

Quality of Life Matters®

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

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Record 1.56 Million Patients Served by Hospice

Non-cancer diagnoses accounted for 60% of all admissions

Nearly 42% of all those who died in this country in 2009 were being cared for by a hospice service at the time of death, according to an annual report released by the National Hospice and Palliative Care Organization (NHPCO). Further, performance measures show that family ratings of satisfaction with the quality of care they and their loved ones received remain very high.

“This rising statistic shows that more Americans facing a life-limiting illness are opting for care that addresses medi-

cal, emotional, and spiritual needs at the end of life,” commented J. Donald Schumacher, PsyD, NHPCO president and CEO. “That is the compassionate care that hospice and palliative care bring to patients and families in need.”

Although cancer remains the single most common primary diagnosis upon admission, it now accounts for just 40% of total hospice admissions. The report notes that 2003 was the first year in which the proportion of patients admitted to hospice with a cancer diagnosis accounted for less than half of all admissions; in that year, 950,000 Americans were served by hospice.

The median length of stay in hospice decreased, but only slightly, from the previous year, while the proportion of patients who died or were discharged within two weeks of admission increased, but again, only slightly and not significantly enough to indicate a trend. In contrast, the trend toward smaller proportions of patients remaining for long stays under hospice care continued.

KEY FINDINGS INCLUDE:

- Median length of hospice service in 2009 was 21.1 days (2008, 21.3 days).
- 48.5% of patients died or were discharged within 14 days (2008, 48.4%).
- 34.4% of patients died or were dis-

Primary Non-Cancer Diagnoses Include:

- Heart disease (11.5%)
- Dementia (11.2%)
- Lung disease (8.2%)
- Stroke or coma (4.0%)
- Kidney disease (3.8%)
- Debility unspecified (13.1%)

— “NHPCO Facts and Figures: Hospice Care in America”

charged within 7 days (2008, 35.4%).

- 11.8% of patients remained under hospice care for longer than 180 days (2008, 12.1%).

The number of hospices nationwide continues to grow. The first program opened in 1974. By 1994, hospice programs numbered 3,650. In 2008, 5,000 hospices served patients in all 50 states, the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands.

FAMILY SATISFACTION RATINGS REMAIN CONSISTENTLY HIGH

Family ratings of satisfaction with the care they and their loved one receive from hospice have remained consistently high. In 2009, 96.6% of families reported that the hospice

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Palliative Care Teams: The ‘Fourth Pillar’ of Comprehensive Cancer Care

Oncologists offered practical approach for introducing supportive care into care plan discussions

The early integration of palliative care into curative care can be particularly helpful for patients with cancer, who often experience significant symptom burden and psychosocial distress. Oncologists play a critical role in deciding whether and when to refer their patients to a palliative care program, but in many cases these referrals occur too late to provide needed services, according to an article published in the *Journal of Clinical Oncology*.

“There has been a significant increase in the use of palliative care by oncologists. However, the referral of patients to palliative care occurs late in the trajectory of illness, at an average of 30 to 60 days before death,” write the authors, who are medical oncologists from the University of Texas M. D. Anderson Cancer Center in Houston. **“The majority of families referred to palliative care programs state that they would have preferred an earlier consultation.”**

A major barrier to earlier referral to palliative care is based on a misunderstanding of such care: that it is needed

only at the end of life and that it means giving up hope. The authors encourage physicians to use the term “supportive care,” if they feel that introducing the topic as “palliative care” would be distressing to patients and/or to themselves as a signal of losing hope.

“Cancer is a serious illness. The absence of any plans to manage physical and psychosocial distress and to prepare for the possibility of progressive disease should therefore be considered unreasonable denial rather than hopefulness,” the authors assert.

SETTING CONCURRENT GOALS OF CARE: A CAR TRIP ANALOGY

The article presents the steps one would take in preparing for a car trip as an analogy clinicians can use with patients for setting goals of care. While the goal of a car trip is to travel from point A to point B, the journey is much more enjoyable if preparations are made for one’s comfort while driving. Additionally, it is wise not to assume one will meet with no adverse conditions while on the road and thus to travel in a car without safety features.

Similarly, while the goals of care for cancer patients are often cure or stabilization — even if these may not be the final outcomes in most cases — the patient who is both hopeful and realistic will want to: 1) take measures to maximize comfort along the cancer journey and 2) make plans to be prepared for any challenges that may lie on the road ahead.

