

# HOSPICE MATTERS for physicians

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

# Montgomery HOSPICE

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Volume 3, Issue 4

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## Facing Death in Supportive Setting Improves Quality of Life, Extends Survival

Accumulating medical data suggest that cancer patients who receive supportive care as they approach the end of life not only experience improvement in their quality of life, but also that they live longer lives, according to an article published in the *Journal of the American Medical Association*.

“Even at the end of life, helping patients face death, make informed decisions, mobilize social support, and control pain is not only humane, but also may be medically more effective than simply continuing aggressive anticancer treatment,” writes David Spiegel, MD, associate chair of the Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine.

Spiegel cites the widely reported findings of a 2010 randomized controlled trial of patients with non-small cell lung cancer, in which patients who received early palliative care integrated with standard care had statistically better quality of life, received more hospice care, and had fewer emergency visits and hospitalizations than patients receiving standard oncologic care alone.

Further, the integrated care group — whose monthly visits by a palliative care team focused on care preferences, pain control, and quality of life — lived more than two months longer than the standard anticancer care group (11.6 months vs 8.9 months). “This apparently counterintuitive finding suggests that emotional support is not only psychologically beneficial, but also medically efficacious,” Spiegel points out.

Citing additional recent data, Spiegel notes that supportive care has been found to increase longevity in a variety of cancer patients with poor prognoses, including those with breast cancer,

malignant melanoma, leukemia, and gastrointestinal tract cancers, especially when therapies fail. “Importantly for breast and other cancers,” writes Spiegel, “when aggressive antitumor treatments are less effective, supportive approaches appear to become more useful.”

Spiegel presents research data that may explain how living better at the end of life can help cancer patients live longer. In addition to the effect on disease outcome accounted for by the specific local pathophysiology of that disease, variability in longevity can also be affected by “host resistance” factors: the responses of the endocrine, immune, and autonomic nervous systems to the stress of the disease.

“Modern medicine has focused so intently on fighting disease that it has overlooked a natural ally in the battle — the patient’s personal mental management of the stresses associated with cancer,” he states. **“Treating the patient with the disease, not just the disease within the patient, contributes to overall medical outcome. It is not simply mind over matter — but mind matters.”**

Source: “Mind Matters in Cancer Survival,” *Journal of the American Medical Association*; February 2, 2011; 305(5):502-503. Spiegel D; Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, California.

# Discussing Goals of Care and Initiation of Palliative Care in Patients with CKD: ‘The Earlier the Better’

The time has come for the focus of care for patients with chronic kidney disease (CKD) and renal failure to shift from disease-centered approaches to patient symptom-centered results, and that means following the recent lead of oncology and introducing palliative care earlier into the treatment plans for these patients, according to a team of nephrologists from the U.S. and Canada.

“For patients with earlier stages of CKD, recent studies show that earlier multidisciplinary care emphasizing patient education and active patient involvement in symptom management and care plans results in improved outcomes — including slower progression of disease and fewer complications,” write the authors of an article published in the *American Journal of Kidney Diseases*, the official journal of the National Kidney Foundation.

## COMPARISON OF CKD PATIENTS WITH CANCER PATIENTS

Similar to patients with cancer, which is the most studied disease in palliative care, patients with CKD can benefit from early palliative care and multidisciplinary intervention, as both diseases become increasingly viewed not as terminal diseases to be battled, but as chronic illnesses requiring chronic management strategies to improve quality of life, note the authors. “No longer is palliative care limited to patients in the active dying process, but rather palliative care is provided much earlier in the trajectory of the chronic disease to relieve suffering.”

CKD patients are also similar to cancer patients regarding burdens and demands of the disease experience. These include high symptom burden, rigorous and recurrent treatments, and high overall mortality rates

The small amount of existing research on the topic shows that patients with CKD want to know their prognosis, even if it is poor, and they want to hear it from their nephrologist, point out the authors.

## Approach to Discussing Goals of Care with CKD Patients and Their Families

1. **Discuss prognosis** honestly and compassionately with the patient and the patient’s family.
2. **Initiate discussions** as early as possible in the disease course.
3. **Discuss all treatment options** in addition to dialysis and transplant, including no dialysis, a trial of dialysis, and withdrawal from dialysis when burdens outweigh the benefits.  
“[I]t is helpful to put in writing the goals of care and a timeline to readdress the care plans, especially when a trial of dialysis is undertaken,” suggest the authors. “It is important that the patient and family understand that if the patient has not made a meaningful improvement in quality of life or function, or quality of life has deteriorated beyond what is acceptable to the patient, dialysis therapy should be withdrawn.”
4. **Institute advance care planning** using Physician Orders for Life Sustaining Therapies (POLST) where available.
5. **Offer “aggressive” palliative care and hospice** as the best treatment option when the patient’s trajectory of illness begins to deteriorate.  
“When doing this, it is important that the patient and family know we are not giving up or abandoning the patient, but rather providing the best care for the current situation,” emphasize the authors.
6. **Foster shared decision making.** “Of note, the patient and clinician may not always agree on the treatment plan,” note the authors, “and, critically, the patient has the right to refuse treatment (dialysis); while, conversely, the clinician has the right to refuse to order a treatment (dialysis) when the expected benefits do not justify the risks.”

