Recent Prognosis Discussion Improves Advanced Cancer Patients’ Understanding of Terminal Illness

Patients with advanced cancer who have recent or ongoing discussions of prognosis/life expectancy with their oncologists have an improved and more accurate understanding of their illness, making them better prepared for informed end-of-life care decision making, according to a report published in the *Journal of Clinical Oncology*.

“To our knowledge, our study is the first to directly address and demonstrate these associations between the timing of patient-reported prognostic discussions and improvements in illness understanding by patients,” write the authors. “These results highlight the need for timely (i.e., current) prognostic disclosures to terminally ill patients…. The results also suggest that oncologists should discuss prognosis on an ongoing basis, and as frequently as appropriate, with their terminally ill patients.”

Investigators analyzed responses to interviews conducted between 2011 and 2015 among a sample (n = 178) of participants from the Coping with Cancer II study, a large prospective, multi-site cohort study of patients and their physicians. All patients had advanced cancer refractory to prior chemotherapy, and were expected by their oncologists to die within six months.

Patients were interviewed both before and after a visit with their oncologist to discuss the results of a cancer restaging scan, and were scored (from 0 to 4) for their understanding of the following four indicators deemed essential for informed decision making: patient terminal illness acknowledgment; recognition of incurable disease status; knowledge of the advanced stage of the disease; and expectation to live months as opposed to years.

**OVERALL**

• Before the restaging scan visit, only 5% of patients had sufficient knowledge for making care decisions (i.e., scored 4 out of 4), while 18% scored 0.
• After the scan results were discussed with their oncologist, just 7% had understanding of all four points about their illness; 15% scored 0.
• 38% reported having never discussed prognosis/life expectancy with their oncologist; 38% reported only past discussions, with no prognosis discussion at this most recent visit.

“We were astonished to learn that only five percent of this sample had sufficient knowledge about their illness to make informed decisions about their care,” says co-author Holly G. Prigerson, PhD, professor in geriatrics, Weill Cornell Medical College in New York City. “Many did not know that they were at the end stage of their illness nor that their cancer was incurable. They were basically making treatment decisions in the dark.”

**KEY FINDINGS**

• Patients who reported having only a recent discussion of prognosis (10%) showed significant, positive change in their illness understanding, with a least-squares mean change score of 0.62 (95% confidence interval [CI], 0.23 to 1.01).
• Patients reporting both recent and past discussions of prognosis (13%) also demonstrated an increase in illness understanding (least-squares mean change score, 0.37; 95% CI, 0.04 to 0.70).
• Patients who had only past discussions or no discussions of prognosis/life expectancy showed no significant change in illness understanding, with a least-squares mean change score of 0.21 (95% CI, -0.25 to 0.67).
Despite expectations that physicians would prove to use less aggressive care at life’s end, researchers have found that, while physicians are slightly more likely than non-physicians to use hospice, they also spend more days in an intensive care unit (ICU) in the last six months of life and just as much time hospitalized, according to a report published in the Journal of the American Geriatrics Society.

“The overall narrative that doctors die differently is false,” says senior author Stacy Fisher, MD, associate professor at the University of the Colorado School of Medicine in Aurora. “We found that doctors used more hospice care — about two days on average — but when you look at the length of stay in hospital in the last months of life, there is no difference between them and the rest of the population.”

Both general opinion and the findings of physician surveys suggest that physicians, with their greater understanding of prognosis and of the potential benefits and limitations of modern medicine, are more likely than others to avoid ineffective aggressive care at the end of life, note the authors. But whether physicians differ in actual healthcare use patterns at the end of life has not been previously examined.

Investigators analyzed Medicare claims data and data from the Physician Master-file maintained by the American Medical Association to compare healthcare use in the last six months of life by physicians (n = 192,006) who died between 2008 and 2010. Mean age at death in both physicians (n = 9947) and a random sample of non-physicians was approximately 82 years.

