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## End-of-Life Care Planning Does Not Take Away Hope

Patients with advanced cancer who used an online decision aid to prioritize their goals and values and then generate an advance directive (AD) experienced no loss of hope or diminishment in their psychological well-being, according to a report published in the *Journal of Pain and Symptom Management*.

“Clinicians have long appreciated the importance of having patients maintain a sense of hope,” write the authors. “Our study provides evidence that engaging in advance care planning (ACP) with an interactive computer program does not rob patients of hope or induce anxiety.”

Participants were 200 patients with advanced cancer and an estimated life expectancy of two years or less recruited at a tertiary care center between 2007 and 2012. Patients were randomized into two ACP groups: one used an interactive, online decision aid with educational modules and guidance on identifying values and wishes to produce an AD (intervention); the other used only a state-approved online AD form and educational materials (control).

Investigators compared participants’ pre- and post-session measurements in hope, hopelessness, and anxiety, as well as ACP knowledge, self-determination, and satisfaction.

### KEY FINDINGS:

- There was no decline in hope or increase in hopelessness in either group.
- Anxiety decreased slightly in the intervention group and remained unchanged in the control group.
- Knowledge of ACP increased in both groups, with a greater increase in the

intervention group (13% vs 4%).

- Self-determination increased slightly in both groups.
- Satisfaction with the ACP process was greater in the intervention group ( $P < 0.01$ ).

“This should reassure clinicians that helping patients prepare for the future is not at odds with preserving hope, even among patients with life-threatening illness such as cancer,” note the authors. However, using a computer is not the same as having a conversation with a physician, they caution.

“Taken in conjunction with research showing that honest prognostic information does not diminish hope, it is reasonable to conclude that clinicians need not avoid end-of-life preparation out of a concern for the patient’s well-being, and indeed can confidently engage patients in this important activity.”

The online end-of-life care planning tool, entitled “Making Your Wishes Known: Planning Your Medical Future,” is available at [www.makingyourwishesknown.com](http://www.makingyourwishesknown.com).

*Source: “Advance Care Planning Does Not Adversely Affect Hope or Anxiety among Patients with Advanced Cancer,” Journal of Pain and Symptom Management; Epub ahead of print, December 23, 2014; DOI: 10.1016/j.painsymman.2014.11.293. Green MJ, Schubart JR, Whitehead MM, Farace E, Lehman E, Levi BH; Departments of Humanities and Medicine, Penn State College of Medicine, Hershey, Pennsylvania.*

# Hospice Use Remains High as Median Length of Service Continues to Decline

Approximately 1.5 to 1.6 million patients — well over half with diagnoses other than cancer — were cared for by U.S. hospices in 2013. These figures are similar to those of the previous year, reports the National Hospice and Palliative Care Organization (NHPCO), in the recently published 2014 edition of its annual publication, “Facts and Figures: Hospice Care in America.”

“[T]he number of people with a non-cancer diagnosis continues to track at 63%, reflecting the ability of hospice providers to care for people at life’s end who may be coping with dementia, heart disease, lung disease, stroke, or kidney disease,” states the NHPCO.

However, more than a third of hospice patients received care for a week or less, half received care for less than 18 days, and the median length of stay in hospice is continuing its downward trend of recent years.

“Of ongoing concern to hospice and palliative care professionals is the fact that 34.5% of patients died or were discharged within seven days of admission,” notes the NHPCO. This echoes the concern recently voiced by the Institute of Medicine in its 2014 report on the state of end-of-life care, “Dying in America,” which called for greater access to hospice and palliative care for Americans.

The NHPCO report on trends in the growth, delivery, and quality of hospice care in the U.S. was released in October 2014, and is based on data from the organization’s annual survey, the National Data Set, and NHPCO membership data. Care was provided in 2013 by more than 5800 hospice programs in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands.

## KEY FINDINGS:

- Median length of service was 18.5 days, a decrease from 18.7 days in 2012, 19.1 days in 2011, and 21.2 days in 2009.
- 34.5% of hospice patients died or were discharged within seven days of

## The Hospice Interdisciplinary Team

- The patient’s personal physician
- The hospice physician or medical director
- Nurses
- Hospice aides
- Social workers
- Bereavement counselors
- Clergy or other spiritual counselors
- Trained volunteers
- Speech, physical, and occupational therapists, if needed

enrollment, a slightly smaller proportion compared with 35.5% in 2012.

- Nearly half (48.8%) of patients died within 14 days of admission in 2013, a very slight drop from 2012 (49.5%).
- The same proportion of patients remained in hospice for longer than 180 days in both years (11.5%).
- Two-thirds of hospice care (66.6%) was provided in the place the patient called home, whether in a private residence (41.7%), a nursing home (17.9%), or a residential facility (7.0%).
- 91.2% of hospice care was covered by the Medicare Hospice Benefit.
- Cancer remains the most common admitting diagnosis, but it continues to account for less than half (36.5%) of all hospice admissions.

