

Provided as an educational service by Angels Grace Hospice

Quality of Life Matters®

News & clinical findings about serious illness

Vol. 21, Issue 2 Aug/Sept/Oct 2019

Minimal Knowledge of Palliative Care Among U.S. Adults Highlights Need to Raise Public Awareness

In a national survey of Americans aged 18 years or older, nearly three-quarters reported they had never heard of palliative care, illustrating a serious need to raise awareness of and provide accurate information about the goals and benefits of palliative care to the general public, according to a report published in the *Journal of Palliative Medicine*.

“This finding raises concerns for practitioners and policy makers,” write the authors. “The limited awareness in the general public stands in stark contrast to

movements to increase early integration of palliative care as a standard of care regardless of curative intent.”

Patients and the general public need to know that palliative care has been shown to help improve quality of life, relieve symptom burden, and reduce psychosocial distress, note the authors. “Educating the public and newly diagnosed patients about palliative care has been found to decrease fear and increase intention to use palliative care services,” they write.

Raising awareness about palliative care can help:

- Normalize palliative care and reduce any stigma caused by misperceptions
- Improve patient self-advocacy
- Increase overall demand for palliative care services at patients’ time of need

Investigators analyzed data collected in 2018 on a nationally-representative sample of U.S. adults (n = 3445; nonwhite, 20.1%) from the most recent version of the Health Information National Trends Survey (HINTS), administered by the National Cancer Institute.

OVERALL

- 71% of respondents had never heard of palliative care.
- 18% said they knew “a little” about palliative care.
- 11% felt they knew enough to explain palliative care to someone else.

“Concerted efforts to promote awareness and understanding of palliative care among the general public may help support informed decision making...”

— Trivedi et al,
Journal of Palliative Medicine

The main finding that such a large percentage of Americans are unfamiliar with palliative care “is an important reminder for clinicians not to assume that patients and caregivers know about palliative care or its benefits,” comment the authors. “Specifically, low awareness of palliative care could explain why many in the United States do not inquire about palliative care despite suffering from serious illnesses.”

Limited awareness may also contribute to misperceptions about this type of supportive care, requiring extra efforts on the part of clinicians to explain this care and its benefits, they note. “Research suggests that when patients are informed and educated about palliative care, they largely choose to receive it.”

PREDICTORS OF PALLIATIVE CARE AWARENESS

- Female gender (odds ratio [OR], 2.41; 95% confidence interval [CI], 1.84 to 3.17; $P < 0.001$)

Continued on Page 3

Inside:

NewsLine..... 1-3

- ✓ Minimal Knowledge of Palliative Care Among U.S. Adults Highlights Need to Raise Public Awareness
- ✓ Heart Disease Patients More Likely to Be Referred to Palliative Care by Generalists Than Cardiologists

Research Monitor..... 4-6

- ✓ Medicare Community-Dwelling Older Adults with Dementia Have Higher Symptom Burden Than Others in Last Year of Life
- ✓ Intervention Found to Improve Oncologists’ Serious Illness Communication, While Lowering Patient Anxiety

Clinician Resources..... 7

- ✓ Free Dementia Care Toolkit Helps Clinicians Support Patients and Their Caregivers

NEWSLINE

Heart Disease Patients More Likely to Be Referred to Palliative Care by Generalists Than Cardiologists

More than one-fourth of patients with cardiovascular disease (CVD) who were referred for palliative care (PC) consults had significant symptom burden, a proportion that did not change over the three-year study period, Duke University researchers have found. Cardiologists provided relatively few of these referrals — fewer referrals than did general practitioners and other specialists — and their referrals decreased proportionately over time.

“These findings reinforce the need for cardiologists to be more engaged with PC and consider referring appropriate patients with CVD sooner,” write the authors of a report published in *JAMA Network Open*. “Further work is needed to develop clinical guidelines that provide tailored PC to patients with advanced CVD.”

The leading cause of death in the U.S., CVD is characterized by a high symptom burden, yet PC remains underused among these patients, the authors note. Leading professional and health agency organizations, such as the American College of Cardiology and the American Heart Association, have recommended the early incorporation of PC into routine cardiovascular care.

