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Quality of Life Matters®

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

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‘Surprise Question’ Found to Be Better Predictor of Patient Death than Other Measures

“Would you be surprised if this patient died within the next year?” When clinicians responded to this query — called the Surprise Question — with “No,” they were able to correctly identify nearly 60% of patients with cancer who did not survive the following year, researchers from the Dana-Farber Cancer Institute/ Ariadne Labs in Boston have found.

“The Surprise Question identifies cancer-center patients at high risk of death within one year better than clinical variables such as cancer type, stage, patient age, or time since diagnosis,” write the authors of a study presented at

the American Society of Clinical Oncology (ASCO) Palliative Care in Oncology Symposium in October 2015.

According to ASCO, there currently is no generally accepted systematic approach for identifying seriously ill patients who would benefit from conversations about their goals and values so that their medical care can be aligned with what matters most to them as they fill the remainder of their lives.

“We know that earlier conversations lead to better outcomes, including improved quality of life, better patient and family coping, and patients’ getting the kind of care that they want,” says senior author Rachelle E. Bernacki, MD, director of Quality Initiatives, Psychosocial Oncology and Palliative Care at Dana-Farber. “So the whole purpose of the Surprise Question is to make sure the right care is getting to the patients who need it the most.”

The Surprise Question was developed in the 1990s, but evidence of its utility has been limited by the small number of patients and clinicians enrolled in only a few studies. As part of an ongoing four-year clinical trial to test the impact of the Serious Illness Care Program, a structured intervention to improve end-of-life discussions, researchers evaluated the effectiveness of using the Surprise Question as the first step: identifying patients appropriate for such discussions.

The randomized controlled trial was

“With [the Surprise Question], physicians can harness their clinical impressions to plan the most appropriate care for each patient.”

— Don S. Dizon, MD,
Massachusetts General Hospital, Boston

conducted at the Dana-Farber Cancer Institute from 2012 to 2014. Oncology clinicians (n = 81) answered the Surprise Question for 4617 patients (aged 19 to 95 years) diagnosed with all stages and different types of cancer, including breast, gastrointestinal, genitourinary, head and neck, and thoracic cancer, as well as sarcoma and lymphoma.

FINDINGS

- Clinicians answered “Yes, I would be surprised” to the question for 83% of the patients and “No, I would not be surprised” for 17%.
- The propensity-adjusted one-year survival rate for “Yes” patients was 93% (95% confidence interval [CI], 91% to 96%) compared to 53% (95% CI, 46% to 60%) for the “No” patients ($P < 0.0001$).
- Sensitivity of the “No” response was 59% (95% CI, 49% to 68%) and specificity was 90% (95% CI, 86% to 93%).

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NEWSLINE

‘Proactive Primary Palliative Care’ Urged for COPD Patients

Patients with chronic obstructive pulmonary disease (COPD) have significant symptom burden, quality of life impairment, and aggressive use of health care resources at the end of life, yet these patients are frequently under-supported throughout their disease course as well as at life’s end, according to an article published in the *International Journal of Chronic Obstructive Pulmonary Disease*.

“Despite refractory symptoms and recurrent hospitalization, many patients with COPD die without access to palliative care,” write the authors, a team of experts in hospice and palliative medicine and pulmonary disease from Northwestern University Department of Medicine, Chicago.

The authors propose an approach to addressing the unmet needs of COPD patients through the practice of “proactive primary palliative care” — the incorporation of palliative care into the routine management of COPD. [See sidebar.]

“Proactive palliative care should be incorporated early into the patient’s illness...to address complex refractory symptoms and advance care planning, and to increase outpatient resources for patients and caregivers,” write the authors. “Not all patients who would benefit from proactive palliative support need to be referred to palliative care physicians.”

COPD, a chronic and disabling disease for which there is no cure, is the fifth leading cause of death worldwide, point out the authors. Unlike other major causes of death such as heart disease and stroke, which have seen a decrease in mortality rates in recent years, COPD is increasing in prevalence, and its symptom burden is heavy.

“The burdens of significant symptoms and comorbid health conditions in COPD are comparable to or worse than other

chronic illnesses including heart failure, HIV, and metastatic cancer,” write the authors. “Patients with COPD, however, are less likely to have adequate treatment of symptoms at the end of their life, are more likely to have a decreased health-related quality of life, and are significantly less likely to receive specialist palliative care referral.”

