

Quality of Life Matters®

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

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Experts Call for a Moratorium on Using the Phrase ‘Do Everything’

Agreeing to “do everything” for a seriously ill patient is agreeing to a nebulous care plan that is unexamined, undiscussed, and potentially harmful. It is the opposite of making a commitment, according to the authors of an article published in the *Archives of Pediatric and Adolescent Medicine*.

“The phrase is vague at best and vacuous at worst, permitting an increasingly harmful vacillation in the face of critical illness, which can eventually result in medical care that is harmful to the patient,” argue Chris Feudtner, MD, PhD, MPH, and Wynne Morrison, MD, MBE, of Children’s Hospital of Philadelphia.

WHY PHYSICIANS MUST DROP THE PHRASE ‘DO EVERYTHING’

1. We simply cannot “do everything.” A family member cannot hold the hand of a dying loved one, for instance, while the code team attempts defibrillation. One must choose.

“Whether acknowledged or not, choices are woven throughout the fabric of medical care,” the authors maintain. However, what they call the “darkening veil” of agreeing to do everything causes a clouding of choices and of the responsibility for making them. No one is clear about exactly what has been decided upon.

The phrase, “There is nothing more we can do” is the flip side of this muddled message. “Just as we cannot do everything, we can always do something,” state the authors. “When operating within the confines of the increasingly tight constraints that progressive disease can cause, clinicians need to be more precise, complete, and empathetic.”

Physicians can say, “*I wish there were more we could do that would halt the progress of this disease. But none of the treatments we have are able to do this. We are still devoted to taking care of your loved one and will do everything in our power to keep pain and discomfort away.*”

2. “Do everything” leaves too much room for misunderstanding what the different parties mean and what they believe will actually be done. Families do not know the full range of medical options or their physical implications.

Physicians can say, “*Yes, we will do everything we can do that will possibly help your loved one.*”

3. Using the phrase “do everything” blocks the establishment of a family-physician connection. These words may be a cry of distress from the family, meaning, “Don’t abandon us.” Agreement with its use by the physician cuts off meaningful discussion, allowing for the avoidance of responding to emotions or exploring what can and cannot be done, and why.

“We argue for taking the time in these conversations to explore the choices that could be made,” comment the authors. “When confronted with requests or demands to ‘do everything,’ we view this as a starting point for a discussion, not an ending point.”

Physicians can say: “*I respect how deeply committed you are, and we are also absolutely committed to figuring out what is the best thing to do. Let’s talk for a few minutes about what the different options might look like.*”

4. As medical technologies become increasingly effective, they are also increasingly invasive. Some treatment options may inflict pain and suffering while merely forestalling death only briefly, the authors note.

Physicians can say: “*We always ask ourselves what we can do to help the patient. To answer this question, we have to be clear about what we are hoping for — recovery, comfort, dignity — and do*

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Heart Failure Patients More Likely Than Cancer Patients to Enter Hospice in the Last Week of Life

Compared with patients with advanced cancer, end-stage heart failure patients are more likely to enter hospice very late in the course of their disease, to be referred from acute care hospitals or nursing facilities, and to utilize or die in acute care settings, according to a report published in the *Journal of Pain and Symptom Management*.

“Whereas patients with advanced heart failure or cancer are known to experience significant symptom burdens near the end of life, few studies have directly compared the clinical courses of these two populations after hospice enrollment,” comment the authors.

“This is the first population-based study to our knowledge that specifically compares sources of hospice referrals and examines acute care utilization after hospice enrollment between heart failure patients and cancer patients.”

Researchers used data from Medicare linked to Pennsylvania’s state cancer registry and pharmacy assistance program to analyze patterns of enrollment and clinical events among hospice patients with end-stage heart failure (n = 1580) or advanced cancer (n = 3840) who died between 1997 and 2004. Patient mean ages were 86.0 years (heart failure) and 80.1 years (cancer). “Late” hospice enrollment was defined as admission within seven days of death.

