendency to refer their residents to hospice have significantly higher odds of dying under hospice care, while those in nursing homes with a greater tendency to hospitalize are much less likely to receive hospice services, according to a report published in The Gerontologist.

“This is the first study we are aware of to focus on nursing home self-reported end-of-life practice styles as independent explanatory factors for hospice utilization,” write the authors. “It demonstrates the independent importance of end-of-life self-reported practices in affecting residents’ probability of hospice use and their duration of hospice enrollment.”

An increasing percentage of Americans die in nursing homes each year, yet the rate of hospice use for this population has remained generally low, note the authors. “Presently, no end-of-life guidelines are specifically developed for nursing homes, and most facilities do not have formal end-of-life/palliative care programs or care protocols,” note the authors. “As a result, residents who are indeed at the end of life may not be identified — and thus not referred to hospice — until very close to death, if at all.”

Investigators examined the relationship between facility end-of-life practices and hospice use by 4540 long-term-care residents aged 65 years or older (mean age, 86.6 years) who died in 2007 in one of 290 nursing homes in New York State. Data from Medicare hospice claims were linked to survey responses from directors of nursing of participating facilities.

OVERALL:

- 18% of decedents used Medicare hospice services in nursing homes.
- Median length of hospice stay for these residents was 23.5 days.
- Average length of hospice stay was 93 days, with a large variation (standard deviation = 144.75).
- Only 14.4% of study residents were recognized as having a life expectancy of six months or less in the last three months of life.

“Although virtually all nursing homes experience a significant proportion of deaths among their residents each year, the staff typically do not view themselves as caring for the dying,” the authors write. “They receive very limited or no training in end-of-life care and may be limited in the skills to effectively recognize end-stage illness.”

FACILITY END-OF-LIFE PRACTICE SIGNIFICANTLY ASSOCIATED WITH RESIDENTS’ HOSPICE USE

- Living in facilities with a reported higher tendency to offer hospice substantially increased residents’ odds of using hospice (odds ratio [OR], 2.76; confidence interval [CI], 1.14 to 6.71).
- Residents in nursing homes with a higher tendency to hospitalize patients nearing the end of life had lower odds of using hospice (OR, 0.68; CI, 0.53 to 0.87).
- Residents in facilities with a higher tendency to initialize feeding tubes had higher odds of using hospice (OR, 1.46; CI, 1.13 to 1.88).

The authors express some puzzlement at the finding that feeding tube use is linked to the likelihood of hospice enrollment. “Although scientific evidence suggests that feeding tubes are not the standard of care for individuals with advanced dementia, once a decision is made to initiate a feeding tube, it may be more difficult for families and nursing home staff to stop such an intervention, even at the end of life,” they suggest. There is also a possibility that the use of feeding tubes may be seen as a way to demonstrate caring, with hospice care as an extension of this caring approach. Further research on this relationship is warranted, they note.

FACILITY CHARACTERISTICS ASSOCIATED WITH HOSPICE USE

Residents had greater odds of using hospice when living in facilities with:

- A higher proportion of staffing by licensed practical nurses (LPNs) and certified nurse aides (CNAs) (OR, 5.42; CI, 3.04 to 9.69).
- Facility religious affiliation (OR, 2.00; CI, 1.29 to 3.10).
- A greater percentage of Medicare residents (OR, 1.08, CI, 1.04 to 1.11).

FACTORS ASSOCIATED WITH LENGTH OF HOSPICE STAY

Only one facility end-of-life practice was associated with length of hospice use: the tendency to hospitalize terminally ill patients. “Residents in nursing homes with one point higher score for tendency to hospitalize used about 27% fewer hospice days,” report the authors. However, in addition to greater odds of hospice use, religious affiliation and higher LPN and CNA staffing hours also were found to be associated with longer hospice stays.

“Potential interventions to effect greater use of hospice may need to focus on facility-level care processes and practices,” conclude the authors.

Source: “Hospice Utilization in Nursing Homes: Association with Facility End-of-Life Care Practices,” The Gerontologist; Epub ahead of print, December 10, 2012; DOI: 10.1093/gerontgn153. Zheng NT, Mukamel DB, Caprio TV, Temkin-Greener H; Aging, Disability, and Long-Term Care, RTI International, Waltham, Massachusetts; Department of Medicine, Health Policy Research Institute, University of California, Irvine.
Patients with advanced cancer are as likely to receive targeted therapy at the end of life as they are to receive chemotherapy, researchers have found. Given the increasing number of targeted therapeutic options and their potential for adverse effects, guidelines are needed for their use in the last weeks of life.

This is according to the authors of a report published in the *Journal of Pain and Symptom Management*.

“Chemotherapeutic agents are generally associated with significant toxicities and limited benefits when given to patients with poor performance status and/or survival,” write oncologist David Hui, MD, MSc, of the University of Texas Department of Palliative Care and Rehabilitation Medicine, Houston, and colleagues.

“Thus, published literature considers the use of chemotherapy in the last two to four weeks of life a negative quality-of-care indicator,” continue the investigators. “Our study raises the question whether targeted therapy also should be considered as another [negative] quality-of-care indicator.”

Researchers analyzed data on 816 adult patients (mean age, 62 years; range, 21 to 97 years) who died of advanced cancer between September 2009 and February 2010, and who were seen at the University of Texas M.D. Anderson Cancer Center, Houston; in the last three months of life. The most common malignancies were gastrointestinal (22%), lung (20%), and hematologic (14%).

