

Provided as an educational service by Angels Grace Hospice

Quality of Life Matters®

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

Vol. 19, Issue 3 Nov/Dec/Jan 2017–2018

Gap Persists in U.S. Between End-of-Life Care Desired and Care Received

Patients who die at home are more likely to receive care consistent with their wishes

One in eight bereaved family members report that the care their loved ones received in the last month of life was not in concordance with their preferences. Such perceived inconsistent care is likely to be accompanied by reports of a higher percentage of unmet symptom needs and poor communication with patients/families in the last month of life, but is less likely to occur among patients who die at home.

“Despite national efforts to improve advance care planning, our data suggest that too often decisions do not respect the patient’s wishes and are made without enough input from the dying patients or their family,” write the authors of a report published in the *Journal of Palliative Medicine*.

Investigators analyzed interview responses of bereaved family members/close friends (n = 1212) regarding their perceptions of the quality of care received in the last month of life by Medicare patients (male, 22.3%; white, 79.9%; aged 85 years or older, 21.0%) who participated in the nationally representative National Health and Aging Trends Study between 2012 and 2015.

be rated as fair/poor (19.1% vs 4.8%) and less likely to be rated as excellent/very good (62.0% vs 81.7%).

INCONSISTENT CARE LINKED TO:

- A greater percentage of reports of unmet needs for management of pain (27.3% vs 15.2%) and dyspnea (19.0% vs 11.1%).
- More reports that decisions were made without sufficient patient or family input (26.0% vs 6.8%) and that the family was not always kept informed about the care plan (29.8% vs 17.0%).
- Greater concerns that the patient was not always treated with respect (23.0% vs 12.1%).

“These results support the Institute of Medicine’s [2014] call to improve communication between clinicians, patients, and families to better match care to patients’ values and preferences, and provide insight into measurement of goal-concordant care,” write the authors.

Source: “How Often Is End-of-Life Care in the United States Inconsistent with Patients’ Goals of Care?” *Journal of Palliative Medicine*; Epub ahead of print, June 30, 2017; DOI: 10.1089/jpm.2017.0065. Khandelwal N, Curtis JR, Teno JM; Department of Anesthesiology and Pain Medicine; Division of Pulmonary and Critical Care Medicine; and Division of Gerontology and Geriatric Medicine, Harborview Medical Center, University of Washington, Seattle.

Inside:

NewsLine..... 1–3

- ✓ Gap Persists in U.S. Between End-of-Life Care Desired and Care Received
- ✓ Palliative Care Exposure: An ‘Inflection Point’ After Which Intensity of Healthcare Decreases for Terminally Ill Patients
- ✓ Most Advanced Dementia Proxies Prefer Comfort Care

Research Monitor..... 4–5

- ✓ Trust in Home Hospice Staff, Coordinated Care Influence Quality of Death
- ✓ Racial/Ethnic Disparities in Cancer Care at the End of Life Raise Concerns

Clinician Resources..... 6–7

- ✓ Clinical Oncologists Offered Guide to Best Practices in Effective Communication
- ✓ Clinicians Urged to Promote a More Therapeutic Type of Hope in Patients with Terminal Illness

OVERALL

- 12.6% of bereaved family members reported that care in the last month of life was inconsistent with their loved one’s wishes.
- Care inconsistent with preferences was less likely to be reported when death occurred at home (27.9% vs 38.1%).
- Inconsistent care was more likely when death occurred in the hospital (30.3% vs 21.6%) or a nursing home (22.9% vs 17.8%).
- Care inconsistent with wishes was more likely than consistent care to

NEWSLINE

Palliative Care Exposure: An 'Inflection Point' After Which Intensity of Healthcare Decreases for Terminally Ill Patients

In the period following a palliative care (PC) encounter, patients with advanced cancer experience significantly less aggressive end-of-life care, with lower rates of hospitalization, fewer invasive procedures and chemotherapy administrations, and higher rates of hospice enrollment. Further, this effect is most marked when PC is delivered earlier in the course of the disease, according to a report published in the *Journal of Oncology Practice*.

“The key findings of this study relate to the marked reductions in healthcare use at the end of life after exposure to palliative care,” write the authors. “Essentially, we found palliative care represents an inflection point in patient care, with higher use of healthcare services before palliative care consultation and lower use after.”

