Enrollment in hospice during the last six months of life is associated with improved patient satisfaction and pain control, as well as fewer hospital days and lower rates of hospital and intensive care unit (ICU) mortality among Medicare patients, according to a report published in BMJ Supportive & Palliative Care.

“Consistent with other studies demonstrating benefit, the use of hospice care is associated with better quality-of-care outcomes, including patient-centered care metrics,” write the authors, adding that their findings highlight the importance of “greater expansion of hospice use to reduce deaths in the hospital setting and improve the quality of care for chronically ill patients.”


Patients represented in the study were more than 163,000 Medicare beneficiaries who died in 2010 and had been hospitalized one or more times in the previous two years for at least one of the following nine chronic illnesses associated with high mortality rates: malignant cancer/leukemia, chronic pulmonary disease, coronary artery disease, congestive heart failure, peripheral vascular disease, severe chronic liver disease, diabetes with end-organ damage, chronic renal failure, and dementia.

**KEY FINDINGS**

- 46.8% of patients were enrolled in hospice in the last six months of life.
- 31.1% of all patients died in the hospital.
- 21.9% of patients died in an ICU.

Hospice care in the last six months of life was associated with the following variables representing high-value end-of-life care. These included:

- Fewer hospital deaths (linear correlation coefficient $[r] = 0.842; P = 0.01$)
- Reductions in hospital days ($r = 0.517; P = 0.01$)
- Better pain control ($r = 0.491; P = 0.01$)
- Patient satisfaction ratings ($r = 0.448; P = 0.01$)
- Fewer deaths in an ICU ($r = 0.358; P = 0.01$)

In additional analyses, structural equation modeling (SEM) identified the use of hospice care as inversely related to hospital mortality (SEM coefficient $= -0.885; P = 0.01$), ICU mortality (SEM coefficient $= -0.457; P = 0.01$), and number of days hospitalized in the last six months of life (SEM coefficient $= -0.517; P = 0.01$). Hospitals that used hospice care had higher patient reports of satisfaction.

“The results of this investigation demonstrate that greater use of hospice care during the last six months of life is associated with improved patient experience, including satisfaction and pain control, as well as clinical outcomes of care, including decreased ICU and hospital mortality,” write the authors.
Heart Disease and Stroke Patients Need Palliative/Hospice Care, Says AHA/ASA Policy Statement

A new policy statement issued jointly by the American Heart Association (AHA) and American Stroke Association (ASA) promotes the routine integration of palliative care into the management of advanced cardiovascular disease (CVD) and stroke patients, and urges timely referral of appropriate patients to hospice care. The statement was published in the journal *Circulation*.

“Palliative care provides that much-needed level of support for patients and families dealing with cardiovascular disease and stroke,” says Lynne Braun, CNP, PhD, lead author and chair of the AHA committee that produced the statement. “This approach to care can help patients better understand the disease they are fighting, their treatment options, and their prognosis.

“More than that, it can give them the strength they need to carry on in their day-to-day life by easing the burden of care for the family, as well as providing extra relief from symptoms, distress, and pain the patient may be experiencing,” adds Braun.

Heart failure affects an estimated 5.7 million Americans over 20 years of age, and about 6.6 million Americans in that age group have had a stroke, notes the statement. These patients frequently have long-term poor health-related quality of life (HRQOL) due to deteriorating health, symptom distress, and complex care regimens. In addition, their caregivers often experience psychological stress and significant burden.

Palliative care, which is “critical” to those with heart disease or stroke and their families, is defined as “patient- and family-centered care that optimizes HRQOL by anticipating, preventing, and treating suffering.” The statement urges that palliative care be integrated early in the disease course by the patient’s primary treating interdisciplinary care team; if needed, the team can work with palliative care specialists to address more complex and challenging needs and concerns.

**INTEGRATED PALLIATIVE CARE:**
- Helps meet the priority needs of patients
- Supports clinical care best practices
- Better aligns care with patient preferences
- Contributes to improved quality of care and outcomes for patients and families
- Improves preparation for end-of-life care

**END-OF-LIFE PREPARATION**
CVD’s unpredictable disease trajectory can prevent clinicians from discussing future care options and end-of-life issues with patients and their families, the authors note. “However,” they continue, “this communication simply must take place.” They suggest that uncertainty be used as a trigger for exploration of patient values, rather than as a reason to avoid discussing prognosis and goals of care. “[I]t is essential that discussions about health status, disease progression, and prognosis begin early in the trajectory of HF,” they write. “These conversations are important and need to occur over time.”

