

# Quality of Life Matters<sup>®</sup>

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

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## Discontinuing Dialysis: Researchers Identify Survival Predictors, Offer Ways to Improve End-of-Life Care

Patients with end-stage renal disease (ESRD) who discontinue dialysis to enter hospice typically have short survival times, but individual survival time varies greatly. According to a report published in the *Clinical Journal of the American Society of Nephrology*, four patient characteristics — including being admitted from an inpatient facility and having lower functional status — have been identified as independent predictors of survival.

“Using these characteristics, clinicians could begin to stratify patients according to predicted survival, allowing education and care planning to more accurately reflect prognosis,” write the authors. “Individualized survival predictions would allow clinicians to better counsel patients

and families about what to expect after dialysis discontinuation.”

Investigators analyzed data on 1947 patients (mean age, 78 years) with a primary diagnosis of ESRD who had discontinued dialysis before being admitted to 1 of 10 participating hospices between January 2008 and May 2012. All hospices in the study were members of the Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE) network.

To determine functional status, the researchers used the Palliative Performance Scale (PPS), which is scored in 10-point increments from 0 to 100, with higher numbers indicating better function.

Mean or average survival was used for analysis rather than median, because all patients in the study died within 46 days.

- More than half (52.8%) of renal patients entered hospice from a hospital, compared with only about one-fourth of all other hospice patients (27.1%).

### INDEPENDENT PREDICTORS OF EARLIER MORTALITY

- Referral from a hospital (HR, 1.40; 95% CI, 1.23 to 1.59)
- Presence of peripheral edema (HR, 1.24; 95% CI, 1.09 to 1.25)
- Male sex (HR, 1.12; 95% CI, 1.01 to 1.25)
- Lower functional status

A higher PPS upon hospice admission was strongly predictive of longer survival (HR, 0.39; 95% CI, 0.33 to 0.46). While patients with a PPS  $\leq$  20 had an adjusted mean survival of 5.7 days (95% CI, 5.3 to 6.1), those with a PPS  $>$  20 had an adjusted mean survival of 14.0 days (95% CI, 12.9 to 15.2).

“Although these differences are small in absolute terms, even a small variation in survival of a week is enough to affect decisions regarding care and information for patients and families,” point out the authors. For example, if the patient is likely to die within days rather than weeks, intensive palliative care and preparation are indicated. The hospice team will work with the patient and family to make sure plans are in place, and that the family receives the appropriate counseling.

“As the prevalence of ESRD continues to increase, the discontinuation of dialy-

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### KEY FINDINGS

- Mean survival after hospice enrollment for patients who discontinued dialysis was 7.4 days (range, 0 to 46 days).
- Mean survival for other patients (n = 124,673) with nonrenal hospice diagnoses was 54.4 days.
- Patients who discontinued dialysis were less likely to have completed an advance directive, compared with nonrenal patients (25.7% vs 30.8%).
- Almost half (45.6%) of renal patients had functional status scores of PPS  $\leq$  20, indicating fluctuating levels of consciousness, limited oral intake, and severely limited physical function.

## Patients with Hematologic Malignancies Receive More Aggressive Care at End of Life

Among patients with advanced cancer, those with hematologic malignancies are over six times more likely to receive aggressive care in the last weeks of life than are those with solid tumors. Further, nearly one-half die in the hospital, compared to the vast majority of those with solid tumors who die outside of acute care facilities, according to a report published in *Cancer*, a journal of the American Cancer Society.

“We found that patients with hematological malignancies were more likely to have multiple emergency room visits, intensive care unit (ICU) admissions and death, and cancer treatments in the last weeks of life compared with patients with solid tumors,” write the authors.

“The findings of the current study highlight the need for clinicians to minimize aggressive interventions at the end of life, and the need for further research to optimize care in the last days of life for patients with hematological malignancies.”

Investigators analyzed data from a review of the medical records of 816 patients (mean age, 62 years; white race, 61%) treated consecutively at The University of Texas MD Anderson Cancer Center in Houston, and who died from advanced cancer between September 2009 and February 2010. Of these, 14% had hematologic malignancies (leukemia, lymphoma, or myeloma).

