

Quality of Life Matters®

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

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Improving Care, Cutting Costs: Oncologists Encouraged to Change Their Treatment Choices for Seriously Ill Patients

Specialists in oncology can contribute greatly to the effort to reduce the nation's health care costs and improve care for patients with advanced disease by reconsidering their use of commonly ordered diagnostic tests or treatments of little proven benefit, and by expanding their focus on palliative and hospice care, according to two Virginia oncologists.

"The first step is a frank acknowledgment that changes are needed," write the authors of an article published in The

New England Journal of Medicine. "Oncologists need to recognize that the costs of care are driven by what we do and what we do not do."

They suggest that oncologists not only re-examine their routine use of expensive tests, chemotherapy, and supportive drugs, but that they also consider the effect on quality of care by not initiating advance care planning discussions with patients and their families.

"We also drive up costs and provide poorer care as a result of what we fail to do: engage in discussions about the possibility of death, end-of-life choices, and ways patients make the transition to the prospect of dying," they write. "The importance of this discussion is now evident: people who have these conversations experience less depression or anxiety, receive less aggressive end-of-life care, and rarely die in an intensive care unit or on a ventilator."

RECOMMENDED CHANGES IN ONCOLOGISTS' BEHAVIOR

1. Use surveillance testing or imaging only in situations for which proven benefit has been shown.

Support: There is no benefit to surveillance testing with imaging or serum tumor markers for most cancers, despite their routine use in many practices, according to guidelines from both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN).

Exception: Colon cancer

Benefits: Besides lowering medical costs, "switching to a new norm of less testing and better survivorship counseling could reduce patient anxiety."

2. Limit treatment to sequential monotherapies.

Support: "[T]here is no compelling evidence that combination regimens are superior to sequential single agents." Research has found that as a first-line treatment, combination therapy has a small advantage over single agents, but causes more toxicity. ASCO and NCCN guidelines concur.

Exceptions: Lymphoma and second-line treatment in colon cancer

Benefits: "Patients will live just as long but will avoid toxic effects." Fewer hospitalizations due to toxicity and less use of chemotherapy and supportive drugs will cut health care costs.

3. Limit chemotherapy to patients with good performance status.

"We suggest a simple rule: patients must be well enough to walk unaided into the clinic to receive chemotherapy."

Support: Performance status has been consistently shown to be a major independent predictor of treatment response and survival in many types of cancer.

Exceptions: Highly responsive disease, or existence of functional limitations due to other conditions

Benefit: "Implementation of such a simple

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Physicians Urged to Honor Patient Autonomy and Assist Seriously Ill Patients by Taking Greater Responsibility for Medical Decisions

More than 20 years after the patient's right to self-determination was legally established in the courts and by the U.S. Congress, patient autonomy could be undermined rather than honored by some physicians' increasing hesitation to offer medical recommendations, argue two Boston specialists in hospice and palliative medicine.

"[W]e contend that excessive or reflexive deference to patient autonomy in recent decades has sometimes compromised this very principle, shifting too much of the terrible burden of life-or-death choices onto patients and families," write the authors of an article published in the *Archives of Internal Medicine*.

The authors encourage physicians to take much greater responsibility for technical medical decisions for their seriously ill patients, and suggest an approach to decision-making discussions that would simultaneously promote patient autonomy.

APPROACH TO RESPECTING PATIENT AUTONOMY WHILE TAKING PROFESSIONAL RESPONSIBILITY

- Ascertain the patient's desire for information.
 - Elicit the patient's values, goals, and beliefs. "Values can change, so values discussions should be revisited intermittently, especially when the patient's condition changes significantly," advise the authors.
 - Determine the quality-of-life and functional outcomes that would be acceptable to the patient.
 - Recommend a treatment plan based on this knowledge, explaining the possible benefits and burdens of treatment in a way the patient can comprehend.
- "The patient is the expert on his or her

"A fundamental patient-physician covenant is breached when clinicians do not use the very knowledge and experience for which patients consulted them."

