

# HOSPICE MATTERS for physicians

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

# Montgomery HOSPICE

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[www.montgomeryhospice.org](http://www.montgomeryhospice.org)

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## Family Members Yearn for Better Communication and Earlier Hospice Care

While many bereaved family members of patients referred to hospice just days before death perceive late referral as unavoidable and therefore acceptable, others — including some whose loved ones had refused earlier enrollment — wish that hospice care had been available sooner, according to a study published in the *Journal of Pain and Symptom Management*.

“Perceptions of the optimal time for hospice enrollment may be earlier for families than for patients,” write the authors. “Retrospectively, families gain a better appreciation of how earlier enrollment might have been helpful for the patient.”

Investigators examined 100 narrative interviews conducted across the U.S. with family members of hospice patients who died within the first week of enrollment. Decedents included patients with both cancer (40%) and noncancer diagnoses who were cared for at one of seven different hospice programs in geographically diverse areas.

Overall findings:

- Most respondents rated the quality of hospice care as either excellent or very good (68% and 18%, respectively).
- While 41% of family members whose loved ones died within one week of hospice enrollment believed the referral occurred “too late,” 58% believed the referral was “at the right time.”
- Nearly one-third of respondents stated that an earlier referral was not possible, due to patient refusal or a sudden, acute illness resulting in death.

Among family members who thought their loved ones were referred “at the right time,”

reasons given for late referral included:

- Acute change in the patient’s medical condition (34%)
- Patient refusal of hospice (14%) or a futility model of decision making, i.e., the pursuit of aggressive treatment with no discussion of hospice (8%)
- A perception that it was “meant to be” (19%)

Reasons for late referral given by those who felt hospice was initiated “too late” included:

- Problems with the health care providers’ role in decision making (59%)
- Inadequate physician communication (17%) and lack of recognition that the patient was dying (27%)
- Nursing home staff’s disregard of family requests for hospice or failure to recognize the patient’s health decline (12%)
- Patient refusal (15%), which was honored despite the wishes of family members

The authors suggest that continued attention be paid to the challenges of delivering high-quality care to those who will be receiving hospice services for such a short period of time.

Source: “It Is ‘Too Late’ or Is It? Bereaved Family Member Perceptions of Hospice Referral When Their Family Member Was on Hospice for Seven Days or Less,” *Journal of Pain and Symptom Management*, April 2012; 43(4):732-738. *Teno JM, et al; Warren Alpert School of Medicine at Brown University, Providence, Rhode Island.*

# Older Adults Not Enrolled in Hospice Have High Rates of Emergency Department Use in the Last Month of Life

*Most patients are subsequently admitted to the hospital, where many die*

More than half of older Americans in the final month of life seek medical help from an emergency department, where the focus is on stabilization and triage, not end-of-life care. Thus, more than three-quarters of these patients are admitted to an acute care facility, and more than two-thirds spend their final days there, according to a report published in *Health Affairs*.

“Emergency departments are not designed to provide end-of-life care and in many ways are poorly suited to doing so,” write the authors, led by Alexander K. Smith, MD, MS, MPH, assistant professor of medicine in the Division of Geriatrics at the University of California, San Francisco.

“Early enrollment in hospice [i.e., enrollment prior to the last month of life] was the strongest predictor of lack of emergency department use,” the authors continue. “In our study, early enrollment was associated with 80% less use of the emergency department in the last month of life, and dramatically reduced rates of hospitalization and of death in the hospital, compared to the rates for patients who did not enroll early.”

Researchers analyzed the health records of 4158 persons aged 65 years and older (mean age, 83 years; female, 47%) who died between 1992 and 2006. Data were drawn from the nationally representative Health and Retirement Study and linked with data from Medicare claims.

## DECEDENT CHARACTERISTICS

- Mean number of chronic diseases was 1.4 (out of four: heart condition, cancer, stroke, and lung disease).
- 77% of patients were dependent in at least one activity of daily living; 67% were dependent in three or more activities of daily living.
- 57% of patients had a heart condition; 31% had cancer.
- 43% were cognitively impaired.
- 46% experienced moderate to severe pain.
- Only 9% were enrolled in hospice for longer than one month prior to death.

Many of the symptoms that lead patients to visit the emergency department — such as pain, shortness of breath, and confusion — are common among those nearing the end of life, and are the very symptoms that hospice professionals are trained to manage, point out the authors.

## USE OF EMERGENCY MEDICAL SERVICES

- 51% of decedents visited the emergency department in the last month of life; 75%, in the last six months of life.

