

Quality of Life Matters®

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

Vol. 16, Issue 3 Nov/Dec/Jan 2014-2015

Caregivers Give High Marks to Hospice Care in National Survey

The hospice experience received consistently high ratings from bereaved family caregivers of Medicare patients, with a mean score of 93.0 out of 100 in all quality measures and across all patient, caregiver, and hospice characteristics, according to the results of a survey conducted for the Centers for Medicare & Medicaid Services (CMS).

The “Hospice Experience of Care Survey” was developed and conducted as a field test for a new national survey slated to join the Consumer Assessment of Healthcare Providers and Systems (CAHPS) family of surveys, which have been funded and maintained by CMS and

the U.S. Agency for Healthcare Research and Quality (AHRQ) for the past 15 years.

“The Centers for Medicare & Medicaid Services has implemented care experience surveys for a variety of settings, but none for hospice care,” notes the federal agency. “These surveys cover topics that are important to consumers and focus on aspects of quality that consumers are best qualified to assess, such as the communication skills of providers and ease of access to health care services.”

Survey respondents were 1136 primary caregivers for 1136 hospice decedents (mean age at death, 79.8 years) cared for by one of 33 hospice programs. Nearly three-quarters (72.6%) of respondents were female, 44.8% were aged 65 years or older, and 5.8% were black. Nearly half (46.6%) of respondents were adult children of the hospice patient; one-third were spouses or partners. Characteristics of decedents were generally similar to the population of Medicare beneficiaries receiving hospice care.

- Providing support for religious and spiritual beliefs, 96.2
- Would recommend hospice, 93.1

DECEDENTS' FINAL SETTING OF WHERE THEY RECEIVED HOSPICE CARE

- The patient's home or an assisted living facility, 34.7%
- Freestanding hospice inpatient unit, 29.7%
- Nursing home, 27.9%
- Acute care hospital, 7.8%

Scores varied somewhat among settings of care. Ratings for “Understanding the side effects of pain medication” had the widest variation, ranging from 89.5 for home hospice care to 71.1 for nursing home care. No differences in satisfaction scores were found for any outcomes in relation to the size of hospice (measured in number of deaths per month).

CMS developed the survey to make information available to beneficiaries and their families as a decision aid in selecting a hospice program, to help hospices with internal quality improvement efforts and external benchmarking, and to provide CMS with information for monitoring the care provided.

National implementation of the new survey — to be known as the CAHPS Hospice Survey — is slated to begin in 2015. The current survey report can be viewed at http://www.hospicecahpsurvey.com/Documents/Hospice_Field_Test_Report_2014.pdf.

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CAREGIVER RATINGS OF HOSPICE EXPERIENCE INCLUDE:

- Overall, 93.0 out of 100
- Treating family member with respect, 95.7
- Information continuity, 94.9
- Getting help for symptoms, 90.2
- Getting timely care, 90.2
- Hospice team communication, 91.2
- Providing emotional support, 91.0

Careful Targeting and Optimal Timing Can Yield Quality Advance Care Planning, Say Experts

Identifying those patients at risk for facing decisions about life-sustaining treatment limitation, and choosing the optimal time in their disease trajectory for the discussion of end-of-life care are two key factors in effective advance care planning (ACP), according to an article published in *JAMA Internal Medicine*.

“Timing is important because the completion of an advance directive too far from or too close to the time of death can lead to end-of-life decisions that do not optimally reflect the patient’s values, goals, and preferences,” write authors J. Andrew Billings, MD, and Rachele Bernacki, MD, of the Harvard Medical School Center of Palliative Care in Boston.

The authors call selecting the timing of ACP discussions the “Goldilocks Phenomenon,” in which the bears’ soup was found to be too hot, too cold, or just right. “Likewise, decisions about limiting life-sustaining treatment can occur too early, too late, or at just the right time.” If too early, patients not likely to need an advance directive in the near future can make “unrealistic hypothetical choices.” If too late, such discussions tend to be rushed through during a medical crisis, when “assessing preferences in the emergency department or hospital in the face of a calamity is notoriously inadequate.”

The major benefit of initiating ACP discussions at the appropriate time is the promotion of agreement between patients’ wishes for end-of-life care and the care that is actually received, note the authors. But there’s an additional benefit: ACP discussions in the clinical setting may open the door to such conversations between patients and their families and with other care teams.

