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Most Heart Failure Patients Want to Discuss Prognosis and End-of-Life Care Plans, Study Finds

Discussions between patients with heart failure (HF) and their physicians about what to expect with the illness and prognosis are fairly common, but conversations about advance care planning (ACP) for the end of life — although desired by most patients — are less so, according to a report published in the *Journal of Palliative Medicine*.

“The fact that most patients reported having conversations with their clinicians about HF management, prognosis, and choice of surrogate shows that in this setting, clinicians are not waiting till end of life to discuss them,” write the authors. “Still, there is more work to be done to make these important conversations universal, as most patients who did not have these discussions want to have them.”

Investigators analyzed survey responses of 104 adult patients (mean age, 53 years; male, 66%) with New York Heart Association class II (57%) or class III (43%) HF cared for from July 2007 to November 2009 at HF clinics within a large urban medical center. The patients, 66.3% of whom were of white/European descent, had been living with HF for a mean 7.0 years (range, < 1 to 46 years).

KEY FINDINGS

- Most patients reported they had discussed what to expect in the future regarding their HF (76.5%) and prognosis (68.0%) with their clinicians.
- Fewer than half (46.5%) said they had discussed ACP.

- Overall, 63.7% still had questions about their condition.
- Nearly all (90.3%) reported having thought about their choice of a medical surrogate, but only 63.4% had discussed their choice with their clinician.

“A potential ‘safe entrance’ for clinicians to initiate potentially sensitive topics could be discussion regarding choice of surrogate decision maker,” suggest the authors. “Despite the majority of patients having thought of a surrogate decision maker, less than two-thirds had shared this important information with their clinician.”

Among HF patients who had not had patient-physician conversations on these topics:

- 87.5% would like to discuss what to expect regarding their HF.
- 80.6% wished to discuss prognosis.
- 59.6% would like to discuss ACP.

“These conversations are critical to ensure that care aligns with patient preferences,” write the authors. “[P]atients want these discussions, and often want to have them initiated by their physician. Our findings should embolden clinicians to routinely discuss ACP.”

Source: “Let Us Talk about It: Heart Failure Patients’ Preferences toward Discussions about Prognosis, Advance Care Planning, and Spiritual Support,” Journal of Palliative Medicine; Epub ahead of print, September 7, 2016. Gordon NA et al; Frank H. Netter MD School of Medicine, Quinnipiac University, North Haven, Connecticut; Palliative Care Program; School of Medicine; and School of Nursing, University of California, San Francisco.

Two-Fold Rise in Ventilator Use among Advanced Dementia Patients Linked to ICU Bed Increase

The use of mechanical ventilation among hospitalized nursing home residents with advanced dementia has doubled in recent years — from 39 to 78 per 1000 hospitalizations — without evidence of improved survival, researchers have found. Further, the risk of being put on a ventilator increased by 6% for every 10 intensive care unit (ICU) beds added over time by admitting facilities.

“Our results call for reconsideration of the role that the excess supply of ICU beds plays in the ICU admission and subsequent mechanical ventilation of patients with advanced dementia,” write the authors of a report published in *JAMA Internal Medicine*.

“Furthermore, our results highlight the urgency of developing a multifaceted approach to address the increasing intensity of care for the growing population of patients with advanced dementia,” the authors, led by Joan M. Teno, MD, MS, of the University of Washington, Seattle, continue. “Mechanical ventilation may be lifesaving, but in certain persons, such as those with advanced dementia, it may prolong patient suffering without a clear survival benefit.”

Currently, more than five million Americans are living with dementia, with deaths from the disease expected to reach 1.6 million yearly by 2050, the authors point out. The natural progression of dementia, which includes problems with eating for 86% of patients and recurrent infections for many during the final year of life, can often lead to patterns of burdensome hospitalization before death.

Investigators analyzed data on 380,060 Medicare patients with advanced dementia living in nursing homes for at least four months prior to hospitalization between 2000 and 2013. The study cohort (mean age, 84.4 years; female, 69.5%) represented a total of 635,008 hospitalizations during the period. Overall, 98.2% of patients were bedbound and 23.2% had a feeding tube placement. Of those without a feeding tube, 63.4% were hand-fed a soft diet.

FROM 2000 TO 2013:

- ICU admissions increased from 16.9% to 38.5% of hospitalized advanced dementia patients.
- Mean length of hospital stay decreased from 7.1 days to 6.3 days, while the mean length of ICU stay increased from 5.0 days to 5.4 days.
- The mean number of ICU beds among facilities studied rose from 22.4 to 34.2.
- One-year mortality for all patients receiving mechanical ventilation was consistent at > 80% across all study years.

