Quality & Life Matters® End-of-life care news & clinical findings for physicians

Vol. 17, Issue 3 Nov/Dec/Jan 2015-2016

Perception of U.S. End-of-Life Care Worsens, Except When Hospice Is Involved

Bereaved family members' ratings of the quality of care received by their loved ones nearing the end of life have declined over the past decade, despite national efforts to improve care of dying patients. Yet when hospice care is received, family members are more than twice as likely as those without hospice to rate the quality of care received as "excellent," according to a report published in the *Journal of Palliative Medicine*.

"We report that if hospice was involved in the care of the dying patient in the last month of life, the respondent was 2.2 times more likely to say the care

Inside:

NewsLine..... 1-3

- ✓ Perception of U.S. End-of-Life Care Worsens, Except When Hospice Is Involved
- ✓ Chemotherapy Use in the Last Months of Life May Be More Harmful Than Palliative, Study Finds

Research Monitor..... 4-6

- ✓ Oncology Fellows Want More Training in End-of-Life Care, Survey Finds
- Heart Failure Patients Discharged from Hospital with Unrelieved Symptoms, No Palliative Care
- Overview of Pediatric Palliative and Hospice Care Finds Both Progress and Challenges

Clinician Resources...... 7

✓ Advance Care Planning: How to Open the Conversation was excellent," write the authors. "Striking changes in health care have occurred in the past decade. Although there were improvements, our report found that respondents rated the quality of end-of-life care lower overall."

Investigators compared the results of two national surveys on the quality of end-of-life care received by community-dwelling decedents (aged \geq 65 years) during two time periods. Interviews were conducted with bereaved family members or close friends whose loved ones had died in 2000 (n = 622, representing 794,341 deaths) and in 2011–2013 (n = 586, representing 2,257,759 deaths).

Part of the 2000 survey included indepth, qualitative interviews with 111 of the participants. Questions from this survey were incorporated into the National Health and Aging Trend Study (NHATS), which was used for the 2011–2013 arm of the study. In a separate round of NHATS, respondents were asked whether hospice care was involved in the last month of their loved ones' care.

FINDINGS

- The overall rating of quality as excellent decreased over time (from 56.7% in 2000 to 47.0% in 2011–2013; adjusted odds ratio [AOR], 0.70; 95% confidence interval [CI], 0.52 to 0.95).
- A higher proportion of respondents reported unmet needs for pain management in 2011–2013 than in 2000

- (25.2% vs 15.5%; AOR, 1.9; 95% CI, 1.1 to 3.3).
- The reported rates of unmet needs for palliation of dyspnea and anxiety/depression changed little during the time period; these rates remained high.
- The percentage of those reporting that their loved one was not always treated with respect increased from 12.7% in 2000 to 15.2% in 2011–2013.
- Ratings for addressing spiritual needs did improve over time; respondents in the later period were less likely to report that spiritual and religious issues were ignored (58.3% not addressed vs 72.4%; AOR, 1.4; 95% CI, 1.1 to 1.9).
- 60.9% stated care was excellent when hospice was involved, compared with 46.7% who rated care as excellent without hospice (AOR 2.2, 95% CI, 1.3 to 4.0).

"Our research question is not whether hospice or palliative care services improve the quality of care for individual patients and families," explain the authors. "Rather, our research examines changes from a population perspective on how the United States is experiencing end-of-life care in the last month of life."

UNSHARED DECISION MAKING

More than 11% of informants in both time periods reported that a medical decision was made without enough input

Continued on Page 3

NewsLine

Chemotherapy Use in the Last Months of Life May Be More Harmful Than Palliative, Study Finds

Treating end-stage cancer patients with chemotherapy — often called "palliative chemotherapy" — is intended to improve quality of life (QOL) and perhaps even extend survival. But data on patients followed prospectively suggest that not only does palliative chemotherapy not affect survival or improve QOL, it may even worsen patients' QOL near death (QOD).

"Our results raise questions about the benefits and use of chemotherapy in patients in the end stage of their illness regardless of their performance status," write the authors of a report published in JAMA Oncology.

The authors continue, "Although palliative chemotherapy is used to improve QOL for patients with end-stage cancer, its use did not improve QOD for patients with moderate or poor performance status and worsened QOD for patients with good performance status."