COMFORT MEASURES

Comfort measures such as treatment of pain and depression can improve quality of life, lessen stress, and increase adherence to cancer treatment. Car analogy: air

conditioning, back cushion.

SAFETY FEATURES

Safety features such as planning in advance for changes in living arrangements, mobility, safety aids in bathroom and bedroom, family knowledge, advance directives, and resuscitation status can minimize patient and family distress when illness advances and at the end of life. Car analogy: seat belts, airbags, auto insurance.

“Early introduction of supportive/palliative care might provide patients with better physical and emotional symptom control, allowing them to make informed decisions with less distress,” comment the authors. “Indeed, early referral to palliative care can facilitate timely diagnosis and treatment of symptoms, longitudinal psychosocial support and counseling, as well as a gradual transition of care.”

Because the evaluation of cancer patients requires complex multidisciplinary interventions by the primary oncologist, the authors recommend the integrated-care approach for high-quality supportive/palliative care.

The American Society of Clinical Oncology has declared the goal of integrating palliative care into its model of comprehensive cancer care by the year 2020. Meanwhile, state the authors, “Supportive/palliative care can be integrated into the collaborative model that exists among surgical, radiation, and medical oncologists as the fourth pillar of comprehensive cancer care, supporting patients and their families alongside oncologists.”

Source: “Integrating Supportive and Palliative Care in the Trajectory of Cancer: Establishing Goals and Models of Care,” Journal of Clinical Oncology; September 1, 2010; 28(25):4013-4017. Bruera E, Hui D; University of Texas M. D. Anderson Cancer Center, Houston.

Providing Supportive/ Palliative Care Concurrently with Oncologic Care Can:

- Maximize physical and emotional care
- Support patients through cancer therapies
- Enhance patient adherence to treatments
- Facilitate transitions of care
- Prepare patients and families for challenges to come

— Adapted from Bruera and Hui, *Journal of Clinical Oncology*

Geographic Access Less of a Barrier: 88% of U.S. Population Lives within Half-Hour Drive of a Hospice Facility

A cross-sectional analysis of geographic access to hospice by national Census tracts has found that, although state and community level variation still exists, the vast majority of the population lived within reasonable driving distance of at least one hospice facility in 2008.

“Given that more than 90% of hospice care involves staff making home visits and staff visit multiple homes in a given day, proximity to a hospice is important in ensuring access to these services,” write the authors of a report published in the *Journal of Palliative Medicine*.

PROXIMITY FINDINGS INCLUDE:

- In 2008, 88% of the population lived in communities within 30 minutes driving time of at least one hospice; 98% lived within 60 minutes of at least one hospice.
- An estimated 74% of the U.S. population lived within 30 minutes driving time of at least two hospices; 94% lived within 60 minutes of at least two hospices.
- The average driving time between community centers and the nearest hospice ranged from five minutes for Washington, DC, to 84 minutes for Alaska.

- Mean time to the nearest hospice was 15 minutes (range, 0 to 403 minutes).

Community characteristics linked to greater proximity to hospices included:

- Higher population density
- Higher median household income
- Lower percentage of population with less than a high school education
- Higher percentage of black residents

“While there exists a small subset of communities for which geographic access to hospice remains a concern, future research regarding variation in hospice use should focus on other potential barriers to hospice care, including hospice admission criteria, hospice size/capacity, and patient-level financial and cultural factors,” the authors conclude.

Source: “Geographic Access to Hospice in the United States,” Journal of Palliative Medicine; November 2010; 13(11):1311-1338. Carlson MDA, Bradley EH, Du Q, Morrison RS; Brookdale Department of Geriatrics and Palliative Medicine, Mount Sinai School of Medicine, New York City; Department of Epidemiology and Public Health, Yale University School of Medicine, New Haven, Connecticut; James J. Peters Veterans Affairs Medical Center, Bronx, New York.

Record 1.56 Million Patients Served by Hospice

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team clearly explained the plan of care; 75.6% rated the patient’s care as “excellent;” and 76.9% said the bereavement services met their needs “very well.”

“Health care professionals must work to help patients and families understand where the course of their illness may take them. And, when cure is not possible, it is our duty to offer the robust benefits that the hospice team can provide,” asserts Schumacher.

The full report, entitled “NHPCO Facts and Figures: Hospice Care in America,” is available at www.nhpc.org.