“We should be encouraged that practitioners, professional societies, healthcare systems, and research funding agencies are starting to recognize the importance of palliative care for patients with serious cardiovascular disease,” write the authors.

The role of specialty PC is to provide multidisciplinary care for patients with serious illness that is complementary to primary and other specialty care, point out the authors. PC specialists can be consulted when complex symptom management issues arise, so that patients’ goals of care can be established and documented and their psychosocial issues can be addressed.

“Future work should focus on fostering capacity and competency among cardiologists and other healthcare practitioners to provide early, primary palliative care and to appropriately refer patients to palliative care specialists,” write the authors.

Investigators analyzed data on 1801 adult patients with CVD (mean age, 77.7 years; female, 48.6%; white race, 74.3%) referred to a PC specialist and presenting for an initial visit from 2015 through 2017. Data collected were from a national, physician-entered, patient-reported registry that included specialty PC consultations conducted at 16 diverse academic and community institutions across the U.S.

POOR FUNCTIONAL STATUS; HIGH SYMPTOM BURDEN

28.9% of CVD patients had a low palliative performance score (PPS), a percentage that showed no evidence of change over time.

“Efforts should be made to further engage all clinicians, including cardiologists, in providing early and appropriate access to palliative care for their patients.”

— Warraich et al, *JAMA Network Open*

A low PPS (0 to 30 out of a possible 100) indicates a patient who is bedridden, drowsy or comatose, and fully dependent.

61.9% of CVD patients had a moderate PPS (40 to 60), indicating a patient who is frequently bedbound with moderate dependency.

The finding that over one-quarter of CVD patients had a low PPS score at the time of initial consultation, suggesting a disease in its later stages, contrasts with only 10% of cancer patients with a low PPS score at time of PC consultation, as reported in a 2017 analysis using the same database registry, the authors note.

“Our data suggest that patients with CVD are referred to PC fairly late in their disease trajectory,” they write. “Although palliative care can be of particular value for patients in the last days of life, more value could be gained by patients if they were able to access palliative care earlier.”

THE MOST COMMON MODERATE-TO-SEVERE SYMPTOMS INCLUDED:

- Poor well-being (52%)
- Tiredness (50.3%)
- Anorexia (35.7%)
- Dyspnea (27.9%)
- Pain (19.7%)

In unadjusted analysis, there was a reduction over time in the proportion of patients with moderate-to-severe pain (from 22.8% to 16.5%) and drowsiness (from 21.7% to 12.7%), but the proportion of those with poor well-being increased (from 37% to 53.5%).

After adjustment, later year of encounter was associated with improved symptoms of pain (odds ratio [OR], 1.25; 95% confidence interval [CI], 1.05 to 1.50) and constipation (OR, 1.32; 95% CI, 1.03 to 1.69). No other changes through time in patient characteristics or symptoms were noted.

Continued on Page 3

NEWSLINE

Minimal Knowledge of Palliative Care Among U.S. Adults Highlights Need to Raise Awareness (from Page 1)

- White vs nonwhite race (OR, 1.84; 95% CI, 1.23 to 2.75; $P < 0.001$)
- Higher educational attainment, i.e., compared with high school or less, those with some college (OR, 2.73; 95% CI, 1.83 to 4.06; $P < 0.001$), a college degree (OR, 4.37; 95% CI, 2.80 to 6.81; $P < 0.001$), or postgraduate work (OR, 11.08; 95% CI, 6.95 to 17.67; $P < 0.001$)
- Older age, i.e., compared with those aged 18–34 years, respondents aged 35–49 years (OR, 1.79; 95% CI, 1.10 to 2.90; $P < 0.001$), 50–64 years (OR, 2.44; 95% CI, 1.57 to 3.81; $P < 0.001$) or ≥ 65 years (OR, 2.62; 95% CI, 1.72 to 3.97; $P < 0.001$)

Lower odds of palliative care awareness were found among those reporting Hispanic vs non-Hispanic ethnicity (OR, 0.59; 95% CI, 0.36 to 0.98; $P = 0.04$). Previous cancer diagnosis and recent experience as a caregiver were not significantly associated

with palliative care awareness.