Investigators analyzed data on 312 patients (mean age, 58.6 years; male, 54.8%; white, 61.5%) with progressive metastatic cancer enrolled from 2002 to 2008 in a long-term, prospective, multi-institutional cohort study and followed them until their deaths. All subjects had been identified by their physicians as having a life expectancy of no more than six months and had received at least one regimen of chemotherapy.

The researchers assessed at baseline (a median of 3.8 months before death) chemotherapy use along with Eastern Cooperative Oncology Group (ECOG) performance status (scored from 0 to 5). From caregiver interviews conducted a median of 2.4 weeks after each patient's death, ratings of patients' physical and psychological distress and overall QOL were used to determine QOD in the last week of life.

OVERALL FINDINGS

- 58.1% of patients enrolled in the study died during the observation period.
- Of these, 50.6% were receiving chemotherapy at baseline.
- Patients receiving chemotherapy were younger, better educated, had lower comorbidity, better performance scores, and were more likely to have pancreatic or breast cancer and to be receiving care at an academic medical center.

KEY FINDINGS

- For patients with good performance status (ECOG score = 1), chemotherapy use was associated with lower QOD (odds ratio [OR], 0.35; 95% confidence interval [CI], 0.17 to 0.75) and remained significantly associated with worse QOD (*P* < .01) after adjustment for receipt of intensive care in the last week of life.
- Among patients with moderate (ECOG score = 2) and poor (ECOG score = 3) baseline performance status, chemotherapy was unrelated to patients' QOD.
- In adjusted analysis, clinical setting was the factor most strongly associated with chemotherapy use: academic medical center vs community clinic (adjusted odds ratio [AOR], 17.1; 95% CI, 6.6 to 44.0), hospital vs community clinic (AOR, 4.07; 95% CI, 1.70 to 9.70).
- Other factors that were independently associated with chemotherapy use included: pancreatic vs other cancers (AOR, 4.17; 95% CI, 1.30 to 13.37); breast cancer vs other cancers (AOR, 2.45; 95% CI, 1.00 to 5.99); and performance status score (AOR, 0.67; 95% CI, 0.49 to 0.93).
- Chemotherapy use was not associated with survival, not even after adjustment for confounding factors such as perfor-

mance status and clinical settings.

"Although we did not find a survival advantage associated with use of chemotherapy, this study was not designed to examine survival," says lead author Holly G. Prigerson, MD, co-director of the Center for Research on End-of-Life Care and professor in geriatrics, Weill Cornell Medical College, New York City.

"Nevertheless, these data show that incurable cancer patients with a limited life expectancy who use chemotherapy are likely to impair the quality of their remaining days. Oncologists may presume there to be no harm in giving dying patients chemotherapy, but these data point to more harm than benefit."

CALL TO UPDATE GUIDELINES

As part of the ABIM Foundation's 2012 Choosing Wisely campaign to identify common and costly procedures and treatments whose clinical use is not supported by the evidence, the American Society for Clinical Oncology (ASCO) "identified chemotherapy use among patients for whom there was no evidence of clinical value as the most widespread, wasteful, and unnecessary practice in oncology," note the authors.

Accordingly, ASCO guidelines currently recommend the use of palliative chemotherapy only for late-stage metastatic cancer patients with good functional status, under the presumption that they are best able to tolerate it and the most likely to benefit from it. But "our results suggest these guidelines may identify the patients most likely to be harmed by it," the authors state.

"Not only did chemotherapy not benefit patients regardless of performance status, it appeared most harmful to those patients

Continued on Page 3

NewsLine

Perception of U.S. End-of-Life Care (from Page 1)

from the decedent or family (11.7% in 2000; 13.8% in 2011–2013). A similar proportion reported decisions contradicting the patients' wishes. "Decisions were made that the decedent would not have wanted in 11% of deaths in 2011–2013," write the authors. "Of the 11.9% that died in an ICU in 2011–2013, 20.9% [of respondents] stated their family member got care that they did not want."

This finding is troubling, note the authors, given that the Institute of Medicine (IOM) defines patient-centered care as "care that is respectful of and responsive to individual patient's preferences, needs, and values," and "ensures that patients'

values guide clinical decisions."