Cancer is the second leading cause of death in the U.S., note the authors, and often involves intense treatment that can burden the patient-family unit and strain the resources of the healthcare system. Delivery of PC has been shown to improve cancer patients' symptom management, quality of life, and satisfaction with care — and even to prolong survival. But the relationship between PC and end-of-life care has not previously been validated in a real-world, population-based setting.

“It's critically important to validate research in a real-world setting,” says senior author James Murphy, MD, MS, of the University of California, San Diego. “Our study supports the findings of previous randomized clinical trials.” In addition, by “using a representative and diverse cohort of patients, our study shows the practical benefits of palliative care as it is actually implemented in an everyday practice setting.”

Investigators analyzed data from the National Cancer Institute's SEER (Surveillance, Epidemiology, and End Results) Medicare-linked database on 6580 beneficiaries diagnosed between 2000 and 2009 with advanced prostate, breast, lung, or colorectal cancer. Healthcare use among 3290 of these patients before and after a PC consultation was compared to that of a matched non-PC cohort.

OVERALL

- The median time from diagnosis to death was 4.8 months (interquartile range [IR], 2.1 to 11.0 months).
- PC delivery was more common among patients with lung cancer and more prevalent on the West Coast.
- The timing of the PC consultation was relatively late, with a median time from consultation to death of 12 days (IR, 4 to 38 days).

While patients in the PC cohort had higher rates of healthcare usage than non-PC patients prior to PC consultation, in the period from consultation to death, PC patients had lower healthcare utilization rates and greater hospice enrollment than those in the control group.

KEY FINDINGS: BEFORE CONSULT

Thirty days prior to a PC consult, the PC cohort had higher rates of:

- Hospitalization (risk ratio [RR], 3.33; 95% confidence interval [CI], 2.87 to 3.85)
- More than one ER visit (RR, 2.47; 95% CI, 2.15 to 2.84)
- Invasive procedures (RR, 1.75; 95% CI, 1.62 to 1.88)

- Chemotherapy administration (RR, 1.61; 95% CI, 1.45 to 1.78)

KEY FINDINGS: AFTER CONSULT

In the period from consult to death, the PC cohort had:

- Lower rates of hospitalization (RR, 0.53; 95% CI, 0.44 to 0.65)
- Less likelihood of more than one ER visit (RR, 0.62; 95% CI, 0.52 to 0.74)
- Fewer invasive procedures (RR, 0.52; 95% CI, 0.45 to 0.59)
- Reduced chemotherapy administration (RR, 0.46; 95% CI, 0.39 to 0.53)
- Higher likelihood of hospice enrollment (RR, 1.24; 95% CI, 1.15 to 1.32) with longer hospice stays (25.5 days vs 21.3 days)

However, despite the overall longer hospice stays, the PC cohort was more likely to be enrolled in hospice within 3 days of death than was the non-PC cohort (RR, 1.67; 95% CI, 1.49 to 1.87).

EARLIER PC YIELDS BETTER OUTCOMES

Patients who received a PC consultation earlier in the disease course had larger absolute reductions in healthcare use compared with those whose consultations took place closer to death. Earlier PC exposure was associated with greater reductions in chemotherapy use ($P < 0.001$) and average hospitalization days ($P < 0.05$), as well as with increased enrollment time in hospice. Still, many PC consultations occurred late in patients' disease courses, with a median time of 12 days from consult to death.

“Given the increasing number of older

Continued on Page 3

NEWSLINE

Most Advanced Dementia Proxies Prefer Comfort Care

Most care proxies for advanced dementia patients in nursing homes want their loved ones to receive comfort care, and are more likely to choose palliative care over more aggressive levels of medical care when they are aware of the patient's six-month prognosis and have been asked to articulate their goals of care, according to a report published in the *Journal of Pain and Symptom Management*.

"Delivering goal-directed care is a hallmark of high-quality palliative care, but requires an understanding of preferences," write the authors. "To our knowledge, no prior research has reported factors influencing level of care preferences among proxies of persons with advanced dementia. This study highlights several factors for clinicians to consider when discussing treatment preferences with proxies of nursing home residents with advanced dementia."