More Benefits of Hospice Care

Several major studies reporting in the past few years have found that:

- **Hospice care may improve survival among some terminally ill patients.** Researchers found a mean survival benefit of 29 days among hospice vs nonhospice patients across four disease categories, with congestive heart failure patients living a mean 81 days longer than their nonhospice counterparts. (Connor SR, et al: “Comparing Hospice and Nonhospice Patient Survival among Patients Who Die within a Three-Year Window;” *Journal of Pain and Symptom Management*; March 2007; 33(3):238-246).
- **Early adoption of palliative care may prolong survival in cancer patients.** Lung cancer patients receiving early palliative care lived nearly 3 months longer than those whose palliative treatment was delayed, as is currently standard. (Temel JS, et al: “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer;” *New England Journal of Medicine*; August 2010; 363(8):733-742).
- **Hospice services save Medicare an average of \$2,309 per patient.** Researchers additionally found that if hospice were used for a longer period of time, Medicare costs would be reduced for 7 out of 10 hospice recipients. (Taylor DH, et al: “What Length of Hospice Use Maximizes Reduction in Medical Expenditures Near Death in the U.S. Medicare Program?” *Social Science & Medicine*; October 2007; 65(7):1466-1478).

While Nearly All Hospices Now Serve Patients with Dementia, Family and Provider Awareness May Be Lacking

In 1995, only 1% of all hospice patients entered with a primary diagnosis of dementia, and only 21% of hospices served these patients, according to the authors of a recent study published in the *Journal of the American Geriatrics Society*. During the past year, 11.2% of hospice patients enrolled with a diagnosis of dementia, and 94% of hospices and 72% of nonhospice palliative care programs had cared for a dementia patient.

“Almost all hospices and a majority of nonhospice palliative care programs serve patients with dementia,” write the authors. “This finding is encouraging news, in that more patients with dementia and their families may be getting needed help in manag-

ing the disease.”

The investigators analyzed survey responses from executive directors of 426 programs providing the following services: hospice care only; both hospice care as well as nonhospice palliative care outside of the traditional hospice insurance benefit; or nonhospice palliative care only.

Ninety-six percent of respondents agreed or strongly agreed that dementia is a terminal illness, and 98% agreed or strongly agreed that palliative care is effective for these patients.

BARRIERS TO PALLIATIVE CARE

The most frequently cited barriers to palliative care included:

- Lack of awareness about palliative care for patients with dementia by families (54%) and referring clinicians (50%)
- Policies making reimbursement for care of dementia patients more difficult than for those without dementia (58%)
- The need for formal respite services for caregivers (46%)

Lack of awareness of palliative care programs for dementia patients by providers and families can lead to infrequent referrals and extremely late referrals, according to many administrators. “We may not get referrals on these patients until they are in the dying process,” one respondent commented.

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Less Than Half of Cardiologists Surveyed Would Discuss Palliative Care with Late-Stage Heart Failure Patients

Despite clear guidelines from the American College of Cardiology/American Heart Association recommending discussion of prognosis, advance directives, and palliative care with patients with advanced heart failure (symptomatic despite therapy), not even half of cardiologists responding to a national survey indicated they would hold such discussions, a research team has found.

“Over half of the cardiologists sampled for this study recommended care that was discordant from these guidelines, and this discordance was worse in the regions performing more intense medical care in the last six months of life,” write the authors of a study published in the *Journal of Palliative Medicine*.

The team analyzed the responses of 614 cardiologists to a questionnaire presenting two scenarios of elderly patients with late-stage heart failure. By practice address,

each respondent was assigned to a hospital referral region (HRR). The HRRs were categorized into one of five quintiles, based on the intensity of care in that region during patients’ last six months of life.

KEY FINDINGS

- In a 75-year-old patient with stage IV heart failure and non-sustained ventricular tachycardia, less than one-third of cardiologists would “initiate or continue discussions about palliative care.”
- Cardiologists in the highest-intensity quintile were less likely than those in the lowest-intensity quintile to hold such discussions in this scenario (23% vs 32%).
- In an elderly patient with stage IV heart failure and an acute exacerbation, less than half of cardiologists indicated they would hold a palliative care discussion.

- Again, cardiologists in highest-intensity regions were less likely than those in lowest-intensity regions to have such discussions (35% vs 47%).