The observed demographic differences point to a need for targeted palliative care communication and education efforts directed to younger individuals, men, and ethnic minorities, suggest the authors.

“This analysis is one of the first to examine a nationally-representative sample of U.S. adults’ awareness of palliative care,” comment the authors. “Concerted efforts to promote awareness and understanding of palliative care among the general public may help support informed decision making; such endeavors should begin with the populations with the least awareness and most needs.”

Source: “Awareness of Palliative Care Among a Nationally Representative Sample of U.S. Adults,” Journal of Palliative Medicine; Epub ahead of print, April 30, 2019; DOI: 10.1089/jpm.2018.0656. Trivedi N, Peterson EB, Ellis EM, Ferrer RA, Kent EE, Chou WS; Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, Maryland.

Heart Disease Patients More Likely to Be Referred to Palliative Care by Generalists Than Cardiologists (from Page 2)

OVERALL

- CVD patients represented 13.9% of all 12,914 adult patients evaluated and treated by PC specialists during the study period. This proportion did not change over time.
- Most CVD patients had a primary diagnosis of heart failure, although the proportion with this diagnosis decreased slightly over time, from 74.4% to 60.5%, while the proportion of non-heart failure CVD diagnoses (such as coronary artery disease, valvular heart disease, and peripheral vascular disease) increased from 25.6% to 30.1%.
- 70.5% of CVD patients were hospitalized at the time of the consult, 14.7% were residing in nursing facilities, and 11.9% were living at home.

“Given that Medicare beneficiaries admitted with heart failure have a median survival of two years, hospitalization might be an opportunity to introduce palliative care to patients with heart failure,” suggest the authors.

KEY FINDINGS

- While the percentage of PC referrals from general medicine and critical care rose over the three-year period (from 43.2%

to 52.9% and from 3.1% to 6.6%, respectively), the proportion of referrals initiated by cardiologists declined, dropping from 16.5% to 10.5%.

- The proportion of black patients referred to PC decreased over time from 11.9% to 6.3%.
- At consult start, 51% of CVD patients chose DNR orders, while after PC consultation, 68.4% of CVD patients elected not to be resuscitated.

The finding that most patients had an advance directive (69.2%) and an identified healthcare proxy (93.8%) in proportions higher than found in the general population is encouraging, note the authors, suggesting recent improvement in the PC delivered by the primary referring teams. “Efforts should be made to further engage all clinicians, including cardiologists, in providing early and appropriate access to PC for their patients.”

Source: “Characteristics and Trends among Patients with Cardiovascular Disease Referred to Palliative Care,” JAMA Network Open; May 3, 2019; 2(5):e192375. Warraich HJ, Wolf SP, Mentz RJ, Rogers JG, Samsa G, Kamal AH; Department of Medicine, Duke University Medical Center; Department of Biostatistics and Bioinformatics, Duke University; Duke Clinical Research Institute; and Duke Cancer Institute, all in Durham, North Carolina.

RESEARCH MONITOR

Medicare Community-Dwelling Older Adults with Dementia Have Higher Symptom Burden Than Others in Last Year of Life

In a nationally representative sample of community-dwelling older adults — nearly 40% of whom had dementia — the presence of dementia was associated with greater prevalence of most symptoms, higher symptom burden, and more limitations in social activities in the last year of life than found among those with no dementia, according to a report in the *Journal of Palliative Medicine*.

“Older patients with dementia or physical symptoms may benefit from earlier emphasis on palliative care and quality of life,” write the authors. “Given higher symptom burden in decedents with dementia, earlier palliative care should be considered in a disease where life expectancy can be challenging to predict.”

Investigators analyzed interview responses of 1270 community-dwelling older adults (mean age, 82.5 years) who enrolled in the 2011 National Health and Aging Trends Study (NHATS) and died by 2015. An ongoing, longitudinal study of a nationally representative cohort of Medicare beneficiaries, NHATS conducts annual follow-up interviews with respondents or their proxies. 37.3% of participants were either diagnosed with dementia or determined to have probable dementia.

