End-of-Life Experiences Vary Widely in Advanced Lung Cancer Patients

Recognizing individual trajectories may lead to better quality of care

Wide variation found in the patterns of care experienced from diagnosis to death by patients with an aggressive form of lung cancer reveals a need for better understanding of individuals’ care trajectories and may help shape efforts to tailor healthcare options for improved individualized care in this population, according to a report published in Health Affairs.

Investigators analyzed data from national cancer registries linked to Medicare claims for 14,257 patients diagnosed from 1995 to 2009 with extensive-stage small-cell lung cancer. Because of this aggressive cancer’s short survival time, “end-of-life care begins at diagnosis for many people,” note the authors.

Rather than identifying generalized healthcare usage for the entire group, the researchers compared patients’ care experiences when classified into four categories based on the setting in which they spent the majority of their time from diagnosis to death, and found substantially different patterns of care. “This variability would have been obscured in summaries of average utilization,” the authors write.

Home-dominated. Overall, 66% of patients spent most of their time in a home setting without hospice. Of these, 51% eventually enrolled in hospice, one-third in the final week of life. Mean hospice length of stay (LOS) was 13 days.

Acute-dominated. 17% spent a large proportion of time in a hospital inpatient unit. 45% died in acute care. 31% enrolled in hospice, about 75% of these within 1 week of death. Mean hospice LOS was 2 days.

Hospice-dominated. 11% were primarily in hospice care from diagnosis to death. Everyone in this class enrolled in hospice at some point. 94% died in hospice care. Mean hospice LOS was 69 days.

ICU-dominated. 6% spent a significant amount of time in the ICU. Nearly 75% died while in acute care; 20% enrolled and died in hospice. Mean hospice LOS: 1 day.

Earlier Hospice Referrals Needed

Hospice use has increased dramatically over time, from 23% of Medicare decedents in 2000 to 48% in 2014, note the authors. “However, one-third of Medicare decedents receive less than a week of hospice,” they note, adding that the use of aggressive care near the end of life has also increased over time, despite guidelines recommending integration of palliative care at diagnosis and early referral to hospice.

The authors conclude that more study is needed to understand patient experiences within the spectrum of care trajectories, “particularly those experienced by the sickest of the sick” in order to continue to improve the quality of care at the end of life.

Source: “Medicare Beneficiaries with Advanced Lung Cancer Experience Diverse Patterns of Care from Diagnosis to Death,” Health Affairs; July 2017; 36(7):1193–1200. Schuler MS, Joyce NR, Huskamp HA, Lamont EB, Hatfield LA; RAND Corporation; Department of Health Care Policy, Harvard Medical School; Division of General Medicine, Brigham and Women’s Hospital; Massachusetts General Hospital Cancer Center; and Department of Medicine, Harvard Medical School, all in Boston.
Patients with advanced dementia are more likely to be discharged from hospital to hospice services when their attending physician is a hospitalist rather than a generalist or specialist, according to findings of a retrospective cohort study. But although most hospitalists report feeling confident in leading conversations with patients/families about serious illness, many identify concerns and a need for improvement, a national survey has found.

**IMPROVING HOSPICE REFERRALS**

“[W]hile hospice referrals for admitted patients with advanced dementia have increased from 2000 to 2010, patients cared for by hospitalists as compared to non-hospitalist generalists are more likely to be referred to hospice,” write the authors of a report published in the *Journal of the American Geriatrics Society*. “This study has implications for how hospice referrals for high-risk patients might be increased.”

Patients dying from advanced dementia, many of whom reside in nursing homes, are known to benefit from hospice, point out the authors. Research shows these hospice enrollees have improved symptom management with fewer unmet needs, hospitalizations, and burdensome transactions, along with better surrogate perceptions of quality of end-of-life care.

“Despite the benefits of hospice care, there is significant variation in who is enrolled in hospice that is not driven by patient preferences for care,” the authors note, adding that while patient and system characteristics contribute to the occurrence of hospice enrollment, physician characteristics have been shown to be a major predictor.

Investigators analyzed hospice referral patterns in a 20% sample of Medicare nursing home residents with advanced dementia and four or more impairments in activities of daily living who were hospitalized between 2000 and 2010 (n = 128,989). Rates of hospice referral within one day following discharge were compared among three groups of attending physicians: general practitioners, specialists, and hospitalists.