— Billings and Krakauer,
Archives of Internal Medicine

values, goals, and preferences, while the physician is the expert on the medical means for honoring the patient's perspective," they write. "Simply asking patients whether they want a life-sustaining treatment such as cardiopulmonary resuscitation or mechanical ventilation deprives them of the expert personalized advice they need to achieve the best possible outcomes and to minimize the risk of bad outcomes — such as an unacceptably poor quality of life — as defined by their own criteria."

When discussing care with surrogates, how questions regarding life-sustaining treatment for patients unlikely to survive are posed can elicit strong emotions and generate misunderstanding, caution the authors. The clinician may ask, "If her heart stops, shall we try to bring her back?" The surrogate hears, "Do you want her to live?" and may opt for treatment of little benefit or of possible harm to the patient.

PHYSICIAN-PATIENT DIALOGUE: THE ART OF MEDICINE

"This is an effective approach to communication and medical decision making that should be taught to all physician trainees," declare a pair of New York City specialists in hospice and palliative medicine, in their commentary accompanying the article.

The pair identify several factors that led

to the development of the principle of patient autonomy in the United States. These factors include:

- Increased publicity regarding patient safety in medical research
- A public better educated regarding medical matters
- The "transition of medicine from an art to a contractual marketplace enterprise"
- Erosion of trust between patient and physician
- The deployment of ever more sophisticated therapies "that may or may not prolong life or improve its quality"

"Given the array of treatments now available for advanced and chronic illness," they write, "it has become nearly impossible for a patient or a patient's surrogate decision maker to fully anticipate or comprehend the intricacies, burdens, and benefits of all available options.

"It is therefore the responsibility of the clinician, who possesses an understanding of these intricacies, to guide and facilitate medical decisions so that treatments provided are matched as well as possible to the patient's values and goals for medical care.

"These dialogues between physician and patient are at the heart of the art of medicine — bringing the wonders and complexities of modern medical science to bear on the fellow human being in front of us," they conclude.

Source: "On Patient Autonomy and Physician Responsibility in End-of-Life Care," *Archives of Internal Medicine*; May 9, 2011; 171(9):849-853. Billings JA, Krakauer EL; *Palliative Care Service and Optimum Care Committee, Massachusetts General Hospital, Harvard Medical School Center for Palliative Care*; and *Department of Global Health and Social Medicine, Harvard Medical School, Boston*. "A Swinging Pendulum," *ibid.*, p. 854. Goldberg GR, Meier DE; *Hertzberg Palliative Care Institute, Mount Sinai School of Medicine, New York City*.

Elderly Americans Spend Fewer of Their Final Days in the Hospital, But Intensity of Care Has Increased for Those Admitted in Last Six Months of Life

According to an April 2011 report from the Dartmouth Atlas Project, Medicare patients diagnosed with severe chronic illness were less likely to die in a hospital and more likely to receive hospice care in 2007 than in 2003, yet hospitalized elders received many more physician visits in the last months of life and spent more time in intensive care units (ICUs).

"In addition to its effects on patients' quality of life, unnecessarily aggressive care carries a high financial cost," says lead author David C. Goodman, MD, MS, director of the Center for Health Policy Research, Dartmouth Institute for Health

Policy and Clinical Practice. "It may be possible to reduce spending, while also improving the quality of care, by ensuring that patient preferences are more closely followed."

The report documents national trends in the medical care provided to seriously ill Medicare beneficiaries nearing the end of life, and traces geographic variations in the intensity of that care.

HOSPICE USE

- The average number of hospice days in the last six months of life increased substantially (from 12.4 days to 18.3 days),

with only a few regions exhibiting a decrease in hospice use.

- However, regional use of hospice varied by a factor of six, ranging from 39.5 hospice days per patient in Ogden, UT, to 7.3 days and 6.1 days in Elmira, NY, and Manhattan, respectively.

HOSPITALIZATION

- Hospital deaths among chronically ill patients dropped nationally from 32.2% to 28.1%. The highest rates of in-hospital deaths were found in New York

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threshold could dramatically decrease the use of chemotherapy at the end of life."