Once the topic of ACP has been introduced, subsequent discussions may

Characteristics of a ‘Just Right’ Advance Care Planning Discussion

- Patients understand their medical condition — their diagnosis, prognosis, and clinical options — and are aware of the trade-offs involved in any choices to undergo or forego potentially life-prolonging therapies.
- Patients’ values, goals, and preferences are elicited and later used to make choices about specific methods of life-sustaining care.
- When appropriate, an involved clinician makes a recommendation, based on the patient’s values, goals, and preferences.
- Decisions are made with adequate time for reflection, discussion with family, and further consultation.
- Decisions are carefully documented, conveyed to the family, and made available to other health care practitioners.
- As the medical situation changes, especially on hospital admission or institutional transfer, choices are revisited.

— Billings and Bernacki, *JAMA Internal Medicine*

become easier, which is desirable, since changes in the patient’s medical situation will call for fresh discussion of the goals of care. “Advance directives need to be refreshed regularly, probably at least annually for patients facing an imminently life-threatening illness, as well as whenever a serious life-threatening medical condition develops or changes significantly.”

THE CHALLENGES OF PROGNOSTICATION

The key to optimal timing of ACP discussion is the patient’s prognosis. “Unfortunately, prognostication is difficult, and empirical data do not offer the precision that clinicians desire,” write Billings and Bernacki. Life expectancy tables have proven to be “surprisingly unhelpful,” and prognostic models tend to be disease specific, whereas many patients with chronic conditions have multiple comorbidities.

Triggers that can help clinicians identify patients who have less than one to two years to live include hospitalization, which “often indicates a major health transition in elderly patients,” and functional status, which is “a consistent predictor of mortality in older adults.”

In targeting patients for ACP discussions, clinicians can be guided by clinical intuition, their general awareness of a patient’s risk of dying soon, and by using the Surprise Question (“Would I be surprised if this patient died in the next year?”).

Prognostic indices can also “lend confidence to clinician judgments about prognosis and provide an objective measure that supports clinical intuition,” write Billings and Bernacki. “Combining clinical estimates with prognostic indices may result in more accurate estimates than either alone.”

Continued on Page 3

Training in Spiritual Support May Help Clinicians Improve Care for Seriously Ill Patients

National care quality standards consider provision of spiritual care (SC) a central dimension of end-of-life care. Though clinicians often wish to support the spiritual needs of their patients with advanced disease, they encounter a number of barriers to its provision, the most prominent of which is lack of training, a team of Boston researchers has found.

“[M]ost terminally ill patients,” along with “nurses and physicians, agree that spiritual support from medical professionals is important, appropriate, and positively beneficial to patients and the patient-clinician relations,” write the authors of a report published in the *Journal of Pain and Symptom Management*, the official journal of the American Academy of Hospice and Palliative Medicine.

“This study highlights the importance of spiritual care training for nurses and physicians as the primary means to complement SC provided by clergy and chaplains, and incorporate SC into the care of patients facing serious illness in accordance with national core quality

standards,” the authors write.

Research has demonstrated the importance of religion/spirituality (R/S) to patients with serious illness, and its influence on their medical care and quality of life, note the authors. Thus, providing SC has “central relevance within palliative care,” highlighting a need for a patient-centered approach “that does not impose R/S views and/or violate professional roles.”

Provision of spiritual support for a seriously ill patient by the medical team has been identified as a core domain by the National Consensus Project for Quality Palliative Care’s 2013 clinical practice guidelines and the World Health Organization, and was highlighted as an end-of-life priority in the 2013 standards manual of the Joint Commission.

IDENTIFYING BARRIERS TO SPIRITUAL CARE

Investigators analyzed the survey responses of oncology physicians (n = 204) and nurses (n = 118) caring for

patients with incurable cancer at one of four Boston academic centers. Questions and definitions used in the survey, which ran from October 2008 through January 2009, were developed by a panel of experts in palliative care. Overall:

- Most clinicians desired to provide spiritual care for their terminally ill patients at least “occasionally” (physicians, 60%; nurses, 74%).
- 40% wished they provided SC more often than they actually do.
- Most clinicians would like to receive SC training (physicians, 51%; nurses, 79%).

