

Provided as an educational service by Your Organization

# Quality of Life Matters®

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

Vol. 19, Issue 4 Feb/Mar/Apr 2018

## Racial Disparity Gap in End-of-Life Care Narrowing, But Improvements in Overall Care Needed

Although family perceptions of the quality of care received by both black and white patients in the last month of life did not differ by race among those cared for by hospice, fewer black patients than whites were enrolled in hospice between 2011 and 2015. Further, black patients overall were more likely than whites to die in the hospital, particularly in an ICU, and less likely to die at home, according to a report published in *JAMA Internal Medicine*.

“Prior studies have identified racial disparities in multiple areas of end-of-life care,” write the authors. “Recent efforts to improve palliative care and hospice services may help reduce these disparities.” However, less than one-third of black patients and less than one-half of white patients studied received hospice services in the last month of life, with approximately the same low proportion overall dying at home, researchers from the University of Washington, Seattle, found.

Investigators analyzed interview responses of bereaved family members or close friends (n = 1106) familiar with the end-of-life experience of Medicare beneficiaries (black race, n = 281; white race, n = 825) who had participated between 2011 and 2015 in the National Health and Aging Trends Study (NHATS), a prospective study of functioning in later life.

Although the study did not differentiate between hospice and non-hospice patients in reporting respondents’ perceived quality of care for the specific end-of-life quality measures, the authors did find that “among patients who used hospice in the last month of life, there were no significant racial differences in care quality.”

### KEY FINDINGS

- Fewer black than white patients used hospice in the last month of life (31.0% vs 42.3%).
- Black patients were less likely to die at home (31.5% vs 40.0%).

- Death in an ICU was much more likely for black than for white patients (20.0% vs 8.6%).
- Approximately 20% of respondents for both black and white decedents reported that the family was not always kept informed.
- Overall quality of end-of-life care was rated as “excellent” by less than half of respondents for both black (47.7%) and white (49.4%) decedents.

“[R]espondents reported many deficiencies in the quality of end-of-life care for both black and white decedents,” write the authors, “including unmet symptom needs, problems with communication, and sub-optimal decision making.”

The authors note that their finding of an overall mediocre rating for care quality adds to “concerns that the quality of end-of-life care may be worsening for older people in general and suggests that improvements are needed for all patients in the United States.”

Source: “Association of Racial Differences with End-of-Life Care Quality in the United States,” *JAMA Internal Medicine*; December 1, 2017; 177(12):1858–1860. Sharma RK, Freedman VA, Mor V, Kasper JD, Gozalo P, Teno JM; Division of General Internal Medicine, University of Washington, Seattle; Institute for Social Research, University of Michigan, Ann Arbor; Department of Health Services, Policy, and Practice, Brown University School of Public Health, Providence, Rhode Island; and Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland.

### Inside:

#### NewsLine..... 1–3

- ✓ Racial Disparity Gap in End-of-Life Care Narrowing, But Improvements in Overall Care Needed
- ✓ Hospice Use Increases Among Leukemia Patients, Improving Quality of Life
- ✓ Patients with Chronic Liver Disease Enter Hospice Late in Disease Course, Following Aggressive Inpatient Care

#### Research Monitor..... 4–5

- ✓ Despite High Symptom Burden, Nursing Home Residents Unlikely to Receive Palliative Care
- ✓ Heart Failure Patients: Clinicians Urged to Incorporate Primary Palliative Care into ‘Everyday Practice’

#### Clinician Resources..... 6–7

- ✓ Patient-Facing Advance Care Planning Guides Found Helpful and Effective
- ✓ Conversation Card Game Spurs Patients’ Advance Care Planning Activity

# NEWSLINE

## Hospice Use Increases Among Leukemia Patients, Improving Quality of Life

*However, transfusion-dependent patients remain disadvantaged by very late referral*

A growing proportion of Medicare beneficiaries with leukemia were enrolled in hospice during the previous decade, and were found to be markedly less likely to die in the hospital or receive chemotherapy near death compared with non-hospice leukemia patients. Even so, only about half of eligible patients in this population used hospice services. Hospice lengths of stay remained short, especially among the one-fifth of patients dependent on blood transfusions.