Investigators analyzed data from baseline in-person interviews conducted from March 2013 to August 2016 as part of the ongoing EVINCE (Educational Video to Improve Nursing Home Care in End-stage Dementia) study among 402 proxies for an equal number of dementia patients (mean age, 86.7 years; female, 80.3%; white race, 87.1%) living in 62 Boston-area nursing

homes. All dementia patients were Stage 7 in the Global Deterioration Scale, indicating the most severe stage of dementia.

Proxies were asked to select the type of medical care they wished the patient to receive from among three levels: intensive, using all available medical treatments, including CPR, ventilators, feeding tubes, and ICU; basic, using some available medical treatments, including IV medications and hospitalization for sudden illness, but avoiding invasive procedures and ICU; and comfort care, using only treatments that relieve pain and discomfort and hospitalizing only for pain relief.

OVERALL

- 62.2% of proxies preferred comfort care for their loved ones; 31.3% chose basic medical care; and only 6.5% opted for intensive medical treatments.
- 68.4% of proxies said they had been asked about goals of care.
- Despite the residents' advanced stage of disease, only 13.2% of proxies thought the patient had less than six months to live.

KEY FINDINGS

In multivariable analysis, the follow-

ing were independently associated with a proxy preference for comfort care:

- The proxy's perception that the patient most likely had less than six months to live (adjusted odds ratio [AOR], 12.25; 95% confidence interval [CI], 4.04 to 37.08)
- The proxy's opinion about goals of care having been solicited (AOR, 1.71; 95% CI, 1.07 to 2.74)

The most important takeaways from their findings for clinicians, observe the authors, are the importance of offering proxies a choice (i.e., basic medical care) between the two extremes of intensive medical care and comfort-only care, and the suggestion that counseling proxies regarding the limited life expectancy of advanced dementia patients and discussing goals of care may help guide proxies to consider palliative care.

Source: "Level of Care Preferences Among Nursing Home Residents With Advanced Dementia," *Journal of Pain and Symptom Management*; September 2017; 54(3):340-345. Mitchell SL, Palmer JA, Shaffer ML, et al; Hebrew SeniorLife, Institute for Aging Research, and Department of Medicine, Beth Israel Deaconess Medical Center, both in Boston; and Department of Pediatrics, University of Washington and Children's Core for Biomedical Statistics, Seattle Children's Research Institute, Seattle.

Palliative Care Exposure: An 'Inflection Point' (from Page 2)

patients with advanced cancer, this study provides important context for the need of early integration of palliative care in oncology," Murphy says. "Providing a consultation earlier rather than later represents an important area for practice improvement."

In addition, the authors point out that although PC can be delivered before, during, and after treatment, "introducing

PC sooner after diagnosis helps patients to better understand their prognosis and goals of treatment, manage their expectations, and maintain their quality of life."

The authors note that data used for this study did not include details on the consultations themselves, such as what triggered their initiation or which members of the multidisciplinary team conducted them. Future research with a focus on what

drives healthcare utilization by patients with life-limiting illnesses is needed, they suggest.

Source: "Effect of Palliative Care on Aggressiveness of End-of-Life Care among Patients with Advanced Cancer," *Journal of Oncology Practice*; September 2017; 13(9): e760-e769. Triplett DP, LeBrett WG, Bryant AK, Bruggeman AR, Matsuno RK, Hwang L, Boero IJ, Roeland EJ, Yeung HN, Murphy JD; Moores Cancer Center, University of California, San Diego, La Jolla.

RESEARCH MONITOR

Trust in Home Hospice Staff, Coordinated Care Influence Quality of Death

Trust in the hospice staff and high levels of care coordination were found to be significantly associated with good quality of death (QOD) for loved ones, as perceived by bereaved relatives of cancer patients who died at home in Japan, according to a report published in the *Journal of Palliative Medicine*.

Investigators analyzed questionnaire responses from a nationwide, multicenter survey of bereaved family members of older adult cancer patients who died before 2014. The study focused on respondents (n = 486) whose loved ones had died at home with hospice care.

In addition to questions related to aspects of care, participants were asked to rate their loved one's QOD by evaluating each of the following nine domains of

the Good Death Inventory (GDI): freedom from physical and psychological discomfort, staying in a favorite place, maintaining hope and pleasure, not being a burden to others, spending time with the family, maintaining independence, living in a comfortable environment, being respected as an individual, and fulfillment at the end of life.