**HOSPICE USE**

- Overall, 46.4% of physicians and 43.2% of non-physicians used hospice in the last six months of life.
- Physicians were not only more likely than non-physicians to use hospice (adjusted odds ratio [aOR], 1.23; 95% confidence interval [CI], 1.18 to 1.29), they also spent a mean of 2.44 more days in hospice than did non-physicians (P = .001).
- Overall, decedents in both physician and non-physician groups spent an average of about 19 days in hospice (19.4 days and 19.3 days, respectively).
- However, the proportion of physicians entering hospice within 7 days of death (an indicator of poorer quality end-of-life care) was significantly greater than that for non-physicians (aOR, 1.08; 95% CI, 1.02 to 1.14).

**HOSPITAL-BASED SERVICES**

- Overall, a smaller proportion of physicians than of non-physicians had at least one hospitalization in the last six months of life (66.6% vs 69.5%; P = .001) as well as in the last one month (50.1% vs 52.5%; P = .001). After adjustment, the lesser likelihood for physicians of hospitalization within the last one month of life remained statistically significant (aOR, 0.91; 95% CI, 0.87 to 0.96).
- The mean number of hospital days in both the last six months and one month of life was nearly identical in both the physician and non-physician groups (12.2 vs 12.4 days; P = .28; and 5.3 vs 5.3 days; P = .87, respectively).
- There were no significant differences between the proportions of physicians and non-physicians who died in the hospital (25.3% vs 25.9%; P = .18), including after adjustment (aOR, 0.99; 95% CI, 0.95 to 1.04).
- While there was no significant difference between the two groups in ICU use in the final six months of life, physicians spent more days than non-physicians in ICU care, both in the last six months (3.1 vs 2.8 days; P = .001) and the last one month (1.7 vs 1.5 days; P = .001).

“Based on prior survey research of physician attitudes toward end-of-life care, it was expected that physicians would have less use of high intensity hospital-based care at the end of life,” the authors write. “The findings, in contrast, were mixed. Taken together, these results suggest that physician decedents use slightly more resources in general.”

**INSIGHTS INTO FINDINGS**

As to why their findings conflict with earlier evidence demonstrating physician preferences for less aggressive end-of-life care, the authors suggest three possible reasons:

1. **Generational differences.** All decedents in the study were aged 65 years and older, with the median age of physicians being 82.7 years. “Many of these physicians trained and practiced medicine at a time before hospice or palliative care and before many of the technological advances in intensive care,” note the authors.

2. **Death avoidance.** “[F]ear and avoidance of dying are strong motivators of much of human behavior and perhaps physicians are not immune to these...”

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Families Report a Better Quality of Dying in Patients with Cancer or Dementia vs Other Diseases

Families report better end-of-life care quality for patients with cancer or dementia than for patients with other diagnoses, largely because cancer and dementia patients are more likely to die in a designated hospice or palliative care bed, less likely to die in an intensive care unit (ICU), and have higher rates of palliative care consultations and do-not-resuscitate (DNR) orders, according to a report published in *JAMA Internal Medicine.*

“These findings suggest a need for greater attention to diagnosis-related disparities in the quality of end-of-life care,” write the authors. “Setting of death, palliative care consultation, and DNR order at death were independently associated with family-reported overall quality of end-of-life care (P = .001) and with several other family-reported quality measures.”

Investigators analyzed the medical records of 57,753 patients (mean age, 74.1 years) who died in one of 146 inpatient facilities within the Veterans Affairs (VA) health system between 2009 and 2012, along with survey data from 34,005 of the patients’ family members who participated in the VA’s Bereaved Family Survey. In the survey, next of kin are asked to assess the quality of care received by their loved ones in the last 30 days of life.

Patient diagnoses were categorized as end-stage renal disease (ESRD), cancer, cardiopulmonary failure (congestive heart failure or chronic obstructive pulmonary disease), dementia, or frailty (including Parkinson’s disease and stroke).

**FINDINGS: QUALITY OF CARE**

- While nearly 60% of families of patients with cancer (59.2%) or dementia (59.3%) said care in the last 30 days was “excellent” (a rating of five on a five-point scale), ratings for patients with ESRD (54.8%), cardiopulmonary failure (54.8%), or frailty (53.7%) were significantly lower.
- 79.1% and 80.4% of family members of cancer and dementia patients, respectively, said the patient always received the desired care; among other diseases, the proportion ranged from 73.4% to 76.8%.
- Factors independently associated with family-reported excellence of care included palliative care consultation, setting of death, and presence of a DNR order.