BURDENS OF COPD

- **Disability.** COPD is the eleventh leading cause of disability worldwide, and is projected to be the seventh leading cause by 2030.
- **Shortness of breath.** Breathlessness is a distressing symptom in itself and one associated with decreased quality of life and greater risk for further exacerbations and functional decline. Nearly all COPD patients, even those with stable lung function, report shortness of breath, state the authors.
- **Fatigue, cough, and pain.**
- **Depression and anxiety.** These burdens often go unrecognized and untreated.

Approach to Providing Primary Palliative Care in COPD

- Screen for and address unmet needs in the management of symptoms such as breathlessness, depression, and anxiety.
- Conduct early and regular discussions about future care and concerns. Ask the patient, “*Would it help to talk about what to expect or what to prepare for as your illness worsens?*”
- Encourage advance care planning by identifying decision makers and clarifying any desired limits to potential interventions. “*Are there treatments or interventions that you would not want as you approached the end of life?*”
- Build a team. Share responsibility for care with nurses, social workers, respiratory and physical therapists, chaplains, and — if complex symptom management and support are required — experts in palliative medicine.

— Adapted from Vermeylen et al, International Journal of COPD

Palliative care has been found to improve symptom burden, quality of life, and patient satisfaction in patients with COPD, the authors note. In its 2008 official policy statement on palliative/hospice care, the American Thoracic Society recommended that palliative services be available to patients with respiratory diseases “at all stages of illness.” However, delivery of these services to COPD patients is still far from the norm, due to several major barriers.

BARRIERS TO PROVISION OF PALLIATIVE CARE

Prognostication. The variable and prolonged course of COPD makes determining prognosis and addressing end-of-life goals challenging for physicians, patients, and their families, resulting in late referrals to palliative and hospice care. Because COPD patients typically experience a slow decline punctuated by episodes of acute exacerbation — which the patient will often survive — being

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NEWSLINE

'Surprise Question' (from Page 1)

- Positive predictive value was 49% (95% CI, 45% to 54%) and negative predictive value was 93% (95% CI, 90% to 95%).

“Our results show that oncology clinicians’ own judgment using the Surprise Question identified about 60% of patients with a short life expectancy,” points out lead author Judith B. Vick, an MD candidate at Johns Hopkins School of Medicine, Baltimore. “This tool is framed as a question because it leaves space for uncertainty and allows clinicians to consider something that is difficult for clinicians to consider, which is how long

their patients may have to live.

“However, given that 40% of these patients were not identified by the Surprise Question, more research is needed to understand why,” Vick continues. Further study is planned, she says, to examine physician and patient characteristics that may cause patients in their last year of life to be overlooked.

“This important work shows that one question that clinicians actually ask themselves may be more effective than the usual clinical and laboratory parameters to identify patients who have a risk of dying within a year,” said moderator

Don S. Dizon, MD, clinical co-director of gynecologic oncology at Massachusetts General Hospital in Boston, at a press briefing held on the study results.

Dizon added that “with this tool, physicians can harness their clinical impressions to plan the most appropriate care for each patient.”

Source: “The Utility of the Surprise Question in Identifying Patients Most at Risk of Death,” Journal of Clinical Oncology; October 10, 2015; 33(29_suppl; abstr 8). Vick JB, Pertsch N, Hutchings M, Lipsitz S, Gawande A, Block S, Bernacki R; Johns Hopkins University School of Medicine, Baltimore; Ariadne Labs and Dana-Farber Cancer Institute, Boston.

'Proactive Primary Palliative Care' (from Page 2)

able to recognize the terminal phase of COPD is extremely difficult.

The authors recommend a care approach that does not rely on precise prognostication and the identification of imminent death, but instead proactively provides early access to palliative services.

Communication. Physicians may tend to avoid conversations about palliative and hospice care due not only to the difficulty in determining prognosis, but also because they feel they lack the training or time to hold such discussions. In addition, some physicians may view palliative care as a service reserved for the actively dying, and do not wish to take away a patient’s hope by introducing the topic “too early.”

Patients may feel reluctant to think about or discuss the end of their lives, or be uncertain with which physician they should broach the topic. But many COPD patients still desire to have emotional support and the peace of mind from knowing that their suffering will be addressed and their wishes will be respected.

System barriers. Few U.S. health care systems are organized to deliver specialty palliative care to patients with COPD, or to reimburse physicians for providing palliative care throughout the course of an illness, observe the authors. However, initiatives are recently being promoted to provide concurrent curative and palliative care through Medicare and to reimburse physicians for discussing advance care planning with patients.