### **PATIENTS WITH HEMATOLOGIC MALIGNANCIES VS THOSE WITH SOLID TUMORS**

In the last 30 days of life, patients with hematologic malignancies were more likely than those with solid tumors to have:

- Emergency room visits (54% vs 43%;  $P = .03$ )

*Researchers urge clinicians to “minimize aggressive interventions at the end of life” and call for “further research to optimize care in the last days of life for patients with hematological malignancies.”*

— Hui et al,  
Cancer

- Any number of hospital admissions (81% vs 47%;  $P < .001$ ), including  $\geq 2$  hospital admissions (23% vs 10%;  $P < .001$ )
- $> 14$  days of hospitalization (38% vs 8%;  $P < .001$ )
- ICU admissions (39% vs 8%;  $P < .001$ ) and ICU death (33% vs 4%;  $P < .001$ )
- Hospital death (47% vs 16%;  $P < .001$ )
- Chemotherapy use (43% vs 14%;  $P < .001$ )
- Targeted therapy use (34% vs 11%;  $P < .001$ )

Multivariate analysis showed the presence of a hematologic malignancy to be an independent predictor for aggressive care at the end of life (odds ratio, 6.63; 95% confidence interval, 4.1 to 10.7 [ $P < .001$ ]).

### **USE OF PALLIATIVE CARE**

Patients with hematologic malignancies were less likely to have palliative care unit admissions (8% vs 17%;  $P = .02$ ) or to receive any inpatient (33% vs 47%;  $P = .006$ ) or outpatient (22% vs 48%;  $P = .003$ ) palliative care consultation in the last 30 days of life.

Inpatient palliative care units, which are staffed by an interprofessional team, “represent an appropriate alternative to the ICU for some patients with hema-

tological malignancies,” comment the authors.

Palliative care units provide:

- Intensive symptom control
- Psychosocial care
- Assistance with complex discharges
- Transition to end-of-life care

The literature shows that “compared with patients who died at home with hospice care, patients who died in an ICU or hospital had greater physical and emotional distress and worse quality of life and their caregivers had a high risk of prolonged grief,” observe the authors. “Thus, active efforts are needed to improve the transition to home care at the end of life for patients with hematologic malignancies.”

The high rate of use of acute care facilities near the end of life in patients with hematologic malignancies may be explained by the high frequency of hematologic complications requiring transfusions, antibiotics, and other interventions, note the authors. Further, these patients often receive systemic therapies in the last days of life, requiring hospitalization and adding yet another layer of treatment-related adverse effects.

### **IMPROVING THE QUALITY OF END-OF-LIFE CARE**

The authors offer the following suggestions for improving the quality of end-of-life care among patients with hematologic malignancies:

- **Patient education.** Hematologists and oncologists caring for patients with advanced hematological malignancies “need to ensure that their patients and caregivers have a good understanding of the incurable nature of their illness and their general prognosis,” write the

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## Discontinuing Dialysis (from Page 1)

sis is likely to become a more common event,” the authors state. They suggest further research on survival trajectories following dialysis discontinuation, with attention to changes in functional status and symptom burden over time, advance directives, decision making, and the family’s experience of this process.

### EARLIER PALLIATIVE CARE

Hospice access is not uniform and occurs too late for patients who discontinue dialysis to realize much benefit, note the authors of an editorial accompanying the report. They also express “worry that the care before hospice does not sufficiently treat their symptoms or prepare them for when they may decide to end dialysis.”

In the authors’ experience as nephrologists, two types of patients discontinue

dialysis: those who experience an acute event, and those who tire of the burden. “This latter subset represent a unique population who may benefit from earlier introduction of palliative care services,” they write. “Early and repeated efforts to assist patients and families in identifying goals of care are a palliative care intervention worthy of our time and effort.”

Patients experience multiple transitions throughout the kidney disease course, such as disease progression, dialysis initiation, and consideration of dialysis withdrawal. “These transitions illustrate the need to regularly readdress symptom needs and initiate end-of-life planning with patients and families,” the authors observe. “Advance care planning would reasonably then lead to earlier hospice referral and improved symptom management.”

### UNDERUTILIZATION OF HOSPICE

The report emphasizes that ESRD patients are only half as likely as patients with other hospice-eligible diagnoses to receive hospice services. Barriers to hospice access include:

- Lack of education in the palliative care aspects of clinical nephrology
- Lack of training in how to initiate and conduct discussions in care planning and end-of-life counseling
- The current Medicare financing structure for ESRD patients, which mandates that two Medicare benefits (e.g., hospice and dialysis) can be used only if each is covered under a distinct diagnosis

Thus, ESRD patients must forgo dialysis if they want hospice. But, one or two weeks — the typical survival following dialysis discontinuation — is too short a time in which to realize the full benefits of hospice. “We believe this time is insufficient to meet the symptom and end-of-life needs in ESRD....