KEY FINDINGS

- Heart failure patients were more likely than those with advanced cancer to be enrolled in hospice within three days of death (20% vs 11%; $P < 0.01$) as well as within seven days of death (19% vs 13%; $P < 0.001$).
- Median length of hospice stay was significantly shorter for heart failure patients than for cancer patients (12 days vs 20 days; $P < 0.001$).
- Although the prevalence of death in acute care settings was low in both groups after hospice enrollment (4% heart failure vs 2% cancer; $P < 0.01$), heart failure patients were more likely to visit emergency departments (13% vs 10%; $P < 0.004$) or to be hospitalized (9% vs 6%; $P < 0.001$).
- Compared with cancer patients, those with heart failure were more likely to be referred from hospitals (35% vs 24%; $P < 0.01$) and nursing facilities (9% vs 7%; $P < 0.01$) than from home settings.
- Overall, patients referred from either acute care settings or nursing homes were more likely to enter hospice within seven days of death (odds ratio [OR], 1.81; 95% confidence

“The acceptance of palliative care and hospice use in cardiology has not been studied, and may be less than that of oncology, in part the result of less formal training and exposure to palliative care. In contrast, oncology has traditionally placed a significant emphasis on symptom palliation as a routine part of comprehensive care.”

— Cheung, et al, *Journal of Pain and Symptom Management*

interval [CI], 1.56 to 2.09 and OR, 1.84; CI, 1.45 to 2.35, respectively).

The finding that heart failure patients were more frequently referred to hospice from acute care settings and nursing homes suggests a lack of coordination of palliative care services for these patients, point out the authors. Many of the heart failure patients were already in the terminal days of disease and their “referrals were likely prompted by health care providers rather than patients themselves.” In contrast, most cancer patients were referred from home settings, suggesting greater awareness of palliative services and referrals that were patient- or family-initiated.

“The use of hospice services by patients with terminal cancer increases their satisfaction, improves their quality of death, and minimizes their personal as well as their family’s physical and psychological distress,” observe the authors. However, both the current analysis and previous studies suggest that the delivery of similar hospice care to end-stage heart failure patients is in need of improvement.

“Future work should evaluate whether educational interventions that emphasize the importance of hospice and supportive care programs can improve the rate of patient-initiated referrals for heart failure,” the authors suggest. In addition, they call for assessment of programs targeting better access to and coordination of palliative care services for heart failure patients.

Source: “Enrollment and Events of Hospice Patients with Heart Failure vs Cancer,” Journal of Pain and Symptom Management; Epub ahead of print, September 3, 2012; DOI: 10.1016/j.jpainsymman.2012.03.006. Cheung WY, Schaefer K, May CW, Glynn RJ, Curtis LH, Stevenson LW, Setoguchi S; Division of Medical Oncology, British Columbia Cancer Agency, Vancouver, British Columbia, Canada; Dana-Farber Cancer Institute and Brigham and Women’s Hospital, Boston; and Duke Clinical Research Institute, Durham, North Carolina.

Standardizing Terminology Used for Palliative and End-of-Life Care Could Improve Patient Care

Commonly used terms for the care and support of patients with serious disease and their families are rarely — and inconsistently — defined in medical literature, making it no surprise that this care is often misunderstood by clinicians and patients. Establishing consensus definitions for these terms could lay the groundwork for a more seamless delivery of care, according to an article published in *Supportive Care in Cancer*.

“Palliative care has evolved from a philosophy of care for the dying to an interprofessional discipline that addresses quality of life for patients and their families throughout the disease trajectory,” write the authors.

“As this discipline matures, we urgently need consensus definitions to help standardize clinical care, research, and program development.”

Investigators analyzed the definitions for and conceptualizations of the terms “best/supportive care,” “palliative care,” and “hospice care” as found in 10 current medical dictionaries, five commonly used palliative medicine textbooks, and 25 journal articles published from 1948 to 2011.

Sources were nearly unanimous in conceptualizing all three terms as care aimed at controlling symptoms and improving the quality of life for patients with advanced, noncurable disease. Beyond that, however, use of the terminology varied widely.

A CONCEPTUAL MODEL OF PALLIATIVE CARE

Based on the findings from their literature review, the authors have developed a “preliminary conceptual framework” toward an understanding of “the overlap-

ping yet unique function of each term.” It is their hope that this framework may help clinicians, researchers, and policy makers formulate standardized definitions.

In their model, “hospice care” is part of “palliative care,” which overlaps with “supportive care.” Yet, note the authors, the boundaries are fluid, as each definition has been evolving over time and expanding its scope of service to reach patients earlier in the disease trajectory.