The authors provide a list of triggers for when to initiate or escalate palliative care interventions for patients with COPD. In addition, they suggest that any patients with symptoms refractory to initial treatment would benefit from early primary palliative care and perhaps even consideration of intensive outpatient support from a palliative care team.

PALLIATIVE CARE TRIGGERS

Triggers for initiating or intensifying palliative care for COPD patients:

- Advanced age (≥ 75 years)
- Comorbidities, particularly cardiac

- Poor functional status and/or patient-reported minimal physical activity
- Poor health-related quality of life
- Low forced expiratory volume in one second ($< 30\%$)
- Low body mass index ($< 20\%$)
- One or more hospitalizations within the past year

“[P]rimary care providers as well as specialty pulmonologists should be trained and capable of screening patients who would benefit from proactive outpatient supportive care and of providing primary palliative care,” the authors maintain. “These frontline providers should provide increased focus on symptom management, advance care planning, and support for patients as part of comprehensive COPD care.”

Source: “Palliative Care in COPD: An Unmet Area for Quality Improvement,” International Journal of Chronic Obstructive Pulmonary Disease; August 6, 2015; 10:1543-1551. Vermylen JH, Szmuilowicz E, Kalhan R; Section of Palliative Medicine, Asthma and COPD Program, Department of Medicine, Northwestern University Feinberg School of Medicine, Chicago.

RESEARCH MONITOR

Advance Care Planning Incidence Drops While Aggressive End-of-Life Care Increases, National Study Finds

Despite increased efforts to encourage early advance care planning (ACP) nationwide, the percentage of decedents with cancer who completed living wills or discussed their end-of-life (EOL) care wishes with physicians or loved ones declined between 2000 and 2012. The only form of ACP that increased in prevalence during that period was durable power of attorney (DPOA), which was also found to be the only form that did *not* limit aggressive care.

“Decedents who were most likely to receive aggressive EOL care were those who did not have a living will and had not discussed their EOL treatment preferences prior to death; among this group, the assignment of a DPOA did not further reduce the likelihood of receiving aggressive EOL care,” write the authors of a report published in *JAMA Oncology*.

“[T]hese findings suggest that if patients’ EOL treatment preferences have not been explicitly communicated, whether through writing or conversation, health care proxies may default to providing all care possible instead of limiting potentially intensive, life-prolonging care.”

Cancer is the second leading cause of death in the U.S. In contrast to other leading disease-related causes of death, “cancer has a distinct trajectory of functional decline and a predictable terminal period, during which patients might benefit from ACP and palliative care,” point out the authors. Early ACP is recommended in guidelines from major professional oncologic organizations as key to the appropriate delivery of palliative and EOL care consistent with patient preferences.

Nevertheless, ACP use continues to stagnate or decline, and studies for more than a decade have shown a persistent use of aggressive services near death, “despite evidence that aggressive EOL interven-

tions may not be associated with better medical or quality-of-life outcomes,” the authors note.

Investigators analyzed survey data from a subset of cancer patients who died between 2000 and 2012 and had participated in the Health and Retirement Study (HRS), a nationally representative longitudinal study employing biennial interviews with adults over the age of 50 years and their spouses. Postmortem “exit interviews” with knowledgeable next-of-kin surrogates (n = 1985) were examined to determine trends in ACP use and associations of ACP type with EOL treatment intensity.

OVERALL FINDINGS

- 81% of decedents had engaged in at least one form of ACP from 2000 to 2012. However, there was no significant increase over time in the percentage of decedents participating in ACP.
- DPOA was the only form of ACP that rose during that period (from 52% to 74%; $P = .03$), but also the only form that did not affect care.
- The percentage of patients who had living wills (49% to 40%; $P = .63$) or end-of-life care discussions (68% to 60%; $P = .62$) declined slightly from 2000 to 2012.
- Aggressive treatments were limited or withheld in 88% of decedents with both a living will and EOL discussions, but in only 53% of decedents who had neither.
- Surrogate reports that patients received “all care possible under any circumstances in order to prolong life” at the end of life increased eight-fold during the period (7% to 58%; $P = .004$).

KEY FINDINGS

- Creation of a living will was significantly associated with increased odds of having aggressive EOL treatments

limited or withheld (adjusted odds ratio [AOR], 2.51; 95% confidence interval [CI], 1.53 to 4.11; $P < .001$).