Primary non-cancer admitting diagnoses in 2013 included:

- Dementia (15.2%)
- Heart disease (13.4%)
- Lung disease (9.9%)
- Stroke or coma (5.2%)

Nursing homes showed the greatest increase as location of death for hospice patients, rising from 17.2% in 2012 to 17.9% in 2013. As Americans live longer, an increasing number die of chronic, progressive diseases requiring more prolonged care, most often in nursing homes, explains the report. Previous research has shown that as Medicare-certified hospice programs in nursing homes rose, so did the

percentage of nursing home decedents receiving hospice care, from 14% in 1999 to 33.1% in 2006.

Meanwhile, percentage of deaths in a hospice inpatient facility fell from 27.4% to 26.4%. In addition to providing hospice care in the patient’s place of residence, about one in three hospice agencies operate a dedicated inpatient unit. Some of these facilities provide a mix of general inpatient and residential care. Short-term inpatient care is also made available when the caregiver needs respite, or when a patient’s pain or symptoms become too difficult to manage at home. Overall in 2013, however, routine home care accounted for 94.1% of patient care days.

Patients of non-Caucasian race continued to account for less than one-fifth of hospice users in 2013, with a slight increase in the proportion of enrollees, from 18.5% in 2011 to 19.1% in 2013. Hospice “provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes,” notes the NHPCO. Support is also provided to the patient’s loved ones.

“There’s a common misconception that hospice care is giving up,” says J. Donald Schumacher, PsyD, NHPCO president and CEO. “Nothing could be farther from the truth. Hospice provides high quality medical care and services from an interdisciplinary team of professionals and trained volunteers that maximizes quality of life and makes the wishes of the patient a priority.” [See sidebar, which lists members of a typical hospice care team.]

“While many dying Americans are opting for hospice care at the end of their lives, far too many receive care for a week or less,” adds Schumacher. “We need to reach patients earlier in the course of their illness to ensure they receive the full benefits that hospice and palliative care can offer.”

For more details, visit [www.nhpc.org](http://www.nhpc.org).

# Both Regional and Patient Factors Influence Receipt of Intensive Procedures at Life's End

Individual characteristics and regional medical practice patterns have been identified as important determinants of intensive procedure use in the last six months of life, with black race and living in a high-intensity treatment region more than doubling the odds of undergoing an intensive procedure near the end of life, according to a report published in the *Journal of the American Geriatrics Society*.

“The most important finding from this study is that regional health care intensity has a strong independent effect on the medical care that individuals receive at the end of life, even after controlling for individual medical, social, and functional characteristics,” write the authors. “The effect of nonclinical factors highlights the need to better align treatments with individual preferences.”

Investigators analyzed Medicare claims linked to data for 3,069 individuals aged 66 years or older (mean age, 83.2 years) enrolled in the Health and Retirement Study (HRS), a nationally representative longitudinal cohort study of older adults. Subjects were those decedents for whom a proxy had completed an interview between 2000 and 2008.

HRS data was linked to participants' hospital referral region and to the Dartmouth Atlas of Health Care database information on each region's supply of medical resources (number of hospital beds, physicians, and specialists) and the Hospital Care Intensity (HCI) Index, a measure of local practice pattern intensity (days spent in hospital and intensity of physician services received while hospitalized).

The most common chronic medical conditions among the subjects were ischemic heart disease (35.6%), congestive heart failure (31.2%), diabetes mellitus (29.4%), and chronic obstructive pulmonary disease (28.3%).

## OVERALL:

- 17.8% of patients underwent at least one intensive procedure in the last six months of life.
- 5.2% underwent two or more procedures.
- Of those who underwent at least one intensive procedure, 79% had such a procedure in the final month of life.

The frequency of each procedure among those who underwent at least one intensive procedure was as follows: intubation and mechanical ventilation (67.6%); gastrostomy tube insertion (25.5%); enteral or parenteral nutrition (23.1%); cardiopulmonary resuscitation (11.2%); and tracheostomy (8.1%).

One factor that increased the odds was when patients were living in a region with higher HCI (AOR, 2.16; 95% CI, 1.48 to 3.13). Thus, point out the authors, an older person living in Miami, FL (HCI Index, 1.78) would have more than double the probability of undergoing an intensive procedure at the end of life than if he or she were living in Rochester, MN (HCI Index, 0.64).

Black race also more than doubled the odds of receiving an intensive procedure in the last six months of life (AOR, 2.02; 95% CI, 1.52 to 2.69). This was a strong independent association, note the authors, and not a proxy for other determinants of care intensity, such as urban residence. Hispanic ethnicity, while not statistically significant in the primary analysis, was associated with three-times higher odds of undergoing gastrostomy tube placement.