SUGGESTED REASONS FOR LOWER RATINGS

- The increase in aggressive care and short hospice stays over the past decade, giving little time for patients and families to experience the full support of the hospice care team
- Financial incentives, which have rewarded procedures and ICU use rather than the timely advance care planning discussions so crucial to ensuring delivery of patients' preferred care
- The increasing public focus on endof-life care, raising caregivers' ex-

pectations for care and awareness of symptoms

"Our findings support the 2014 IOM report that calls for improved advance care planning, a major restructuring of our health financing, increase in transparency, and more accountability of health care providers," the authors conclude.

Source: "Is Care for the Dying Improving in the United States?" Journal of Palliative Medicine; August 2015; 16(8):662-666. Teno JM, et al; Department of Health Services, Policy, and Practice, Brown University School of Public Health, Providence, Rhode Island; Institute for Social Research, University of Michigan, Ann Arbor; Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore.

Chemotherapy Use in the Last Months of Life (from Page 2)

with good performance status," write the authors. "ASCO guidelines regarding chemotherapy use in patients with terminal cancer may need to be revised to recognize the potential harm of chemotherapy use in patients with progressive metastatic disease."

In a study report published last year, the authors' research team found that patients who used palliative chemotherapy were more likely to receive aggressive interventions near the end of life and more likely to die in intensive care. The current study found that, for patients with good performance status, receipt of chemotherapy was independently associated with worse QOL in the final week of life, even after adjustment for receipt of aggressive life-prolonging care.

"Thus, chemotherapy appears to contribute directly to worse QOD," they suggest, "presumably through adverse and toxic effects that impair the QOL of those who are initially feeling well." They suggest that future studies focus on

identifying better predictive biomarkers for selecting patients who are most likely to benefit from chemotherapy, especially in the palliative setting.

'DO NO HARM'

"It is disturbing that this trial demonstrated no benefits of chemotherapy for patients with solid tumors or poor prognosis, and it is disconcerting that oncologists still recommend and use systemic therapy so close to patient death," write two experts in oncology and palliative medicine from the Oregon Health & Science University, Portland, in their accompanying commentary, which commends the research team for "a well-conducted study involving a difficult but important issue."

Although the study data do not conclusively attribute poorer QOL to the effects of chemotherapy, note the experts in their commentary, "we feel that the last six months of life are not best spent in an oncology treatment unit or at home suffering

the toxic effects of largely ineffectual therapies for the majority of patients."

Until there exist irrefutable data defining who might actually benefit from palliative chemotherapy, "if an oncologist suspects the death of a patient in the next six months, the default should be no active treatment," they state.

"Let us help patients with metastatic cancer make good decisions at this sad, but often inevitable stage," they write. "Let us not contribute to the suffering that cancer — and often associated therapy — brings, particularly at the end."

Source: "Chemotherapy Use, Performance Status, and Quality of Life at the End of Life," JAMA Oncology; September 1, 2015; 1(6):778-784. Prigerson HG, et al; Center for Research on Endof-Life Care; Division of Geriatrics and Palliative Medicine, Department of Medicine; Weill Cornell Medical College, New York City; "Chemotherapy Near the End of Life: First — and Third and Fourth (Line) — Do No Harm," ibid., pp. 785-786. Blanke CD, Fromme EK; Division of Hematology & Medical Oncology, Knight Cancer Institute, and Palliative Care Service, Oregon Health & Science University, Portland.

RESEARCH MONITOR

Oncology Fellows Want More Training in End-of-Life Care, Survey Finds

A national survey has found that 100% of fellows in hematology/oncology think that learning how to care for dying patients is important. Yet more than one-quarter report receiving no explicit training in key palliative care skills, such as assessing prognosis, conducting a family meeting to discuss treatment options, and when to refer a patient to hospice/palliative care services, according to a report published in the *Journal of Palliative Medicine*.

"The findings from our study demonstrate that oncology fellows value palliative care and want to learn more about it," write the authors. However, because fellows report feeling unprepared to deliver palliative care to their patients, they note, fellowship programs will need to improve their quality of training. "The results from our study suggest that one particularly effective way to do this is to include a palliative care rotation in the required oncology fellowship curriculum."