**OVERALL**

- The rate of hospice referral among advanced dementia patients increased from 2.8% in 2000 to 11.2% in 2010.
- 10.6% of patients died while hospitalized; the mortality rate in the year post-hospitalization was 66.6%.
- Over time, all physician groups had increasing hospice referral rates, from 2.7%, 2.6%, and 3.6% in 2000 to 9.9%, 10.2%, and 13.8% in 2010 for generalists, specialists, and hospitalists, respectively.

**KEY FINDINGS**

- Hospitalists were more likely than generalist physicians to refer patients to hospice at discharge (adjusted odds ratio [AOR], 1.27; 95% confidence interval [CI], 1.20 to 1.40) in bivariate analysis.
- Adjustment for the increasing use of hospitalists over time revealed an even stronger likelihood of hospice referral for patients cared for by hospitalists (AOR, 1.75; 95% CI, 1.50 to 1.86).
- Continuity of care from outpatient setting to hospital (i.e., having cared for the patient within 120 days prior to admission) was linked to lower likelihood of hospice referral (AOR, 0.78; 95% CI, 0.73 to 0.85).

“It is interesting that generalists with continuity were less likely to refer persons to hospice, indicating that the presence of fresh eyes might be important to reevaluate a patient’s clinical course,” note the authors.

**SUGGESTED REASONS FOR HIGHER RATE OF HOSPITALIST REFERRALS**

- Hospitalists probably care for greater numbers of seriously ill inpatients than do generalists, and may thus have become more comfortable discussing advance care planning and suggesting hospice.
- A lack of care continuity with patients may reduce hospitalists’ fears of inducing patient-perceived abandonment and may also improve prognostication.
- Hospitalists may be practicing within health systems in which they have greater exposure to palliative care teams, or in systems that encourage hospice referral as a means of reducing readmissions and inpatient deaths.

**RELATED SURVEY FINDS HOSPITALISTS CONFIDENT HOLDING DISCUSSIONS, BUT THEY IDENTIFY BARRIERS**

A report in the *Journal of Palliative Medicine* outlines areas in which hospitalists feel confident in discussing goals of care with patients/families, as well as areas of concern and barriers to communication they encounter, pointing to directions in which hospice referral by hospitalists might be improved, according to the authors.

Researchers conducted a survey among a national sample of 332 practicing hospitalists (mean age, 41 years; mean years in practice, 9.4) from 43 states in the spring of 2016. Most respondents were members of the Society of Hospital Medicine, which identifies palliative care as a core competency.

**KEY SURVEY RESULTS**

- Most hospitalists reported feeling confident or very confident in discussing goals of care (93%), DNR orders (92%), and prognosis (87%).
- Most also felt confident in breaking bad news (90%), as well as in describing comfort care (90%) and hospice (85%).
- Fewer respondents felt confident in their ability to manage conflict (50%), counsel...
Neurologists Urged to Address
Shared Decision-Making Issues in Severe Stroke Cases

Stroke patients’ likelihood of receipt of comfort measures only (i.e., comfort or hospice services within 48 hours of hospital arrival) vary widely, not only by patient characteristics and stroke type (3.0% to 19.4%), but also by hospital location (0.6% to 37.6%), according to a report published in *Neurology® Clinical Practice*.

The results of the study illuminate the difficulties experienced in shared decision making in real time following severe stroke, note the authors of an editorial accompanying the report. Although “we do our best...as we earnestly try to understand and make the right decisions,” neurologists “can do better” to help improve care of the seriously ill and dying. The editorial suggests several areas to target for greater integration of palliative care.

**TARGETED AREAS**

**Education.** Renewed and improved education is needed in the skills neurologists use to elicit patients’ goals, values, and preferences and to then “fine-tune their treatment recommendations to align with those aims.” Training could also help neurologists explore the reasons that surrogates often have opinions that differ from their own, and how to manage such conflicts.

**Research.** The timing and quality of advance care planning and end-of-life decision making must be more deeply explored for patients with stroke. “Quality measures need to move well beyond the existing stroke process measures” to include domains such as comfortable dying, symptom screening, documentation of beliefs and values, and care and treatment preferences.