“Ideally, concurrent dialysis and hospice services would encourage early assessment and management of symptoms and end-of-life planning in a way that improves patient experience and preparations for end of life,” write the authors of the editorial. “For timely palliative care integrations into nephrology, early access to hospice services is needed.”

*Source: “Survival after Dialysis Discontinuation and Hospice Enrollment for ESRD,” Clinical Journal of the American Society of Nephrology; December 2013; 8(12):2117-2122. O’Connor NR, Dougherty M, Harris PS, Casarett DJ; University of Pennsylvania Perelman School of Medicine, Philadelphia; and Kansas City Hospice and Palliative Care, Kansas City, Missouri. “Opportunities to Improve End-of-Life Care in ESRD,” *ibid.*, pp 2028-2030. Schell JO and Holley JL; Section of Palliative Care and Medical Ethics, Renal-Electrolyte Division, University of Pittsburgh School of Medicine, University of Pittsburgh Medical Center, Pittsburgh; Carle Physician Group and University of Illinois, Urbana-Champaign, Urbana, Illinois.*

## Hematologic Malignancies (from Page 2)

authors. “This would form the basis for discussions surrounding goals of care and advance care planning.”

- **Early involvement of palliative care.** In the outpatient setting, introducing palliative care may facilitate the needed communications about care planning and complex decision making. However, clinical pathways for integrating palliative care early in the disease trajectory need to be developed. “In contrast to the treatment guidelines for solid tumors, palliative care has not yet been fully incorporated into the National Comprehensive Cancer Network guidelines for patients with hematologic malignancies,” note the authors.
- **Changes in reimbursement policy.** Rewarding physicians for the time spent in discussions of advance care planning may help hematologists and oncologists to limit the prescribing of systemic therapies for patients with limited prognosis.

Further research on the impact of various interventions on end-of-life outcomes among patients with hematologic malignancies “would help clinicians, administrators, and policy makers to identify gaps in care and areas for improving the quality of end-of-life care for these patients.”

*Source: “Quality of End-of-Life Care in Patients with Hematologic Malignancies,” Cancer; Epub ahead of print, February 18, 2014; DOI: 10.1002/cncr.28614. Hui D, Didwaniya N, et al; Department of Palliative Care and Rehabilitation Medicine, The University of Texas MD Anderson Cancer Center, Houston; Department of Internal Medicine, College of Medicine, Kosin University, Busan, South Korea; Department of Biostatistics; and Clinical Operations Informatics, The University of Texas MD Anderson Cancer Center, Houston.*

## 15% of Preventable Readmissions Linked to End-of-Life Care Issues

Potentially avoidable 30-day hospital readmissions among patients nearing the end of life are not uncommon, Boston researchers have found. To help clinicians prioritize palliative and hospice care resources to the most high-risk patients, the team has identified four risk factors significantly associated with readmission for end-of-life care issues.

“Taken together, the four variables provide a very promising prediction model with high discrimination,” report the authors of a study published in the *Journal of Hospital Medicine*. “Patients with these risk factors might benefit from palliative care consultation prior to discharge in order to improve end-of-life care and possibly reduce unnecessary rehospitalizations.”

Investigators identified all 30-day readmissions from among 10,275 consecutive patients discharged from tertiary care centers in Boston between July 2009 and June 2010. Readmissions were differentiated as potentially avoidable or not. Criteria for determining avoidable readmissions as due to end-of-life issues included the patient having a terminal clinical condition and the readmission being part of the terminal disease process that was not adequately addressed during the index hospitalization.

### OVERALL FINDINGS

- 22.3% of all discharges in the one-year study period were followed by a 30-day readmission. Of these, 8% (n = 826) were identified as potentially avoidable.
- 15% of potentially avoidable readmissions among a random sample (n = 534) were related to end-of-life care issues.
- Notably, only 20% of patients readmitted with end-of-life care issues had received palliative care consultations during the index hospitalization.