- Participation in an EOL discussion was also significantly linked to limiting or withholding aggressive treatments at the end of life (AOR, 1.93; 95% CI, 1.53 to 3.14; $P = .002$).

“[C]ancer care in the U.S. continues to be intensive, with evidence of increasing rates of hospitalizations, intensive care unit stays, and emergency department visits in the last month of life, along with persistently high rates of terminal hospitalizations, late hospice referrals, and burdensome transitions near death,” write the authors.

“In this cohort, between 25% and 30% of terminally ill patients with cancer died in the hospital,” they note. “In addition, patients were more likely, not less, to receive all potentially life-prolonging care at EOL over time.”

The stagnation of growth in the creation of living wills and/or participation in EOL discussions, which have both been shown to reduce EOL treatment intensity, indicates that “new avenues must be pursued for bolstering their adoption,” state the authors. “Efforts that bolster communication of EOL care preferences and also incorporate surrogate decision makers are critically needed to ensure receipt of goal-concordant care.”

MEDICARE TO REIMBURSE CLINICIANS FOR ACP CONVERSATIONS

Recognizing the critical importance of end-of-life care discussions between patients and their physicians for ensuring delivery of appropriate and desired care, the Centers for Medicare and Medicaid Services (CMS) has approved two new

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RESEARCH MONITOR

Emergency Department Referral to Palliative Care Services Yields Earlier Symptom Management

Advanced cancer patients referred directly to an on-site palliative care (PC) service after presenting to an emergency center (EC) received earlier symptom control than patients who received PC consults only after being admitted to the hospital, according to a report published in *Supportive Care in Cancer*. In addition, emergency patients with PC referrals who were subsequently hospitalized had shorter stays than those referred to PC as inpatients.

“[E]arly PC involvement, especially in the first few hours of the EC visit, is extremely important, as important decisions are made then about the patient’s disposition and about plans for his or her care,” write the authors of the report. However, they add that “although hospice and palliative medicine have recently been recognized as subspecialties of emergency medicine, PC teams and EC providers still interact very little.”

The MD Anderson Cancer Center at the University of Texas in Houston maintains a 44-bed EC for a variety of acute oncologic emergencies. From a total of 4294 PC consultations at the center, investigators analyzed symptom control and health care

utilization for two cohorts: 200 patients with advanced cancer referred to PC services directly from the EC (“EC patients”) and 200 matched advanced cancer patients referred to PC services after hospital admission (“inpatients”) from January 2010 through December 2011. All patients’ symptom profiles obtained at baseline (the initial PC consultation) were compared with their symptom grades at follow-up, within 24 to 48 hours.

KEY FINDINGS

- At follow-up, most symptoms had improved for a significant proportion of patients in both the EC patient and the inpatient groups, respectively: pain (58%; 48%), sleep (49%; 43%), fatigue (49%; 33%), well-being (34%; 42%), anxiety (38%; 39%), and shortness of breath (33%; 29%).
- The proportion of EC patients with DNR orders increased from baseline to follow-up (19% vs 45%), while the percentage of inpatients with these orders remained low (0.5% vs 7%).
- EC patients who were hospitalized were discharged from the hospital 1.4 days earlier than inpatients.

- 33% of EC patients were discharged to home, 33% were hospitalized, 23% were admitted to the inpatient PC unit for symptom control and transition to hospice, and 11% were discharged to home or inpatient hospice.

The finding that symptom improvement did not differ significantly between the groups suggests that a PC intervention in the EC can be as effective in relieving symptoms as the more traditional inpatient consultation, note the authors. Thus, “supportive PC-EC partnerships could provide earlier benefits to patients, families, and payers..., and could even prevent hospital admission or future EC visits altogether.”

Source: “Characteristics and Outcomes of Patients with Advanced Cancer Evaluated by a Palliative Care Team at an Emergency Center: A Retrospective Study,” Supportive Care in Cancer; Epub ahead of print, November 21, 2015; DOI: 10.1007/s00520-015-3034-9. Delgado-Guay MO, et al; Department of Palliative, Rehabilitation, and Integrative Medicine and Department of Biostatistics, The University of Texas MD Anderson Cancer Center, Houston; Programa de Medicina Paliativa y Cuidados Continuos, Facultad de Medicina, Pontificia Universidad Católica de Chile, Santiago, Chile; Department of Internal Medicine, College of Medicine, Kosin University, Busan, South Korea.