Patient preferences should also be elicited early in the disease course, the authors urge. “The early elicitation of patient preferences may be especially important in the CVD population, considering the numerous options of diagnostic testing and advanced therapies even in end-stage disease.”

**HOSPICE**
“Despite the availability of hospice care, most patients dying of advanced CVD die in hospitals,” write the authors. They note that the goal of hospice care is to support a peaceful death for the patient while providing support for the family. Hospice services include in-home visits, provision of requisite medications and equipment, 24-hour emergency hotlines, in-patient hospice care, and support and relief for the family caregivers.

“Heart failure patients enrolled in hospice have been found to have longer...
Hospice Care Linked to Improved Outcomes (from Page 1)

TARGETING HIGH-VALUE END-OF-LIFE CARE

The study’s examination of the association of hospice use with “value-based outcomes,” such as high-quality care and patient experience, focused on specific outcomes that have had plausible associations with hospice care but have “not been extensively explored,” the study authors note.

“Promoting high-value, safe and effective care is an international healthcare imperative,” the authors declare. They point out that in the U.S., the 2014 Institute of Medicine report, “Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life,” stated that “providing high-quality care for people who are nearing the end of life is a professional commitment and responsibility.”

The authors conclude, “As the risk trajectory for death after hospital discharge can range from 25% to 35%, and as nationally, 10% to 20% of patients admitted to the ICU will die in the ICU, providing quality end-of-life care (including integration of hospice care), patient-centered, and family-centered care become important goals for targeting healthcare that is focused on high value.”

Source: “Exploring the Association of Hospice Care on Patient Experience and Outcomes of Care,” BMJ Support Palliative Care; Epub ahead of print, August 16, 2016; DOI: 10.1136/ bmjspcare-2015-001001. Kleinpell R, Vasilevskis EE, Fogg L, Ely EW; Rush University Medical Center and Rush University College of Nursing, Chicago; Department of Medicine, Vanderbilt University Medical Center, Veteran’s Affairs, Tennessee Valley Geriatric Research Education Clinical Center (GREDD), Nashville, Tennessee.

Heart Disease and Stroke Patients (from Page 2)

survival than those not enrolled in hospice,” the authors observe. In addition, incorporation of hospice services can ease caregiver burden. Nevertheless, hospice services “remain underused in this population.”

In addition to promoting the importance and attributes of palliative and hospice care, the AHA/ASA statement outlines barriers to delivery of this care, and offers specific recommendations for policy decisions.

BARRIERS TO PROVISION OF PALLIATIVE/HOSPICE CARE:

- Reluctance on the part of clinicians to refer patients to palliative care, sometimes due to lack of knowledge about the benefits or due to the lack of availability of services
- Failure to recognize patients for whom palliative care would be needed and appropriate
- Limitations in payment systems, although Medicare is beginning to address this issue, for instance by now reimbursing physicians for time spent in advance care planning discussions
- Provider discomfort in communication with patients and families about palliative and hospice care
- Patient/family lack of awareness of or confusion about palliative care and hospice services
- Family dynamics, as well as cultural, religious, and language differences

POLICY RECOMMENDATIONS:

- Reimbursement by federal and state agencies for comprehensive delivery of palliative care services
- Data sharing between payers and providers to better identify patients in need of palliative care
- Development of improved payer models, quality standards, and outcome measures
- Strengthening of health system policies to address palliative issues for hospitalized patients, such as goals of care, treatment decision making, family caregiver needs, and assistance with transition to other care settings
- Education and training of health care professionals in palliative care for licensure requirements
- Research that could close knowledge gaps regarding optimal palliative care, long-term care outcomes, and the effectiveness of primary palliative care

“Palliative care is an essential health benefit for every chronically ill patient, regardless of his or her background or age,” says AHA CEO Nancy Brown. “We hope these policy recommendations are adopted as soon as possible, so more heart disease and stroke patients and their families can receive the palliative care they want and deserve.”

Hospice Benefits for Patients with Advanced Lung Cancer Include Less Aggressive Care, Longer Survival

Fewer hospitalizations, intensive care unit (ICU) admissions, and emergency department (ED) visits in the last 30 days of life were experienced among patients with advanced non-small cell lung cancer (NSCLC) receiving hospice services compared to those with no hospice. In addition, these hospice patients had a significantly longer survival than their nonhospice counterparts, according to a report published in the Journal of Palliative Medicine.

“This study demonstrates that, among patients with metastatic NSCLC, hospice enrollment was associated with optimized end-of-life oncological care and a significantly longer median survival,” write the authors. “The results of this study add to the growing body of evidence supporting the utility and benefits of hospice services in the care of stage IV NSCLC patients, without incurring a lower survival rate.”