The most commonly reported symptoms among all community-dwelling Medicare recipients in the last year of life were:

- Low energy (68.6%)
 - Pain (58.9%)
 - Lower extremity weakness (56.3%)
 - Poor balance or coordination (55.5%)
- Dementia participants were more likely than those without dementia to be:
- Older (85.0 years vs 80.6 years; $P < 0.001$)
 - Female (59.4% vs 52.5%; $P = 0.02$)
 - Of nonwhite race/ethnicity (10.6% vs

8.3%; $P < 0.003$)

- Less well-educated (less than high school education, 71.8% vs 61.1%; $P < 0.001$)

DEMENTIA AND SYMPTOM BURDEN

Except for insomnia and breathing problems, participants with dementia had higher prevalence of all 13 clinical symptoms and impairments when examined than did those with no dementia. These symptoms included, in descending order: low energy, balance/coordination difficulty, limited strength or movement in extremities, pain, depression, hearing impairment, difficulty speaking/being understood, vision impairment, and anxiety.

Presence of dementia was associated with a significantly greater likelihood of high vs low symptom burden in:

- Sensory symptoms (OR, 4.52; 95% CI, 3.08 to 6.63; $P < 0.001$)
- Physical symptoms (OR, 3.49; 95% CI, 2.48 to 4.91; $P < 0.001$)
- Psychiatric symptoms (OR, 2.80; 95% CI, 1.98 to 3.95; $P < 0.001$)

Association of dementia with medium vs low symptom burden for sensory and physical symptoms showed a similar pattern, while no difference was found between those with and without dementia in psychiatric symptoms.

LIMITATIONS IN SOCIAL ACTIVITY

Social engagement is an aspect of quality of life that is frequently identified by patients as being of value, and has been associated with better health outcomes. But its importance — and the symptoms that impact it — may be overlooked or underemphasized toward the end of life, the authors note.

Having dementia was associated with participation limitations in all six social

activities examined. After adjustment, dementia was independently associated with social limitations in three activities:

- Going out for enjoyment (OR, 2.38; 95% CI, 1.58 to 3.57; $P < 0.001$)
- Participating in clubs or organized activities (OR, 1.84; 95% CI, 1.34 to 2.53; $P < 0.001$)
- Volunteering (OR, 1.55; 95% CI, 1.08 to 2.24; $P < 0.001$)

Among all participants, both with and without dementia, higher likelihood of social limitation in at least three of six activities was found among those who had problems with speaking, poor balance/coordination, and limited lower extremity strength or movement.

“Of note,” write the authors, “physical symptoms that were independently associated with participation limitations in the remaining social activities (visiting family/friends, attending religious services, and engaging in a favorite activity) are commonly seen in advanced dementia.

“In the context of our study, a goal-oriented approach to patient care may be an optimal paradigm, especially in the last years of life,” suggest the authors. Such an approach, which focuses on the symptoms and activities identified by patients as most important to their quality of life, is provided by the multidisciplinary services of palliative care and its subset, hospice, they note.

Source: “Before Hospice: Symptom Burden, Dementia, and Social Participation in the Last Year of Life,” *Journal of Palliative Medicine*; Epub ahead of print, May 6, 2019; DOI: 10.1089/jpm.2018.0479. Amjad H, Snyder SH, Wolff JL, Oh E, Samus QM; Division of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine, Baltimore; Division of Geriatric and Palliative Medicine, Walter Reed National Military Medical Center, Bethesda, Maryland; Department of Health Policy and Management; and Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, Baltimore.

RESEARCH MONITOR

Intervention Found to Improve Oncologists' Serious Illness Communication, While Lowering Patient Anxiety

A communication improvement program has resulted in earlier, more patient-centered serious illness conversations and increased documentation of cancer patients' values and goals in the electronic medical record (EMR), while decreasing patients' symptoms of moderate to severe anxiety and depression, according to two reports on a clinical trial published in *JAMA Oncology* and *JAMA Internal Medicine*.