4. Replace the use of white-cell-stimulating factors, known as colony-stimulating factors (CSFs), with a reduction in chemotherapy dose.

Support: "To our knowledge, no randomized trial-based evidence for any of the four most common cancers — metastatic, hormone-refractory breast or prostate cancer, non-small-cell lung cancer, and colon cancer — has shown that CSF-supported therapies improve overall cancer survival or quality of life."

Exceptions: Induction therapy in leukemia and intense therapy for lymphoma

Benefit: CSFs are among the most expensive drugs used in oncology. Curbing their misuse as support in low-risk combination therapies would yield tremendous savings.

5. Routinely switch patients to nonchemotherapy palliative care when there is no response after three consecutive regimens. "This should not be seen as a 'three strikes and you're out' program but rather as a switch to a different team."

Support: A 2011 ASCO policy statement recommends discon-

tinuing chemotherapy when the chance of success is minimal.

Exception: Participation in a clinical trial or within a prospective registry

Benefit: Delivery of hospice and palliative care has been shown to improve quality of life, with equal or longer survival and with high ratings of patient and family satisfaction.

The authors acknowledge the challenges and financial obstacles oncologists face in implementing these changes. Anti-cancer drugs are second in sales only to drugs for heart disease in the United States, and much of the revenue of an oncology practice can come from the sale of chemotherapy agents and CSFs. Their article includes suggestions for policy changes, including ways oncologists can be compensated for cognitive care and support services.

"A system in which over half the profits in oncology are from drug sales is unsustainable," they assert, and call for a national, "politically independent agency for guidance in making tough choices in the public interest, so that doctors do not have to make them at the bedside."

Source: "Bending the Cost Curve in Cancer Care," *The New England Journal of Medicine*; May 26, 2011; 364(21):2060-2065. Smith TJ, Hillner BE; Division of Hematology-Oncology and Palliative Care, Division of General Internal Medicine, and the Massey Cancer Center, Virginia Commonwealth University, Richmond.

Promoting High-Quality Palliative Care among Nursing Home Residents with Dementia May Decrease Burdensome Interventions of Little Benefit

While most older Americans with advanced cancer or other terminal conditions die at home or in the hospital, with palliative care available and eligible for payment by Medicare, 70% of persons with advanced dementia die in nursing homes, where palliative care for this population is not well reimbursed, and quality of care is often suboptimal, according to the authors of a study published in the Archives of Internal Medicine.

"Nursing home residents with advanced dementia commonly experience burdensome and costly interventions (e.g., tube feeding) that may be of limited clinical benefit," write the authors. "Strategies that promote palliation in advanced dementia may shift expenditures away from these aggressive treatments in advanced dementia toward a more comfort care approach (e.g., hospice)."

Investigators analyzed data on 323 nursing home residents (mean age, 85.3 years; female, 85.5%; white race, 89.5%) with advanced dementia living in 22 facilities in the greater Boston area. Patient assessments were conducted at baseline and quarterly for up to 18 months, and health care proxies (mean age, 59.9 years) were interviewed at the same intervals, with a follow-up interview within 14 days of death.

KEY FINDINGS

- The largest proportion of expenditures were for hospitalization (30.2%) and hospice care (45.6%), with care in a skilled nursing facility (SNF) after hospitalization accounting for 11.3% of spending.
- Total mean Medicare expenditures were \$2303 per 90 days over an 18-month period, but were highly skewed; spending was less than \$500 in 77.1% of 90-day assessments and

Modifiable Factors

Modifiable factors associated with reduced costs and improved care in nursing home residents with advanced dementia include:

- Advance care planning, or, at the very least, the presence of a do-not-hospitalize order
- Absence of a feeding tube
- Residence in a special care dementia unit

— Goldfeld et al,
Archives of Internal Medicine

more than \$12,000 in 5.5%.

"Roughly one-third of all Medicare expenditures were for hospitalizations," point out the authors, adding that "most hospitalizations in this cohort were for conditions that were potentially treatable with the same efficacy and at reduced costs in the nursing home compared with the hospital setting (e.g., pneumonia, 68%)." Additionally, more than half of residents with a qualifying hospitalization were transferred to an SNF post-discharge.