Investigators analyzed data from the medical records of 197 deceased NSCLC patients (mean age, 67 to 69 years) diagnosed with stage IV disease at one of two tertiary medical centers in the same North Carolina county from 2008 to 2010. The majority of both hospice and nonhospice patients were white (72.9% and 80.4%, respectively) and male (58.3% and 62.7%, respectively).

OVERALL:
- 73.8% of patients enrolled in hospice.
- Median length of hospice stay was 48.9 days (range, 1 to 396 days).
- 15.8% of hospice patients were enrolled for ≤ 7 days.

Overall, patients not enrolled in hospice were significantly more likely to die in an acute care setting (P < 0.0001). “Patients who die in these acute care settings often experience greater distress and poorer quality of life than those who pass away in their homes,” comment the authors.

“A benefit of hospice includes access to another inpatient alternative [i.e., inpatient hospice care], which is able to provide a high level of supervision and skilled nursing care often required at the EOL, but in a less severe and intimidating environment for the patient, their family, and caregivers.”

KEY FINDINGS
In the last 30 days of life, hospice patients had a significantly lower mean number per patient of:
- Hospitalizations (0.44 hospice vs 0.84 nonhospice; P = 0.0003)
- ED visits (0.36 hospice vs 0.67 nonhospice; P = 0.0062)
- ICU admissions (0.0086 hospice vs 0.16 nonhospice; P = 0.0004)

A lower percentage of hospice patients were administered a new chemotherapy agent in the last 30 days of life (3.47% hospice vs 11.76% nonhospice; P = 0.0038) or any chemotherapy in the last 14 days of life (1.39% hospice vs 13.73% nonhospice; P = 0.0014).

Median survival, measured from diagnosis to death, was significantly longer for hospice patients than for nonhospice patients (145.5 days vs 87 days; P = 0.02). Analysis of estimated survival probability up to one year after diagnosis “clearly demonstrated” higher survival probability of hospice patients (225.4 days vs 179.8 days), the authors note.

Lung cancer is the leading cause of cancer-related deaths in the U.S., and NSCLC, which is often already at an advanced stage when initially diagnosed, is its most common form. Curative treatments are rarely effective in and seldom offered to these Stage IV patients, the authors note.

“This raises an opportunity for the incorporation of palliative medicine, in the forms of both early palliative care and hospice services, for which NSCLC patients are often eligible at the time of diagnosis,” the authors write. “Early palliative care can inform the use of hospice services as well as smoothing the transition to hospice and optimizing length of stay there before death.”

Among all patients in both the hospice and nonhospice groups, 28% of patients received a palliative care consultation. However, note the authors, “Early palliative care was rarely evidenced, as the vast majority of the consults occurred in the inpatient setting within three weeks of the patient’s death.” Further, formally structured palliative care programs were not available for NSCLC patients at the study settings during the period studied, which was prior to publication of studies demonstrating the benefit of early palliative care for these patients, the authors note.

ENCOURAGING FINDINGS
The finding that nearly three-quarters of patients entered hospice following diagnosis with advanced lung cancer demonstrates “a shift in the utilization of hospice care among this population,” since previously reported rates have been below 50%, note the authors. “We are encouraged by this transition in care as the patients who received hospice services were found to have less intense end-of-life care in contrast to their nonhospice enrolled counterparts.”

Although there was no significant difference between the hospice and nonhospice groups in mean number of hospital admissions or mean number of lines of...

Continued on Page 5
Feeding Tube Use in Decline in Patients with Advanced Dementia

Insertion of a feeding tube in nursing home patients with advanced dementia who develop difficulty with eating — a common symptom in this terminal illness — has decreased by about 50% over 14 years and across racial groups, although its use remains relatively higher among African-American patients, according to a research letter published in the Journal of the American Medical Association.

“This decline parallels the emergence of research, and subsequent expert opinion and recommendations by national organizations discouraging this practice,” write the authors, led by Susan L. Mitchell, MD, MPH, of the Hebrew SeniorLife Institute for Aging Research at Harvard University in Boston, who has been reporting her findings on the effects of tube feeding in this population for about two decades.

In 2014, the American Geriatrics Society (AGS) issued a position statement advocating against the use of feeding tubes in patients with advanced dementia. In the previous year, the organization led its list of “Ten Things Clinicians and Patients Should Question” as part of Choosing Wisely®, an initiative of the ABIM Foundation, with the following statement: “Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding,” states the AGS. “Careful hand-feeding for patients with severe dementia is at least as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status, and patient comfort. Food is the preferred nutrient.”

Further, there are risks and burdens associated with the interventions that do not outweigh any potential benefit, noted the AGS. “Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.”