*“The type of care that patients receive in hospice...is of benefit long before the final days of life.”*

— Smith et al, *Health Affairs*

- 77% of those visiting the emergency department in the last month of life were admitted to the hospital.
- Of those patients admitted in the last month of life, 68% died while hospitalized.
- 39% of those hospitalized in the last month of life were admitted to an intensive care unit.
- Repeat visits to the emergency department were common: 41% of decedents made more than one visit in the last six months of life, and 12% visited the emergency department more than once in the last month of life.

The rates of end-of-life hospitalization are unlikely to decrease without a decrease in the rates of emergency department use, note the authors. “Many health problems and symptoms in late life are predictable, and some visits to the emergency department could potentially be avoided with access to high-quality outpatient care.”

## PHYSICIANS IN AN OUTPATIENT SETTING CAN:

- Prepare older patients and their families for end-of-life symptoms that may occur.
- Engage in ongoing discussions about goals of care.
- Arrange for treatment aligned with the patient’s values and wishes.
- Document patient preferences in a way that is easily accessible to other providers.

“For patients whose terminal trajectories are clear, we can do better in the outpatient setting,” observe the authors. “Outpatient providers can help prepare families for the eventuality of death, including by giving them early referrals to hospice and, where available, to outpatient palliative care services.” In addition, the authors recommend that “policies that require physicians to disclose a terminal prognosis and that provide reimbursement for advance care planning should be encouraged.”

Source: “Half of Older Americans Seen in Emergency Department in Last Month of Life; Most Admitted to Hospital, and Many Die There,” *Health Affairs*; June 2012; 31(6):1277-1285. Smith AK, McCarthy E, Weber E, Cenzer IS, Boscardin J, Fisher J, Covinsky K; Division of Geriatrics, Department of Medicine; and Department of Emergency Medicine, University of California, San Francisco; Departments of Medicine and Emergency Medicine, Harvard Medical School, Boston.

# Study Identifies Factors Linked to Better Quality of Life at End of Life

Previous research has provided data on end-of-life (EOL) factors considered important by physicians, patients, and caregivers, and on factors that predict quality care at the EOL, but few data exist on what predicts better quality of life (QOL) at the EOL for patients dying of cancer, according to a report published in the *Archives of Internal Medicine*.

“The aim of this study was to identify the best set of predictors of QOL of patients in their final week of life,” write lead author Baohui Zhang, MS, formerly of the Dana-Farber Cancer Institute in Boston, and colleagues. “By doing so, we identify promising targets for health care interventions to improve the QOL of dying patients.”

Investigators conducted a multi-site, prospective, longitudinal study of 396 patients with advanced cancer (mean age, 58.7 years; white race, 65.0%) and their informal caregivers, as part of the federally funded Coping with Cancer study. Patients with an estimated life expectancy of less than six months were followed from their enrollment (from 2002 to 2008) to death, a median of 4.1 months later.

The team identified a set of nine factors that explained the most variance in patients’ QOL at the EOL. Only one factor, site of cancer care, had random effects on QOL, while the majority of the variance in QOL remained unexplained.

## NEGATIVE IMPACT ON QOL

Factors with a negative impact on QOL at the EOL included:

- Intensive care unit (ICU) stays in the final week of life (explained 4.4% of the variance in QOL)
- Hospital deaths (2.7%)
- Patient worry at baseline (2.7%)
- Feeding tube use in the final week (1.1%)
- Chemotherapy in the final week (0.8%)

“Two of the most important determinants of poor patient QOL at the EOL were dying in a hospital and ICU stays in the last week of life,” write the authors. “Therefore, attempts to avoid costly hospitalizations and to encourage transfer of hospitalized patients to home or hospice might improve patient quality of life at the end of life.”

## POSITIVE IMPACT ON QOL

Factors with a positive effect on QOL included:

- Religious prayer or meditation at baseline (2.5%)
- Pastoral care within the hospital or clinic (1.0%)
- Patient-physician therapeutic alliance at baseline (0.7%)

A therapeutic alliance is a physician-patient relationship described by the patient as: being seen by the physician as a whole person; being treated with respect; respecting and trusting the physician; and feeling comfortable with asking the physician

*“By reducing patient worry, encouraging contemplation, integrating pastoral care within medical care, fostering a therapeutic alliance between patient and physician that enables patients to feel dignified, and preventing unnecessary hospitalizations and receipt of life-prolonging care, physicians can enable their patients to live their last days with the highest possible level of comfort and care.”*

— Zhang et al, *Archives of Internal Medicine*

questions about health care.