—Adapted from Germain et al, *American Journal of Kidney Diseases*

## OPTIONS AVAILABLE FOR POOR PROGNoses

“Reassuringly, communicating a poor prognosis does not result in depression or loss of hope,” they write. “Options exist for those with poor prognoses.”

Options include early palliative care and timely hospice care, and must be discussed with patients and families. The authors include an approach to such discussions, based on the clinical practice guidelines released in 2010 by the Renal Physicians Association, entitled “Shared Decision Making in the Appropriate Initiation and Withdrawal from Dialysis.” [See sidebar.]

“There is an urgent need to test these

recommendations in multicenter clinical trials to assess their effect on both quality of life and quality of dying for patients with kidney disease,” write the authors. “We...know that patients desire a peaceful death with control of pain and other symptoms. They want family members with them and want to have settled their worldly and existential affairs. They do not want to die in the hospital. Sadly, most deaths occur in the acute hospital setting.”

Source: “Palliative Care in CKD: The Earlier the Better,” *American Journal of Kidney Diseases*; March 2011; 57(3):378-380. Germain MJ, Tamura MK, Davison SN; Baystate Medical Center, Springfield, Massachusetts; Stanford University, Palo Alto, California; and University of Alberta, Edmonton, Canada.

# One-Third of Tube-Fed Dementia Patients Are Restrained Near Death

40% of family members report that risks were not discussed prior to insertion

Over an 18-month period in the disease trajectory, 86% of advanced dementia patients suffer from eating problems. The majority of these patients' family members will make decisions about the management of their loved ones' feeding issues, yet little attention is given to this form of decision making, according to a report published in the *Journal of the American Geriatrics Society*.

"The majority of such decisions are made in an acute care hospital," write the authors, and "the results of our study suggest that physicians play an important role in feeding-tube decision making. Nearly 40% of the surveyed family members reported that a physician was strongly in favor of a feeding tube, with 11.1% reporting feeling pressured by the physician to insert a feeding tube."

Researchers surveyed 486 bereaved family members of nursing home residents with advanced dementia, representing 9653 patients in five states. States were purposely selected as having either high prevalence (TX, AL, FL) or low prevalence (MA, MN) of feeding tube placement among residents.

## KEY FINDINGS

- 10.8% of decedents with dementia had a feeding tube inserted, ranging from 2.4% (MA) to 62.6% (TX).
- Respondents whose loved ones died while intubated were less likely to report excellent end-of-life care (adjusted odds ratio, 0.42; 95% confidence interval, 0.18-0.97).
- 13.7% of family members reported that a feeding tube was inserted without discussion beforehand. Of these, 91.1% believed that this discussion should have occurred.
- 38.2% believed the physician was strongly in favor of feeding tube insertion.
- 39.3% of relatives of tube-fed patients said they were not informed of associated risks.

## ADVERSE OUTCOMES REPORTED:

- 39.8% of respondents felt the patient was bothered by the feeding tube.
- 26.8% of intubated patients were sent to emergency departments for problems related to the feeding tube.
- 29.2% of tube-fed patients were given

sedatives to prevent them from pulling on the feeding tube.

- 25.9% were physically restrained, with either the hands or upper body tied down to prevent them from pulling at the tube.
- Overall, 34.9% of patients were restrained physically, pharmacologically, or both.

**"An important finding of this research is that there are important risks to feeding tube insertion that previous research had not adequately quantified,"** report the authors, further noting that some of these risks have long-term effects. "Based on these findings, there is need for improving decision making in the use of feeding tubes in persons with dementia."

Source: "Decision-Making and Outcomes of Feeding Tube Insertion: A Five-State Study," *Journal of the American Geriatrics Society*; May 2011; 59(5):881-886. Teno JM, Mitchell SL, et al; Health Services, Policy, and Practice, Warren Alpert School of Medicine, Brown University, Providence, Rhode Island; Hebrew Senior Life Institute for Aging Research, Roslindale, Massachusetts; and Department of Geriatric Medicine, University of Texas Southwestern Medical Center, Dallas.