That is according to the results of a study presented at the annual meeting of the American Society of Hematology (ASH) in December 2017. The abstract has been published in the society's journal *Blood*.

"While hospice use in leukemias appears to be increasing," write the authors, "patients with blood cancers use palliative and hospice services at end of life less frequently than those with solid tumors." Further, "markedly shorter time on hospice among transfusion-dependent patients indicates that the need for transfusion support may significantly delay hospice enrollment."

Using the linked Surveillance, Epidemiology, and End Results (SEER) Medicare database, investigators analyzed data on 21,076 beneficiaries with acute or chronic leukemia (median age, 79 years; women, 44%; acute leukemia, 46%) who died between 2001 and 2010. Transfusion dependence was defined as receiving two or more transfusions at least five days apart within 30 days prior to death or hospice enrollment.

### AMONG ALL LEUKEMIA PATIENTS:

- Hospice use increased from 35% to

49% from 2001 to 2011 ( $P < .0001$ ).

- Median length of hospice stay was only 9 days.
- Inpatient deaths decreased (from 51% to 38%), as did the receipt of chemotherapy within 14 days of death (from 15% to 10%).
- 20% of leukemia patients were transfusion dependent.

Hospice care was found to improve the quality of the patient's end-of-life experience. Leukemia patients who received hospice services had dramatically improved performance scores on quality end-of-life care measures compared with those who did not receive hospice care.

### HOSPICE LEUKEMIA PATIENTS:

- Had a dramatically lower likelihood of death in the hospital (3% vs 75%)
- Were less likely to receive chemotherapy in the last 14 days of life (5% vs 16%)
- Had a lower rate of end-of-life Medicare spending (\$7,662 vs \$17,783)

### TRANSFUSION DEPENDENCE DETERS 'MEANINGFUL' HOSPICE USE

"We found a significant association between transfusion dependence and less meaningful use of hospice care at the end of life among patients with leukemia," says senior author Thomas W. LeBlanc, MD, associate professor of medicine, Duke Cancer Institute, Durham, NC.

Although transfusion-dependent patients had a slightly higher likelihood of hospice enrollment (risk ratio [RR], 1.07; 95% confidence interval [CI], 1.03 to 1.11), they also had a 51% shorter time in hospice (RR, 0.49; 95% CI, 0.44 to 0.54)

and a 38% higher risk of receiving hospice services for less than three days (RR, 1.38; 95% CI, 1.26 to 1.52). "These findings suggest that patients are having to choose between getting the transfusions they need and getting high-quality end-of-life care," says LeBlanc.

### KEY FINDINGS

- While median hospice length of stay for all leukemia patients was very short at only 9 days, for transfusion-dependent patients it was significantly shorter (6 days vs 11 days;  $P < .0001$ ).
- Further, a greater proportion of transfusion-dependent patients received hospice care for less than 3 days (27% vs 19%;  $P < .0001$ ).

"This [finding] suggests that clinicians tend to enroll patients in hospice during the very last few days of life, but we know from other studies that the earlier patients enter hospice care, the more likely they are to obtain the full benefit of what hospice can offer in terms of an improved quality of life," says lead author Adam J. Olszewski, MD, assistant professor, the Warren Alpert Medical School, Brown University, Providence, RI.

Thus, while more leukemia patients are receiving hospice care, albeit very late, those who need palliative blood transfusions are receiving this quality care even closer to death, preventing the hospice multidisciplinary team from having the time needed to provide the full array of palliative and supportive end-of-life services, note the authors. They advocate for a change in Medicare policy regarding the provision of palliative transfusions.

*Continued on Page 3*

# NEWSLINE

## Patients with Chronic Liver Disease Enter Hospice Late in Disease Course, Following Aggressive Inpatient Care

Patients with chronic liver disease (CLD) have higher morbidity, longer hospital stays, more hospital readmissions, and higher annual hospital costs before being referred to hospice than do non-CLD patients, indicating that “patterns of healthcare use at the end of life remain uneven among diseases,” according to a report published in *The American Journal of Gastroenterology*.