The investigators analyzed the survey responses of 176 fellows (male, 52%; Caucasian or Asian, 70%; aged 31 to 35 years, 65%) from 93 of the nation's 138 hematology/oncology fellowship programs in 2013. Respondents were asked

to rate the quality of their palliative care training during fellowship and their perceived preparedness to care for patients at the end of life.

OVERALL

- All or nearly all respondents felt that caring for dying patients was important (98%), believed that physicians have a responsibility to help patients at the end of life (99%), and that learning how to care for dying patients was important (100%).
- 89.7% reported personal disagreement on at least one occasion when a treatment plan did not include palliative care for a patient with poor prognosis.
- 44.9% had a rotation in palliative care during fellowship.

KEY FINDINGS

- Respondents rated their overall fellowship training as being of higher quality than their training in EOL care $(4.25 \pm 0.78 \text{ vs } 3.53 \pm 0.99 \text{ on a } 1-5 \text{ scale}; P < 0.0001).$
- Fellows reporting better teaching (and rotation) in EOL care also reported feel-

- ing better prepared to care for patients at EOL (r = 0.52; P < 0.0001).
- About 25% of respondents reported having received no training in determining when referral to hospice or palliative care would be appropriate, how to conduct a family meeting on treatment options, or how to relay a poor prognosis.
- 37.5% were unfamiliar with the "surprise" question ("Would I be surprised if this patient died in the next year?"), which is found to be an effective tool for determining appropriateness of hospice/ palliative care.

"This study also points to one very definite change in the fellowship curriculum that is likely to be beneficial: fellows who had rotated on a palliative care service reported better teaching in EOL care and better preparedness to treat cancer patients at the EOL," the authors conclude.

Source: "Palliative Care Training during Fellowship: A National Survey of U.S. Hematology and Oncology Fellows," Journal of Palliative Medicine; September 2015; 18(9):77-751. Thomas RA, et al; West Virginia University; Department of Statistics, West Virginia University, Morgantown; Breast Oncology Program, Cleveland Clinic Foundation, Cleveland, Ohio; Supportive Care Services, West Virginia University, Morgantown.

Palliative Care for All Seriously III Patients: Time for the 'Next Era,' Say Experts

The expansion of palliative care programs in the past 20 years has demonstrated the value of involving palliative care specialists early and routinely in the care of seriously ill patients. But for high-quality, advanced-illness care to reach more patients and their families, it is time for palliative care to evolve into the "next era," according to two experts.

"The initial era of palliative care demonstrated proof of concept — that is, that quality of care near the end of life can be improved," write the authors of a commentary published in the *Journal of the American Medical Association*. However, "little has changed for seriously ill patients, who continue to receive poor-quality, high-cost care *without* being

informed of likely treatment outcomes so that they would be able to make decisions that reflect their values."

Although professional guidelines currently recommend earlier and routine consults with palliative care professionals, there is a workforce shortage in this field, making it unlikely that these services can

Continued on Page 5

RESEARCH MONITOR

Heart Failure Patients Discharged from Hospital with Unrelieved Symptoms, No Palliative Care

A lack of symptom improvement — both in symptoms traditionally associated with decompensated heart failure (HF) and in those that are not — was experienced by approximately half of elderly patients following hospitalization, according to a research letter published in *JAMA Internal Medicine*.

"The progressive nature of HF, coupled with high mortality rates and poor quality of life, make it suited for the incorporation of palliative care," write the authors. "There have been numerous calls to include palliative care as a component of HF management, but fewer than 10% of patients with HF receive palliative care."

Investigators analyzed responses of 91 patients (mean age, 71.5 years) hospitalized for HF from 2013 through 2014 at Yale-New Haven Hospital in CT. 75% had an ejection fraction of < 50%. Participants were interviewed at baseline a mean 2.5 days after admission and by phone a mean 9.9 days following discharge. Self-reported Edmonton Symptom Assessment Scale (ESAS) ratings (ranging from 0–10, with 10 as most severe) were compared between the in-hospital and post-discharge assessments.

FINDINGS

- Participants reported no post-discharge improvement in fatigue (58%), dyspnea (42%), pain (41%), and anxiety (41%).
- Only 22% of patients indicated they were familiar with palliative care. However, many of these patients had misperceptions about palliative care, such as believing it was only for cancer patients or for providing comfort near death.
- After being given a standardized explanation of palliative care, 68% of participants were interested in receiving such services.