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‘Mixed’ Results (from Page 2)

fears of dying,” the authors suggest.

3. **System factors.** “The most troubling potential explanation for the findings is that higher-level healthcare system factors affect end-of-life care independent of patient or clinician factors,” observe the authors. Due to the way reimbursement for healthcare services is structured, “the system has evolved to favor hospital-based interventions that may offer less value during a person’s final months.”

“We need to take a critical look at our healthcare system and ask what is driving this low-value care, and by that I mean care that doesn’t offer any real quantity or quality of life,” says Fischer. “And clearly, despite their medical knowledge, physicians are not immune. We hope our study will help spark a national conversation about this increasingly important issue.”


Prognosis (from Page 1)

expectancy demonstrated no improvement in their illness understanding after the restaging scan visit.

“Groups of patients who reported recent only and both recent and past discussions of prognosis/life expectancy with their oncologists had significant positive changes in their illness understanding scores,” write the authors. “This...suggests that, regardless of the approach, the recency of the prognostic discussion matters for prognostic understanding by the patient.”

The authors urge oncologists to discuss the patient’s stage of illness and life expectancy at every appointment, even if it feels repetitive. “Talking about these things at the current visit will have the greatest influence on patients,” adds Prigerson.

Source: “Discussions of Life Expectancy and Changes in Illness Understanding in Patients with Advanced Cancer,” *Journal of Clinical Oncology; Epub ahead of print, May 23, 2016; DOI: 10.1200/JCO.2015.63.6696.* Epstein AS, Prigerson HG, O’Reilly EM, Maciejewski PK; Memorial Sloan Kettering Cancer Center; Center for Research on End-of-Life Care, Cornell University; Weill Cornell Medicine, all in New York City.

Aug/Sept/Oct 2016 QUALITY OF LIFE MATTERS® PAGE 3
‘Substantial Overuse’ of Aggressive Care Continues among Non-Medicare Advanced Cancer Patients

About three-quarters of patients younger than 65 years with one of five common types of metastatic cancer receive aggressive care in the last month of life, care that guidelines warn is potentially harmful to patients at the end of life and their families, and care with utilization rates that have not decreased since cautions were issued. That is according to research presented at the annual meeting of the American Society of Clinical Oncology (ASCO) in June 2016.

“There is substantial overuse of aggressive end-of-life care among younger patients with incurable cancers,” write the study authors, noting that theirs is one of the first, and the largest, of studies assessing the end-of-life care delivered to young and middle-aged cancer patients.

“Aggressive care did not decrease following the 2012 ASCO Choosing Wisely® recommendations.”

Choosing Wisely was an initiative launched by the ABIM Foundation in 2012 to help clinicians make better choices by asking leading physician specialty societies to list their respective “Top Five” tests or procedures that are common practice but should be called into question. The goal of the initiative was to improve outcomes, promote patient-centered care, cut costs, and avoid unnecessary and possibly harmful interventions.

Heading ASCO’s Top Five list of recommendations was a strong caution against delivering cancer-directed care to patients with metastatic disease nearing the end of life, encouraging instead a focus on symptom-directed palliative care for these patients. [See sidebar.]

“While it can be difficult to predict when a patient is nearing his or her final month of life, we need to do a better job of scaling back disease-directed treatment and transition patients to symptom-directed end-of-life care sooner,” says lead study author Ronald C. Chen, MD, MPH.

“Intensive care at the end of life remains appropriate for some patients,” Chen notes. “Still, we need more education of both patients and physicians to improve conversations about goals and expectations.”

Investigators analyzed insurance claims data across 14 states for 28,731 patients aged ≤ 65 years (a non-Medicare population) who were diagnosed with metastatic lung, colorectal, breast, pancreatic, or prostate cancer and who died between 2007 and 2014. Analysis included a comparison of the current (2014) use of aggressive care in the last 30 days of life with its use before the 2012 release of ASCO’s Top Five list of recommendations.