“The work to improve the care of patients with end-stage heart failure is important, challenging, and ongoing,” comment the authors. “[E]fforts to increase awareness of palliative care among cardiologists and knowledge about how to best implement palliative care in heart failure populations are greatly needed.”

Source: “Regional Variations in Palliative Care: Do Cardiologists Follow Guidelines?” Journal of Palliative Medicine; November 19, 2010; 13(11):1315-1319. Matlock DD, Peterson PN, et al; Department of Medicine, University of Colorado, Denver; Department of Medicine, Denver Health Medical Center, Denver; Clinical Research Unit, Colorado Permanente Medical Group, Denver; Veterans Affairs Medical Center, White River Junction, Vermont; Dartmouth Medical School, Hanover, New Hampshire.

More Men with Prostate Cancer Receive Hospice Care, Yet Percentage of Late Referrals Remains High

The increasing use of appropriate hospice care for men dying of prostate cancer may be improving their quality of life at the end of life, but for the 25% of these patients who enroll within a week of death, such care may arrive too late to relieve the burden of illness, according to the authors of a report published in the *Archives of Internal Medicine*.

“We found that the proportion of men dying of prostate cancer who use hospice resources has increased over time, although the percentage of those enrolling very close

to the end of life remains too high,” write the authors.

Researchers used the National Cancer Institute’s population-based registry and Medicare data to identify 14,521 men (age, 66 years and older) who died of prostate cancer between 1992 and 2005. Overall, 53% had used hospice, and the median length of stay was 24 days.

RESEARCH FINDINGS

- The percentage of men with prostate cancer who used hospice increased from

about 30% in 1992 to 61% in 2004.

- Men receiving hospice care were less likely in the last six months of life to receive high-intensity care — including inpatient hospital stays, admissions to intensive care units, and multiple emergency department visits — than their non-hospice counterparts (odds ratio [OR], 0.82; 95% confidence interval [CI], 0.74-0.91).
- The proportion of patients with prostate cancer who died within 7 days of hospice enrollment during the period 1992-2005 rose from about 18% to 25%.

“Hospice stays shorter than seven days are too brief to maximize the benefit of enrollment, and individuals making shorter stays receive fewer services and benefit less from the input of the full interdisciplinary team,” state the authors. **“Late hospice referral and low hospice enrollment indicate low-quality end-of-life care.”**

Sociodemographic characteristics associated with increased hospice use included:

- White ethnicity
- Partnered relationship status
- Higher socioeconomic status
- More recent year of death

“Our findings suggest that increasing hospice enrollment... may provide avenues for controlling cost and maximizing quality of life, by minimizing expensive interventions that improve neither the quality of care nor the quality of life at the end of life,” comment the authors.

Source: “Hospice Use and High-Intensity Care in Men Dying of Prostate Cancer,” Archives of Internal Medicine; October 11, 2010; doi:10.1001/archinternmed.2010.394. Bergman J, Saigal CS, Lorenz KA, et al, for the Urologic Diseases in America Project; Departments of Urology and Health Services, and Jonsson Comprehensive Cancer Center, University of California, Los Angeles; Department of Veterans Affairs Greater Los Angeles Healthcare System, Los Angeles.

Dementia Patients (from page 4)

Palliative care needs and services most often rated as “extremely important” in the care of patients with dementia included:

- Family information regarding disease progression (83%)
- Management of behavioral symptoms (83%)
- Assistance with caregiver burden or guilt (78%)

“Most of my time is spent with emotional support, teaching and reassuring the family caregivers,” commented one respondent, while another noted, “many dementia patients live at the edge for long periods of time. Families and caregivers are overwhelmed.”

SUCCESSFUL STRATEGIES

Strategies considered critical for success in caring for dementia patients included the following:

- An interdisciplinary team structure
- Collaboration with community organizations, such as nursing homes or local support groups
- Alternatives to aggressive end-of-life care

“Education and policy efforts should focus on education for families and providers, support for caregivers, and reforming reimbursement structures to provide coverage for interdisciplinary palliative care earlier in the disease, when patients have high needs but are not hospice eligible,” the authors conclude.