## Lung Cancer Patients Receive Aggressive End-of-Life Care in Both U.S. and Canada

Non-small cell lung cancer patients in the U.S. and Ontario use health care services extensively in the last five months of life, but patterns of resource use differ markedly, an analysis of the national registries on 21,633 patients in both countries who died during 1999-2003 has found.

## KEY FINDINGS

- Ontario patients were more likely than U.S. patients to be hospitalized in the last 30 days of life (78.6% vs 49.9%) and to die in the hospital (48.5% vs 20.4%), although polls show most Canadians prefer to die at home.
- More Ontario than U.S. patients visited an emergency department five months before death (41.5% vs 24.0%) and in

the last month of life (67.2% vs 43.9%).

- 58% of U.S. patients received hospice care during the last month of life; Ontario has no formal hospice program.
- In the last five months of life, chemotherapy rates were significantly higher among U.S. than Ontario patients (33.2% vs 9.5%).

"I think both health care systems could learn from our findings," says author Joan L. Warren, PhD, of the National Cancer Institute. "First and foremost is that the chemotherapy use we saw among U.S. patients shows an opportunity for both physicians and their patients to evaluate if there is any potential benefit to this, because you don't give chemotherapy unless you have a significant prob-

ability of cure or life prolongation.

"On the other hand, I think Ontario has an opportunity to assess their health care system and say, 'What can we do to provide a more formalized system of support that will allow people to die in a setting outside of the hospital?'"

Source: "End-of-Life Care for Lung Cancer Patients in the United States and Ontario," *Journal of the National Cancer Institute*; June 8, 2011; 103(11); DOI: 10.1093/jnci/djr186. Warren JL, Barbera L, et al; Health Services and Economics Branch, Applied Research Program, National Cancer Institute, Bethesda, Maryland; Department of Radiation Oncology, University of Toronto; Toronto General Research Institute, University Health Network; Canadian Centre for Applied Research in Cancer Control, St. Michael's Hospital; and Institute for Clinical Evaluative Sciences, all in Toronto; and Information Management Services, Silver Spring, Maryland.



## 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 heart disease or CHF, look for the following indicators:

- NYHA Class IV; discomfort with physical activity
- Symptomatic despite maximal medical management with diuretics and vasodilators
- Arrhythmias resistant to treatment
- Ejection fraction < 20%

Call us any time, any day.

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



## Expanded Hospice Eligibility Project Must Focus on Access and Quality, Not Just Costs

A three-year demonstration project mandated by the U.S. Congress under the Affordable Care Act will begin this year to provide aggressive care concurrently with hospice care. This offers an opportunity to improve care delivery under the Medicare hospice benefit, but only if it measures more than potential cost savings, according to David J. Casarett, MD, of the Center for Bioethics, University of Pennsylvania School of Medicine.

**“Ultimately, the concurrent care model should not be judged solely on its ability to reduce costs. In addition, a comprehensive evaluation should include measures of access, quality, and survival,”** writes Casarett in an article published in the *Journal of the American Medical Association*.

“More broadly, any hospice eligibility criteria should be judged by how well those criteria can ensure that the right patients receive the right services at the right time.”

Casarett points out that hospice eligibility criteria are not based on patient care needs, in contrast to other Medicare services. Requirements of a six-month prognosis and a stated preference for comfort care cause undesirable delays in hospice enrollment and reduce access for some — most notably, black patients — whose de-

sire for life-prolonging treatment forces them to forgo needed hospice services.

Thus, the concurrent care project has potential to identify ways of improving hospice care delivery for those in need of services, notes Casarett, but only “if it is designed to measure the right outcomes.”

### **SUGGESTED OUTCOME MEASURES**

- **Access.** The project should judge if earlier hospice enrollment and length of stays improve, and whether concurrent care reduces ethnic disparities.
- **Quality.** The evaluation should assess symptom control, quality of life and of care, and whether patients felt the care was consistent with their preferences.
- **Survival.** This must be measured since prolonged survival is an end-of-life goal for some patients. Adding palliative care to life-sustaining treatment may extend survival, or complications of aggressive treatments may shorten survival in the concurrent care group. **Thus, lack of survival benefit does not denote failure if there are improvements in access, quality, and costs.**

Source: “Rethinking Hospice Eligibility Criteria,” *Journal of the American Medical Association*; March 9, 2011; 305(10):1031-1032. Casarett DJ; Center for Bioethics and the Leonard Davis Institute of Health Economics, University of Pennsylvania School of Medicine, Philadelphia.