Factors independently associated with higher expenditures for acute and subacute care included:

- Acute illness in the previous 90 days (odds ratio [OR], 3.95; 95% confidence interval [CI], 2.91-5.37)
- Lack of a do-not-hospitalize (DNH) order (OR, 2.68; CI, 1.96-3.67)
- The presence of a feeding tube (OR, 2.31; CI, 1.08-4.92)
- Chronic obstructive lung disease (OR, 1.94; CI, 1.14-3.30)
- Not living in a special care dementia unit (OR, 1.43; CI, 1.03-1.97)
- Greater cognitive impairment (OR, 1.37; CI, 1.00-1.88)

"The strong association between the lack of a DNH order and higher acute care expenditures supports the notion that advance care planning may be a key step toward preventing aggressive end-of-life care while reducing costs," comment the authors. "Tube feeding, a potentially burdensome intervention with no demonstrable benefits in advanced dementia, was also independently associated with higher nonhospice expenditures."

Medicare does not pay for nursing home care; that cost is generally covered by Medicaid, after patients' individual resources have been exhausted. However, Medicaid does not reimburse as highly for nursing home care as Medicare does for acute and subacute care (such as post-hospitalization transfer to an SNF). Thus, there may currently be a strong financial incentive for nursing homes to use the potentially avoidable services of hospitals and SNFs, note the authors. They suggest efforts at better understanding and addressing fiscal incentives that drive care.

Medicare does, however, pay for hospice care, which should be an incentive for greater use by nursing homes of this service of proven benefit to terminally ill patients. "Dementia is a terminal illness, yet prior work suggests that persons dying with this disease receive suboptimal end-of-life care," state the authors, noting that only 22% of their cohort were enrolled in hospice.

Source: "Medicare Expenditures among Nursing Home Residents with Advanced Dementia," Archives of Internal Medicine; 171(9):824-830. Goldfeld KS, Stevenson DG, Hamel MB, Mitchell SL; Department of Biostatistics, Mailman School of Public Health, Columbia University, New York City; Department of Health Care Policy, Harvard Medical School, Department of Medicine, Beth Israel Deaconess Medical Center, and Hebrew SeniorLife Institute for Aging Research, Boston, Massachusetts.

Palliative Care Consultations Found Effective in Improving Care at the End of Life, with Palliative Care Units Found Even More Effective

Family members of hospitalized patients who received a palliative care (PC) consultation are more likely to rate their loved one's care in the last month of life as "excellent" compared with families of patients who received usual care (51% vs 46%). Further, families whose loved ones were cared for in a dedicated PC unit are even more likely to report excellent care, when compared with those whose loved ones received PC consultations (63% vs 53%).

A national survey of bereaved families of patients (n = 5901) who died between July 2008 and December 2009 at one of 77 Veterans Affairs medical centers providing both PC delivery models also found that PC units scored higher than PC consultations in three of four process measures (a do-not-resuscitate order at the time of death, chaplain support, and bereavement contact).

"The fourth, goal discussions, occurred at such a high rate among patients who received palliative care consultations that further improvement would be difficult to achieve," the authors write in their report published in the Archives of Internal Medicine.

IMPLEMENTING THE BEST COMPONENTS OF PALLIATIVE CARE MODELS

"This study provides evidence that either of these two palliative care models can play a key role in improving the care of patients who die in hospitals and nursing homes," write the authors of a commentary accompanying the report. "The question for those planning a hospital palliative care program may not be whether to choose a dedicated unit or consultative

services, but rather how to implement the best components of each."

The advantages of dedicated PC units include: A care setting designed for the needs of seriously ill patients; the presence of skilled interdisciplinary PC staff; and direct control over the implementation of clinical recommendations.

The advantages of PC consultation teams include: Lower intensity of resource use; potential to deliver care to many more patients and families; and a wider audience in which to promote the importance of the PC approach.