"This communication quality improvement intervention resulted in more, earlier, better, and more accessible serious illness conversations documented in the EMR," write the authors. "To our knowledge, this is the first such study to demonstrate improvement in all four of these outcomes."

Encouraging clinicians to initiate conversations earlier and then document the notes for easy access in the EMR addresses an issue essential for patient safety, the authors note. "If clinicians, especially those clinicians who are unfamiliar with the patient and facing an emergency, cannot easily retrieve documentation of patient goals, values, and preferences, patients may be at increased risk of receiving unwanted care."

Investigators analyzed results of a cluster randomized clinical trial of a communication quality improvement intervention, the Serious Illness Care Program (SICP), which had been designed and tested by the team to help oncology clinicians improve the occurrence, timeliness, quality, and accessibility of documentation of serious illness conversations.

The intervention was aimed at addressing common barriers to timely, high-quality serious illness conversations. These barriers include:

- Lack of clinician training in communication skills
- Clinician time constraints
- Patient anxiety
- Clinician uncertainty about appropriate timing or patient readiness for a discussion of serious illness issues
- Ambiguity concerning responsibility among clinicians for holding these discussions
- Inadequate system support for clinicians to elicit and document patient goals

The trial was conducted at ten disease centers at the Dana-Farber Cancer Institute in Boston and two of its affiliated satellite clinics between 2012 and 2016. Participants were 91 oncology clinicians (including physicians, nurse practitioners, and physician assistants) and 278 of their adult patients who died within two years of enrollment in the study. The participants were randomized into an intervention arm (48 oncology clinicians, 134

"Oncologists should initiate conversations...Not because this will necessarily improve outcomes, but because patients want, require, and deserve to know what is coming."

— Kiely and Stockler, *JAMA Oncology*

patients) and a control arm (43 clinicians, 144 patients).

THE INTERVENTION

The intervention included clinical tools, clinician training, and system changes. The primary clinician tool, the structured Serious Illness Conversation Guide (SICG), was reinforced by a brief clinician training session conducted by palliative care experts. Also included were patient tools, such as a Family Guide for intervention patients to continue the conversation with their loved ones.

System components included: the "surprise question" ("Would you be surprised if this patient died in the next year?") for identifying patients appropriate for a serious illness discussion; email reminders; a structured EMR documentation template with training provided for its use; and coaching as needed on the use of the SICG by palliative care faculty.

Clinicians in the control group provided usual care, and also used the surprise question to identify patients, but did not receive any of the intervention components. They were made aware of the EMR module, but not trained in the SICG.

The investigators evaluated both the process outcomes of the intervention (occurrence, timing, quality, and documentation of the discussions) and patient outcomes (goal-concordant care, peacefulness at the end of life, therapeutic alliance between clinician and patient, anxiety, depression, and survival).

OVERALL FINDINGS

- 97.9% of clinicians rated the intervention as effective (mean score, 4.3 out of a possible 5.0).
- Of the 83% of clinicians who received a reminder, 87.2% completed at least one serious illness conversation.
- Median conversation duration was 19 minutes (range, 5 to 70 minutes).
- Median survival did not differ between groups (intervention, 13.9 months vs control, 13.6 months).

Continued on Page 6

RESEARCH MONITOR

Intervention Found to Improve Oncologists' Serious Illness Communication, While Lowering Patient Anxiety (from Page 5)

PROCESS OUTCOMES

Serious illness conversations should include a scope of topics, with a focus wider than on informed preferences for specific treatments at the end of life, as crucially important as those are, note the authors. Four domains of serious illness conversation were targeted by the intervention: values or goals; prognosis or illness understanding; end-of-life care planning; and life-sustaining treatment preferences.