According to the authors’ conceptual model:

- Supportive care begins in the early stages of disease and continues until death.
- Palliative care begins when an illness reaches an advanced stage, and continues through bereavement support.
- Hospice care begins when expected survival is six months or less, and continues through bereavement support.

Rather than trichotomizing patient care into three different services, this model supports the provision of patient care by a single discipline comprised of a team of health care professionals with expertise in:

- Symptom management
- Psychosocial care
- Spiritual support
- Caregiver care
- Communication
- Complex decision-making skills
- End-of-life care

“A better understanding of the key concepts and defining features for ‘supportive care,’ ‘best supportive care,’ ‘palliative care,’ and ‘hospice care’ could provide a common ground for clinical and research communication and pave the way for standardization,” conclude the authors.

Source: “Concepts and Definitions for ‘Supportive Care,’ ‘Best Supportive Care,’ ‘Palliative Care,’ and ‘Hospice Care’ in the Published Literature, Dictionaries, and Textbooks,” Supportive Care in Cancer; Epub ahead of print, August 31, 2012. Hui D, De La Cruz M, et al; Department of Palliative Care & Rehabilitation Medicine, and Research Medical Library, University of Texas MD Anderson Cancer Center, Houston; Department of Palliative Medicine, Seirei Hamamatsu General Hospital, Shizuoka, Japan; Graduate College of Social Work, University of Houston, Houston, Texas; and Department of Family Medicine, Myong Ji Hospital, Kwandong University, College Of Medicine, Gyeonggi, South Korea.

‘Do Everything’ (from page 1)

all that we can that has a reasonable chance of getting us there.”

“The bottom line is simple,” conclude the authors. “Saying that we are going to ‘do everything’ is dangerous nonsense. If we really don’t mean it, then we really must not say it. A moratorium is warranted, halting all medical personnel from further casual utterances of ‘do everything.’”

Source: “The Darkening Veil of ‘Do Everything,’” Archives of Pediatric and Adolescent Medicine; August 2012; 166(8):694-695. Feudtner C and Morrison W; Department of Anesthesiology and Critical Care Medicine, Department of Medical Ethics, and Pediatric Advanced Care Team, Children’s Hospital of Philadelphia, Philadelphia.

Patients with Pulmonary Arterial Hypertension Experience High Symptom Burden, Little Palliative Care at End of Life

In what investigators consider to be the first study of the end-of-life experience of patients with pulmonary arterial hypertension (PAH), findings show that two-thirds of these patients die in the hospital — most in intensive care — with a high symptom burden and without palliative care.

The end-of-life experience for diseases with similar survival, such as lung cancer, have been well described, leading to the development of interventions aimed at improving end-of-life care for these patients. “However, to our knowledge, there has never been an investigation of the end-of-life symptoms in patients with PAH,” write the authors of a report published in the *Journal of Palliative Medicine*. “It is unclear how well patients and their families understand this disease, its prognosis, and available support options.”

Investigators evaluated the survey responses of 36 recently bereaved surrogates of patients with PAH. Surveys were distributed from 2009 to 2011. In addition to providing information on their loved one’s diagnosis and care, respondents were asked to rate the intensity of the patient’s symptoms during the last days of life, using the Edmonton Symptom Assessment Scale (ESAS), which ranges from 0 to 10, with 10 indicating the highest intensity.

Despite the small size of their study population, the authors write, “we believe that our available results provide unique and important information about the end of life in patients with PAH and will inform further studies and pilot efforts.”

KEY FINDINGS

- Most PAH patient deaths (90%) were related to the disease.
- The majority of patients (67%) died in the hospital.

- Of those who died while hospitalized, 83% died in intensive care.
- Only 11% of patients had a palliative care physician involved in their care.
- 58% of patients were on prostacyclin therapy.
- 27% of surrogates had little or no knowledge of palliative care resources available to them; 19% had little or no knowledge of available hospice resources; and 58% had little or no knowledge of support group resources.
- Patients died with a high symptom burden, particularly with dyspnea (mean ESAS score, 8.5).