**AGGRESSIVE CARE USE HIGH**

Rates of aggressive care use and use of hospice were essentially unchanged across the five studied cancers. There was no decrease in the use of cancer-targeted therapy (i.e., chemotherapy or radiation), no decrease in the use of hospital-based care, no change in the percentage of hospital deaths, and no increase in the use of hospice over time since the release of the Choosing Wisely recommendations.

**FINDINGS**

- Overall, at least one form of aggressive care within the last 30 days of life was received by 71% to 76% of patients across all five cancers.
- Hospital admission/emergency department visit was the most common form of aggressive care used, ranging from 61% to 65% of patients.
- Chemotherapy use in patients ranged from 24% to 32%.
- Radiotherapy use in patients ranged from 6% to 21%.
- Invasive procedures (e.g., biopsy and surgery) were undergone by 26% to 31% of patients.

**ASCO’s Choosing Wisely® Recommendation**

The first recommendation in ASCO’s Choosing Wisely list is to not use cancer-directed therapy for solid tumor patients with the following characteristics:

- Low performance status (3 or 4)
- No benefit from prior evidence-based interventions
- Not eligible for a clinical trial
- No strong evidence supporting the clinical value of further anti-cancer treatment

“Because further cancer treatment is unlikely to be effective in these patients, emphasis should be placed on palliative and supportive care to treat symptoms and concerns, which can increase quality of life and, in some cases, extend survival,” ASCO states.

— ASCO, Choosing Wisely: Five Things Physicians and Patients Should Question

**CONTINUED ON PAGE 5**
Families Report a Better Quality of Dying (from Page 3)

FINDINGS: MEASURES OF CARE

- Rates of palliative care consultation were significantly higher among patients with cancer (adjusted proportion, 73.5%) and dementia (61.4%), than among those with ESRD (50.4%), cardiopulmonary failure (46.7%), or frailty (43.7%).
- Existence of DNR orders was also higher among cancer (95.3%) and dementia (93.5%) patients, compared with those with ESRD (87.0%), cardiopulmonary failure (86.3%), or frailty (88.6%).
- A higher proportion of patients with cancer (42.9%) or dementia (32.3%) died in an inpatient hospice unit, while less than one-fourth of those with ESRD (24.3%), cardiopulmonary failure (22.9%), or frailty (20.3%) died in a hospice or palliative care bed.
- About one-third of patients with ESRD (32.3%), cardiopulmonary failure (34.1%), or frailty (35.2%) died in an ICU, more than twice the rate of those with cancer (13.4%) or dementia (8.9%).

Most people in the U.S. die of diseases other than cancer, note the authors, yet research assessing the quality of care received by those with other illnesses — as well as research comparing care across diagnoses — has been sparse. Although results of the current study might not apply to people treated outside of the VA system (which integrates palliative care with disease-targeted treatment), the authors hope the findings add to the growing body of evidence indicating that patients and families are more satisfied with medical care at the end of life that offers the opportunity to die outside of a hospital and to receive palliative care focused on symptom relief and the quality of their remaining time.

CALL TO ACTION

 “[W]e need to continue to strive for parity in our current palliative interventions for all patients at the end of life, both within the VA health system and beyond,” write Stacy M. Fischer, MD, of the University of Colorado School of Medicine, Aurora, and colleagues, in a commentary accompanying the study. The authors call for a change in the “broader culture” around palliative/end-of-life care, particularly earlier in the illness trajectory.

For instance, the VA’s approach to care of seriously ill patients “has supported integration of palliative care services with disease-focused treatment to reduce the ‘terrible choice’ of treatment focused on disease versus a comfort approach to care,” they note. Yet, workforce shortages may continue to limit access to palliative care.

“Not every patient needs a palliative care consultation with a specialist palliative care physician, nurse, and social worker,” they observe. “Understanding which patients need which components and expanding primary palliative care may be the only way to meet the growing need for patients with advanced progressive medical illnesses.”