“To date, this is the first study to fully describe the characteristics of Medicare beneficiaries with CLD who were discharged to hospice,” write the authors. “Our findings support previous research showing that patients with chronic illnesses are generally referred to hospice late in their disease course, which may lead to inadequate time to benefit fully from hospice care,” and further highlights “that this trend is substantially more prominent among patients with CLD.”

Investigators analyzed data on Medicare patients with CLD (n = 2179) discharged to hospice between 2010 and 2014 compared with a control group of non-CLD patients (n = 34,986). The most frequent causes of CLD were non-alcoholic fatty

liver disease (33.3%), followed by alcoholic liver disease (28.8%) and hepatitis C virus (25.7%).

### OVERALL FINDINGS

- CLD patients discharged to hospice were younger (70 vs 83 years of age); more likely to be male (57.7% vs 39.3%), and more likely to be diabetic (40.9% vs 30.1%) than were controls.
- A larger percentage of CLD patients were at higher risk for mortality as indicated by a Charlson Comorbidity Index score of 4 or above (34.9% vs 30.6%).
- Patients with CLD were more likely at hospice enrollment to be eligible for Medicare due to disability (23.5% vs 3.1%) than were controls.
- CLD patients spent less time in hospice compared with controls (mean, 13.7 days vs 17.7 days).

### ANNUALLY, PATIENTS WITH CLD AVERAGED:

- Longer hospital stays than controls (19.4 vs 13.0 days;  $P < 0.001$ )

- Higher rates of 30-day readmissions (51.6% vs 34.2%;  $P < 0.001$ )
- More hospital transfers (6.2% vs 2.5%;  $P < 0.0001$ )
- Higher hospital charges (\$175,281 vs \$108,999;  $P < 0.0001$ )
- A higher mean number of hospital visits (2.73 vs 1.97;  $P < 0.0001$ )

“These results support the observation that patients with advanced CLD often receive more aggressive life-prolonging therapies until their disease is highly advanced and hospice care is unlikely to be optimally beneficial,” write the authors. They add that their findings “should raise awareness for timely hospice referral and incite conscious efforts to improve access to hospice services, which will be essential for enhancing the quality of end-of-life care of our patients with CLD.”

Source: “Demographics, Resource Utilization, and Outcomes of Elderly Patients with Chronic Liver Disease Receiving Hospice Care in the United States,” *The American Journal of Gastroenterology*; November 2017; 112(11):1700–1708. Fukui N et al; Center for Liver Disease and Department of Medicine, Inova Fairfax Hospital; Betty and Guy Beatty Center for Integrated Research, Inova Health System, both in Falls Church, Virginia.

## Hospice Use Increases Among Leukemia Patients (from Page 2)

Medicare does not currently reimburse hospice agencies separately for the cost of blood transfusions. Instead, they must be covered within the flat per-diem compensation that hospices receive. There are also logistical challenges, since delivering blood to patients receiving care in the home, where most hospice patients receive care, can be a complex process.

“Allowing patients to receive transfusion support as part of palliative care could

transform the attitude of both patients and clinicians toward hospice care,” says Olszewski. “That could significantly change the mindset of patients and hematologists who have been expressing concerns about this, and have had an unwillingness to discuss hospice out of fear of bringing up the issue of having to terminate this support, which patients need,” he adds.

“If that creates a significant barrier to enrolling patients in hospice earlier, then

this could help,” Olszewski notes. “We are all working hard trying to make the lives of our patients more meaningful and also help them in the terminal phase of their disease.”

Source: “Transfusion Dependence and Use of Hospice Among Medicare Beneficiaries with Leukemia,” *Blood*; December 7, 2017; 130 (Suppl 1): Abstract 277; American Society of Hematology (ASH) 2017 Annual Meeting and Exposition, presented December 9, 2017. Olszewski AJ, Egan PC, LeBlanc TW.

# RESEARCH MONITOR

## Despite High Symptom Burden, Nursing Home Residents Unlikely to Receive Palliative Care

Nearly 70% of nursing home (NH) residents in facilities in northern California were found to be eligible for palliative care (PC), yet not one was receiving such care, and only two were enrolled in hospice, according to a research letter report published in *JAMA Internal Medicine*.