KEY FINDINGS

Trust. 92.0% of bereaved family members reported that they trusted and felt their values were respected by the home hospice physician; 94.6% trusted and felt respected by the home hospice nurses.

Care coordination. 97.2% reported a high level of care coordination between the home care physician and nurses;

94.4% reported high quality coordination between the care manager and home care nurses.

Availability. Nearly all respondents reported that the home hospice physician and nurses were available to consult with them about their concerns (92.5% and 95.5%, respectively).

Trust by the patient and family in the home hospice physician had the strongest significant association with a positive GDI score, followed closely by trust in the nurses, and then by good quality of care coordination.

Source: "Trust in Physicians, Continuity and Coordination of Care, and Quality of Death in Patients with Advanced Cancer," Journal of Palliative Medicine; Epub ahead of print, July 21, 2017; DOI: 10.1089/jpm.2017.0049. Hamano J et al; University of Tsukuba, Tsukuba, Japan.

Many Emergency Department Visits by Cancer Patients May Be Preventable

More than half of emergency department (ED) visits by newly diagnosed cancer patients may result from inadequately controlled cancer and chronic disease symptoms, symptoms that could be managed with timely care in an outpatient setting, according to a presentation at the annual meeting of the American Society of Clinical Oncology in June 2017.

"My hope is that seeing this data will promote innovative thinking and investment in how oncology teams manage patient symptoms," says lead author Laura Panattoni, PhD, of the Fred Hutchinson Institute for Cancer Outcomes Research Center in Seattle. "Managing nausea, pain, dehydration, diarrhea, and other symptoms in an outpatient setting has great potential to improve patient experience and decrease the cost of care."

Investigators analyzed five years of cancer registry data linked to commercial insurance claims on 7053 adult patients newly diagnosed with solid tumors who were undergoing initial chemotherapy, radiation treatment, or both in Washington state. Potentially preventable symptoms were identified using a new metric from the Centers for Medicare & Medicaid Services (CMS) as well as symptoms from emerging evidence found in patient-outcomes literature but not included in the CMS metric.

KEY FINDINGS

- 36% of patients visited the ED without being admitted in the year following initial treatment, most commonly for pain, dyspnea, and symptoms related to hypertension and COPD.

- Using just the CMS metrics, 38% of ED visits were found to include at least one potentially preventable symptom.
- When both sources were used, the percentage of ED visits for potentially preventable symptoms rose to 63%.

"[W]e certainly advocate that providers consider managing symptoms targeted by both the CMS metric and the patient-reported outcomes literature," says Panattoni, "and we advocate for further research, especially in symptoms with emerging evidence...and including chronic conditions."

Source: "The Role of Chronic Disease in the Costs of Potentially Preventable Emergency Department Use during Treatment: A Regional Study," ASCO Annual Meeting presentation, June 5, 2017; Abstract 6505. Panattoni LE et al; Fred Hutchinson Cancer Research Center, Seattle.

RESEARCH MONITOR

Racial/Ethnic Disparities in Cancer Care at the End of Life Raise Concerns

Ovarian cancer patients of minority race and ethnicity are more likely than white patients to receive intensive and invasive care in the last month of life and less likely to enroll in hospice, according to a report published in the *Journal of Clinical Oncology*. Aware of the persistence of such disparities, four major cancer organizations have recently released a joint statement recommending research strategies to improve care.

SUBOPTIMAL END-OF-LIFE CARE PERSISTS

“Our analysis confirmed that, irrespective of other sociodemographic factors, patients of black and Hispanic racial and ethnic backgrounds were less likely to meet end-of-life quality-care metrics,” write the study authors. Ovarian cancer is the leading cause of death among gynecologic cancers, and the fifth most common cause of cancer death among women.

Investigators analyzed data from the Texas Cancer Registry — the nation’s fourth largest statewide population-based registry — linked to Medicare claims from 2000 to 2012 on 3666 patients with ovarian cancer aged ≥ 66 years at the time of death (white, 77%; Hispanic, 15%; black, 7%; other, 1%).