Source: “Palliative Care for Patients with Dementia: A National Survey,” Journal of the American Geriatrics Society; November 2010; 58(11):2114-2121. Torke AM, Holtz LR, Hui S, Castelluccio P, Connor S, et al; Indiana University Center for Aging Research; Fegenstrief Institute, Inc.; Fairbanks Center for Medical Ethics; and Division of Biostatistics, Department of Medicine, Indiana University, all in Indianapolis, Indiana; Worldwide Palliative Care Alliance, London, United Kingdom; and National Hospice and Palliative Care Organization, Alexandria, Virginia.

CLINICIAN RESOURCES

Clinicians Offered Practical Updates in Palliative Care

Experts glean recommendations from previous year's journal articles

A pair of experts in palliative care have reviewed and critiqued the literature of the past year to identify the most clinically significant findings with potential to impact the practice of palliative and hospice care.

Wendy G. Anderson, MD, assistant professor of medicine, division of hospital medicine and palliative care program, University of California, San Francisco, and Nathan E. Goldstein, MD, assistant professor of geriatrics and palliative medicine, Mount Sinai Medical Center, New York, published their recommended updates in the *Journal of Palliative Medicine*.

Below are several of their recommendations, with a brief summary of the original research, followed by Anderson and Goldstein's "clinical bottom line."

PSYCHOSOCIAL CARE

Provide phone support from nurses to cancer patients living in rural areas.

A randomized controlled trial of an educational intervention among 681 cancer patients in a rural cancer center and a VA medical center found that those patients receiving the multicomponent intervention had higher quality of life, lower depressed mood, and a trend toward lower symptom intensity. (Bakitas M, et al, *Journal of the American Medical Association* 2009; 302:741-749.)

Clinical bottom line: "Providing rural patients with advanced cancer with nurse-led telephone support and education to encourage patient activation, self-management, and empowerment improves quality of life and decreases rates of depression."

LONG-TERM CARE, KIDNEY DISEASE

Explain to nursing home patients and their families the association of initiating dialysis with functional decline and mortality.

A secondary analysis of the U.S. Renal Data system and the Minimum Data Set for nursing home residents found that among 3,902 residents who started dialysis, there was a significant decline in every activity of daily living, with only about 12% of residents maintaining their functional status following dialysis initiation. (Kurella Tamura M, et al, *New England Journal of Medicine* 2009; 361:1539-1547.)

Clinical bottom line: "The initiation of dialysis in nursing home patients is associated with a rapid decline in functional status and high rates of mortality at one year. Presenting this prognostic information may help older nursing home residents and their

families to make decisions about the initiation of dialysis that are consistent with their goals and values."

LONG-TERM CARE, DEMENTIA

Determine proxy knowledge of the course of dementia; it is linked to the type of care received at the end of life.

In a prospective cohort study of 323 nursing home residents with advanced dementia, only 22% were referred to hospice, although 96% of family members acting as their proxies reported comfort as the main goal of care. During the last three months of the resident's life, only 20% of proxies thought their loved one had six months or less to live, and only 18% reported receiving prognostic information from a nursing home physician. Residents whose proxies said they understood the complications of the disease and believed their loved one had six months or less to live were less likely to undergo invasive therapies during the last three months before death. (Mitchell SL, et al, *New England Journal of Medicine* 2009; 361:1529-1538.)

Clinical bottom line: "Nursing home patients with advanced dementia have high morbidity, mortality, and symptom burden. Proxy knowledge and understanding of the clinical course of dementia is associated with decreased interventions near the end of life."

SPIRITUAL CARE

Provide spiritual support for patients with advanced cancer to improve their quality of life at the end of life.

A prospective, longitudinal cohort study of 343 decedents treated at seven geographically diverse sites found that family members rated their loved ones' care higher when patients had reported receiving spiritual support from the medical team. Patients receiving pastoral care were more likely to report medical team support of their spiritual needs, and those patients who felt their spiritual needs were supported by the team were more likely to use hospice. (Balboni TA, et al, *Journal of Clinical Oncology* 2010; 28:445-452.)

Clinical bottom line: "Supporting patients' spiritual needs may change their utilization of health care and increase their quality of life near death."

Source: "Update in Hospice and Palliative Care," *Journal of Palliative Medicine*; November 2010; 11(13):1305-1310. Anderson WG, Goldstein NE; Division of Hospital Medicine and Palliative Care Program, University of California, San Francisco, San Francisco; Department of Geriatrics and Palliative Medicine, Mount Sinai School of Medicine, New York City; James J. Peters VA Medical Center, Bronx, New York.