Source: "The Optimal Delivery of Palliative Care," Archives of Internal Medicine; 171(7):649-655. Casarett D, et al; School of Medicine, University of Pennsylvania, Philadelphia. "Identifying the Effective Components of Palliative Care," ibid., pp. 655-656. Chai E, Meier DE; Mount Sinai School of Medicine, New York City.

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City and surrounding areas (45.8% to 39.9%); the lowest, in regions of North Dakota (12.0%), Florida (19.0%), and Oregon (19.6%).

- The national rate of hospital days per patient in the last six months of life dropped slightly, from 11.3 to 10.9, with patients in Manhattan spending four times as many days in hospital than those in Ogden, UT (20.6 days vs 5.2 days).

INTENSITY OF CARE

- Physician labor used per patient jumped significantly, with 36.1% vs 30.8% of hospitalized patients receiving visits from

10 or more physicians in the last six months of life in 2007 than in 2003.

- Days spent in an ICU in the last six months of life increased slightly overall, from 3.5 days to 3.8 days. But patients' experiences varied widely by region, from an average of 10.7 days in Miami, FL, to 0.7 days in Minot, ND.

"Throughout this period, the constant was the importance of geography," write the authors. "The care patients received in the months before they died depended largely on where they lived and received their care."

The authors conclude, "Patients can look to these data to get a sense of where care

is likely to be more or less aggressive. Providers can look to these data for insights into the likely magnitude of savings they can achieve through improved care of chronic illness that allows patients to remain safely out of the hospital.

"Finally, policymakers can look to these data to identify regions that may have promising approaches — and those that may benefit from more support in improving the care of patients with serious chronic illness."

The report, entitled "Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness," is available at www.dartmouthatlas.org.

CLINICIAN RESOURCES

Addressing a Patient or Surrogate's Belief in Miracles: A Respect-Based Approach to Clinical Decision Making

How does a clinician respond when a patient or surrogate wishes to continue life-sustaining measures the physician has deemed futile, and states that the decision is based on a belief in miracles? Encouraging patients and family members to voice their spiritual beliefs, and respecting what they say is the approach suggested by a team conducting a literature review on what can be a complex clinical problem.

"Belief in miracles is found to be common in the United States and is an important determinant of how decisions are made for those with advanced illness," write authors of a report published in the *Journal of Pain and Symptom Management*. "There is a growing amount of evidence that suggests end-of-life outcomes improve with the provision of spiritual support from medical teams, as well as with a proactive approach to medical decision making that values statements given by patients and family members."

To guide an empirical approach to this clinical problem, the team separated it into a series of focused clinical questions.

PREVALENCE OF BELIEF IN MIRACLES

In a 2010 survey of the general U.S. population, 35,556 respondents were asked whether "miracles still occur today as in ancient times." With little variation by age group, 79% agreed that yes, miracles do occur. In one of the few surveys on the topic in the medical literature, 61% of public respondents said they believed that a person in a persistent vegetative state could be saved by a miracle, as compared with 20.2% of trauma professionals who believed this.

"The question for the clinician isn't really whether miracles happen, but rather what they mean to patients and families, and how we can support patients and families with their meaning," com-

ments lead author Eric W. Widera, MD, assistant clinical professor in the Division of Geriatrics, Department of Medicine, University of California, San Francisco.

WHAT PATIENTS/FAMILIES MEAN BY 'HOPING FOR A MIRACLE'

Several review articles have suggested that by saying they hope for a miracle in a medical context, people may be expressing different things: a belief in divine intervention; hope for unexpected recovery; denial of impending loss; or anger, frustration, or disappointment regarding aspects of medical care.

IMPACT OF BELIEF IN MIRACLES ON MEDICAL DECISION MAKING

Little research was found examining how believing in miracles might influence end-of-life preferences or medical decision making, although a 2009 study revealed that 64% of surrogates were reluctant or unwilling to accept physicians' futility predictions, with one-third of these basing this rejection on religious grounds. These surrogates were found to be four times more likely than others to request continuation of life support in the face of very poor prognoses.

