Patients who enter hospice with an advance directive (AD) already completed may have an enhanced hospice experience. Compared with patients who enroll without an AD, they have longer lengths of stay, are less likely to die in an inpatient setting, and are less likely to leave hospice voluntarily, according to a report published in the Journal of the American Geriatrics Society. “Most people prefer to die at home if possible, and these results suggest that advance directives may help to shape trajectories of care in ways that are more consistent with low-intensity care,” write the authors.

“Individuals enrolled in hospice for longer periods are able to receive more services, and their families have more time to anticipate and plan for the individual’s death,” the authors point out. “This additional time is important, because previous studies have shown that longer stays in hospice are associated with greater satisfaction.”

Investigators analyzed data on patients (n = 49,370) admitted between 2008 and 2012 to one of three U.S. hospice programs participating in the CHOICE (Coalition of Hospices Organized to Investigate Comparative Effectiveness) network. Overall, 73% of subjects had an advance directive at the time of hospice enrollment, and 58.2% had both an advance directive and a do-not-resuscitate (DNR) order.

SUBJECTS WITH ADVANCE DIRECTIVES WERE:

- Older (81.0 vs 74.4 years of age)
- More likely to be female (48.5% vs 42.4%)
- More likely to have a DNR order before enrollment (79.9% vs 49.1%)
- Less likely to have cancer as an admitting diagnosis (32.3% vs 40.6%) and more likely to be diagnosed with dementia (13.5% vs 8.2%)

In adjusted analysis, hospice enrollees with ADs:

- Were less likely to die within the first week after entering hospice (24.3% vs 33.2%; adjusted odds ratio [AOR], 0.83; 95% confidence interval [CI], 0.78 to 0.88; P = .001)
- Were less likely to leave hospice voluntarily (2.2% vs 3.4%; AOR, 0.82; 95% CI, 0.74 to 0.90; P = .003)
- Were less likely to die in a hospital or inpatient hospice unit rather than at home or in a nursing home (15.3% vs 25.8%; AOR, 0.82; 95% CI, 0.77 to 0.87)

“Participants with advance directives were enrolled in hospice for a longer period of time before death than those without, and were more likely to die in the setting of their choice,” write the authors. “More time might have allowed participants and families to prepare for the end of life by organizing caregiving resources, making death at home more likely.”

The finding that patients with ADs are less likely to withdraw from hospice may reflect a desire to avoid life-sustaining treatments that prompts the completion of a directive, the authors suggest. An AD might also serve as “a reminder of individual preferences as people near the end of life, reducing the likelihood of disagreements between family members, particularly when the individual is no longer able to participate in these decisions,” they add.

Although the evidence increasingly shows an association of ADs with better outcomes and less aggressive treatment in hospice, the authors note that the results do not prove causality. "Advancing the quality of care involves not only improving the outcomes of individual patients, but also carefully assessing the impact of interventions on the quality of the care received by patients and their families. Further research is needed to understand the mechanisms through which advance directives influence hospice care and to identify strategies to improve the use and effectiveness of advance directives in hospice settings.\"
World Health Assembly Calls for Access to Palliative Care throughout Continuum of Care

The policy-making body of the World Health Organization (WHO) adopted a resolution in May of this year which states that hospice and palliative care services must be integrated into the national health policies and budgets of all its member nations, with training in palliative care included in the curricula for health professionals.

“National health systems need to include palliative care in the continuum of care for people with chronic, life-threatening conditions, strategically linking it to prevention, early detection, and treatment programs,” states the World Health Assembly (WHA) resolution. “It should not be considered as an optional extra.”

The ground-breaking resolution calls for nations to:
• Integrate palliative care services into the structure and financing of national health care systems at all levels of care.
• Promote education and training in palliative care practices for health care professionals.
• Ensure the availability of essential medicines for managing pain and other symptoms.
• Support research to assess needs and identify standards for palliative care.
• Identify successful models of service.

WHO defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.”