When mean scores from the ESAS symptom domains for patients with PAH were compared with those from a previous study of patients with cancer near the end of life, ratings for dyspnea, anxiety, and depression were found to be extremely high. Although the authors advise approaching such direct comparisons with caution, they note the implications for understanding the symptom burden among PAH patients.

“Despite advances leading to the approval of many medications now used to treat PAH, it remains a deadly disease, with a 48% five-year survival,” write the authors. “Therapy is extremely expensive, and existing treatments may involve complicated delivery systems which require specialized training to administer.” An example of this would be long-term prostacyclin therapy, which costs more than \$100,000 per year.

“A major finding of our study is that two-thirds of patients died in the hospital setting, and the vast majority of deaths were related to PAH. Of patients who died in the hospital, 83% died in an intensive care unit.” This is in stark contrast to findings regarding preference for place

of death among patients with other life-limiting illnesses, most of whom wish to die at home, note the authors.

A possible reason for the high rate of in-hospital mortality among PAH patients might be the finding that many patients have excessive dyspnea, which families may feel is difficult to manage at home, the authors suggest. Further, many hospitals restrict the use of continuous prostacyclin therapy to the intensive care unit, where its use can be monitored by staff proficient in the therapy. Thus, death would be more likely to occur in intensive care.

Additional obstacles to hospice care for PAH patients may include:

- Inaccurate patient and physician perceptions of prognosis
- A lack of palliative care resources
- Difficulty determining near-term prognosis

Despite these difficulties, observe the authors, “patients with PAH have a serious, life-limiting, life-threatening illness with high symptom burden and appear to be ideal candidates for palliative care.”

The authors conclude that further study is warranted. “A prospective intervention involving the early utilization of palliative care, and identifying barriers to hospice resources, may lead to improved patient satisfaction with medical care and lower symptom burden.”

Source: “The End-of-Life Experience for a Cohort of Patients with Pulmonary Arterial Hypertension,” Journal of Palliative Medicine; October 2012; 15(10):1065-1070. Grinnan DC, Swetz KM, Pinson J, Fairman P, Lyckholm LJ, Smith T; Division of Pulmonary and Critical Care Medicine, Virginia Commonwealth University, Richmond; Palliative Medicine Program, Mayo Clinic, Rochester, Minnesota; VCU Massey Cancer Center, Medicine and Ethics, Richmond, Virginia; and Johns Hopkins Medical Institutions, Sidney Kimmel Comprehensive Cancer Center, Baltimore, Maryland.

End-of-Life Preferences among Heart Failure Patients Vary Widely, Must Be Individually Elicited for Improved Patient Care

The increasing awareness of the need for high-quality palliative care for patients with advanced heart failure is countered by the small amount of evidence in the literature regarding the type of care these patients desire, according to a team of researchers whose structured narrative review of patient preferences was published in the *American Heart Journal*.

“A critical message from this review is that patient preferences are not easy to predict and must be actively elicited in various forms (e.g., location of care/death, resuscitation, and implantable cardioverter defibrillator [ICD] deactivation), but we need to understand their limitations,” write the authors. “The meta-message is that intervention must be matched to patient goals of care and needs — personalization is critical.”

The researchers conducted a systematic review of available literature on the palliative and end-of-life care wishes of patients with advanced heart failure. The publication dates of these original research studies ranged from the earliest reports from SUPPORT (Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment) in 1995 to several 2011 studies.

“Although the SUPPORT study is old, being conducted in the early 1990s, these data still provide the most comprehensive summary of advance care planning (ACP) maneuvers in the advanced heart failure setting,” point out the authors. They note that the more recent studies shed very little light on patient preferences for heart failure device therapies.

KEY FINDINGS

- Most heart failure patients had not discussed advance care planning with their physicians, or indicated their preferences for limiting ICD use near the end of life.
- While a substantial minority of patients strongly preferred improved quality of life to longer survival, individual preferences were not easy to predict.
- A majority of patients preferred a “sudden” death at home. In light of the expanding use of ICDs — whose purpose is to prevent sudden death — the informed management of these devices is critical, note the authors.

“Given the dearth of evidence regarding patient preferences for specific heart failure therapies, we believe that there may be an increasing gap between availability of life-sustaining interventions versus our knowledge of their actual acceptability to patients,” comment the authors. The authors also observed “large gaps” in patient understanding of ICD risks and benefits

when approaching the end of life.