Investigators analyzed data on 71,251 nursing home residents with advanced dementia who had a new feeding tube inserted in the 12 months following development of an eating dependency between 2000 and 2014. Patient characteristics, which were similar across the study years, included the following: mean age, 84 years; female, 76.4%; white, 85.6%; African-American, 9.5%; prior stroke, 13.6%.

FROM 2000 TO 2014:

- The overall proportion of patients receiving feeding tubes dropped from 11.7% to 5.7% (adjusted risk ratio [ARR], 0.41; 95% confidence interval [CI], 0.38 to 0.45).
- Among white patients, feeding tube insertion declined from 8.6% to 3.1% (ARR, 0.37; 95% CI, 0.33 to 0.41).
- Among African-American patients, the drop was from 37.5% to 17.5% (ARR, 0.47; 95% CI, 0.41 to 0.55).
- African-American residents were significantly more likely than white residents to be tube fed in 2000 (ARR, 4.4; 95% CI, 4.0 to 4.7) and even more likely compared to whites in 2014 (ARR, 5.6; 95% CI, 5.0 to 6.2).

Fiscal and regulatory policies are needed, urge the authors, to ensure that racial disparities in the use of tube feeding in this population are reduced, and to both discourage the use of feeding tubes and to “promote a palliative approach to feeding problems in patients with advanced dementia.”


Hospice Benefits for Patients with Advanced Lung Cancer (from Page 4)

chemotherapy received from diagnosis to death, the findings that in the last month of life, hospice patients had significantly fewer hospitalizations, ED visits, and ICU admissions demonstrates “a more optimal end-of-life time course,” observe the authors.

Also of encouraging note, and consistent with several previous studies, the current findings show that stage IV NSCLC patients enrolled in hospice services had a significantly longer median survival than their nonhospice counterparts, point out the authors.

“Moreover, they also received optimized end-of-life oncological care... which is theorized to be one of the potential mechanisms of their longer survival,” the authors write. “It is also proposed that hospice services provide better monitoring, palliative treatment, and increased social support, factors which have individually been associated with improved survival.”

Hematologists Accept Standard Quality End-of-Life Measures, Urge Increased Access to Hospice Care

In a nationwide survey, a majority of hematologic oncologists endorsed standard measures of quality end-of-life (EOL) care for patients with solid tumors as acceptable for their patients with blood cancer. Nearly all believed the top barrier to delivery of quality care was unrealistic patient expectations (97.3%) and supported increasing access to hospice (92.2%), according to a report published in the Journal of Clinical Oncology.

The authors had expected that hematologists would find the standard measures for solid tumor cancers unacceptable, and that uncertainty about prognosis would be identified as the major barrier to quality EOL care, they note.

“In contrast to our hypothesis, the majority of the hematologic oncologists in this large national sample reported that current EOL quality measures are acceptable for assessing EOL care for patients with hematologic cancers,” write the authors. “The top barrier to quality EOL care reported was unrealistic patient expectations, which may be best addressed with more timely and effective advance care discussions.”

Investigators analyzed survey responses (n = 349) from a national cohort of hematologic oncologists (median age, 52 years; male, 75.6%) surveyed in 2015. Respondents were asked to rate eight standard oncology end-of-life-care quality measures (developed for solid tumor cancers) plus two new quality measures specific to blood cancers as “acceptable” or “not acceptable.” Supported acceptability overall was defined as agreement among at least 55% of respondents.

**SUPPORTED QUALITY MEASURES INCLUDED:**
- No intubation in the last 30 days of life (80.5%)
- No chemotherapy ≤ 14 days before death (79.9%)
- Hospice enrollment > 7 days before death (77.9%)
- No intensive care unit admission within the last 30 days of life (63.9%)
- Not dying in an acute care facility (62.5%)
- Not dying in a hospital (92.2%)
- Not dying in an acute care facility (85.1%)
- Policies allowing hospice enrollment during disease-directed treatment (90.1%)
- Integrating palliative care services with oncologic care at diagnosis (> 80%)

Patients with blood cancers are significantly more likely than those with solid tumors to receive chemotherapy and be hospitalized close to death, and are less likely to enroll in hospice, “suggesting suboptimal EOL care for this population,” point out the authors.

**IMPORTANT FIRST STEP, BUT MORE STEPS NEEDED**

As an analysis of hematologic oncologists’ opinions, the current study “represents an important first approach to the understudied topic of end-of-life care for patients with blood cancer,” write the authors of an editorial accompanying the report. However, a notable barrier to provision of quality end-of-life care for these patients is the “dearth of data” on patient and family experience and patient outcomes, they note.