KEY FINDINGS

- Significantly more intervention group patients than controls had at least one documented discussion (96% vs 79%; $P = 0.005$).
- Intervention patients' discussions included more domains of high-quality serious illness discussions than did controls' (mean 3.2 vs 1.9 domains out of a possible 4; $P < 0.001$).
- A higher proportion of intervention discussions included prognosis or illness understanding (91% vs 48%; $P < 0.001$).
- More intervention discussions included patient values and goals (89% vs 44%; $P < 0.001$).
- Significantly earlier timing for the first conversation was found among intervention patients compared with control patients (median time before death, 143 days vs 71 days; $P < 0.001$).
- Intervention conversations were more likely to include discussion of life-sustaining treatment preferences (63% vs 32%; $P = 0.004$).
- Documentation of end-of-life care planning did not differ significantly between the two arms, nor did median survival (intervention group, 13.9 months; controls, 13.6 months).
- Intervention patients were more likely to have their discussions documented in the accessible structured EMR module (61% vs 11%; $P < 0.001$).

PATIENT OUTCOMES

- Significant reductions in the percentage of patients with symptoms of moderate to severe anxiety were found in the intervention group compared with the controls, at 14 weeks (5.0% vs 10.2%; $P = 0.05$) and at 24 weeks (4.2% vs 10.4%; $P = 0.02$). At baseline, proportions of anxiety were similar in both groups, at about 9%.
- The proportion of patients reporting moderate to severe depression symptoms was also significantly lower among those in the intervention group at 14 weeks (10.6% vs 20.8%; $P =$

0.04), but the reduction in depression was not sustained at 24 weeks (12.5% vs 17.8%; $P = 0.31$). Proportions of those experiencing anxiety at baseline were similar in both groups, at about 20%.

- No significant differences were found in goal-concordant care (as assessed post-death by caregivers) and peacefulness at the end of life between intervention and control groups.
- Patients' scoring of therapeutic alliance did not differ between arms, either at baseline or at 14-week or 24-week follow-ups.

The authors acknowledge disappointment in the null findings of several of their patient outcomes. "However," they conclude, "the significant reductions in anxiety and depression in the intervention group are clinically meaningful and require further study.

"We expect these findings to be transferrable to other clinical contexts that treat patients with advanced cancer while also recognizing that these intervention components require substantial organizational resources."

IMPLICATIONS FOR CLINICIANS

"Much can be learned from the two reports of an elegant, rigorous, and innovative clinical trial of the SICP...," write the authors of an accompanying editorial. "Oncologists should be reassured that having these conversations is unlikely to increase anxiety or depression in their patients."

The editorial authors ask, "How should this trial influence clinical practice? Oncologists should initiate conversations about serious illness with patients who have a significant risk of dying in the foreseeable future. Not because this will necessarily improve outcomes, but because patients want, require, and deserve to know what is coming."

Sources: "Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial," *JAMA Internal Medicine*; Epub ahead of print, March 14, 2019; DOI: 10.1001/jamainternmed.2019.0077. Bernacki R et al; Harvard Medical School; Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Ariadne Labs; Department of Medicine; and Department of Psychiatry, Brigham and Women's Hospital, all in Boston. "Evaluating an Intervention to Improve Communication Between Oncology Clinicians and Patients with Life-Limiting Cancer: A Cluster Randomized Clinical Trial of the Serious Illness Care Program," *JAMA Oncology*; Epub ahead of print, March 14, 2019; DOI: 10.1001.jamaoncol.2019.0292. Paladino J et al; Harvard Medical School; Ariadne Labs; and Department of Medicine, Brigham and Women's Hospital; Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; and Department of Psychiatry, Brigham and Women's Hospital, all in Boston. "Discussing Prognosis, Preferences, and End-of-Life Care in Advanced Cancer: We Need to Speak," *ibid.*; DOI: 10.1001.jamaoncol.2019.0291. Kiely SE, Stockler MR; University of Sydney, Camperdown, NSW, Australia.

CLINICIAN RESOURCES

Free Dementia Care Toolkit Helps Clinicians Support Patients and Their Caregivers

Aiming to guide clinicians and institutions in improving care for patients with dementia and their caregivers, the Center to Advance Palliative Care (CAPC) has developed both an online toolkit and an educational course, offered free of charge to members and nonmembers alike.