Previous research suggests that clinicians may need to engage in proactive counseling and patient education to ensure completion of advance directives by their heart failure patients, note the authors. “However, there is not a consensus recommendation on how to coordinate advance care planning between heart failure providers, palliative care specialists, and the patients’ other providers,” they observe.

PATIENT PERSPECTIVE ON PROVISION OF CARE

In a review of care provision conducted in 2011, heart failure patients reported:

- Poor communication between different health settings
- Inadequate professional support
- Lack of privacy and dignity in care
- Absence of a palliative care discussion with their physician

PALLIATIVE CARE EDUCATION RECOMMENDED FOR CARDIOVASCULAR CLINICIANS

“One need is clear: If we are to expand the scope of heart failure care to include end-of-life care, then the cardiovascular workforce will require enhanced skills in palliative medicine,” the authors state.

They recommend that a palliative care curriculum be added to requirements for certification by the American Board of Internal Medicine in the new subspecialty of Advanced Heart Failure and Transplant Cardiology. “New heart failure specialists would benefit from formal training in advanced symptom management, communication skills, care settings and resources, and ethics/legal decision making.”

Recommendations for future research include future trials of heart failure drugs and devices that address end-of-life care issues by incorporating patient preferences as end points. Also needed are clinical prediction models that are integrated with individual patient data, “to improve understanding of a person’s likely illness trajectory, communication, and personalized health care planning in line with goals of care.”

Source: “Preferences of People with Advanced Heart Failure — A Structured Narrative Literature Review to Inform Decision Making in the Palliative Care Setting,” American Heart Journal; September 2012; 164(3):313-319.e5. Dev S, Abernethy AP, Rogers JG, O’Connor CM; Phoenix Veterans Administration Health Care System, Phoenix, Arizona; and Duke Clinical Institute, Duke Cancer Institute, and Duke Clinical Research Institute, Duke University School of Medicine, Durham, North Carolina.

CLINICIAN RESOURCES

Telling the Truth with Empathy: Physicians Offered Approach to Difficult Prognosis Discussions

Many physicians have not received the training in communication skills needed to feel comfortable delivering bad news the way they've been trained to perform a difficult medical procedure. As a result, instead of facing the truth together with the patient, physicians might offer reassurance and false hope. Yet, "although patients want hope, they also want candor," states the author of an article published in the *Journal of Clinical Oncology*.

"The fear that candor is incompatible with hope is unfounded, but telling a patient the truth in a way that is caring and not brutal requires skill," writes medical oncologist Timothy Gilligan, MD, Department of Solid Tumor Oncology, Cleveland Clinic, Cleveland, OH.

"The urge to reassure can get us into trouble. It is a major impediment to caring for our patients empathically, although it seems like such a caring and benign impulse."

Gilligan offers the following advice, learned through his training by the American Academy of Communication in Healthcare:

- Don't reassure; empathize.
- Explore the patient's experience.
- Listen more, talk less.
- Acknowledge the patient's emotions and provide support.
- Stay with the patient's emotions until the strong feelings subside.
- When the news is bad, "find a way to let patients know that you understand that their illness is terrible for them."

Possible reasons for a physician's impulse to reassure a patient in distress include:

- It is difficult to watch someone facing a bad outcome and becoming upset. "In oncology, our bad outcomes are profoundly bad," observes Gilligan. It

is easier to offer the patient false hope or to change the subject.

- Physicians want people to feel better, and would prefer not to feel uncomfortable themselves. "As physicians, our gut instinct and our medical training often instruct us to fix whatever problems we encounter, and this gets us into trouble when the problem cannot be fixed."
- Sometimes patients will collude with their physicians to stay upbeat. "Can we learn to be with them in their crisis and support them without providing false hope or making promises we cannot keep?"

Suggested Responses to Difficult Patient Questions about Prognosis

"Am I going to be okay?"

The physician can:

- Explore the patient's concerns more specifically. "Can you tell me what you mean by okay? What are you most worried about?"
- Explore the underlying emotion. "This must be scary for you."
- Offer supportive or partnering statements. "I know that this is a terribly difficult situation, and I want you to know that I'm going to be here for you every step of the way."

"Can I still be cured?"