The high rate of unnecessary readmissions of patients nearing the end of life, note the authors, has been previously linked to such factors as undertreatment of pain, lack of awareness of patient wishes or advance directives, and unwanted overtreatment. “Repeated hospitalizations are frequent toward the end of life, where each admission should be viewed as an opportunity to initiate advance care planning to improve end-of-life care and possibly reduce future unnecessary readmissions,” comment the authors.

### RISK FACTORS FOR READMISSION

The following risk factors were found to be significantly associated with avoidable readmission due to end-of-life care issues:

- Neoplasm (odds ratio [OR], 5.60; 95% confidence interval [CI], 2.85 to 10.98)
- Opiate medication prescribed at discharge (OR, 2.29; 95% CI, 1.29 to 4.07)
- Elixhauser comorbidity index (OR, 1.16 per five-point increase; 95% CI, 1.10 to 1.22)
- Number of admissions in the previous 12 months (OR, 1.10 per admission; 95% CI, 1.02 to 1.20)

The authors stress the need to help providers better identify at-risk patients in order to provide them with the best care. “The risk factors identified in this study could be used informally by physicians at the bedside to identify such patients.”

Hospitals could employ these factors to provide a second-level screen for identifying patients who may not otherwise have been referred to palliative and hospice care teams, suggest the authors. “Such efforts could have a substantial effect on improving care near the end of life and potentially reducing unnecessary hospitalizations.”

*Source: “Risk Factors for Potentially Avoidable Readmissions Due to End-of-Life Care Issues,” Journal of Hospital Medicine; Epub ahead of print, February 14, 2014; DOI: 10.1002/jhm.2173. Donzé J, et al; Division of General Medicine and Primary Care, Brigham and Women’s Hospital; Harvard Medical School.*

## CMS to Test Concurrent Hospice and Curative Care

The Centers for Medicare & Medicaid Services (CMS) has announced the launch of a pilot program to determine whether allowing Medicare beneficiaries to continue to receive services from their curative care providers while enrolled in hospice will improve quality of care, increase patient and family satisfaction, and affect the timing of hospice enrollment.

“The Medicare Care Choices Model empowers clinicians and patients with choices,” says Patrick Conway, MD,

deputy administrator for innovation and quality and CMS chief medical officer. “Specifically, clinicians, family members, and caregivers in this model will no longer need to choose between hospice services and curative care.”

Currently, only 44% of Medicare patients use the hospice benefit at the end of life, and most who do utilize hospice services for only a short period of time, according to Medicare claims data cited by CMS. Because the Medicare Hospice

Benefit requires that patients must forgo all curative care to receive the palliative and supportive care services of hospice, many patients perceive electing hospice as “giving up,” and postpone enrollment until all other options have been exhausted.

“End of life is a sensitive and difficult time for patients and families, filled with confusing and complicated choices,” says J. Donald Schumacher, PsyD, president and CEO of the National Hospice and

*Continued on Page 5*

## ICU Admission for NH Residents with Advanced Dementia

During the last decade, intensive care unit (ICU) utilization in the last 30 days of life among nursing home (NH) residents with advanced cognitive and functional impairment increased by 70%, with wide variations in use across geographic regions, a report published in the *Journal of Palliative Medicine* has found. Being nonwhite, having a feeding tube, and living in certain regions of the country increased the likelihood for ICU admission in the last month of life.

“Our finding that nearly one in ten nursing home residents with advanced cognitive impairment and severe functional impairment has an ICU stay appears to be at odds with family stated goals of care to focus on comfort,” write the authors. “Our study provides further evidence of the need to improve the quality of decision making for patients at the end of life with advanced cognitive impairment.”

Investigators analyzed data from the Minimum Data Set linked to Medicare claims from 2000 to 2007 for Medicare nursing home residents (n = 474,829) with advanced dementia.

### OVERALL

- From 2000 to 2007, 7.6% of residents with advanced dementia had an ICU admission in the last 30 days of life.
- 73% of advanced dementia residents had a do-not-resuscitate (DNR) order; only 7% had a do-not-hospitalize order.
- Only 12% had an order not to insert a feeding tube.

- 36% had a durable power of attorney.
- ICU utilization in the last month of life among this population increased from 6.1% in 2000 to 9.5% in 2007.
- The likelihood of ICU admission was higher in 2007 compared to 2000 (adjusted odds ratio [OR], 1.71; 95% confidence interval [CI], 1.60 to 1.81).
- Wide geographic variation in ICU utilization ranged from 0.82% in Montana to 22% in the District of Columbia.