Two perceived barriers to providing SC to terminally ill patients cited most often by clinicians were lack of time and lack of privacy, yet neither was associated with actual provision of spiritual care. However, lack of training in SC was. Multivariate analysis revealed that barriers actually associated with the provision of spiritual care differed from those perceived by clinicians.

“Lack of training was the only barrier endorsed by most nurses and physicians and found in multivariate analysis to be associated with less frequent SC provision to patients,” note the authors.

“This study points toward SC training as the critical next step to narrow the gap between national care quality standards and the current infrequent practice of SC at the end of life,” write the authors. “Evidence-based SC training holds promise to advance competency and practice among medical professionals and to improve patient well-being and medical care quality at the end of life.”

Source: “Nurse and Physician Barriers to Spiritual Care Provision at the End of Life,” *Journal of Pain and Symptom Management*; September 2014; 48(3):400-410. Balboni MJ, Sullivan A, et al; Departments of Psychosocial Oncology and Palliative Care, Medical Oncology, and Radiation Oncology, Harvard Medical School, Boston.

Advance Care Planning (from Page 2)

The authors direct clinicians to an online toolbox of evidence-based geriatric prognostic indices incorporating multiple comorbidities. Designed for older adults who do not have a dominant terminal illness, the toolbox is available from ePrognosis at eprognosis.ucsf.edu.

Patients often expect their physician to initiate the ACP discussion, but although “the primary care clinician or specialist who is following patients longitudinally may be in a good position to target many appropriate patients for ACP,” clinicians have generally not been trained to conduct these discussions. Based on their review of the literature, the authors offer an outline of the ideal features of a well-timed or “just right” ACP discussion. [See sidebar, page 2.]

Source: “Strategic Targeting of Advance Care Planning Interventions: The Goldilocks Phenomenon,” *JAMA Internal Medicine*; April 2014; 174(4):620-624. Billings JA and Bernacki R; Cambridge Health Alliance; Massachusetts General Hospital; The Dana Farber Cancer Center; Department of Psychosocial Oncology and Palliative Care; Brigham and Women’s Hospital; Ariadne Labs; and Harvard Medical School Center for Palliative Care, all in Boston.

Many Nursing Home Dementia Patients Receive Medications of ‘Questionable Benefit,’ National Study Finds

According to a report published in *JAMA Internal Medicine*, more than half of nursing home residents with advanced dementia are prescribed medications that are of questionable benefit, potentially burdensome or even harmful, and frequently counter to the goals of care — which typically in this population would be for comfort.

“Lower use of questionably beneficial medications was found among residents with advance directives who were enrolled in the hospice setting,” write the authors. “These findings highlight the importance of careful medication review in residents with advanced dementia, particularly in the context of discussions about the risks and benefits of rehospitalization and the role of do-not-resuscitate (DNR) orders and hospice.”

Investigators analyzed data from a nationwide long-term care pharmacy linked to the Minimum Data Set for 460 facilities across the U.S. from October 2009 through September 2010. Subjects were nursing home residents aged 65 years or older with advanced dementia (n = 5406). Medications previously identified by experts in palliative care as “never appropriate” for use in advanced dementia were considered to be of “questionable benefit” for this study.

Overall, 53.9% of residents with advanced dementia received at least one medication with questionable benefit.

LOWER LIKELIHOOD

Factors linked to lower likelihood of receiving questionably beneficial medications included:

- Hospice enrollment (adjusted odds ratio [AOR], 0.69; 95% confidence interval [CI], 0.58 to 0.82)
- Eating problems (AOR, 0.68; 95% CI, 0.59 to 0.78)
- Presence of a DNR (AOR, 0.65; 95%

CI, 0.57 to 0.75)

- Feeding tube placement (AOR, 0.58; 95% CI, 0.48 to 0.70)

Most frequently prescribed medications of questionable benefit include:

- Cholinesterase inhibitors (36.4%)
- Memantine hydrochloride (25.2%)
- Lipid-lowering agents (22.4%)

The two most commonly prescribed medications of questionable benefit, cholinesterase inhibitors and memantine hydrochloride, are typically prescribed in the earlier stages of dementia. They are considered ineffective in late-stage disease, note the authors, and their continued use places patients at excess risk of adverse drug effects (ADEs).