The physician can:

- Make "I wish" statements. "I wish I had a cure for your cancer."
- Explore with new patients what others have told them about prognosis and treatment. "Can you tell me what your other physicians have told you about that?"
- Acknowledge the underlying emotion. "It must be frightening to have to ask that question."

"Isn't there something else we can try?"

The physician can:

- Acknowledge the underlying emotion. "I know how badly you want to keep fighting the cancer. It's hard to think about what happens when we run out of treatments for it."
- Acknowledge how much the patient has done to fight the cancer. "I appreciate what a tough fighter you've been and how much you've been willing to go through."
- Clarify the goals of treatment. "There are always more drugs we can give you. However, it's important to ask whether they will help you or just make you feel sicker."

— Adapted from Gilligan, *Journal of Clinical Oncology*

The physician's urge to solve problems and "fix" the patient can sometimes mislead oncologists into giving third-, fourth-, and fifth-line chemotherapy to patients with advanced illness, rather than facing reality themselves. "Perhaps, if we had more candid conversations, we would not have so many patients receiving chemotherapy when they have only days or a few weeks to live, and we would not have so many hospice referrals delayed until a few days before death."

Source: "If I Paint a Rosy Picture, Will You Promise Not to Cry?" *Journal of Clinical Oncology*; September 20, 2012; 30(27):3421-3422. Gilligan T; Department of Solid Tumor Oncology, Taussig Cancer Institute, Cleveland Clinic, Cleveland, Ohio.

CLINICIAN RESOURCES

FREE END-OF-LIFE CARE PLANNING TOOL

The Conversation Project

The Conversation Project, a public engagement campaign whose stated goal is “to have every person’s end-of-life wishes expressed and respected,” encourages Americans to begin end-of-life conversations now, “around the kitchen table,” rather than in medical offices, emergency departments, or intensive care units. The project’s website, which debuted in August 2012, offers tools and resources for preparing to talk about end-of-life values and preferences, along with a forum for sharing stories and experiences online.

Key to opening the conversation is the starter kit, a free, downloadable booklet, which guides users through the process of considering what is important to them and how they might want to discuss these issues with their loved ones — and then later, with their physicians.

The booklet cites survey results released in February 2012 by the California Healthcare Foundation (CHCF) showing that although 80% of people report that if they were diagnosed with a serious illness they would want to discuss their end-of-life wishes with their physician, only 7% of all adults and 13% of those over the age of 65 years have ever been asked to do so.

Physicians are encouraged to direct their patients to the project’s website at theconversationproject.org.

The CHCF survey report, “Final Chapter: Californians’ Attitudes and Experiences with Death and Dying,” is available at www.chcf.org/publications/2012/02/final-chapter-death-dying.

HEALTH CARE ORGANIZATIONS COMMIT TO BEING ‘CONVERSATION READY’

Recognizing that most Americans are unhappy with the way their loved ones are dying and are apprehensive about the circumstances of their own deaths within the current health care system, the Institute for Healthcare Improvement (IHI) — which collaborated in the development of The Conversation Project — has announced the launch of a companion initiative.

Nearly a dozen health system organizations, advised by prominent experts in end-of-life care, have committed to being “conversation ready;” that is, being prepared to hear, record, and follow up on the end-of-life care wishes and instructions their patients will be communicating after participating in The Conversation Project.

“Like many important issues in health care targeted for improvement, end-of-life care has often suffered from good intentions without enough good systems in place to change behaviors, attitudes, and practices,” says Maureen Bisognano, BSN, MSN, president and CEO of IHI.

“When families and loved ones have discussed their wishes and preferences ahead of time, they can engage with the medical community differently. Doctors and nurses, in turn, have the opportunity to act in a supportive fashion, using their clinical knowledge to help patients experience a ‘good death’ as opposed to the ‘hard death’ that so many people fear and have witnessed.”

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

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

www.epec.net

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

www.nhpco.org

National Hospice & Palliative Care Organization

www.caringinfo.org

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

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.hospicenet.org

Resources for patients and families

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/palliativecare.htm

Medical College of Wisconsin Palliative Care Center

www.painpolicy.wisc.edu

University of Wisconsin Pain and Policy Studies Group

www.capc.org

Center to Advance Palliative Care

www.stoppain.org

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