Another study (2010) identified several factors that surrogates use to arrive at their own prognostic estimates. These include: their own knowledge and observation of the patient; their belief in the power of their supportive presence; and their own intuition and faith. Only 2% of surrogates reported basing their view of their loved one's prognosis solely on the physician's estimate.

COMMUNICATION APPROACH

The team found nothing in the medical literature specifically addressing the best approach to discussing end-of-life decisions with patients/surrogates who decline to follow their physician's recommendations because of a belief in miracles. They

VALUE Communication System

1. Value and appreciate what surrogates communicate.
2. Acknowledge their emotions with reflective summary statements.
3. Listen carefully.
4. Understand who the patient is as a person by asking open-ended questions.
5. Elicit questions.

— Widera et al,
Journal of Pain and Symptom Management

did, however, find evidence of the effectiveness of a more general communication approach, known by the mnemonic VALUE. [See sidebar.]

A 2008 study found that, when used proactively in family conferences in an intensive care setting, the VALUE communication system decreased conflicts surrounding decisions to forgo life-sustaining treatments and improved family members' bereavement outcomes. "Although this study does not address a specific question of how to address a family member hoping for a miracle, it does emphasize the importance of a communication framework that values and appreciates what families say," comment the authors.

"[All] of the evidence points to the fact that belief in miracles is not only common among those we care for, but this belief plays a crucial and under-recognized role in medical decision making," Widera concludes.

Source: "Approaching Patients and Family Members Who Hope for a Miracle," *Journal of Pain and Symptom Management*; Epub ahead of print, June 3, 2011. Widera EW, Rosenfeld KE, et al; Department of Veterans Affairs Medical Center, San Francisco, and Division of Geriatrics, University of California, San Francisco; Division of General Internal Medicine, Section of Palliative Care, Veterans Administration Greater Los Angeles Healthcare System, Los Angeles.

CLINICIAN RESOURCES

Online Report Calls for Expansion of Public Awareness, Discussion of End-of-Life Care

www.caringinfo.org

Issues surrounding death and dying — an experience common to all, but not easily discussed in our society — must be openly addressed on a national, local, professional, and personal level, according to a new report released by Caring Connections, the national consumer and community engagement initiative of the National Hospice and Palliative Care Organization (NHPCO).

“Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care,” presents an outline of the progress made in end-of-life care nationwide and a “call to action” for urgently needed expansion of awareness and services through consumer engagement and health care reform.

“In the past 30 years, we’ve made some tremendous advances in medical care, particularly in the care of the dying,” states J. Donald Schumacher, PsyD, NHPCO president and CEO. “Yet, far too many Americans still suffer from unnecessary pain, discomfort, and unaddressed needs at life’s end.”

The 36-page report identifies specific areas in need of improvement and provides a framework for a national agenda for public engagement in end-of-life issues. Recommendations include:

- Individuals should talk about their wishes with family, friends, and health care professionals, then document their values and preferences.
- Health care professionals should initiate timely discussions about the burdens and benefits of treatment options for the final stages of an illness, in a way that is both honest and culturally relevant.
- Health care payors should ensure access to quality palliative care throughout the continuum of a serious illness.
- Policy makers should eliminate barriers to timely palliative and hospice care.
- The media should explore ways to normalize the experience of dying, by demystifying the discussion of death.

RESOURCES AVAILABLE ON CARING CONNECTIONS

In addition to resources for national and community initiatives to promote awareness of end-of-life care, the Caring Connections website offers advice for physicians, as well as information and support for individuals who are living with an illness, planning ahead, caring for a loved one, or grieving a loss. Resources for physicians, patients, and families include:

- Physician brochures offering tips on caring for dying patients and how to talk about treatment options and palliative care
- Links to state-specific advance directives, which can be downloaded and printed
- A search feature for hospices by name, location, and services
- The downloadable document “Legal Guide for the Seriously Ill,” from the American Bar Association and NHPCO
- A link to online services offering private storage of medical information, which can be shared with designated family members and physicians

For more information, visit www.caringinfo.org.

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.nhpc.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.medicaring.org

Palliative Care Policy Center

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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