Advance Care Planning Incidence (from Page 4)

billing codes for physician compensation for time spent eliciting patients’ values and wishes for goals of care and counseling them on care plans to match their preferences.

Effective in early 2016 as part of the Medicare Physician Fee Schedule and billable under Medicare Part B, one code will reimburse physicians for the first 30 minutes spent in early discussion of care options; the second code will cover additional 30-minute blocks of time in the

ongoing process of advance care planning.

“Establishing separate payment for advance care planning codes to recognize additional practitioner time to conduct these conversations provides beneficiaries and practitioners greater opportunity and flexibility to utilize these planning sessions at the most appropriate time for patients and their families,” states CMS.

For more information on the new Medicare billing codes, visit www.cms.gov/Newsroom/MediaReleaseData

base/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html.

Source: “Trends in Advance Care Planning in Patients with Cancer: Results from a National Longitudinal Survey,” JAMA Oncology; August 1, 2015; 1(5):601-608. Narang AK, Wright AA, Nicholas LH; Department of Radiation Oncology and Molecular Radiation Sciences and Department of Surgery, Johns Hopkins School of Medicine, Baltimore; Department of Medical Oncology, Dana-Farber Cancer Institute, Boston; Harvard Medical School, Boston; Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore.

CLINICIAN RESOURCES

Reframing the Presentation of End-of-Life Medical Options

According to an article published in *JAMA Internal Medicine* as part of the journal's "Teachable Moment" series, a more thoughtful, personalized, and selective approach is needed when presenting possible options for medical interventions to those making decisions for patients nearing the end of life.

"American health care culture is often biased toward doing everything," write the authors. But particularly for a patient who is nearing death, not all possible interventions need to be — or should be — presented to the patient or family as good options simply because they are available, the authors maintain.

The article opens with a clinical vignette of a patient whose surrogate was offered the option of palliative surgery to resect two large brain masses in the hopes of reducing neurologic deficits and extending the patient's life. The patient was elderly, with widely metastatic cancer and dementia, and was undergoing anticoagulation for recurrent venous thromboembolism. The authors ask: Should this patient have been offered the option of surgery at all?

Unable to make complex medical decisions for himself, the patient had no living will or advance directives, but had previously asked his primary team to "do everything." The team stressed the high risk of surgery, but because it had been offered, the patient's wife felt obligated to try the intervention, despite the primary team's concerns and her own private reservations.

Postoperatively, the patient's cognition was unchanged. He experienced intracranial hemorrhaging, which was successfully evacuated, but he remained minimally responsive. After several days, the patient's wife asked for a transition to comfort care, and the patient died in inpatient hospice 11 days later.

"Patients with more medical comor-

bidities and poorer functional status may mandate a higher threshold for invasive procedures, but surgical interventions remain common near the end of life," point out the authors. They cite findings from a large study of all Medicare patients who died in 2008. Nearly one-third underwent at least one surgical procedure in the last year of life, with 18.3% of patients undergoing surgery in their final month. "Patients with more comorbidities paradoxically underwent more surgeries," the authors note.

Physicians can help those making medical decisions on behalf of terminally ill patients by keeping in mind the conflicted feelings surrogate decision makers may have regarding their responsibilities, suggest the authors. When offered an array of possible interventions — including those with potential for greater harm than benefit — surrogates may feel that selecting less than doing everything possible would be abandoning their loved one, or that it would constitute withholding care.

PHYSICIANS CAN:

- 1) Invest time to fully explore the patient's goals of care.** This is "a crucial first step to providing optimal care," the authors state.
- 2) Reframe conversations with family/surrogate.** "Not all possible interventions need to be, or should be, presented as good options." If the wife in the case study had been told simply, "*Brain surgery is not a good option for your husband,*" she might have been spared the burden of feeling obligated to choose such aggressive care.
- 3) Maintain clear communication between primary and consulting teams.** "This unifies the message that just because an option is available does not mean it is good." Primary teams who

consider a procedure not in the patient's best interest should make that clear at the initial consult. Likewise, surgeons who sense a "nuanced" situation regarding the wisdom of proceeding should communicate with the primary team before making a recommendation to the family.