Healthcare systems such as the Centers for Medicare & Medicaid Services could adopt systems like the VA’s Bereaved Family Survey to understand and improve end-of-life care for all Americans, the authors suggest. Combined with evidence-based interventions and quality improvement efforts, “we will begin to lift the fog of illness” that seems to descend upon patients, families, and healthcare professionals “when they are navigating the difficult situation at the end of life.”

Source: “Quality of End-of-Life Care Provided to Patients with Different Serious Illnesses,” JAMA Internal Medicine; Epub ahead of print, June 26, 2016; DOI: 10.1001/jamainternmed.2016.1200.

HOSPICE UNDERUTILIZED

“End-of-life care is highly personal for each patient, and palliative care — including hospice — remains one of our most underutilized resources,” says ASCO expert in palliative care Andrew Epstein, MD, a medical oncologist at Memorial Sloan Kettering Cancer Center, New York City.

Epstein continues, “There is no ‘one size fits all’ approach for end-of-life care, and there shouldn’t be. At every step of care, patients and their doctors must have thoughtful discussions about the balance of benefits to risks, including cost and side effects. Our ultimate goal as oncologists is to help patients live the longest and best life possible, even in their last days.”

The Chen et al study abstract is available at http://meetinglibrary.asco.org/content/170424-176. A PDF of ASCO’s expanded Choosing Wisely Top Five list can be found at www.choosingwisely.org/wp-content/uploads/2015/02/ASCO-Choosing-Wisely-List.pdf.

Source: “Aggressive Care at the End of Life for Younger Patients with Cancer; Impact of ASCO’s Choosing Wisely Campaign,” Journal of Clinical Oncology; 2016; 34 (suppl; absr: LBA10033).
A set of resources recently issued by the American Hospital Association (AHA) offers guidance to hospitals, clinicians, and patients in considering and discussing intensive care unit (ICU) treatment with patients and their families, so as to best align treatment with patient priorities and goals in the face of life-limiting illness.

“The healthcare system should encourage early intervention and discussion about priorities for medical care in the context of progressive disease and robust communication between patients and their providers to understand the patient’s goals,” states the AHA.

Discussions should address:
- The likelihood of acceptable (to the patient) recovery
- The risk of the patient’s long-term impairment or death
- The options for palliative care concurrent with disease-directed therapy
- The benefits of hospice care concordant with the patient’s priorities

“Discussing acceptable levels of recovery and ensuring clear understanding about the risks associated with treatment options allow providers to deliver the care that best matches the patient’s wishes,” says AHA chief medical officer John R. Combes, MD. “Sharing the options of palliative care co-management at the same time as disease-directed treatment and the benefits of hospice care can help patients remain in control of their final days.”

Entitled “Aligning Treatment with Patient Priorities in the Context of Progressive Disease for Use of the ICU,” the toolkit was produced in collaboration with the Society of Critical Care Medicine (SCCM), the National Hospice and Palliative Care Organization (NHPCO), the Center to Advance Palliative Care (CAPC), Education in Palliative and End-of-Life Care (EPEC), and the Coalition to Transform Advanced Care (C-TAC).

The website resources are presented in three sections, one each for hospital and health systems, for clinicians, and for patients. The clinician resources section includes brief descriptions of and links to fact sheets, communication guides, journal articles, tip sheets, a seven-item palliative care screen, and a webinar on improving end-of-life care through better communication with families in the ICU.

Patient resources include links to a webcast and periodical article giving an overview of approaches to death and dying, and many downloadable handouts regarding palliative care, advance directives, and ICU- and treatment-specific concerns for patients, their families, and caregivers.

The toolkit is available at www.aha-physicianforum.org/resources/appropriate-use/ICU/index.shtml.