**Systems and practices.** Approaches to integration of palliative care include identifying better care and payment models and advocating for better reimbursements for the comprehensive delivery of palliative care to patients with stroke and their families.

“The take-home message from this study is simple,” write the authors. “What matters most remains the quality of the conversation — how well clinicians teach and how well we listen.”

**Hospitalists Play Increasingly Prominent Role (from Page 2)**

patients/families who request medically inappropriate treatments (57%), or respond to patients/families who have not accepted the seriousness of the illness (59%).

- More than half reported having concerns on most shifts or every shift about a patient/family’s understanding of prognosis (53%) or code status (63%).
- Only 37% felt confident in the use of self-care techniques to prevent burnout and compassion fatigue.

“[O]ur respondents reported lower confidence in what might be considered more complex or emotionally charged serious illness talks,” write the authors. “Our results suggest the need to develop opportunities to support hospitalists in leading serious illness communication.”

Frequently cited barriers to goals-of-care discussions included:

- Lack of time (76%)
- Unrealistic prognostic expectations (72%)
- Lack of prior outpatient discussions (67%)
- Difficulty in finding records of previous discussions (64%)
- Frequent handoffs between hospitalists (57%)

Three-quarters (74%) of hospitalists said they had received previous training in palliative care during residency: 34%, during medical school. “That most respondents reported education in palliative care is heartening; however, that many still felt unprepared to engage in more advanced serious illness communication tasks indicates that there is still need for improvement,” write the authors.

**SUGGESTIONS FOR IMPROVEMENT**

- Increase the time hospitalists have for discussions.
- Refine documentation systems to include prior goals-of-care discussions.
- Improve communication between inpatient and outpatient clinicians.
- Develop training focused on challenging communication scenarios.

While 25% of hospitalists reported receiving only limited institutional support for end-of-life communication, almost half (46%) reported that hospitalists at their institutions had been asked to participate in palliative care improvement efforts.

“As the physicians caring for many of the most seriously ill patients in the United States, hospitalists are well-positioned to be providers of primary palliative care, especially where hospitals lack adequate or, in many cases, any palliative care consultation services,” the authors conclude.

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 pulmonary disease (COPD), look for the following indicators:

- Dyspnea at rest
- Poor response to bronchodilators
- Recurrent pulmonary infections
- Right heart failure
- Unintentional weight loss
- Bed to chair existence

Call us any time, any day.

Geoffrey Coleman, MD
Medical Director
Montgomery Hospice

Successful Advance Care Planning Campaign
Opens with Teaser, ‘WGYLM?’

A group of physicians and nurses affiliated with an academic health system in California identified a need for increased documentation of patient-clinician discussions of advance care planning, and launched a project to improve matters by raising awareness of the importance of making one’s wishes known in an unusual way.

In early 2017, the team at the University of California (UC) San Diego Health posted signs with the cryptic acronym “WGYLM?” at the healthcare system’s two hospitals and seven of its largest clinics. A month later, larger signs carried the acronym spelled out — “What Gives Your Life Meaning?” — accompanied by a whiteboard with pens and sticky notes for patients and clinicians to post their responses, anonymously, if they wished.

“This was a social experiment designed to encourage employees to think about advance care planning,” says Cassia Yi, MSN, critical care clinical nurse specialist at UC San Diego Health. “Planning for end of life is a topic that most people avoid. But the hospital felt it was important for our employees to have these crucial conversations so that they can help patients do the same.”

‘HAVE YOU TOLD ANYONE?’

It’s not enough to simply answer the question for oneself, note members of the project team. The next step is to share with loved ones and clinicians what is important for one’s quality of life and how one wants to be treated in a medical emergency or as death approaches.

So, as the next project step, with the white boards brimming with thousands of responses, the group added the headline, “Have You Told Anyone?” As of April 2017, the project had yielded a 50% increase in documented advance care conversations among patients at the facilities.

“Our clinical teams always want to do what’s best for the patient,” says project participant Kyle Edmonds, MD, quality medical director for the health system’s Palliative Care Service. “But to do what’s best for the patient, we have to know what they really want, and their wishes need to be documented in their medical record.”

Yi and Edmonds add that end-of-life planning involves ongoing exploration of values and discussion of preferences, plus the designation of a surrogate decision maker. They credit the School of Nursing at California State University San Marcos for the inspiration for the project.