KEY FINDINGS

- Use of mechanical ventilation among hospitalized nursing home residents with advanced dementia increased steadily from 39 per 1000 in 2000 to 78 per 1000 in 2013 ($P = < 0.001$).
- The odds of receiving mechanical ventilation increased among these patients by 6% for every 10 ICU beds added over time (odds ratio [OR], 1.06; 95% confidence interval, 1.05 to 1.07).
- In 2013, hospitals in the top decile for number of ICU beds were more highly reimbursed per hospitalization (\$9611.89) than were those hospitals in the lowest decile (\$8050.24), with no improvement in one-year mortality (65.2% vs 64.6%).

ICU BEDS:

A ‘TECHNOLOGICAL IMPERATIVE?’

Currently there are no Medicare regulations regarding the use of ICU beds, note the authors. “Despite the expense and potential burdens of ICU care, ICU admission remains one of the few Medicare sites of care without regulatory oversight,” they write. Thus, there are striking variations in ICU use found across hospitals and regions. Further, although the number of hospital beds in the U.S. has decreased during the past decade, the number of ICU beds has risen.

“During times of a public health crisis, such as an earthquake or influenza epidem-

ic, an excess capacity of ICU beds may be lifesaving, but multiple commentaries have expressed concerns that excess ICU bed capacity potentially creates a technological imperative to use those beds by persons who may not benefit from ICU care, such as those with advanced dementia,” comment the authors.

To ensure that care of hospitalized advanced dementia patients is consistent with their preferences or those of their surrogates, efforts at improvement will need to be multifaceted, observe the authors.

SUGGESTED TARGETS FOR IMPROVEMENT INCLUDE:

- Enhancing communication skills
- Providing performance feedback to clinicians and institutions
- Addressing cultural norms
- Aligning financial incentives with quality rather than volume of care
- Developing regional strategies regarding ICU bed capacity to ensure appropriate access

ADVANCE DIRECTIVES ARE KEY

“Teno and colleagues have made an important contribution in demonstrating the increasing use of mechanical ventilation in this population during the past decade associated with increased availability of ICU beds,” write the authors of an editorial accompanying the report.

“As long as it is easier to access an ICU bed than comprehensive hospice and palliative care services in nursing homes, this trend is likely to continue,” they warn.

The final stage of dementia is frequently marked by infections, which accounted for most of the increased ventilator use in the current study, note the editorial authors. Taken together, both pneumonia and septicemia increased the risk for mechanical ventilation by 11%. As an admitting diagnosis among these patients, septicemia increased from 10.0% to 25.0% during the period studied. “Importantly, infections

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Half of Patients with Advanced Cancer Believe Their Disease Is Curable, International Study Finds

Perception of the curability of their disease varies around the globe among patients with advanced cancer, differing significantly by performance status, education level, and the country in which their cancer care is received, according to study findings presented at the 2016 Palliative Care in Oncology Symposium (PCOS).

Among the 10 other countries included in the study, patients in six were more likely than those in the U.S. to have an accurate perception of their disease curability, while patients in four countries were more likely than those in the U.S. to believe their cancer was curable.

“We are seeing more patients with advanced cancer. Unfortunately, these patients still have significant symptoms that are uncontrolled,” says lead author Sriram Yennu, MD, MS, of the Department of Palliative Care and Rehabilitation Medicine, The University of Texas MD Anderson Cancer Center, Houston.

“They are also being referred late [to hospice and palliative care], despite good evidence now that early referral helps. And they are also getting aggressive care. And so these are the key issues we are facing in helping our patients improve their quality of life.”

Investigators analyzed survey responses

from an international cohort of 1390 patients with advanced cancer (median age, 58 years; female, 59%) who were receiving palliative care in one of 11 countries on the continents of North and South America, Europe, Asia, and Africa.

OVERALL

- 49% of patients believed that their cancer was curable.
- 60% felt the goal of therapy was “to get rid of their cancer.”
- 79% believed the goal of therapy was “to make them feel better.”
- 62% perceived themselves as being “relatively healthy.”

PERCEPTION OF NON-CURABILITY

Accurate perception of non-curability of advanced disease was associated with:

- Better Karnofsky performance status (odds ratio [OR], 1.009; $P = 0.04$)
- Education level at college or above (OR, 0.52; $P = 0.0001$)
- Residence in France (OR, 0.30; 95% confidence interval [CI], 0.17 to 0.52; $P < 0.0001$), Brazil (OR, 0.49; 95% CI, 0.30 to 0.82; $P = 0.006$), or South Africa (OR, 0.50; 95% CI, 0.27 to 0.96; $P = 0.36$) as compared with the U.S.

Cancer patients living in the Philippines (OR, 18.5; 95% CI, 6.72 to 51.08; $P < 0.0001$), Jordan (OR, 6.21; 95% CI, 3.08 to 12.54; $P < 0.0001$), and India (OR, 3.07; 95% CI, 0.92 to 10.27; $P = 0.07$) were more likely than those in the U.S. to have the misperception that their cancer was curable. Patient factors such as age, gender, marital status, religion, and decision control preferences were not significantly associated with perception of curability.