The resolution notes that palliative care also respects the choice of patients and helps families with practical issues, “including coping with loss and grief throughout the illness and in case of bereavement.” Services should be provided concurrently with potentially curative treatment, and adapted to the increased needs of patients, families, and caregivers as the disease progresses into the terminal phase.

“Increasing access to hospice and palliative care services as part of a seamless continuum of care for people facing serious and life-threatening illness has been a priority among many hospice providers in the United States,” says J. Donald Schumacher, PsyD, President and CEO, National Hospice and Palliative Care Organization (NHPCO). “Having global attention on this issue will help make needed progress to alleviate pain and suffering for millions.”

Hospice services in the U.S. are covered by Medicare for those aged 65 years and older, and by Medicaid and most insurance plans for other patients. Access to palliative care services for those with serious illness remains an area under development in this country, although a high percentage of teaching hospitals now have palliative care teams.

According to WHO, successful models for delivering palliative care include:
• A multidisciplinary approach
• Adaptation to specific cultural, social, and economic settings
• Integration into existing health systems, “with emphasis on primary health care and community- and home-based care”

The need for palliative care continues to rise, says the resolution, due to the increasing prevalence of noncommunicable diseases and the aging of many countries’ populations. WHO estimates that of the 20 million people worldwide who need end-of-life palliative care services, 80% live in low- and middle-income countries, and about two-thirds (67%) are elderly.

According to the first Global Atlas on Palliative Care at the End of Life, published in early 2014 by WHO and the Worldwide Hospice Palliative Care Alliance (WPCA):
• 42% of countries have low or no access to hospice and palliative care services.
• Only 20 countries have palliative care that is well integrated into their health systems.
• 80% of countries have low or extremely restricted access to strong pain medications for those who experience chronic pain. According to the NHPCO, this means that “millions of people worldwide are living and dying in pain and distress with no or little quality care.”

**BARRIERS TO PROVISION OF PALLIATIVE CARE INCLUDE:**

• Health policies that do not meet needs
• Uncertain access to opioid analgesics
• Misconceptions about palliative care

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Advance Directives  (from Page 1)

Palliative Care  (from Page 2)

- Limited palliative care training for health care professionals

The eight-page WHA resolution, entitled “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” can be viewed at http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_31-en.pdf.

EXPERT CALLS FOR IMPROVING EDUCATION/TRAINING OF U.S. PHYSICIANS

The crucial need for improving education and training of U.S. physicians in palliative care is the focus of an article on the overtreatment of patients near the end of life, published in the journal Health Affairs.

“Doctors care deeply about their patients, and most aim to express that care exactly as they were taught to express it,” writes Diane E. Meier, MD, director of the Center to Advance Palliative Care and professor, Department of Geriatrics and Palliative Medicine, Icahn School of Medicine, Mount Sinai, New York, NY. “[T]he commitment to care and help is behind physicians’ recommendations to their patients — recommendations firmly based on what they learned during their training.”

In other words, because physicians are trained to diagnose and treat diseases — and not how to continue to care for patients when disease-modifying treatments no longer work — they often find themselves expressing their continued commitment to help terminally ill patients in the way they know best: by ordering more tests and interventions.

Patients with progressive illness assume that if their physicians order tests and treatments, it is because the doctors believe such interventions will be of benefit, notes Meier. “Patients and families also assume that doctors will tell them when time is running out, what to expect, and how best to navigate these unknown and frightening waters,” she writes.

But traditional medical school and residency training have provided physicians with little or no training in this type of care, notes Meier.

To better suit patients’ needs, physician training is needed in:

- The core skills of care during serious illness and near the end of life
- Communication about what matters most to patients and families
- Expert pain and symptom management
- Coordinated care across the illness trajectory

Both physicians and patients wish to sustain their “human connection, the relationship between doctor and patient that is at the heart of quality care,” writes Meier. “With the right training and skills, doctors can honor that relationship throughout their patient’s experience of illness, even and especially when disease-focused treatment is no longer beneficial. Our patients, and their doctors, deserve no less.”