OVERALL

- 69% of ovarian cancer patients had advanced disease.
- In the final 30 days of life, 23% received invasive care; 16% were admitted to an ICU; 14% had > 1 hospital admission; 11% had life-extending care; and 10% had > 1 ED visit.
- In the last 14 days of life, 10% received chemotherapy.

HOSPICE USE

- 72% enrolled in hospice.

- The median hospice length of stay was 20 days.
- 49% of hospice patients enrolled while hospitalized, rather than as outpatients.
- 9.4% of those who entered hospice did so within the last three days of life.

KEY FINDINGS

- Black and Hispanic patients were less likely to enroll and die in hospice (odds ratio [OR], 0.66; 95% confidence interval [CI], 0.50 to 0.88; and OR, 0.76; 95% CI, 0.61 to 0.94, respectively) than were white patients.
- Hispanic patients were more likely than others to be admitted to an ICU in the last 30 days of life (OR, 1.37; 95% CI, 1.05 to 1.78).
- Black patients were more likely to have > 1 ED visit (OR, 2.20; 95% CI, 1.53 to 3.16) and to receive a life-extending procedure (OR, 2.13; 95% CI, 1.49 to 3.04) in the final 30 days of life.

One notable strength of their investigation is the large proportion of black and Hispanic patients in their cohort, enabling analysis of outcomes for these two minorities separately, rather than simply as nonwhite vs white, point out the authors.

“More investigation is needed to determine not only how to best reduce the overall number of patients with ovarian cancer who receive aggressive and invasive care, but also how to lessen the disparity of who receives more aggressive and invasive care,” they urge.

MAJOR GROUPS ISSUE GUIDE TO DISPARITIES RESEARCH

Better research methods are needed to understand why underserved populations, such as racial and ethnic minorities and those with low socioeconomic status, experience worse cancer outcomes, according to a position statement written

jointly by experts from four leading national cancer organizations: the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology (ASCO), and the National Cancer Institute.

“Our hope is that these consensus recommendations will help guide stakeholders across cancer research, including public and private groups, toward actions that will meaningfully advance cancer health disparities research and ultimately ensure that all cancer patients are able to benefit from innovations that can improve cancer care,” says ASCO president Bruce E. Johnson, MD.

After identifying research needs and top priorities for reducing disparities, the statement offered recommendations in the following areas:

- 1. Measurement tools.** Use the highest-quality tools for measurement of the most granular data possible on factors that impact disparities in cancer care and patient outcomes.
- 2. Incidence.** Establish a research network to advance knowledge in multi-level factors related to disparities in cancer incidence, such as biological, environmental, and genetic determinants.
- 3. Survival.** Address disparities in survival through best-practice strategies to engage underserved populations in research studies and clinical trials.
- 4. Community engagement.** Encourage and support/promote training, scheduling, and funding for community-engaged research.
- 5. Real-time monitoring.** Ensure that cancer treatment systems monitor patient experiences in real time and intervene when care and outcomes disparities are detected.

“Because patients with cancer exist in

Continued on Page 6

CLINICIAN RESOURCES

Clinical Oncologists Offered Guide to Best Practices in Effective Communication

A new consensus guideline issued by the American Society of Clinical Oncology (ASCO) provides recommendations and strategies that apply across the continuum of cancer care to “optimize the patient-clinician relationship, patient care, and the well-being of clinicians, patients, and their loved ones,” according to the authors of the guideline, which was developed by a multidisciplinary panel of experts and published in the *Journal of Clinical Oncology*.

“Clinicians face a monumentally difficult task: to guide patients on what may be the scariest and most unpleasant journey of their lives. We need to preserve their hope while at the same time giving them accurate information,” says lead author Timothy Gilligan, MD, of the Cleveland Clinic and co-chair of the ASCO guideline panel. “Helping oncology clinicians improve their communication skills ultimately helps patients, and that is what is most important.”

Because of the complexity of cancer and its treatments, and the range of emotions experienced by patients with advanced disease as they confront their mortality, these conversations are often challenging, note the authors, “in many ways akin to complex interventional procedures or operations.” The guideline recommends that all oncologists be familiar with key aspects of effective communication skills and emphasizes the importance of skills training.