“Our work suggests that, although most nursing home residents report high symptom burden and are eligible for PC services, they are not receiving any formal interdisciplinary PC,” write the authors. “Furthermore, only 3.8% of residents had an MDS [Minimum Data Set]-documented prognosis of less than six months survival, an unlikely scenario considering the health status of these residents.”

The Centers for Disease Control and Prevention predicts that by 2030, 40% of Americans will die in NHs. Yet little is known of the PC needs of NH residents, and despite increasing yearly costs, NH care “has been associated with poor symptom control, low family satisfaction, and burdensome and unnecessary care transitions in the last months of life,” note the authors.

Investigators analyzed data gathered in 2015 from a PC quality initiative conducted in three northern California nursing homes that were participating in a broader quality improvement initiative to reduce hospital readmissions. Of the 228 residents studied, 157 (69%) were PC-eligible.

### AMONG PC-ELIGIBLE RESIDENTS OVERALL

- Mean age was 80.6 years; 64.9% were female, 39.5%, white.
- The most common diagnosis was Alzheimer’s disease/dementia (47.4%), followed by congestive heart failure (23.7%), chronic obstructive pulmonary disease (16.7%), and cancer (8.3%).
- 84.1% required extensive or total assistance in  $\geq 3$  activities of daily living.

- 32.7% of residents were in pain.
- The mean number of medications was 15.2 (range, 3 to 34).
- 98.7% had completed a POLST (Physician Orders for Life-Sustaining Treatment) form. 47.7% had selected full treatment; 27.5% opted for limited treatment; and 24.8% chose comfort-focused treatment.
- Nearly half (47.9%) had a hospital readmission within the past year.
- Not one resident was receiving PC.
- Only 3.8% had an MDS-documented prognosis of six months or less, and even fewer (1.3%) were enrolled in hospice.

“This finding suggests that accurate assessment of prognosis is likely not occurring; as a result, an opportunity for enhanced discussion of goals of care is missed,” the authors observe.

The investigators also conducted a substudy, analyzing data obtained from the Quality of Life at the End of Life (QUAL-E) instrument administered to a convenience sample of 17 PC-eligible, cognitively intact residents and their families ( $n = 28$ ), all of whom had also completed semi-structured interviews.

### SUBSTUDY FINDINGS

- 52.9% of residents rated their condition as fair to very poor.
- 63% believed that physical symptoms were quite or completely important to their overall quality of life.
- Although nearly all residents had completed a POLST form, few residents or family members in the subsample could recall having signed the form or having had a discussion about advance care planning.

Investigators also found that symptom burden as reported by residents was higher

than what their families perceived it to be.

### RESIDENT REPORTS VS FAMILY PERCEPTIONS

- The resident usually or always experienced bothersome symptoms in the past week (residents, 70.6%; families, 64.3%).
- Symptoms were severe or very severe (residents, 82.3%; families, 60.7%).
- Symptoms interfered moderately to completely with resident’s quality of life (residents, 70.6%; families, 57.1%).

“Increasing access to PC for nursing home residents is critical given mounting evidence confirming that PC care in the NH setting is associated with improved care quality and satisfaction, enhanced symptom management, and fewer emergency department visits, particularly when such care is initiated earlier in the disease course,” the authors write.

“Early identification of PC-eligible residents can help health systems target efforts designed to meet documented patient preferences, improve symptom management, ensure timely referral to hospice care, and reduce burdensome care transitions at the end of life.”

A major barrier to access to PC in NHs is the lack of PC-trained clinicians able to care for patients in these settings, note the authors. They suggest that newer strategies, such as telemedicine, be explored and implemented to increase access to this much-needed care.