REASONS TO MINIMIZE PRESCRIPTIONS

- Added burden: Swallowing and eating difficulties make taking and giving medications burdensome for advanced dementia patients and attending staff.
- Health risk: ADEs are common in patients with dementia, yet “ADEs are difficult to detect by clinicians, because these patients have difficulty expressing the symptoms they feel,” the authors point out.
- Life expectancy: This population has frequent clinical complications associated with a high risk of six-month mortality, and “the time-to-benefit from many medications exceeds this life expectancy.”

“While it can be difficult for family decision makers to discontinue medications that treat the chronic diseases of their loved ones as they transition toward comfort care, minimizing questionably beneficial interventions is an important therapeutic option consistent with recommendations by the Institute of Medicine about care quality at the end of life,” state the authors. “As such, it is an important

option for clinicians, families, and patients to consider.

“Nursing home residents with advanced dementia need further efforts on their behalf to address how to reduce the use of unnecessary medications and medications that fail to align with the resident’s goals of care,” the study authors conclude.

‘A TASK FOR ALL CLINICIANS’

“This article should cause all clinicians to reconsider their prescribing practices and other decision making for a broad population of patients late in life,” writes Greg A. Sachs, MD, director of the Division of General Internal Medicine and Geriatrics, Indiana University School of Medicine, Indianapolis, in his commentary accompanying the report.

As one of the team of palliative care experts who created the model on which the study authors based their definition of “questionable benefit,” Sachs urges that, until further research can contribute to prescribing guidelines broader than those currently extant for specific conditions, outcomes should be judged by the patient’s goals of care.

“The more challenging aspect is having conversations with patients or their family members to understand their goals of care,” writes Sachs. “But we ought to begin now to incorporate the conceptual framework and decision-making approach into our daily prescribing practices, as well as tests and treatment ordering.”

*Source: “Use of Medications of Questionable Benefit in Advanced Dementia,” JAMA Internal Medicine; Epub ahead of print, September 8, 2014; DOI: 10.1001/jamainternmed.2014.4103. Tjia J, Briesacher BA, et al; Division of Geriatric Medicine, University of Massachusetts Medical School, Worcester. “Improving Prescribing Practices Late in Life: A Task for All Clinicians, Not Just Nursing Home Physicians,” *ibid.*, DOI: 10.1001/jamainternmed.2014.3277. Sachs GA; Division of General Internal Medicine and Geriatrics, Department of Medicine, Indiana University School of Medicine; Indianapolis.*

Patient Factors Linked to Very Late Hospice Entry

Cancer patients enrolled in hospice within three days of death were more likely than others to have hematologic malignancy, to be married, male, and younger than 65 years, a team of researchers from the University of Pennsylvania has found.

“As efforts to improve palliative and end-of-life care for patients with cancer continue, it will be essential to find ways to optimize transitions to hospice,” write the authors in their report published in the *Journal of Clinical Oncology*. “One measure of the success of these efforts is the timing of referral.”

Approximately one in six patients (16.4%) in the study was admitted to hospice within three days of death. “This is a relatively large proportion, given the benefits of early hospice admissions,” comment the authors. It is, however, consistent with the increasing brevity of hospice stays. In 2012, the median length of service for all hospice patients was just 18.7 days.

“Hospice is associated with less aggressive care at the end of life, improved quality of life for patients, and reduction in grief-related psychiatric illness among caregivers,” point out the authors. Earlier hospice enrollment has been found to provide increased family satisfaction and savings in health care costs.

Investigators analyzed data from electronic hospice medical records on 64,264 patients (male, 50.5%; white, 86.8%; aged ≥ 65 years, 67.0%) enrolled between 2008 and 2013 with a primary diagnosis of cancer. The 12 participating hospices were part of the Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE) network.

Overall, 16.4% had a hospice length of stay of \leq three days, a higher proportion than the 14.3% found among cancer patients in previous studies, the authors note. Further, the proportion enrolled within

“Hospice is associated with less aggressive care at the end of life, improved quality of life for patients, and reduction in grief-related psychiatric illness among caregivers.”

— O'Connor et al,
Journal of Clinical Oncology

three days of death varied considerably among hospices, ranging from 11.4% to 24.5%.

“One unexpected find of this study was the wide variation among participating hospices in the rate of late enrollment,” comment the authors. They suggest the variance could be due to regional differences in the intensity of medical care delivered at the end of life. For instance, lower use of hospice and later referrals have been observed in areas with more teaching hospitals. There may also be differences in referral patterns among individual oncology practices, they suggest.