• Symptoms rated as being of greater severity, both before and after hospitalization, included fatigue (5.0 vs 4.9), decreased well-being (5.2 vs 4.5), and dyspnea (4.7 vs 4.0).

"Our findings suggest that patients who are hospitalized for HF often present with symptoms that are not traditionally associated with HF and that current management approaches may fail to adequately address symptoms," write the authors. They suggest several reasons for this failure.

WHY SYMPTOMS ARE NOT ADDRESSED

- Multiple comorbidities may contribute to symptoms and complicate management.
- Clinicians treating hospitalized patients may not be prepared to assess and treat pain, anxiety, depression, and fatigue.
- Health care systems are under pressure to reduce patients' lengths of stay. "Once patients no longer meet the clinical criteria for hospitalization (e.g., hypoxia or hemodynamic instability), there is an impetus for discharge even if troublesome symptoms persist," write the authors.

"To our knowledge, this is the only study that included longitudinal assessment of symptom burden during hospitalization for HF and shortly after discharge," point out the authors. They suggest future studies to determine whether palliative care in this population will reduce symptoms and hospital admissions.

Source: "Symptom Burden among Patients Who Were Hospitalized for Heart Failure," JAMA Internal Medicine; Epub ahead of print, August 17, 2015; DOI: 10.1001/jamainternmed.2015.3871. Khan RF, et al; Department of Internal Medicine, Yale School of Medicine; and Yale School of Nursing, New Haven, Connecticut.

Palliative Care for All Seriously III Patients (from Page 4)

match the needs of an increasing population of older, seriously ill patients.

SUGGESTED QUALITY IMPROVEMENT STRATEGIES

- Train clinicians in appropriate communication skills.
- Provide tools that facilitate patientcentered goals-of-care discussions.
- Establish policies to ensure that these

discussions occur at the right points in time with the right clinicians.

 Design electronic health records to document patient preferences.

Palliative care will have the greatest benefit in the future through "teaching other clinicians to provide patient and family-centered care, designing systems, and advocating for policy changes," emphasize the authors. They applaud the recent Medicare initiative to reimburse clinicians for holding end-of-life care discussions, which helps "...reward delivery of patient- and family-centered care."

Source: "The Next Era of Palliative Care," Journal of the American Medical Association; Epub ahead of print, September 3, 2015; DOI: 10.1001/jama.2015.11217. Schenker Y, Arnold R; Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, University of Pittsburgh, Pittsburgh, Pennsylvania.

RESEARCH MONITOR

Overview of Pediatric Palliative and Hospice Care Finds Both Progress and Challenges

To promote an understanding of unmet needs of children with life-threatening or complex, chronic conditions and the challenges facing their families, the National Hospice and Palliative Care Organization (NHPCO) has issued a report describing the current state of pediatric palliative/hospice care (PP/HC) in the U.S., and identifying current gaps in service.

Released this past July, the 11-page report, entitled "NHPCO's Facts and Figures: Pediatric Palliative & Hospice Care in America, 2015 Edition," aims to educate funders and policy makers and to help clinicians and providers identify children who may benefit from the support of PP/HC.

"Pediatric palliative/hospice care provides children and their families with high-quality, compassionate, and consistent care delivered through the collaborative efforts of an interdisciplinary team," the NHPCO states. "PP/HC may be provided along with concurrent disease-modifying therapy and can transition to be the main focus of care when disease-modifying therapy is no longer effective and comfort becomes a priority."

CONCURRENT CARE

The Affordable Care Act (ACA) of 2010 includes a section mandating that children in a state's Medicaid or Children's Health Insurance Program who are eligible for hospice care also continue to be eligible for coverage of curative, disease-directed therapies.

Although state-by-state adoption of this concurrent care benefit is still uneven, it represents "an immense milestone," notes the report, as families will no longer need to forgo curative treatment in order to receive the support of a palliative care team. "Earlier involvement allows the team to help the family better navigate

both the health care system and the illness journey and make important decisions with accurate information and support."

PP/HC is both a philosophy and an organized method for care delivery, explains the report. Services are planned, coordinated, and delivered by an interdisciplinary team, which collaborates and communicates with patients, families, and other palliative and non-palliative health care providers about care needs. The child, family, and caregivers are at the center of care.