## LOWERING THE RISK

Factors significantly associated with lower odds of an intensive procedure included:

- Cancer diagnosis (adjusted odds ratio [AOR], 0.60; 95% confidence interval [CI], 0.43 to 0.85)
- Aged 85 to 94 years vs 65 to 74 years (AOR, 0.67; 95% CI, 0.51 to 0.90)
- Residence in a nursing home (AOR, 0.70; 95% CI, 0.50 to 0.97)
- Alzheimer's disease (AOR, 0.71; 95% CI, 0.54 to 0.94)
- Having an advance directive (AOR, 0.71; 95% CI, 0.57 to 0.89)

The presence of an advance directive (AD) reduced the odds of undergoing an intensive procedure by 30%, but when procedures were considered independently, having an AD was associated with lower odds of receiving only two procedures: intubation and cardiopulmonary resuscitation.

“This highlights the need to move beyond advance directives with ‘do not resuscitate’ and ‘do not intubate’ checkboxes to broader discussion and documentation of individuals' goals of care and values that could guide treatment decisions in a wider array of clinical scenarios,” suggest the authors.

The study is the first to simultaneously examine the effect of individual characteristics and regional factors on the likelihood of undergoing one or more intensive procedures at the end of life, note the authors. “By recognizing these factors, clinicians can work more effectively to ensure that the treatment provided to individuals with serious illness is consistent with their individual preferences.

“Most importantly, by confirming that regional factors exert a real and independent influence on the care that individuals receive at the end of life, this study emphasizes the need to investigate the causes of disparate practice patterns and develop models of care that prioritize individuals' values and goals.”

Source: “Factors Influencing the Use of Intensive Procedures at the End of Life,” *Journal of the American Geriatrics Society*; November 2014; 62(11):2088-2094. Tschirhart EC, Du Q, Kelley AS; Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York City; and Geriatric Research, Education, and Clinical Center, James J. Peters Veterans Affairs Medical Center, Bronx, New York.



## WHEN TO REFER TO HOSPICE

Call us if your patient exhibits the following indicators:

- Physical / functional decline
- Weight Loss >10% in last 6 months
- Multiple comorbidities

When life expectancy can be measured in weeks or months, hospice is usually the best option.

For patients with **heart disease or CHF**, look for the following indicators:

- NYHA Class IV; discomfort with physical activity
- Symptomatic despite maximal medical management with diuretics and vasodilators
- Arrhythmias resistant to treatment
- Ejection fraction < 20%

Call us any time, any day.

**Geoffrey Coleman, MD**  
Medical Director  
Montgomery Hospice



## Few Hospitalized Heart Failure Patients Receive Palliative Care

Heart failure (HF) is the leading cause of death in the U.S., and patients with this condition have a high level of symptom burden. Yet few are referred to palliative care (PC), even when hospitalized in a facility with PC consulting services, according to a report published in the *Journal of Palliative Medicine*. The American College of Cardiology and the American Heart Association emphasize the importance of PC, advising that the care of a HF patient should focus on improvement of the patient's quality of life as well as on survival and performance metrics.

Nevertheless, "only a fraction of HF patients who are at high risk for morbidity and mortality receive PC services," write the authors. Since "little is known about why some hospitalized HF patients are referred to PC services whereas others are not," they conducted a study to determine factors predictive of receiving PC.

Investigators analyzed data on 2647 patients admitted with a primary diagnosis of HF between 2005 and 2010 to an academic medical center with an established PC consulting service. Overall, only 6.2% of admitted HF patients were referred to PC by the attending physician during their hospital stay.

Predictors of PC referral were secondary **diagnosis of Alzheimer's disease** (OR, 4.53; 95% CI, 1.40 to 14.65) or **acute renal**

**failure** (OR, 2.39; 95% CI, 1.65 to 3.45); receipt of **thoracentesis** (OR, 4.13; 95% CI, 2.02 to 8.41); **ICU stay** (OR, 2.49; 95% CI, 1.65 to 3.73); **age ≥ 75 years** (OR, 1.92; 95% CI, 1.26 to 2.92); and **HF hospitalization** in the prior year (OR, 1.46; 95% CI, 1.23 to 1.73).

Retrospectively following discharge, the researchers calculated the odds of PC referral using severity of illness (SOI) and risk of mortality (ROM). Over 20% of HF patients had severe SOI, and over 50% had major-to-severe ROM, yet only 6% were referred to PC. "These findings suggest that should such measures become available prospectively, a substantially higher proportion of HF patients might receive PC consultations," note the authors, who call for better-developed prediction models.

"Integrating the management of HF with PC, as early as at diagnosis, may be important in assuring that PC is viewed as a complementary service designed to minimize distressing symptoms, and to assist patients and their families in making the difficult but necessary decision about future treatments," they note.

Source: "Palliative Care Referral among Patients Hospitalized with Advanced Heart Failure," *Journal of Palliative Medicine*; Greener DT, et al; Department of Pathology, Department of Medicine, Department of Public Health Sciences, and Department of Family Medicine, University of Rochester School of Medicine, Rochester, New York; Department of Cardiology, Carmel Medical Center, Haifa, Israel.