**PREDICTORS OF TARGETED THERAPY USE**

Significant predictors of targeted therapy use included:

- Younger age, with a 2% decrease in the use of targeted therapy per year of older age (odds ratio [OR], 0.98; 95% confidence interval [CI], 0.97 to 1.00).
- Hematologic malignancies (OR, 6.1; 95% CI, 2.4 to 15.4).
- Lung cancer (OR, 2.6; 95% CI, 1.0 to 6.6).

“Targeted agents are often perceived to be more tolerable than chemotherapy,” comment the authors. However, “targeted agents are associated with many unique adverse effects, such as rashes, endocrine abnormalities, and electrolyte imbalances.” Folliculitis occurs in up to 80% of patients on epidermal growth factor receptor inhibitors such as erlotinib, bevacizumab, and rituximab.

**OVERALL FINDINGS INCLUDE:**

- In the last 30 days of life, 14% of patients received targeted agents, 18% received chemotherapy, and 5% received both.
- The median interval between the last treatment and death was 47 days (interquartile range [IQR], 21 to 97 days) for targeted agents and 57 days (IQR, 26 to 118 days) for chemotherapeutic agents.
- The median number of antineoplastic agents administered in the last 30 days of life was one (IQR, 1 to 1) for targeted agents and one (IQR, 1 to 2) for chemotherapeutic agents.
- Targeted agents used most commonly in the last 30 days of life were erlotinib, bevacizumab, and rituximab.

“Furthermore, the pursuit of life-prolonging therapy could potentially delay transition of care, diverting patients’ precious time and energy to the pursuit of cancer treatments rather than planning ahead,” write the authors.

Because clinicians often overestimate their patients’ survival, the use of life expectancy as a criteria for quality of care may be challenging, the authors note. “Instead, performance status has been clearly shown to be an important prognostic and predictive factor.” They suggest that when a patient reaches an Eastern Cooperative Oncology Group performance status of three or more, or a Karnofsky Performance Status of 40% or less, “great caution should be exercised when prescribing palliative systemic therapies.”

Palliative therapies are often prescribed with the intention of improving symptom control, sustaining hope, and prolonging survival. However, “when a treatment is given in the last 30 days of life, the benefit is arguably negligible,” state the authors.

“Thus, we urgently need to develop guidelines on when to start and stop palliative systemic therapies for cancer patients with a limited life expectancy.”


Hui D, Karuturi MS, Tanco KC, Kwon JH, Kim SH, Zhang T, Kang JH, Chisholm G, Bruera E; Department of Palliative Care and Rehabilitation Medicine, Department of Medical Oncology, and Department of Biostatistics, University of Texas M.D. Anderson Cancer Center, Houston; Department of Internal Medicine, Kangdong Sacred Heart Hospital, Hallym University, Seoul; Department of Family Medicine, Myong Ji Hospital, and Kwandong University College of Medicine, Gyeonggi; and Department of Internal Medicine, Institute of Health Science, School of Medicine, Gyeongsang National University, Jinju, all in the Republic of Korea.
Approach to Hospice Referral
Directly from the Emergency Department

Terminally ill patients presenting to the emergency department (ED) in the final stages of their disease can be offered the option of hospice care as an alternative to hospitalization, according to a recent monograph published by EPERC (End-of-Life/Palliative Education Resource Center) and written by experts in emergency and palliative medicine.

“Patient-centered care for hospice-eligible, terminally-ill patients may be enhanced by emergency clinicians who acquire skills to make early appropriate hospice referrals from the ED,” write the authors of EPERC’s Fast Facts and Concepts #247.

The authors’ step-wise approach to initiating a hospice referral includes:

- Assessing for hospice eligibility
- Discussing the hospice option with the patient’s personal physician
- Determining whether the patient’s goals are in agreement with the hospice philosophy
- Introducing the topic of hospice
- Making the referral and writing the orders
- Ensuring patient/surrogate understanding

**ELICITING THE PATIENT’S GOALS**

Emergency clinicians can initiate a goals-of-care discussion with four questions:

1. “What have you been told about your illness status, and about what the future holds for you?”
2. “Has anyone discussed your prognosis with you, or talked about how much time you’re likely to have?”
3. “Are there any plans for new treatments aimed at helping to extend your life?”
4. “Has anyone talked to you about hospice services? What do you know about hospice care?”

**WHEN INTRODUCING HOSPICE, PHYSICIANS CAN:**

- Discuss the core aspects of hospice care and the services that can help the patient/family, such as: on-call assistance available 24/7; home visits for symptom management; coordination with the patient’s physician; and emotional and chaplaincy support.
- Address all concerns and clarify any misconceptions.
- Recommend hospice care, using positive language based on the patient’s individual needs and goals of care. “I think the best way to help you stay at home, avoid the hospital, and stay as fit as possible for as long as you have, is to receive hospice care at home.”
- Determine the location of hospice care. For most patients, this will be at home. Inpatient hospice admissions need to be discussed with the local hospice agency.

Source: “Initiating a Hospice Referral from the Emergency Department,” Fast Facts and Concepts #247. Lamba S, Quest TE, Weissman DE; Department of Emergency Medicine, University of Medicine and Dentistry of New Jersey, Newark; Section of Palliative Medicine, VA Medical Center, and Department of Emergency Medicine, Emory University School of Medicine, Atlanta; and Palliative Care Center, Medical College of Wisconsin, Milwaukee. Available at: www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_247.htm.
Hospice
Palliative Care
Grief Support Services

The mission of Arbor Hospice is to give comfort, assurance and care to families and patients who have life-limiting illnesses and to educate and nurture others in this care.