An American Academy of Pediatrics 2013 policy statement outlines its core commitments of PP/HC, which included not only delivering high-quality care that is patient centered and family engaged, but also "ensuring that all clinicians can provide basic palliative care and consult PP/HC specialists in a timely manner."

The U.S. Department of Health and Human Services reports that 15.1% (11.2 million) of American children aged 0-17 years have special health care needs, and the number is increasing. Due to advances in pediatric medical and surgical care, children with chronic illness and complex health care needs are living longer. "These children require creative approaches to delivery of care coordination and PP/HC services over a longer term," states the report. As PP/ HC services have grown, some are also better able to provide short-term services such as grief and bereavement support to families affected by trauma, or sudden serious illness or death.

In 2013, children aged 0–19 years accounted for 1.6% (n = 42,328) of all deaths in the U.S., a number that has continued to decline, according to the Centers for Disease Control (CDC). That same year, there were 18,888 deaths in children ages 1–19 years, or a death rate of 24 per

100,000, which is a significant decrease from the 32.2 per 100,000 in 2005. The leading cause of disease-related death in children aged 1–19 years is malignant neoplasms, with children aged 15–19 years representing the majority of deaths (9480) in this cohort.

The overall percentage of home deaths for children increased from 1999 to 2013 (14.5% to 22.0%), with the largest increase in home deaths occurring among those aged 10–19 years, according to the CDC. However, notes the report, home death does not always reflect the preferred choice of patients and families.

Studies have shown that when parents are encouraged to plan for location of death, they are more likely to be comfortable with the setting of their child's death. Although most children with complex chronic conditions no longer die in childhood, they do have a 15-fold higher mortality when hospitalized, notes the report. For children who die in the hospital, advance care planning makes them less likely to die in intensive care and less likely to be intubated in the final 24 hours of life.

In a 2013 survey of children's hospitals across the U.S., 69% reported having a palliative care team, with nearly 30% of the programs offering home services. According to the most recent survey (2007) on pediatric services conducted by the NHPCO, 78% of member hospices reported serving pediatric patients, and 36.6% had a formal pediatric program in place. Of those hospices with no dedicated pediatric team, 21.7% did have specialized staff to provide only pediatric services.

The NHPCO report, along with other professional resources, can be accessed at www.nhpco.org/pediatric.

CLINICIAN RESOURCES

Advance Care Planning: How to Open the Conversation

For clinicians who feel they lack the experience or confidence to initiate an advance care planning (ACP) discussion, it can be helpful to have both the necessary knowledge of basic palliative care skills and a script to follow, advise two palliative medicine specialists in an article published in the journal *Oncology*.

The authors offer an approach to opening and closing the discussion, both of which can be difficult, they note. The article also includes a table outlining the basics of primary palliative care, skills needed by all clinicians who care for seriously ill patients.

"All the available evidence says that asking patients about their end-of-life preferences early in the disease trajectory, and making sure that palliative care skills are brought to bear, will improve their care," write the authors. "If we want to honor our patients' wishes about the type of care they want to receive, we have to first discern those wishes."

HOW TO INITIATE AN ACP DISCUSSION

- 1. Let go of the myth that broaching end-of-life care topics can be harmful to patients, and recognize that ACP discussions are actually desired by most patients. It is always appropriate to ask, "How much information would you like regarding your illness?" and "What is your understanding of your situation?"
- 2. Get to know the patient before asking questions regarding ACP. Ask, "What is important to you? What are you hoping for? Have you thought about a time when you could get sicker?" Later, move on to, "You are getting sicker, and I'm worried about you. We should have this discussion now."
- **3.** Ask for permission and then make specific medical recommendations. "Would you like me to make a recommendation on what you should do if your body dies, your heart stops, or you stop breathing?" The authors emphasize that physicians should not shy away from using the word "dies."
- 4. Know the expected outcomes of cardiopulmonary resuscitation for various patient groups and be prepared to explain the risks and benefits. Again, the authors suggest having a standardized script, which can be helpful for opening the conversation. "I'm so sorry to tell you that we have reached the point where we cannot cure your disease. There will come a time when the disease will cause death and your heart will stop beating. Since we cannot cure the underlying disease, I would recommend that we focus on a peaceful and comfortable death, rather than using measures to try to restart your heart. How do you feel about this? What questions do you have?"
- 5. For those patients who disagree, it is important to explore their reasons, so their care decisions can be based on their values. Prompt them by saying, "Tell me more." The authors have found that it is also important to say to the patient or caregiver, in closing: "You have not left any medical stones unturned, and you have been a great advocate for yourself (your loved one)."