KEY RECOMMENDATIONS FOR CLINICIANS INCLUDE:

- Actively foster patients’ trust and confidence; collaborate with patients and encourage them to take an active role in their care.
- Clearly establish goals of care and ensure that patients understand their prognosis.
- Address patient concerns about the cost of care.
- Introduce treatment options in the context of goals of care, and ensure that patients are aware of all options, such as clinical trials, concurrent palliative care, and palliative/hospice care only.
- Initiate conversations about end-of-life preferences early, and revisit the topic periodically, such as when clinical conditions deteriorate or patients’ preferences change. Identify and suggest local resources that can strongly support patients and their families who are transitioning to end-of-life care.
- Introduce hospice as a service aligning with goals of care. “*I understand that you don’t want to spend any more time in the hospital, but you are scared about pain control at home. There’s a program called hospice that can help you stay at home and manage your pain and other symptoms.*”

OTHER TOPICS INCLUDE:

- Facilitating family involvement through communication
- Communicating effectively when communication barriers exist
- Meeting the needs of patients in underserved populations
- Training in communication skills

“For communication skills training to be effective, it should foster practitioner self-awareness and situational awareness related to emotions, attitudes, and underlying beliefs that may affect communication as well as awareness of implicit biases that may affect decision making,” states the guideline.

Source: “*Patient-Clinician Communication: American Society of Clinical Oncology Consensus Guideline*,” *Journal of Clinical Oncology*; Epub ahead of print, September 11, 2017; DOI: 10.1200/JCO.2017.75.2311. Gilligan T, Coyle N, Baile WF, et al; Cleveland Clinic, Cleveland; Memorial Sloan Kettering Cancer Center, New York City; and The University of Texas MD Anderson Cancer Center, Houston.

Racial/Ethnic Disparities (from Page 5)

a web of healthcare systems, these systems have an obligation to understand how these patients are being treated in real time and to intervene when system errors occur,” asserts the statement.

The position statement has been simultaneously published by the four co-authoring organizations, in *Cancer Research*; *CA: A Cancer Journal for Clinicians*; the *Journal of Clinical Oncology*; and online at cancer.gov.

Sources: “*End-of-Life Racial and Ethnic Disparities among Patients with Ovarian Cancer*,” *Journal of Clinical Oncology*; June 1, 2017; 35(16):1829–1835. Taylor JS, Rajan SS, Zhang N, Meyer LA, Ramondetta LM, Bodurka DC, Lairson DR, Giordano SH; The University of Texas MD Anderson Cancer Center and The University of Texas School of Public Health, Houston. “*Charting the Future of Cancer Health Disparities Research: A Position Statement from the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute*,” *Cancer Research*; Epub ahead of print, July 24, 2017; DOI: 10.1158/0008-5472.CAN-17-0623. Polite BN, Adams-Campbell LL, Paskett ED; The University of Chicago, Chicago; Georgetown-Lombardi Comprehensive Cancer Center, Washington, DC; and Ohio State University Comprehensive Cancer Center, Columbus.

CLINICIAN RESOURCES

Clinicians Urged to Promote a More Therapeutic Type of Hope in Patients with Terminal Illness

'Intrinsic hope' can help patients heal emotionally when clinical cure is no longer possible

When sustaining the hope for a cure (“focused hope”) begins to falter or appear unrealistic in patients with life-limiting illness who are confronting their mortality, physicians can help support patients’ well-being by encouraging the emergence of a “more profound and resilient” form of hope (“intrinsic hope”), suggest U.S. experts in an opinion piece published in *The BMJ Opinion*, an online forum of *The BMJ (British Medical Journal)*.

“Hope for cure has traditionally been the patient’s best friend and the clinician’s strongest ally,” write the authors. But when cure is no longer a realistic goal, physicians may hesitate to present patients with their poor prognoses, for fear of dashing hope or causing depression. That is where honest disclosure combined with the fostering of the often overlooked phase of hope — intrinsic hope — can be introduced into the continuum of care.

Intrinsic hope “is an inborn hope that all humans share,” maintain the authors. In contrast to the outward-directed or focused hope, “intrinsic hope centers on subjective, personal issues.” It enables patients to help themselves move through their grief about their impending death and evolve into a state of being rather than doing, in which they accept circumstances and live in the moment.