“These results suggest that physicians who are able to remain engaged and ‘present’ for their dying patients — by inviting and answering questions and by treating patients in a way that makes them feel that they matter as fellow human beings — have the capacity to improve a dying patient’s QOL,” comment the authors.

Suggested targets for health care interventions to improve QOL include:

- Limiting aggressive EOL treatments such as chemotherapy and the use of feeding tubes
- Avoiding unnecessary hospitalizations
- Encouraging the transfer of hospitalized patients to home or hospice
- Reducing patient anxiety
- Supporting patient spirituality and peacefulness, and encouraging the use of pastoral services

“Taken together, these results indicate that when medicine is no longer able to cure, physicians may still positively and significantly influence the lives of their patients,” the authors conclude. “By establishing empirically the strongest set of predictors of QOL at the EOL for terminally ill advanced cancer patients, we can guide physicians, patients, and family members in focusing on what matters most for ensuring a high QOL for dying cancer patients.”

The study was published in the online first edition of the *Archives of Internal Medicine* as part of a large group of articles focused on improving QOL at the EOL. The journal has also scheduled articles on this theme for publication in its August 13/27, 2012, print issue.

Source: “Factors Important to Patients’ Quality of Life at the End of Life,” *Archives of Internal Medicine*; Epub ahead of print, July 9, 2012; DOI: 10.1001/archinternmed.2012.2364. Zhang B, Nilsson ME, Prigerson HG; Center for Psychosocial Epidemiology and Outcomes Research and Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute; and Department of Psychiatry, Brigham and Women’s Hospital, Harvard Medical School, Boston.



## WHEN TO REFER TO HOSPICE

Call us if your patient exhibits the following indicators:

- Physical / functional decline
- Weight Loss >10% in last 6 months
- Multiple comorbidities

When life expectancy can be measured in weeks or months, hospice is usually the best option. For patients with **dementia**, look for the following indicators:

- FAST Score stage 7
- Urinary and fecal incontinence (intermittent or constant)
- No consistently meaningful verbal communication
- Requires assistance with ADLs
- History of pneumonia or UTI, sepsis or decubiti within the past 12 months

Call us any time, any day.

**Geoffrey Coleman, MD**  
Medical Director  
Montgomery Hospice



## Early Integration of Palliative Care into Standard Oncology Care Improves Treatment at the EOL

Patients with non-small-cell lung cancer (NSCLC) who receive palliative care integrated with standard oncology care from diagnosis have higher quality end-of-life care, significantly lower rates of intravenous chemotherapy use near death, and longer enrollments in hospice care, a team of Boston researchers has found.

“Although patients with metastatic NSCLC received similar numbers of chemotherapy regimens in the sample, early palliative care optimized the timing of final chemotherapy administration and transition to hospice services — key measures of quality end-of-life care,” write the authors of a report published in the *Journal of Clinical Oncology*.

Investigators conducted a secondary analysis based on a randomized controlled trial of 151 patients newly diagnosed with NSCLC (mean age, 65 years) receiving either early palliative care integrated with standard oncology care or standard oncology care alone. At 18-month follow-up, 88.1% of participants had died. Of these, 68.2% had been referred to hospice.

Compared with those in the standard care group, participants receiving early palliative care had:

- Half the odds of receiving chemotherapy in the final two months of life (odds ratio,

0.47; 95% confidence interval, 0.23 to 0.99;  $P = .05$ )

- A longer interval between the last dose of intravenous chemotherapy and death (median 64 days [range 3 to 406 days] vs median 40.5 days [range, 6 to 287 days];  $P = .02$ )
- A significantly longer median stay in hospice care (24.0 days vs 9.5 days;  $P = .02$ )
- Higher enrollment in hospice care for longer than one week (60.0% vs 33.3%;  $P = .004$ )

“This reduction in chemotherapy use produced no detriment to survival, contrary to popular perception that more aggressive care prolongs life in patients with metastatic cancer,” observe the authors. Rather, the early integration of palliative care in the outpatient setting is a viable approach “not only to improve multiple patient outcomes, but also to enhance oncology practice in conforming to articulated goals for the highest quality cancer care.”

Source: *Effect of Early Palliative Care on Chemotherapy Use and End-of-Life Care in Patients with Metastatic Non-Small-Cell Lung Cancer*, *Journal of Clinical Oncology*; February 1, 2012; 30(4):394-400. Greer JA, Pirl WF, Jackson VA, Muzikansky A, Lennes IT, Heist RS, Gallagher ER, Temel JS; Massachusetts General Hospital Cancer Center, Boston.