The toolkit, “Implementing Best Practices in Dementia Care,” begins by describing the dementia burden incurred by patients, caregivers, and the U.S. healthcare system, then makes the case for the benefits of early and accurate diagnosis of and care for those living with this disease. The bottom line, according to CAPC: “Patients experiencing cognitive impairment — and their caregivers — need timely diagnosis, care management, goal-concordant care plans, and referral to support services.”

TOOLKIT COMPONENTS

- **Cognitive Assessment Tools** contains a list of validated tools available for free use, provides links to other assessment resources, and suggests six steps to take following diagnosis of cognitive impairment. “When the diagnosis is identified, clinicians can act to prevent the health crises and caregiver exhaustion that result in ED visits and hospitalizations.”
- **Assessing Needs of People Living with Dementia** presents a list of free, validated tools for assessing common clinical issues found among those with dementia, notes the most common causes of hospitalization among these patients, and urges attentive care of comorbidities. “If comorbid conditions have been identified, document those conditions and the results of assessments in the EHR [electronic health record] to ensure effective care coordination.”
- **Caring for the Caregiver** offers links to free, validated tools for assessing caregiver well-being. “If caregiver needs are unmet, chances are much higher that your patient’s needs will be unmet as well.” Four steps are suggested for caregiver support.
- **Referral to Community Resources** contains links to online organizations providing directories of local community partners, as well as links to resources and tip sheets for caregiver education. “In many cases, caregivers and people living with dementia are too overwhelmed to seek out these resources on their own. Direct clinician referral to community-based organizations can help.”
- **Dementia Care Resources for Caregivers** can be printed as a handout. It lists names and web addresses of caregiver support organizations.
- **Dementia Care Resources in Our Community** is a single-page template that can be filled out with contact information for local community-based services, to be used by staff or supplied to patients/caregivers.

“Supporting the Caregivers of People Living with Dementia” is an online course presenting strategies clinicians can use to assess caregivers’ well-being and ensure that their needs are met.

Both the course and toolkit are available at www.capc.org/welcome-dementia-care.

End-of-Life Care Websites

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

Information and Support for End-of-Life Care from the National Hospice and Palliative Care Organization
www.nhpco.org/patients-and-caregivers/

Center to Advance Palliative Care
www.capc.org

The EPEC Project (Education in Palliative and End-of-Life Care)
www.bioethics.northwestern.edu/programs/epec/about/

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

Hospice and Palliative Nurses Association
www.hpna.org

Hospice Foundation of America
www.hospicefoundation.org

Medical College of Wisconsin Palliative Care Program
www.mcw.edu/departments/palliative-care-program

National Hospice & Palliative Care Organization
www.nhpco.org

Division of Palliative Care Mount Sinai Health System
www.stoppain.org

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

© 2019 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

Supportive Care in Oncology Symposium: Advancing Palliative Research Across the Care Continuum. October 25–26, 2019, San Francisco, CA. Sponsor: American Society of Clinical Oncology. Website: www.asco.org

National Hospice and Palliative Care Organization Interdisciplinary Conference 2019. November 4–6, 2019, Gaylord Palms Resort and Convention Center, Orlando, FL. Website: www.nhpco.org/education/nhpco-conferences

Center to Advance Palliative Care National Seminar 2019. November 14–16, 2019, Atlanta Marriott Marquis, Atlanta, GA. Areas of focus include: Palliative Care and the Opioid Crisis, Quality with Efficiency, and Telehealth. Website: www.capc.org/seminar

Palliative Medicine and End of Life Care, Including Related Topics in Neurology. December 14–21, 2019, seven-night southern Caribbean cruise conference, round-trip from San Juan, Puerto Rico. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: www.continuingeducation.net

American Geriatrics Society 2020 Annual Scientific Meeting. May 7–9, 2020, Long Beach, CA. Website: www.americangeriatrics.org



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 21st 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 news and clinical findings related to serious illness, 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 other than the publisher. The quarterly newsletter is published by Quality of Life Publishing Co., a firm dedicated to easing the way for patients with serious illness and their families.

We customize copies of the newsletter for healthcare 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 MATERIALS
at www.QOLpublishing.com**

- Tools to improve CMS & CAHPS® performance
- Written to follow health literacy guidelines
- 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