CLINICIAN RESOURCES

EPERC's Fast Fact #204 Outlines Approach to End-of-Life Communication Consistent with Values of African Americans

Values and preferences for care at the end of life among African Americans differ in general from that of the population as a whole, research shows. A recent monograph from EPERC (End of Life/Palliative Education Resource Center) summarizes broad trends in the care desired and received by African Americans and offers recommendations for clinicians to conduct effective end-of-life care planning discussions.

DIFFERENCES IN CARE AT THE END OF LIFE

Compared with European Americans, African Americans are more likely to: receive aggressive treatment at the end of life; disenroll from hospice care to seek life-prolonging treatment; and die in a hospital. Although rates of in-hospital deaths have declined among European Americans over the past few decades, the rates of in-hospital deaths among African Americans have remained steady.

African Americans are less likely to: complete an advance directive; receive hospice/palliative care at the end of life; have their symptoms controlled; and indicate satisfaction with care and communication at the end of life.

Possible reasons for these differences include:

- Deep cultural values, including strong religious faith
- Racism, health care inequalities, and mistrust of the medical system
- Lack of availability of hospices and pharmacies in minority neighborhoods

APPROACH TO END-OF-LIFE COMMUNICATION

- Before making recommendations, ask for the patient's views on end-of-life care and decision making. *"Have you thought about what will happen as you get sicker? Are you the type of person who makes decisions alone, or do you want your family to be involved?"*
- Ask about the importance of religious beliefs and/or spirituality.
- Focus on the positive, on meeting shared goals, rather than on what you are going to do. *"I want to help you live as best as you can, given how sick you are becoming."*
- Notice any issues of trust. Address them openly and try to understand them. Build trust by offering time, careful communication, and close follow-up.
- Recognize that the patient's idea of a "good death" may genuinely differ from yours. Focus on the needs of the patient, seeking shared goals and values. Make your recommendations for best medical care based on the patient's prognosis, options, and goals.

Values and practices within African-American communities are diverse and individual, caution the authors, noting that their outline represents broad trends. "Clinicians are advised not to make assumptions about individual patients based on population data, and to always explore each patient's values and wishes."

Source: "African Americans and End-of-Life Care," *Fast Facts and Concepts*: May 2008; 204. Raghavan M, Smith A, Arnold R. Available at: www.eperc.mcw.edu/fastfact/ff_204.htm

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

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

www.nhpco.org

National Hospice & Palliative Care Organization

www.caringinfo.org

Caring Connections: National Consumer Engagement Initiative to Improve End-of Life Care

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/palliativecare.htm

Medical College of Wisconsin Palliative Care Center

www.painpolicy.wisc.edu

University of Wisconsin Pain and Policy Studies Group

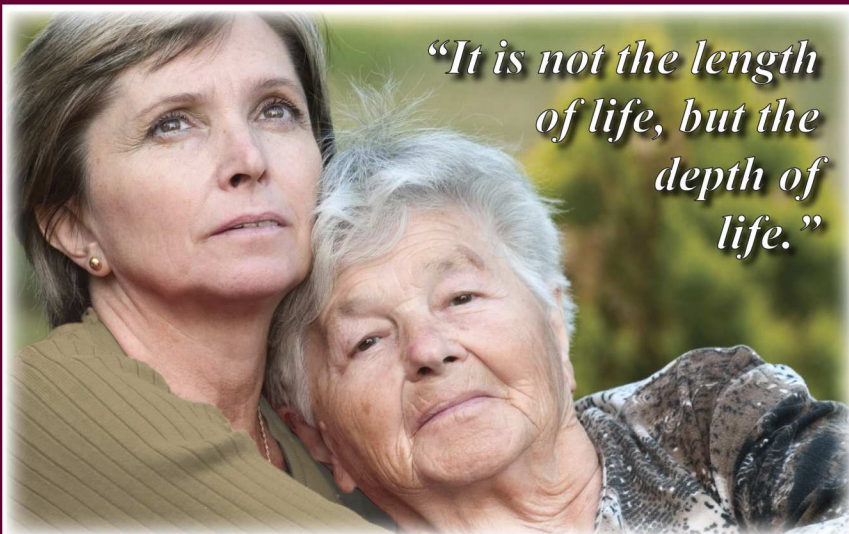
www.capc.org

Center to Advance Palliative Care

www.stoppain.org

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of life, but the
depth of
life.”*

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