States with the highest ICU use rates included California (13.7%), Florida (13.1%), and Texas (10.2%), while other states with low usage rates included Vermont (0.86%), New Hampshire (1.2%), and Maine (1.5%). This variation from state to state was “the same pattern as previously reported in studies of feeding tube insertion and rate of burdensome transition” in this population, the authors note.

Having an ICU admission was more likely among those who:

- Were Hispanic (OR, 2.0; 95% CI, 1.6 to 2.6), black (OR, 1.5; 95% CI, 1.4 to 1.6), or Asian (OR, 1.5; 95% CI, 1.2 to 2.0)
- Did not have a DNR (OR, 3.4; 95% CI, 3.2 to 3.6)
- Had a feeding tube (OR, 1.7; 95% CI, 1.7 to 1.8)

Dementia — the sixth leading cause of death in this country — is “a devastating illness, which brings suffering to those afflicted, their family, and friends,” observe the authors. “Without hope of disease altering treatment, families often wish

for comfort care and a focus on quality of life.”

In contrast, hospitalization of these patients for the expected complications of advanced dementia can result in aggressive and burdensome interventions, such as feeding tube placement and ICU admission, and is often unnecessary. “There is evidence to support successful treatment of the complications of advanced cognitive impairment in the NH setting,” the authors note.

Further, the six-month mortality for patients after these complications develop is high, observe the authors, “ranging from 38.6% (eating problems) to 46.7% (pneumonia),” and is even higher for NH residents hospitalized with two or more complications in the last 90 days.

“Families express a desire for comfort care for the NH resident with advanced cognitive impairment,” the authors point out. “Increasing ICU utilization is not consistent with the preferences of family, or with the evidence that demonstrates successful care with increased comfort in the nursing home.”

*Source: “Intensive Care Utilization among Nursing Home Residents with Advanced Cognitive and Severe Functional Impairment,” Journal of Palliative Medicine; March 2014; 17(3):313-317. Fulton AT, Gozalo P, Mitchell SL, Mor V, Teno JM; Department of Medicine, Warren Alpert Medical School of Brown University, and Butler Hospital, Providence, Rhode Island; Department of Health Services, Policy, and Practice, Brown University Program in Public Health, Brown University; and Institute for Aging Research, Hebrew Senior Life, Boston.*

## Hospice and Curative Care (from Page 4)

Palliative Care Organization. “Such patients who choose to continue with aggressive medical services are denied the opportunity to benefit from the holistic, interdisciplinary care provided by the hospice team.

“We trust that the Medicare Care Choices Model project will demonstrate

that patients who have access to hospice alongside of curative care have better outcomes, higher family caregiver satisfaction, and benefit from the expert support of hospice earlier in their care.”

CMS plans to select at least 30 Medicare-certified hospices (both urban and rural) to participate in the project, with a

projected enrollment of 30,000 beneficiaries over a three-year period. Beneficiary participation is limited to patients with advanced cancers, chronic obstructive pulmonary disease, congestive heart failure, and HIV/AIDS. For more information, visit <http://innovation.cms.gov/initiatives/Medicare-Care-Choices>.

## Increased Use of Hospice and Palliative Care Improves Cancer Care, Reduces Costs

The cost of cancer care is fast becoming unsustainable, even in high-resource countries such as the U.S. But delivering high-quality care to patients with metastatic cancer at lower costs can be achieved if the oncology community is able to address certain practice patterns, according to an article published in *The Lancet Oncology*.

The article focuses on the health care system in the U.S., the country with the fastest rising costs in cancer care. It identifies three major sources of rising costs:

- 1. The growing number of cancer cases in an aging population.** Patients experience increased and longer survival, with higher expectations and rising costs of therapy. In the U.S., 91% of the rise in costs since 2000 has been due to price increases. All aspects of cancer care contribute: hospital care accounts for 54% of total costs; pharmaceuticals, 24%; and physicians, 22%.
- 2. Imaging costs, which in the U.S. have risen by 5.1% to 10.3% per year since 1996.** “Medical imaging costs have increased without attendant changes in mortality from metastatic disease,” note the authors. The American Society of Clinical Oncology (ASCO) guidelines recommend the avoidance of positron emission tomography (PET) as part of routine follow-up, for example, unless there is “high-level evidence that such imaging will change the outcome.”
- 3. The cost of drugs, which has increased 10-fold in the past 10 years,** regardless of whether the drugs are targeted or effective. ASCO recommends clinicians discuss costs with their patients, because patients and families nearly always want this information. But many oncologists are unaware of the costs, or may feel unsure of how to discuss costs with patients. The authors present a three-pronged

approach to delivering “maximum clinical benefit at an affordable price” which includes improving end-of-life care, reducing medical imaging use, and reducing drug prices.