“It is important to understand [our patients’] perception of curability, which is very critical not only in their satisfaction, but also [in their] receiving quality end-of-life care,” says Yennu. “So, as palliative care physicians, our role is not only improving the symptoms, but also improving their understanding of the illness, especially their understanding of the diagnosis, the treatment goals, and the end-of-life care.”

Further studies of the complex issue of patient perception of disease are needed, notes Yennu, to learn how to ensure that palliative and hospice care are accessed earlier.

Source: “Perception of Curability in an International Cohort of Advanced Cancer Patients Receiving Palliative Care,” *Journal of Clinical Oncology; Palliative Care in Oncology Symposium, September 2016; 34(supplement 26S; abstract 5)*. Yennu S, Bruera E, et al; The University of Texas MD Anderson Cancer Center, Houston.

Two-Fold Rise in Ventilator Use (from Page 2)

may be regarded by clinicians as reversible and treatable rather than as symptomatic of the final stage of incurable dementia.”

Supporting family caregivers and surrogate decision makers — most of whom prefer comfort care for their loved ones — is crucial to improving the “in-the-moment” decision making for nursing home residents at an advanced stage of dementia, they point out.

The authors recommend encouraging documentation of advance directives for nursing home residents with dementia, particularly in conjunction with the Physician Orders for Life-Sustaining Treatment

(POLST), which promotes consistency between nursing home and hospital, and “specifically addresses decision making regarding treatment and hospitalization for infections.

“However, patients with POLST documents identifying comfort as their exclusive goal must have ready availability of hospice and palliative care services when they develop symptoms from infections and other acute illnesses if the stated goal of comfort is to be honored in the nursing home setting.”

Source: “Association of Increasing Use of Mechanical Ventilation among Nursing Home

Residents with Advanced Dementia and Intensive Care Unit Beds,” *JAMA Internal Medicine; Epub ahead of print, October 10, 2016; DOI: 10.1001/jamainternmed.2016.5964*. Teno JM, Gozalo P, Khandelwal N, et al; Department of Gerontology and Geriatrics; Cambia Center of Excellence; and Department of Anesthesiology and Pain Medicine, University of Washington School of Medicine, Seattle; Department of Health Services, Policy & Practice, Brown University School of Public Health, Providence, Rhode Island; Department of Medicine, University of Chicago, Chicago. “Intensive Care Unit Bed Availability and Use of Mechanical Ventilation in Nursing Home Residents with Advanced Dementia: When We Build It, Why Do They Come?” *ibid.*; DOI: 10.1001/jamainternmed.2016.6415. Winzelberg GS, Hanson LC; Center for Aging and Health, Division of Geriatric Medicine, University of North Carolina at Chapel Hill School of Medicine, Chapel Hill.

Pallipedia: Online Hospice/Palliative Care Dictionary for Clinicians

Pallipedia, a free online palliative care dictionary (www.pallipedia.org), has been developed by the International Association for Hospice & Palliative Care (IAHPC) as a specialized online resource, with the stated aim of helping to improve palliative/hospice care knowledge and resources for the global community.

Originated in 2009, the dictionary has been relaunched in a newly revised version with updated, alphabetically indexed definitions and an improved search capability. The continuously growing lexicon currently includes nearly 1000 palliative/hospice and general health-related terms, all offered as a centralized, peer-reviewed resource.

“Over the past few years, with the advances in technology and new knowledge resulting from research, the amount of information on the Internet has grown exponentially,” says Pallipedia

editor Roberto Wenk, MD. “As part of this growth, several online dictionaries have been built, but none specific to palliative care. Individuals seeking for the definitions of terms related to the field are forced to look in different sources, some of which do not meet appropriate quality standards.”

Definitions are accepted for online inclusion only if they have been published in peer-reviewed journals, textbooks, or reference publications, or on institutional websites following a sound consensus-based process, states IAHPC. Entries include not only the more than 1300 definitions with source references listed, but also often links to the source material, as well as links to suggested related terms.

Excerpts from sample entries include:

End-of-Life Care. End-of-life care combines the broad set of health and community services that care for the

population at the end of their life. Quality end-of-life care is realized when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community. (Source: *Palliative Care Australia*)

Good Death. The components of good death include being free of pain, surrounded by family, free of conflict, acceptance of death, stopping of curative treatment, being at peace, and preferably dying at home. It implies that one can define a good death and should be able to achieve it. (Source: *Oxford Textbook of Palliative Medicine*)

Quality of Life. Well-being as defined by each individual. It relates both to experiences that are meaningful and valuable to the individual, and his/her capacity to have such experiences. (Source: *Canadian Hospice Palliative Care Association*)

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