Clinician Resources

- **Fast Facts**, maintained online by the Palliative Care Network of Wisconsin, comprise nearly 300 monographs as “teaching tools that can be used for bedside rounds, as well as self-study material for healthcare trainees and clinicians.” Titles include:
  - Palliative Care and ICU Care: Pre-Admission Assessment
  - The Family Meeting: End-of-Life Goal Setting and Future Planning
  - Palliative Care Consultation in the ICU
- **“Choosing Wisely: Five Things”** is a list describing five common practices used in critical care settings whose necessity should be questioned. The list is an initiative of the Critical Care Societies Collaborative, which includes four professional healthcare organizations. [See related article, page 4]
- **The EPEC Project** offers curriculum with a train-the-trainer approach to educating healthcare professionals in the essential clinical competencies of palliative care. Trainer conferences are held regularly; the schedule is available on their website.
- **“Talking about Treatment Options and Palliative Care: A Guide for Clinicians,”** NHPCO’s downloadable, two-page guide offers suggested questions clinicians can ask patients from the time of their diagnosis with a potentially life-limiting illness and onward, so that patients can become familiar and comfortable with the idea of palliative care. New approaches to communicating treatment options are provided, as well as suggestions for what patients might really be thinking when they ask certain questions.
- **“Advice for Physicians Caring for Dying Patients”** from the NHPCO offers physicians tips for discussing end-of-life issues with their patients. Suggestions include: providing a clear overview of the diagnosis, prognosis, and treatment options (including risks, benefits, and outcomes) to help patients and families in their decision making; placing a copy of the patient’s living will or medical power of attorney in the medical record; and utilizing resources such as hospice or palliative care team members, social workers, and spiritual caregivers.
- **SCCM’s Project Dispatch** webcast features an expert in palliative medicine and pulmonary and critical care medicine giving an overview of palliative care in the ICU, and discussing such topics as shared decision making, tools for communication with families, and interdisciplinary communication.
Physicians Offered Explicit Sample Phrases for Pivotal Conversations with Heart Failure Patients

Refocusing commonly-used phrases in important conversations with seriously ill heart failure (HF) patients to be both specific and supportive can promote whole-person care and enhance shared decision making, “particularly in the complex and emotional realm of advancing disease and transitions to end-of-life care,” according to an article published in The American Journal of Cardiology.

Rather than the standard, unexamined phrases used commonly by cardiologists when informing patients of disease state and therapeutic options and limitations, and in discussing advance care planning and end-of-life care, the authors offer explicit alternatives, because “specific language matters.”

A general recommendation is to “focus on the disease and the therapy or intervention in question, rather than on the personhood,” write the authors. “Such focus helps remove the patient (i.e., the person) from potential negative emotions (e.g., feeling judged, incompetent, a failure, and so on) and thus may allow the patient to engage more objectively with the clinician.”

SUGGESTED PHRASES

• Rather than “You are failing the inotrope (or other therapy),” physicians can say, “The (therapy) is no longer working.” The phrase “failing a therapy,” commonly used by cardiologists to indicate that a specific treatment is no longer effective, is “irrational phrasing” that implies the patient is to blame, the authors observe.

• Rather than “You are not a candidate for this therapy,” say, “This therapy will not help you to achieve your goals.” Telling a patient he or she is not a “good candidate” for an intervention that is contraindicated or deemed inappropriate can imply that the burden of responsibility for treatment efficacy is somehow the patient’s, the authors note.

• Rather than “There’s nothing more we can do,” say, “There is no effective therapy to cure (or slow) the disease.” The authors explain, “There is always something that can be done to help,” adding, “Care is always continued, even when life-sustaining therapies are contraindicated.” The focus should now turn to what the patient hopes for in the time left and what type of medical care and services might be helpful.

• Rather than suggesting “withdrawing care” from a patient for whom aggressive life-sustaining interventions appear to be futile, physicians can tell the family, “These interventions are no longer working,” and focus the discussion on what the care team will continue to do.

• Instead of saying “We will switch her to comfort care,” physicians can say, “We will focus on care that will manage her pain, shortness of breath, and any other symptoms that are burdensome.”

The term “comfort care” can have various meanings to different people, the authors point out. It is always best to be specific when describing the care being suggested.

Source: “Choosing Words Wisely in Communication with Patients with Heart Failure and Families,” The American Journal of Cardiology; June 1, 2016; 117(11):1779-17782. Kelemen AM, Ruiz G, Groninger H; Section of Palliative Care, Department of Medicine, MedStar Washington Hospital Center, Washington, DC; and Division of Cardiology, Department of Medicine, MedStar Union Memorial Hospital, Baltimore, Maryland.
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