Efforts are underway to determine appropriate prices for drugs, such as establishing thresholds that link prices to the amount of time that life is extended. The authors suggest that setting such limits will help prevent “medical profiteering without rationing.”

### CHANGING END-OF-LIFE CARE

“Care at the end of life is expensive and sometimes ineffective; changes could actually improve quality and reduce costs,” write the authors. The amount spent on care in last year of life is 25% of Medicare total costs, with 10% of the total Medicare budget being spent in the last month of life.

“End-of-life care has become more intensive, not less, in the past 10 years.” 60% of Medicare cancer patients are admitted to the hospital in their last month of life; 25% are admitted to intensive care units; and 30% die in the hospital. Just 54% use hospice, with a median stay of only eight days. And in many cases, patients who are eligible for hospice care go unrecognized.

### HOW TO IMPROVE CARE

The authors suggest reducing the amount of chemotherapy given in the last month of life. “Since chemotherapy in the last month seems to be highly correlated with hospital admissions, high treatment costs, and poorer quality of care compared with those with less aggressive care, chemotherapy reductions should be a high priority for oncologists.” The high use of chemotherapy worldwide in the last month of life may be due to:

- Difficulty in assessing prognosis
- Patient willingness to accept major

toxicity for small benefit

- Reluctance to hold conversations that would transition patients from chemotherapy to hospice care

The authors also suggest increasing the use of hospice and palliative care. “Strikingly, patients cared for by hospices have equal or better survival outcomes than those treated in hospitals,” they point out. **Increased use of hospice and palliative care improves symptoms, reduces caregiver distress, and saves \$2700 to \$6500 per person in the U.S.**

### WHAT ONCOLOGISTS CAN DO

- Assist patients to better plan for the last months of life, to choose their preferred place to die, and avoid hospital death.
- Integrate palliative care earlier, with transition to hospice when appropriate. Use prompts or triggers to recognize patients who would be eligible for timely hospice entry.
- Communicate with patients about medically appropriate treatments and encourage acceptance of evidence-based treatment only.

“The difficulty of these discussions should not be underestimated,” write the authors. “Cancer is extremely stressful, and patients can feel overwhelmed by the influx of information.” They point out that the international Cancer Support Community has a free treatment-decision support program, Open to Options, to help patients communicate with their providers. The U.S.-based National Coalition of Cancer Survivors has a similar patient resource in its Toolbox.

*Source: “Delivering Maximum Clinical Benefit at an Affordable Price: Engaging Stakeholders in Cancer Care,” The Lancet Oncology; March 2014; 15(3):e112-e118. Kelly RJ and Smith TJ. The Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins Medical Institutions, Baltimore, Maryland.*

# CLINICIAN RESOURCES

## ***Improving Medical Decision Making for the Unrepresented Patient***

Decisionally incapacitated patients with no advance directive, surrogate, or any family member or friend who can be named as surrogate, are known as “unrepresented” or “unbefriended” patients. Currently, substitute medical decision making for these patients is often lacking in even minimal safeguards, according to an article published in *The New England Journal of Medicine*.

“We can do better,” writes Thaddeus Mason Pope, JD, PhD, director of the Health Law Institute, Hamline University, Saint Paul, MN. He suggests the promotion of “measures that aim to keep patients from becoming unrepresented in the first place,” and the establishment of independent ethics committees charged with making timely, expert, and carefully deliberated decisions on behalf of patients.

Unrepresented patients are often elderly, mentally disabled, homeless, or socially isolated, notes Pope. An estimated 3% to 4% of the 1.3 million Americans living in nursing homes are unrepresented, as are 5% of the 500,000 who die in intensive care units each year.

Quite often, the decision-making responsibility for these patients defaults to clinicians, who use substituted judgment when possible. Otherwise, decisions are made in what is considered to be the patient’s best interest. In many cases, however, the clinician has never spoken to the patient. Though these clinicians do their best to make the right decisions, they cannot know which treatments are in accordance with the patient’s preferences and values. If clinicians can get this information, then decisions can be made that are truly in the patient’s best interest.