SHORT HOSPICE STAY

Independent predictors of a short hospice stay include:

- Hematologic malignancies (odds ratio [OR], 1.52; 95% confidence interval [CI], 1.41 to 1.64), ranging from leukemia (OR, 1.82; 95% CI, 1.60 to 2.07) to multiple myeloma (OR, 1.30; 95% CI, 1.11 to 1.54)
- Married (OR, 1.23; 95% CI, 1.17 to 1.29)
- Male sex (OR, 1.22; 95% CI, 1.16 to 1.28)
- Admitted to hospice in a hospital or inpatient hospice unit (OR, 6.22; 95% CI, 5.92 to 6.53)

EARLIER REFERRAL

Predictors of the lower likelihood of

late referral to hospice include:

- Central nervous system malignancies (OR, 0.54; 95% CI, 0.47 to 0.63)
- Oropharyngeal cancer (OR, 0.65; 95% CI, 0.52 to 0.81)
- White race (OR, 0.89; 95% CI, 0.82 to 0.97)
- Aged ≥ 65 years (OR, 0.90; 95% CI, 0.85 to 0.95)
- Medicaid coverage (OR, 0.83; 95% CI, 0.76 to 0.91)
- Self-insured (OR, 0.74; 95% CI, 0.66 to 0.84)

“Among payers, the greatest predictor of short stay was no insurance (19.5%) compared with self-insured (16.8%), Medicare (16.7%), commercial (15.6%), and Medicaid (14.8%),” note the authors. “The greatest predictor of short length of stay was care in a hospital or inpatient hospice (37.1%) compared with care in a nursing home or hospice residence (19.4%) or home (13.5%).”

The authors consider the factors of married status, payer status, and hematologic malignancy to be their “three primary findings” as potentially helpful predictors of very short hospice stays, offering “three new insights into the challenges of late enrollments in hospice for patients with cancer.” They suggest several reasons for these associations.

It is possible that married patients enroll in hospice late because a spouse provides:

- Informal caregiving, including the type of assistance that makes continued medical treatment possible
- The emotional support that motivates patients to continue treatment
- The wish to continue treatment longer for the caring spouse’s sake

Patients with Medicare and self-insurance may enroll earlier because they are:

Continued on Page 6

CLINICIAN RESOURCES

Palliative Doctors: Free Online Resource for Seriously Ill Patients and Their Families

<http://palliativedoctors.org>

The patient website Palliative Doctors aims to help patients with serious illness and their families to understand the role of palliative care and hospice, to decide whether and how it would suit their needs, and to find the care team or program that is right for them.

Developed by the American Academy of Hospice and Palliative Medicine (AAHPM), the site highlights the potential benefits of hospice for those facing the last months of life, and of palliative medicine for “people of any age, and at any stage in illness, whether that illness is curable, chronic, or life threatening.”

As well as the sections on hospice and palliative medicine, there are frequently asked questions, patient stories, and links to other online resources, such as printable brochures from The American Society of Clinical Oncology, the National Institute on Aging, and the Centers for Medicare & Medicaid Services.

The major sections include: Palliative

Care, Hospice Care, The Team Approach, Getting Started, and Patient Stories.

The Getting Started section guides patients to an understanding of their personal goals and wishes so they can make “a plan to live well.” A list of questions that the palliative care team may ask is provided, and an explanation of how they will work with the physician to develop a care plan.

TOPICS INCLUDE:

- Caring for a Loved One
- Medical Treatments
- Talking to Children
- Legal Documents

Regarding when to seek hospice, the site states the following: “Requesting hospice care is a personal decision, but it’s important to understand that at a certain point, doing ‘everything possible’ may no longer be helping. Sometimes the burdens of a treatment outweigh the benefits.

“Unfortunately, most people don’t receive hospice care until the final weeks or

even days of life, possibly missing out on months of helpful care and quality time.”

WHEN HOSPICE CAN HELP

Patients are advised that the following are indications that they may experience better quality of life with hospice care:

- The patient has made several trips to the emergency room, and the condition has been stabilized, but the illness continues to progress.
- The patient has been admitted to the hospital several times within the last year with the same symptoms.
- The patient wishes to remain at home, rather than spend time in the hospital.
- The patient is no longer receiving treatments to cure the disease.