*Source: “Palliative Care Eligibility, Symptom Burden, and Quality-of-Life Ratings in Nursing Home Residents,” JAMA Internal Medicine; Epub ahead of print, November 20, 2017; DOI: 10.1001/jamainternmed.2017.6299. Stephens CE et al; Department of Community Health Systems, University of California, San Francisco; San Francisco Veterans Affairs Medical Center, San Francisco; Asian Health Services, Oakland, California; Division of Geriatrics, Department of Medicine, University of California, San Francisco.*



# RESEARCH MONITOR

## Heart Failure Patients: Clinicians Urged to Incorporate Primary Palliative Care into ‘Everyday Practice’

A literature review of recent clinical research on the impact of palliative care on patients with heart failure (HF) has found that this care approach improves the quality of patient-centered outcomes such as symptom burden and quality of life (QoL) among HF patients. Although the evidence base is still emergent, it suggests several opportunities for clinicians to introduce primary palliative care concurrent with traditional HF treatment, according to a report published in the *Journal of the American College of Cardiology*.

“We should not be waiting until heart failure patients are eligible for hospice care — in other words, truly at the end of life — to start considering palliative options,” says lead author Dio Kavalieratos, PhD, assistant professor of medicine, Section of Palliative Care and Medical Ethics at the University of Pittsburgh. “With improved education, cardiologists and primary care clinicians can integrate palliative care techniques in the everyday practice.”

More than six million Americans are currently living with HF, and approximately 870,000 are newly diagnosed with this chronic, progressive disease each year, according to the authors. Common physical and psychological symptoms that affect the QoL of HF patients, such as pain, depression, and anxiety, are still often under-recognized and undertreated.

Palliative care, which focuses on improving QoL and relieving suffering for patients facing serious illness and their families, is both a clinical specialty and an overall approach, note the authors. It includes both specialty palliative care, to which a patient may be referred if symptoms or needs become complex, and primary palliative care, which can be provided by any clinician.

### KEY FINDINGS: IMPROVED OUTCOMES

Researchers analyzed results of an earlier meta-analysis of randomized clinical trials of palliative care interventions, selecting the six strongest trials, published from 2014 through 2017, that either focused exclusively on HF patients or reported results separately by specific disease group.

Among the benefits of palliative care for HF patients identified within the studied trials were improved QoL, symptom burden, mood, and spiritual well-being, and to a lesser extent, improved New York Heart Association functional class, fewer hospital readmissions, and decreased one-year mortality.

“Although the evidence base for palliative care in HF is na-

scient,” write the authors, “there is generally consistent evidence that a palliative approach improves a variety of patient-centered outcomes, including symptom burden and QoL.”

### ‘NATURAL OPPORTUNITIES’ FOR INTEGRATING PALLIATIVE CARE

Primary and HF clinicians are urged by the authors to be aware of “multiple natural opportunities” for integrating palliative care into HF management — based on need, not prognosis — throughout the disease trajectory. They explain that palliative care can be provided at the following key times:

- **As a response to unmanaged symptoms and distress.** Pain, depression, and poor spiritual well-being are commonly reported issues among HF patients, and can all be managed with palliative care. Among patients with HF, symptoms such as pain are frequently under-recognized, and depression screenings are rare. Ongoing care providers should be alert to the HF patient’s need for palliative care in the management of both physical symptoms and psychosocial/spiritual distress.
- **Upon hospital admission and discharge.** HF patients experience a higher rate of acute care (hospital and ICU admissions and emergency department visits) during the last 30 days of life than do cancer patients, and HF patients’ mortality risk increases with each hospitalization. Because of this, the authors urge clinicians to use the opportunity of hospital admission or discharge for discussing goals of care with patients and for assessing their palliative care needs.
- **During transition to end-of-life care.** Despite high rates of morbidity and mortality among patients with advanced HF, hospice utilization remains low, note the authors. Only about one-third of HF patients receive hospice care at the time of death, and HF patients are more likely to have very short hospice lengths of stay (enrolling within three days of death) compared with cancer patients.

“[N]umerous cardiology professional societies have called for the continued and earlier integration of hospice care for patients with advanced heart disease,” write the authors. However, they stress the importance of understanding that

*Continued on Page 6*

# CLINICIAN RESOURCES

## Patient-Facing Advance Care Planning Guides Found Helpful and Effective

Both an online advance care planning (ACP) tool called PREPARE and an easy-to-read advance directive (AD) — neither of which requires clinician or health system input — were found comfortable to use by patients and effective in increasing documentation of end-of-life care preferences, according to a report published in *JAMA Internal Medicine*.