Source: "Advance Care Planning Discussions: Why They Should Happen, Why They Don't, and How We Can Facilitate the Process," Oncology; August 2015; 29(8):567-571. Norals TE and Smith TJ; MDICS Physicians Inpatient Care Specialists, Washington, D.C.; and Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Baltimore.

End-of-Life Care Websites

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

American Hospice Foundation www.americanhospice.org

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

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

Center to Advance Palliative Care www.capc.org

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

www.epec.net

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

Hospice and Palliative Nurses Association www.hpna.org

Hospice Foundation of America www.hospicefoundation.org

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

National Hospice & Palliative Care Organization www.nhpco.org

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

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

Resources for Patients and Families www.hospicenet.org

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

Quality of Life Matters® is a registered trademark of Quality of Life Publishing Co.

© 2015 by Quality of Life Publishing Co. All rights reserved. No part of this newsletter may be reproduced without prior permission of the publisher.

For reprint requests or questions, contact 877-513-0099, info@QOLpublishing.com

End-of-Life Care Meetings for Clinicians

Palliative Medicine and End-of-Life Care: 2016 Update Including Related Topics in Neurology. February 14–21, 2016, Seven-night Eastern Caribbean cruise conference, from Fort Lauderdale, FL. Topics include Palliative Care and Hospice, Advanced Care Directives/Advanced Care Protocols, Pain Management and Palliative Care, Reimbursement and Coverage Strategies, and more. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: www. continuingeducation.net

35th Annual Scientific Meeting of the American Pain Society. May 11–14, 2016, Austin, TX. Email: info@americanpainsociety.org; Website: www.americanpainsociety.org

2016 Annual Scientific Meeting of the American Geriatrics Society. May 19–21, 2016, Long Beach, CA. Website: www.americangeriatrics.org

9th World Research Congress of the European Association for Palliative Care. June 9–11, 2016, University College, Dublin, Ireland. Co-sponsored by the Irish Association for Palliative Care. Website: http://www. eapcnet.eu/research2016

21st International Congress on Palliative Care. October 17–21, 2016, Palais des Congrès (Montréal Convention Centre), Montréal, Québec, Canada. Presented by Palliative Care McGill University. Website: www. palliativecare.ca

Advertise Your Hospice Here

For more information about hospice and palliative care, or to make a referral, please contact your local hospice and palliative care organization.

Quality of Life Matters® is recommended as an educational resource by the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association.

Quality of Life Matters®

Now in its 17th year of publication, Quality of Life Matters® is recommended as an educational resource by the American Academy of Hospice and Palliative Medicine.

The periodical is dedicated solely to endof-life care news and clinical findings and is researched and written by professional medical journalists specializing in covering palliative care issues.

It is an independent publication; it is not affiliated with any health care organization or company. The quarterly newsletter is published by Quality of Life Publishing Co., a firm dedicated to easing the way for patients with life-limiting illnesses and their families.

We customize copies of the newsletter for hospices and other organizations to provide as an educational service for their local clinicians.

For information, rates, or reprint requests for this and other publications, please contact Quality of Life Publishing Co.

> **TOLL FREE** 1-877-513-0099

EMAIL info@QOLpublishing.com

MAIL

6210 Shirley St., Ste. 112, Naples, FL 34109

EXPLORE OUR FULL LINE OF BRANDED EDUCATIONAL BOOKLETS at www.QOLpublishing.com

- Tools to address CAHPS® survey questions
- · Written to meet health literacy standards
 - · Available in multiple languages



Karla Wheeler Editor-in-Chief & Founder Jan Carlton Doetsch Clinical Editor

Gretchen Landolt Chief Executive Officer

Kelly Brachle Chief Operating Officer

Dashia Larimer VP, Customer Relations Editor, Production Coord.

Katie Jensen

Mike Schadler Billing Associate

Tony Uricchio Publishing Assistant

Vera Zubrick Administrative & Sales Assistant

17-3