### **HOW PROVIDERS CAN HELP**

To prevent patients from slipping into the unrepresented status, providers can:

- 1. Promote and protect patients’ ability to make their own health care decisions** as far as possible. “Capacity is not all or nothing,” writes Pope. “It fluctuates and can often be preserved through ‘supported decision making,’ such as assisting the person to make and communicate preferences and choices.”
- 2. Help patients who still have decision-making capacity to complete an advance directive** or to appoint an agent who can make treatment decisions on their behalf should it become necessary.
- 3. Conduct a diligent and thorough search for a suitable surrogate when none is initially available.** “Casting a wide net to include friends and pastors can at least provide evidence of the patient’s values and treatment preferences,” observes Pope.

For patients who are truly unrepresented, Pope recommends that decisions be made by a designated ethics committee, one that is external to the health care facility. Only five states have formally empowered such institutional multidisciplinary committees to date. In the other 45 states, facilities design and provide their own policies.

“I believe that providers have both the duty and the discretion to design these policies,” Pope states. “Ideally, the mechanisms we develop would not only increase the quality of decisions but also provide a greater sense of social legitimacy.”

Source: “*Making Medical Decisions for Patients without Surrogates*,” *The New England Journal of Medicine*; November 21, 2013; 369(21):1976-1978. Pope TM; Health Law Institute, Hamline University School of Law, Saint Paul, Minnesota.

## **End-of-Life Care Websites**

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

American Academy of Hospice and Palliative Medicine

[www.eperc.mcw.edu](http://www.eperc.mcw.edu)

End-of-Life/Palliative Education Resource Center (EPERC)

[www.epec.net](http://www.epec.net)

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

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

National Hospice & Palliative Care Organization

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

Caring Connections: National Consumer Engagement Initiative to Improve End-of-Life Care

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

Promoting Excellence in End-of-Life Care

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

Hospice Foundation of America

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

American Hospice Foundation

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

Hospice and Palliative Nurses Association

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

Resources for Patients and Families

[www.abcd-caring.org](http://www.abcd-caring.org)

Americans for Better Care of the Dying

[www.mcw.edu/palliativecare.htm](http://www.mcw.edu/palliativecare.htm)

Medical College of Wisconsin Palliative Care Center

[www.painpolicy.wisc.edu](http://www.painpolicy.wisc.edu)

University of Wisconsin Pain and Policy Studies Group

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

Center to Advance Palliative Care

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

Pain Medicine & Palliative Care, Beth Israel Medical Center

# End-of-Life Care Meetings for Clinicians

**Updates in Pain Management, Palliative Care, and End-of-Life Care.** June 28–July 5, 2014. Seven-night Mediterranean cruise conference from Rome, Italy. Topics include: Basic Communication and Delivering Bad News, How to Run a Family Meeting, and Palliative Care vs Hospice. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711. Website: [www.continuingeducation.net](http://www.continuingeducation.net)

**Pain Care for Primary Care.** July 17–19, 2014. Walt Disney World Swan Hotel, Orlando, FL. Sponsors: the *Journal of Family Practice* and the American Pain Society. Accredited by the Accreditation Council for Continuing Medical Education. Contact: Kim Kirchner. Phone: 502-574-9023. Email: [kkirchner@hqtrs.com](mailto:kkirchner@hqtrs.com). Website: <http://pcpc-cme.com>

**American Academy of Pain Management 25th Annual Clinical Meeting: Explore the Science, Practice the Art.** September 18–21, 2014, JW Marriott Desert Ridge, Phoenix, AZ. Website: [www.aapainmanage.org](http://www.aapainmanage.org)

**National Hospice and Palliative Care Organization 15th Clinical Team Conference and Pediatric Intensive.** October 27–29, 2014, Gaylord Opryland Resort and Convention Center, Nashville, TN. Website: [www.nhpco.org](http://www.nhpco.org)

**14th World Congress of the European Association for Palliative Care: Building Bridges.** May 8–10, 2015, Copenhagen, Denmark. Contact: Heidi Blumhuber. Email: [heidi.blumhuber@istitutotumori.mi.it](mailto:heidi.blumhuber@istitutotumori.mi.it). Website: [www.eapc-2015.org](http://www.eapc-2015.org)

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