“The success of both PREPARE and the easy-to-read AD may be explained by their attention to both literacy and cultural considerations designed with and for diverse communities,” write the authors. “This study suggests that PREPARE and the easy-to-read AD may be useful ACP interventions on a population level, especially in resource-limited health systems.”

Earlier trials had shown that, while the previously developed AD increased documentation, there was a need among older adults for more preparation for the complex, ongoing decision making involved in ACP, note the authors. The PREPARE website offers individuals a simple 5-step process, “how-to” videos, and behavior modeling. “Both tools are patient-facing, meaning their use does not require clinician- or systems-level involvement to begin the ACP process,” write the authors.

Investigators analyzed data gathered in a comparative effectiveness clinical trial conducted among participants with two or more chronic conditions (mean age, 71.1 years; nonwhite, 43%; limited literacy, 20%; self-reported fair-to-poor health status, 29%) enrolled from multiple primary care clinics at the San Francisco Veterans Affairs Medical Center from 2013 to 2016. Participants were randomly assigned to use either PREPARE plus AD or the AD alone.

### KEY FINDINGS

- At nine months, ACP documentation was higher in the PREPARE arm than

in the AD-only arm (35% vs 25%). This included legal forms and orders (20% vs 13%) as well as documented discussions (26% vs 20%).

- Patient-reported ACP engagement was also higher for PREPARE, at one-week, three-month, and six-month follow-up.
- Participants in both the PREPARE and AD-only arms gave high ratings for ease of use of the guides (9.0 and 8.7, respectively, on a 10-point scale) and for satisfaction, which was measured on a 5-point scale, for comfort (4.5 and 4.4, respectively), helpfulness (4.4 and 4.3), and likelihood of recommending to others (4.4 and 4.2).

The results suggest that “PREPARE and the easy-to-read AD could serve as scalable, easy-to-disseminate tools to im-

prove the ACP process, especially in busy and resource-poor primary care clinics,” write the authors. “Although these tools are likely to be synergistic with other clinician- and system-level interventions, more research is needed.”

The PREPARE tool can be found at <https://prepareforyourcare.org>.

*Source: “Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement among Veterans: A Randomized Clinical Trial,” JAMA Internal Medicine; August 1, 2017; 177(8):1102–1109. Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE; Division of Geriatrics, Department of Medicine, University of California, San Francisco; San Francisco Veterans Affairs Medical Center, San Francisco; Department of Epidemiology & Biostatistics; and Department of Psychiatry, University of California, San Francisco.*

## Heart Failure Patients (from Page 5)

palliative care is related to but distinct from hospice care, and patients would benefit from palliative care while still undergoing curative treatment.

Greater awareness among primary and HF clinicians of the benefits of hospice and specialty palliative care can help ensure that HF patients get a timely referral to these services, while primary palliative care can help facilitate advance care planning and a transition to hospice.

“Given the growing prevalence of HF, the integration of palliative care within HF management represents an opportunity to affect the public health issue of poor QoL in patients and caregivers while optimizing care delivery,” write the authors. They call for further research to identify unmet needs of HF patients and their families, and to determine the most effective care models, delivery methods, and treatments for addressing symptom burden in this population.

*Source: “Palliative Care in Heart Failure: Rationale, Evidence, and Future Priorities,” Journal of the American College of Cardiology; October 10, 2017; 70(15):1919–1930. Kavalieratos D et al; Department of Medicine, Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, University of Pittsburgh, Pittsburgh; Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York; Geriatric Research Education and Clinical Center, James J. Peters Veterans Affairs Medical Center, Bronx, New York.*

# CLINICIAN RESOURCES

## Conversation Card Game Spurs Patients' Advance Care Planning Activity

For patients with chronic illness and caregivers or surrogates of chronically ill persons, participating in an end-of-life conversation card game was reported to be an enjoyable, positive experience. The community outreach project that used the game increased engagement in activities related to advance care planning (ACP) within three months of the event.

