A recent study has found that terminally ill hospice patients with certain diseases live a significantly longer period of time than do their nonhospice counterparts. Indeed, across all patient groups studied, those enrolled in hospice lived a mean of 29 days longer than those who did not choose hospice.

“This study provides important information to dispel the myth that hospice hastens death and suggests that hospice is related with the longer length of survival by days or months in certain terminally ill patients,” write the authors of a report published in the *Journal of Pain and Symptom Management*.

“This extra time might be particularly important to patients and their families, as it may allow some people to use the end of life as a time of resolution and closure.”

Researchers conducted a retrospective cohort study of 4493 terminally ill patients with congestive heart failure (CHF) or cancer of the lung, pancreas, colon, prostate, or breast. The statistically representative sample was drawn from Medicare records of patients who died within three years of entering the terminal stage of the disease.

Key Findings Include:

- Overall, the mean survival was **29 days longer for hospice patients** than for nonhospice patients.
- The largest difference in survival between the hospice and nonhospice cohort was found among patients with **CHF** (402 vs 321 days, \( P = 0.05 \)).
- Survival time was also significantly longer for hospice patients with **lung cancer** (279 vs 240 days, \( P < 0.0001 \)) and **pancreatic cancer** (210 vs 189 days, \( P = 0.01 \)), and approached statistical significance for the hospice cohort with **colon cancer** (414 vs 381 days, \( P = 0.08 \)).
- Across groups, **no significant association of hospice enrollment with shorter survival times was found**.

“Of note, the largest difference in survival between the hospice and nonhospice cohort was for the CHF patients, where relatively few patients chose hospice care,” point out the authors.

“Our findings are important in helping to dispel the myth that hospice care hastens a patient’s death,” write the authors. “This myth may stem in part from the fact that hospice professionals not uncommonly admit patients who are in very poor shape and near death. Indeed, many patients continue to be referred late for hospice or palliative care.”

The perceived association of hastened death with the use of opioid and sedative medications to alleviate symptoms has also contributed to this myth, point out the authors, noting that “a growing body of literature has amassed to counter this association.”

“There is a perception among some health care providers that symptom relief in hospice, especially the use of opioids and sedatives, could cause patients to die sooner than they would otherwise,” says
Dementia Patients and Their Families Benefit from Hospice Care

By Mark M Murray, President/CEO

Alzheimer’s / Dementia and related illnesses comprise the third most frequent overall diagnoses seen by the Center for Hospice and Palliative Care (CHAPC) and encompass the second most prevalent non-cancer diagnoses. In recognition, from September through November of this year, CHAPC was pleased to co-sponsor, along with Alzheimer’s Services of Northern Indiana and Real Services, a free Lunch and Learn series for caregivers. Additionally, in cooperation with the local Alzheimer’s Services agency, CHAPC recently offered a six week Living With Loss group that provided education and support to address the needs, feelings, and adjustment to life that is distinctive for caregivers dealing with the death of a loved one from Alzheimer’s or a related dementia. Hospice programs and dementia services agencies working together are an outcome of a new recognition of the special challenges for Alzheimer’s patients and caregivers with accessing quality end of life care.

Nationally, the Alzheimer’s Association released its third set of recommendations on improving care for people with Alzheimer’s and other dementias – recommendations focusing on care at the end of life. “Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes,” offers concrete suggestions for addressing issues unique to people with dementia at the end of their lives. The entire hospice community extends its thanks to the Alzheimer’s Association for addressing the needs of people at life’s end and applauds its collaborative efforts in this ongoing work. This new set of recommendations was released during the Alzheimer’s Association’s 15th annual Dementia Care Conference held in Chicago in late August.

Key aspects of the recommendations include:
- The need for advance care planning as soon as possible after diagnosis of dementia. This includes documenting the person’s wishes regarding medical treatments in advanced stages of dementia and designation of a proxy decision-maker.
- Provision of person-centered palliative care to people with advanced dementia.
- The importance of dementia-specific training for residential care workers on end-of-life issues – for example, signs of dying, pain management issues, and communicating with families.

While dementia is one of the leading causes of death in the United States, nationally it accounts for only 11 percent of hospice admissions and little is known about the quality of the care patients receive. However, research published in the July issue of the Journal of Pain and Symptom Management, “Hospice Care for Patients with Dementia,” reinforces the value of hospice care for these patients and their family caregivers.

Researchers found that families of patient’s with dementia evaluated the care received from hospice as highly as patients with other diagnoses. Reports of unmet patient needs for treatment of symptoms were less frequent as well. According to Stephen Connor, vice president of research at the National Hospice and Palliative Care Organization (NHPCO), and co-author of the study, “What this tells hospice professionals is that in spite of the challenges of caring for patients with dementia, hospice is indeed beneficial. Hospices can effectively help patients struggling with dementia at the end of their lives and providers need to continue reaching out to help those patients and families in need.” This research, led by Dr. Susan Mitchell at the Institute for Aging Research at Harvard University, was done in collaboration with NHPCO and researchers at Brown University and was funded by the Alzheimer’s Association.

Researchers used data from the Family Evaluation of Hospice Care (FEHC), an Internet based repository and benchmarking tool that collects data from bereaved families regarding the quality of hospice care. A total of 77,123 surveys submitted by 796 hospices in 2005 were used in this study. Developed by Brown University and NHPCO, the FEHC allows researchers to look at the relationship of length of stay, perceived timing of hospice referral, and quality of end-of-life care. CHAPC is proud to participate in the FEHC survey process and benchmark its results with those of hospices nationwide as well as those in Indiana through aggregate data results from Hoosier hospices.