The website advises patients, “Hospice care can help you continue treatments that are maintaining or improving your quality of life. If your illness improves, you can leave hospice care at any time and return if and when you choose to.”

Patient Factors Linked to Very Late Hospice Entry (from Page 5)

- Less able to handle out-of-pocket expenses for prolonged aggressive or experimental treatment
- Less likely to have dedicated stay-at-home caregivers
- Receiving care in practices or facilities that have different hospice utilization patterns

Hematologic malignancy may cause delay of hospice entry because:

- Curative treatments are often pursued for these patients until late in the course of the disease.
- Patients may be dependent on blood products, the use of which can delay

admission to hospice.

- These patients may have a more abrupt decline close to death than patients with other forms of cancer.

Patient characteristics identified in the study could be included in patient-mix adjustment of quality measures, or used to inform outreach and quality improvement efforts, suggest the authors. “Trustworthy quality measures tied to data and adequate case-mix adjustment strategies will be increasingly important for oncologic practice improvement measures.”

The timing of referral is only one measure of the quality of hospice care and

does not include those patients who are never referred or who refuse hospice care, the authors caution. They suggest further research to measure “other patient characteristics beyond an oncologist’s control,” as well as assessment of the timing and quality of goals of care discussions.

Source: “Hospice Admissions for Cancer in the Final Days of Life: Independent Predictors and Implications for Quality Measures,” Journal of Clinical Oncology; Epub ahead of print, August 25, 2014; DOI: 10.1200/JCO.2014.55.8817. O’Connor NR, Hu R, Harris PS, Ache K, Casarett DJ; Perelman School of Medicine, University of Pennsylvania, Philadelphia; Kansas City Hospice and Palliative Care, Kansas City, Missouri; and Suncoast Hospice, Clearwater, Florida.

CLINICIAN RESOURCES

Vital Talk: Free Online Communication Skills Resource for Busy Clinicians

www.vitaltalk.org

Resources aimed at helping all clinicians improve their skills in the difficult but necessary communication of serious news are available free of charge from Vital Talk, a web resource maintained by experts involved in promoting communication skills courses and faculty training for the past 10 years.

“We want to rapidly scale our dissemination because we see communication as the key clinical skill needed for palliative care to take off in the U.S.,” writes Anthony L. Back, MD, professor of medicine at the University of Washington, Seattle, and co-developer of OncoTalk, now renamed Vital Talk.

Back sees the need for all clinicians to hone their communication skills because “we’ll never have enough fellowship-trained physicians to meet the needs for primary and secondary palliative care.” Further, “no single existing institution has the number of faculty that can do this training that we need.” Thus, the site has two resource areas, one for clinicians and one for teachers.

Offered under “Watch, Read, Reflect” is a list of communication topics for clinicians, with links to related published articles, videos, and PowerPoint presentations. Brief videos of actual clinician-patient encounters cover such topics as establishing a rapport, staying strong, and bearing witness to the end.

QUICK GUIDES

One-page, free, downloadable guides offer step-wise approaches — often with mnemonic titles — and “talking maps” to help direct clinicians through difficult conversations. The guides are also available for a small charge as iOS apps (search for “Vital Talk” in the iTunes App Store). Titles include:

- Addressing Transitions/Goals of Care
- Discussing Prognosis
- Responding to Emotion
- Defusing Conflicts
- Talking about Dying: Saying Goodbye to a Patient

“Addressing Goals of Care,” for example, uses the five-step protocol REMAP (**R**eframe, **E**xpect emotion, **M**ap the future, **A**lign with patient values, **P**lan). Extra ET steps include: **E**xpect questions about more treatment; and **T**alk about services that would help before introducing hospice as the best way to provide such services.

Under the site’s “Hotline” tab, a Q & A section invites questions, which are answered by an expert and then posted on the page. For instance, a request for advice on what to do when a patient begins to get upset but the clinician feels pressed for time yielded this response:

“When you see a patient get upset, it’s normal to feel worried that you won’t get everything done that you hoped. The usual impulse is to try to talk faster, so you can try to get it all in. But while that seems efficient, you’re probably wasting time, because your patient isn’t hearing what you say.

“So pause for a moment, acknowledge the upset (for example, ‘I can see you’re worried about this’), and see what the patient says. Invest in a moment of empathy — it often pays off in the patient telling you what she really needs.”

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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