INTERVENTIONS TO UNLOCK INTRINSIC HOPE

- **Pain management.** “Pain is hope’s bitter enemy,” the authors state. “Aggressive symptom management, readily achieved through palliative care and hospice referral, removes a formidable barrier to the development of intrinsic hope.”
- **Truth-telling,** by which clinicians can do more than merely impart facts; they can also set in motion a process of emotional and psychological education that can trigger hope’s evolution rather than its decline or demise. Wise and timely truth-telling “can help patients understand and accept their limited life expectancy without harming their well-being or the clinician-patient relationship.”
- **Demonstrating a fully empathic presence,** by conveying “equanimity, partnership, and non-abandonment.” This is the “being” component of hope, note the authors, which applies not only to patients, but also to clinicians, and is expressed through the honest and compassionate quality of clinicians’ personal presence.

Delivering this type of care does not require specialized training, point out the authors. “Many clinicians instinctively provide it to patients near the end of life.”

The opinion piece is available online at: <http://blogs.bmj.com/bmj/2017/04/13/the-dual-nature-of-hope-at-the-end-of-life/>.

Source: “*The Dual Nature of Hope at the End of Life*,” *The BMJ Opinion*, April 13, 2017. Stuart B, Begoun A, Berry L; *Coalition to Transform Advanced Care*, Washington, DC; *private practice in clinical psychology*, Palo Alto, California; *Mays Business School, Texas A&M University, College Station, Texas*.

End-of-Life Care Websites

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

American Hospice Foundation
www.americanhospice.org

Information and Support for End-of-Life Care from the National Hospice and Palliative Care Organization
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

Palliative Care Fast Facts and Concepts, a clinician resource from the Palliative Care Network of Wisconsin
www.mypcnow.org

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.nhpc.org

Division of Palliative Care Mount Sinai Beth Israel
www.stoppain.org

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

© 2017 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

American Pain Society 2018 Scientific Summit: Understanding Pain Mechanisms. March 4–6, 2018, Disneyland Hotel, Anaheim, CA. Website: <http://americanpainsociety.org/annual-meeting/2018-scientific-summit>

Annual Assembly of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. March 14–17, 2018, Hynes Convention Center, Boston, MA. Website: <http://aahpm.org/meetings/assembly>

33rd Management and Leadership Conference of the National Hospice and Palliative Care Organization. April 23–25, 2018, Washington Hilton, Washington, DC. Website: www.nhpc.org

2018 Annual Scientific Meeting of the American Geriatrics Society. May 3–5, 2018, Walt Disney World Swan & Dolphin Resort, Orlando, FL. Website: <http://meeting.americangeriatrics.org>

Topics in Primary Care, Hospice, Palliative Care, Impaired Healthcare Professionals, Hematology, Oncology, and the History of Medicine. May 7–17, 2018, 10-night Western Mediterranean cruise conference from Rome (Civitavecchia), Italy, to Barcelona, Spain. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: www.continuingeducation.net



Some people mistakenly think hospice care is just about dying...nothing could be further from the truth. Hospice helps patients and families focus on living. Angels Grace Hospice, LLC, brings comfort, dignity and peace to help people with a life-limiting illness live every moment of life to the fullest. We also provide support for family and friends.

We are licensed in the state of Illinois, Joint Commission Accredited and are locally owned and operated by experienced professionals dedicated to providing excellent end-of-life care for Cook, DuPage, Grundy, Kane, Kendall, and Will counties. Please contact us for more information.

Angels Grace Hospice
440 Quadrangle Dr., Ste. G, Bolingbrook, IL 60440
888-444-8341
www.angelsgracehospice.com

To comfort always... this is our work

Quality of Life Matters®

Now in its 19th 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 end-of-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 healthcare 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
Quality of Life Publishing Co.
6210 Shirley St., Ste. 112, Naples, FL 34109

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

- Tools to meet HIS/CMS & CAHPS® requirements
- Written to meet health literacy standards
- Available in multiple languages



EDITORIAL TEAM

Karla Wheeler
Editor-in-Chief & Founder

Jan Carlton Doetsch
Clinical Editor

Gretchen Landolt
Chief Executive Officer

Kelly Brachle
Chief Operating Officer

Mike Schadler
Production Manager

Tony Uricchio
Graphic Designer

Jenny Wheeler
Assistant Editor