Certain situations should raise an alert that more careful consideration of treatment options is needed — *before* they are presented in a family discussion. These include:

- When the patient's goals are unclear
- If a patient is unable to make complicated medical decisions
- When the patient has serious comorbidities or poor functional status

DO NO HARM

JAMA Internal Medicine's "Teachable Moments" series, which was launched with a call for manuscripts in 2014, was inspired by the Do No Harm Project, created at the University of Colorado, Denver, is now expanding into other institutions and medical schools across the country. The goal of the project is to use clinical vignettes written by trainees as first authors "to improve recognition of harms that may result from medical overuse and to drive a needed culture change in the practice of medicine."

For more information on the Do No Harm Project, visit www.ucdenver.edu/academics/colleges/medicalschooll/departmentsofmedicine/GIM/education/DoNoHarmProject.

Source: "Surgical Intervention in Terminal Illness — Doing Everything: A Teachable Moment," *JAMA Internal Medicine*; Epub ahead of print, November 9, 2015; DOI: 10.1001/jamainternmed.2015.6335. Oberndorfer TA, Anoff DL, Wald HL; Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora.

CLINICIAN RESOURCES

Generalist Palliative Care Resources Online

www.mypcnow.org

The Palliative Care Network of Wisconsin (PCNOW) website offers resources for generalist clinicians, i.e., health care clinicians who do not have specialist training in hospice and palliative medicine. The site provides information for those clinicians wishing to improve the palliative care delivered to their patients in the outpatient setting, as well as a guidebook for implementing patient-centered care planning conversations into the routine care of seriously ill hospitalized patients.

PCNOW's stated mission is "to advance the care of the seriously ill in Wisconsin and beyond, by growing generalist and specialist palliative care services in all health care settings, and by advancing the knowledge and skills of all health professionals providing care to seriously ill patients and their families."

Joining the network is free and gives access to resources such as clinical tools and self-study guides for generalist clinicians. Provision of palliative care at the primary or generalist level should include basic services in pain and symptom management, communication, prognostication, and future planning for all seriously ill patients, notes the network.

CLINICIAN RESOURCES INCLUDE:

- Clinical guideline protocols
- An opioid fact sheet
- A short review of and guide to shared decision making in dialysis
- The National Comprehensive Cancer Network Clinical Practice Guidelines (NCCN Guidelines®) in Oncology: Palliative Care
- Clinical self-study materials appropriate for generalists or specialists
- A series of short lectures at a generalist palliative care level on more than a dozen topics, such as prognostication, delivering bad news, and hospice care
- A self-administered multiple-choice test
- A link to "Palliative Care Fast Facts and Concepts," a collection of over 300 fact sheets organized by topic and written by experts in palliative medicine; based on work by the End-of-Life/Palliative Education Resource Center (EPEC)

PALLIATIVE CARE GUIDEBOOK

The 40-page guidebook, entitled "Improving Generalist Palliative Care for Hospitalized Seriously Ill Patients," can be purchased online in PDF format or softcover book. Along with a step-by-step guide to embedding goals-of-care conversations into routine care, the book includes a clinician communication guide, a sample electronic medical record (EMR) template for documenting advance care planning discussions, clinician education resources, and quality improvement guides.

"All clinicians who care for seriously ill patients provide some level of palliative care, but typically with little training and no health care system in place to guide best practice," states the PCNOW site. The guidebook was designed to help hospitals improve clinician training and to develop a system of care "so that the principles of palliative care are available to all seriously ill patients, not just those who are seen by a palliative care specialist."

End-of-Life Care Websites

American Academy of Hospice and Palliative Medicine
www.aahpm.org

American Hospice Foundation
www.americanhospice.org

Americans for Better Care of the Dying
www.abcd-caring.org

Caring Connections: National Consumer Engagement Initiative to Improve End-of-Life Care
www.caringinfo.org

Center to Advance Palliative Care
www.capc.org

The EPEC Project (Education in Palliative and End-of-Life Care)
www.epec.net

Fast Facts and Concepts in Palliative Care for Clinicians, hosted by the Center to Advance Palliative Care
www.capc.org/fast-facts

Hospice and Palliative Nurses Association
www.hpna.org

Hospice Foundation of America
www.hospicefoundation.org

Medical College of Wisconsin Palliative Care Center
www.mcw.edu/palliativecare.htm

National Hospice & Palliative Care Organization
www.nhpco.org

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

Promoting Excellence in End-of-Life Care
www.promotingexcellence.org

Resources for Patients and Families
www.hospicenet.org

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

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