"[P]articipants felt that playing the game empowered and prepared them to perform ACP while gaining new understandings about death and dying," write the authors of a report published in the *Journal of Pain and Symptom Management*.

Despite the established benefits of ACP, "estimates are that less than 33% of adults have had ACP conversations or completed ADs [advance directives], in part because many people perceive discussions about dying to be unpleasant, intimidating, or uncomfortable," write the authors. They suggest that a friendlier and more social type of intervention such as this game could be used as a tool preceding more traditional educational and decision support tools for AD completion.

For this mixed-methods study, investigators analyzed questionnaire and interview responses of 93 older adults taking part in one of 22 games held at 12 different community venues in Pennsylvania. Participants included 49 patients with chronic illness and 44 unpaid caregivers/surrogates of patients with chronic illness. The most common chronic diagnoses were heart disease (39.1%) and diabetes (37.0%).

Immediately following the game, participants gave the game conversation high ratings for being satisfying, realistic, and of high quality. There were no significant differences in responses based on age, gender, or role.

Both patients and caregivers reported that playing the game among strangers was reassuring when they heard their own perspectives validated by others, and useful for gaining insights when they listened to preferences different from their own. Overall, participants believed the structured game format made discussing sensitive end-of-life topics a comfortable and even enjoyable experience.

### WITHIN THREE MONTHS POST-GAME:

- 77% of participants reported having a better understanding of ACP.
- 75% engaged in at least one aspect of positive ACP behavior; 44% completed an AD document.
- 33% engaged in other ACP-related behavior, such as helping a family member with ACP or researching hospice care.
- 81% said they felt better prepared to have end-of-life conversations.
- However, while 53% said they talked to family about end-of-life issues, only 13% reported having spoken to their healthcare professional about such issues.

The end-of-life conversation game, called "Hello," was formerly known as "My Gift of Grace," and is available for purchase online from the game's creator, Common Practice.

Source: "Community Game Day: Using an End-of-Life Conversation Game to Encourage Advance Care Planning," *Journal of Pain and Symptom Management*; November 2017; 54(5):680–691. Van Scoy LJ, Reading JM, Levi BH, et al; Department of Medicine and Humanities; Department of Medicine; and Department of Pediatrics and Humanities; Pennsylvania State University College of Medicine, Hershey.

## End-of-Life Care Websites

American Academy of Hospice and Palliative Medicine  
[www.aahpm.org](http://www.aahpm.org)

American Hospice Foundation  
[www.americanhospice.org](http://www.americanhospice.org)

Information and Support for End-of-Life Care from the National Hospice and Palliative Care Organization  
[www.caringinfo.org](http://www.caringinfo.org)

Center to Advance Palliative Care  
[www.capc.org](http://www.capc.org)

The EPEC Project (Education in Palliative and End-of-Life Care)  
[www.epec.net](http://www.epec.net)

Palliative Care Fast Facts and Concepts, a clinician resource from the Palliative Care Network of Wisconsin  
[www.mypcnow.org](http://www.mypcnow.org)

Hospice and Palliative Nurses Association  
[www.hpna.org](http://www.hpna.org)

Hospice Foundation of America  
[www.hospicefoundation.org](http://www.hospicefoundation.org)

Medical College of Wisconsin Palliative Care Center  
[www.mcw.edu/palliativecare.htm](http://www.mcw.edu/palliativecare.htm)

National Hospice & Palliative Care Organization  
[www.nhpc.org](http://www.nhpc.org)

Division of Palliative Care Mount Sinai Beth Israel  
[www.stoppain.org](http://www.stoppain.org)

Promoting Excellence in End-of-Life Care  
[www.promotingexcellence.org](http://www.promotingexcellence.org)

University of Wisconsin Pain and Policy Studies Group  
[www.painpolicy.wisc.edu](http://www.painpolicy.wisc.edu)

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

© 2018 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.nhpco.org](http://www.nhpco.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](http://www.continuingeducation.net)

## Advertise Your Organization 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 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](mailto: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](http://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

**Mary Kay Grimaldi**  
Editorial Consultant

19-4