For more information on the Alzheimer’s Association Phase 3 Recommendations, visit www.alz.org.
Heart failure (HF) is the leading cause of hospital admission and readmission in this country, and the only cardiac-related diagnosis that continues to rise in prevalence; deaths from HF have doubled over the past 15 years. The palliative approach to care for patients with advanced HF, although often “challenging to implement,” is gaining widespread support and should be integrated sooner into the care of patients with this disease.

That is according to Brad Stuart, MD, senior medical director of Sutter VNA and Hospice, Emeryville, CA, in a review of palliative and hospice care for patients with advanced HF, which was published in the Journal of Palliative Medicine.

“Palliative care should be integrated with advances in heart failure care to optimize treatment of high-risk patients while discouraging overuse of procedures and devices, and to help patients and families cope with an uncertain future,” writes Stuart, who is also principal investigator for Sutter’s Advanced Illness Management program.

Stuart provides a discussion of the pathogenesis, staging, assessment, prognosis determination, and treatment of HF, offering approaches to advance care planning, managing infusions and implanted defibrillators, and determining hospice eligibility.

Tables include the New York Heart Association (NYHA) functional classification system for heart failure and its “complement,” the staging system of the American College of Cardiology/American Heart Association 2005 Guideline Update, which “for the first time provides Class I recommendations for hospice and palliative care for patients with advanced HF,” comments Stuart, “signifying that these approaches are beneficial, useful, and effective.”

Although end-stage heart disease is now the second most common diagnosis upon hospice admission, it accounts for only 12% of enrollees, points out Stuart, while cancer diagnosis accounts for 46%. Yet 27% of all deaths in the nation in 2004 were caused by heart disease, compared with 23% caused by cancer.

Asserting that “calculated prognosis should not be the major criterion for hospice referral,” Stuart proposes a set of guidelines adapted from the National Hospice and Palliative Care Organization and others for determining hospice eligibility in HF patients with systolic failure. [See sidebar.]

“Uncertain prognosis should not be a barrier to enrollment,” states Stuart. “Patients may stay on hospice for longer than six months as long as clinical decline can be documented. Those who stabilize or improve over several months may be discharged, then reenrolled in hospice if their condition worsens.”

Standard medical treatment of HF is palliative as well as disease-modifying, notes Stuart. “Using a flexible blend of disease-modifying and symptom-relieving measures that evolves as disease advances, clinicians can help ease the transition for seriously ill patients and their families from life-prolonging treatment toward comfort-focused care.”

HeartWize... A Reminder

HeartWize, CHAPC's program designed for patients with heart failure and other advanced heart disease, helps patients through:

- Regularly scheduled visits by staff with specialized training in cardiac evaluation and symptom management
- A cardiac medication kit placed in the home
- Specialized protocols and treatment pathways designed for end-stage cardiac disease
- Patient education materials specifically designed for end-stage cardiac patients
- Use of emotional, spiritual, and complementary approaches to care as appropriate

The program operates within protocols designed in cooperation with local cardiologists, Farid Jalinous, MD and John Jenkins, MD.

For more information about HeartWize, contact CHAPC’s Admission Department at (574) 243-3125 or CHAPC’s Medical Director, David Tribble, MD at (574) 243-3104.

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Guidelines for Hospice Eligibility in Heart Failure

Patients should show evidence of all of the following:

1. Illness severity
   - Documentation of severe left ventricular dysfunction; left ventricular ejection fraction, 20% or less
   - NYHA Class IV symptoms despite optimal treatment

2. Recent clinical progression, including any of the following:
   - Two or more hospital admissions or emergency department visits for HF within six months
   - New dependence in activities of daily living
   - Renal, hepatic, or central nervous system dysfunction without reversible cause

3. Evaluation for advanced therapeutic options
   - Many elderly patients with comorbidities may be hospice-appropriate without being considered for these options. Hospice enrollment is reasonable for younger patients who have been considered and have been found ineligible, refused them, or developed recurrent HF symptoms after undergoing them.

4. Preference for comfort care over life-sustaining treatment
   - Comprehensive advance care planning, which includes discussion of disease process, prognosis, treatment goals, and advance directives
   - Patient/family knowledge and acceptance of life-limiting prognosis
   - Preference for treatment goals directed toward relief of symptoms rather than modification of underlying disease
   - Preference to avoid hospitalization, except for inpatient palliative or hospice care

— Stuart, Journal of Palliative Medicine

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www.centerforhospice.org
The Center for Hospice and Palliative Care has begun construction on a 12,000 sq. ft. facility which will include a Hospice House (inpatient unit) and the Elkhart area satellite office for its residential care staff, business office, bereavement, volunteer and community education services. The facility, located at 25579 Old US 20, Elkhart, will be on approximately 11 acres conveniently near the interchange of the US 20 Bypass (Dean Mock Expressway) and County Road 17.

“This is exciting for The Center for Hospice and Palliative Care and for the people of the Elkhart community who allow us to care for them,” said Mark Murray, president and CEO of CHAPC. “The addition of the Elkhart Hospice House will greatly assist us in meeting the needs of our patients in this area and will help us to continue improving their quality of living.”

A $3 million philanthropic campaign is underway to fund this facility. Operational revenue will be realized through third-party insurance payments via Medicare, Medicaid, and private insurance. In addition, the generous financial support from the community through traditional fundraising programs will allow CHAPC to continue its longstanding commitment of providing care for patients regardless of their ability to pay.

For more information and to watch the progress of this facility, visit www.centerforhospice.org and click on the Elkhart Hospice House banner.