The editorial authors urge that “significant additional steps” must be taken next to arrive at quality measures adequate for guiding patient care — including “engaging patients and families in all steps” of the development process — to determine which treatments are beneficial and which are detrimental.

**INTERVENTIONS THAT WOULD IMPROVE END-OF-LIFE CARE:**
- Increasing access to palliative care services (93.7%)
- Increasing access to hospice care facilities (92.2%)
- Policies allowing hospice enrollment during disease-directed treatment (90.1%)
- Integrating palliative care services with oncologic care at diagnosis (> 80%)

Patients with blood cancers are significantly more likely than those with solid tumors to receive chemotherapy and be hospitalized close to death, and are less likely to enroll in hospice, “suggesting suboptimal EOL care for this population,” point out the authors.

**IDENTIFIED BARRIERS:**
- Unrealistic patient expectations (97.3%)
- Clinician concern about taking away hope (71.3%)
- Unrealistic clinician expectations (59.0%)
- Clinician uncertainty about prognosis (58.7%)
- Lack of clinician time (53.3%)

**RESOURCES:**
Terminally Ill Patients May Not View Mortality as the Worst Outcome

Patients who are severely ill may not want to die, but they may also not want to prolong their lives if it means living with certain debilities or limitations, researchers have found. Yet, “studies of interventions in the hospital...commonly ignore such preferences, assuming implicitly or explicitly that death is an outcome to be avoided no matter what the alternatives are,” write the authors of a research letter published in *JAMA Internal Medicine*.

“This assumption may create untoward incentives for clinicians or healthcare systems to provide care that results in states of severe functional debility that patients prefer to avoid, even if the alternative is death,” the authors suggest.

Investigators analyzed interview responses of 180 patients (aged ≥ 60 years) who were hospitalized with serious illness (advanced cancer, congestive heart failure, or obstructive lung disease) at an academic medical center from July 2015 to March 2016. Patients were asked to rate health states with specific debilities and dependencies on a scale of 1 to 5 as “worse than death” to “much better than death.”

**STATES OR LIMITATIONS AS BAD AS OR WORSE THAN DEATH:**

- Bowel and bladder incontinence (69%)
- Ventilator dependence (67%)
- Inability to get out of bed (> 65%)
- Confused all the time (nearly 60%)
- Reliance on a feeding tube to live (56%)
- Needing care from others all the time (54%)

The only condition rated as “much better than death” by more than 50% of patients was being wheelchair bound. The authors suggest that patients may underestimate their ability to adapt, and that “once-feared states” may become more tolerable than anticipated, once experienced. They offer several reasons why patients may receive life-prolonging care that maintains them in states they deem to be worse than death. These reasons include:

- Changing preferences with the approach of death
- Desire to please family
- Belief in a return to good health
- Lack of physician or surrogate awareness of patient’s values/wishes
- Lack of offered alternatives consistent with priorities

“How can we incorporate this study into our practice?” asks Ross Albert, MD, chief of the division of palliative medicine, Hartford Hospital, Hartford, CT, in his commentary on Pallimed, a hospice and palliative medicine blog. The study report reminds us that “discussing goals of care in the context of simply being alive or not is insufficient,” he notes. “When providers continue treatments that at best would lead to a state of living that patients and families would find worse than dying, they are not practicing person-centered care,” observes Ross. “[G]oals of care discussions must continue to focus on patients’ values and preferences, hopes and worries.”

Support for Patients and Families

Just getting through the day can exhaust anyone caring for a loved one with dementia. Confusion, repetitive behaviors, disrupted sleep patterns and escalating anxiety can overwhelm the energy and patience of even the most committed and loving caregiver. The loss of memory is just one of the many markers along the regressive path of dementia. What may begin as simple forgetfulness can escalate to the need for round-the-clock care and help attending to critical daily tasks.

The Dementia with Dignity Program for Rainbow Patients

- Coordinated care management for patients in the advanced stages of dementia
- Regular visits by specially trained registered nurses
- Social work services for guidance and support
- Chaplain services for spiritual care
- Sensory stimulation using resources recommended by dementia experts
- Massage and music therapy
- Expert consultations and caregiver education

Consultations

A consultation with Rainbow’s specially trained team can take place at a hospital, long-term care facility, or a patient’s home. Consultations offer a great opportunity to set priorities for continuing care and address concerns such as safety and behavioral issues, mealtime challenges, medication management and managing bathing, grooming, dressing and more.

To learn more about Dementia with Dignity and Rainbow’s other services, please call 847-685-9900 or visit www.RainbowHospice.org.