Source: “I Don’t Want Jenny to Think I’m Abandoning Her”: Views on Overtreatment,” Health Affairs; May 2014: 33(5):895-898. Meier DE; Center to Advance Palliative Care; Department of Geriatrics and Palliative Medicine, Icahn School of Medicine, Mount Sinai, New York City.
Taking the Initiative: Are Patients Waiting for Physicians to Discuss Prognosis and Palliative Care Referral?

Studies have shown that most terminally ill patients are willing to hear their prognosis, and that honest communication on the topic rarely takes away all hope or causes them harm. In fact, accurate awareness of prognosis is needed for patients to make informed end-of-life care choices.

Research also shows that seriously ill patients with unmet or complex palliative care needs can benefit from referral to subspecialty palliative medicine services. But patients may not be aware of such services, or of when they might need them, or of how to ask for them.

The results of two reports published in the *Journal of Palliative Medicine* suggest that patients with advanced cancer who are unsure how or when to express their needs for prognostic information or specialized care may benefit when their physicians take the initiative.

**EARLY PROGNOSTIC INFORMATION HELPS PATIENTS**

Few patients with advanced cancer have an accurate idea of their prognosis, although those whose physicians indicate a willingness to discuss prognosis early are more likely to understand their life expectancy than are patients whose physicians would defer the discussion, researchers report.

“In a large...cohort of patients with metastatic lung or colorectal cancer, we found that few patients (16%) who were alive three to six months after diagnosis had an accurate understanding of their prognosis, although 88% had received chemotherapy,” write the authors.

“Knowledge of prognosis is essential for terminally ill patients, because prognosis awareness can influence their preferences for aggressive therapy versus supportive care,” the authors point out. “Physicians’ reluctance or delay in discussing prognosis may have negative consequences for patients with advanced cancer, such as unwanted aggressive treatment and delays in advance care planning.”

Investigators analyzed data on 686 patients diagnosed between 2003 and 2005 with metastatic lung (56.6%) or colorectal cancer, along with survey data from 486 physicians (male, 83%) identified by patients as filling important roles in their cancer care. Interview and medical record data were gathered as part of the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) study, a multi-regional prospective cohort study.

Although median survival after detection of distant metastases is approximately four to six months for lung cancer and less than two years for colorectal cancer, for purposes of the study, patients’ awareness of their prognosis was deemed accurate if they estimated a prognosis of less than two years for stage IV lung cancer and less than five years for stage IV colorectal cancer.

Physicians with a key role in patient care — identified by study patients as the most important doctor in their decision making — were asked when they would discuss prognosis with a patient newly diagnosed with metastatic cancer whom they estimated had four to six months to live, but who was still feeling well. Choices were: “now”; when the patient first develops symptoms; when there are no more non-palliative treatments to offer; only if the patient is hospitalized; or only if the patient and/or family bring it up.

**KEY PATIENT FINDINGS**

- Only 16.5% of patients had an accurate awareness of prognosis. This proportion was similar for patients with lung (18.5%) and colorectal (13.8%) cancer.
- Many patients could not provide a prognosis, answering either “do not know” (35.8%) or “it’s in God’s hands” (11.6%).
- Patients whose physicians would discuss prognosis “now” were more likely to have an accurate idea of their prognosis, compared to those whose physicians would defer such a discussion (18.5% vs 7.6%; odds ratio [OR] = 3.23; 95% confidence interval [CI], 1.39 to 7.52; \( P = 0.006 \)).

“The strikingly lower rate of reporting an accurate estimate of life expectancy among patients whose most-important-doctor did not report discussing prognosis ‘now’ is particularly noteworthy,” observe the authors. “This suggests that some patients may be hindered from having an accurate understanding of their prognosis if the doctors whom they are relying on for their key decisions about their cancer tend to delay or are reluctant to discuss prognosis with them.”

**PHYSICIAN FINDINGS**

- Most key physicians (70.8%) reported they would discuss prognosis “now” with patients estimated to have four to six months to live.
- 12.8% of physicians said they would discuss prognosis only if the patient/family brought it up.
- There was no significant association between physician specialty and patient prognosis awareness.

The findings suggest that “physicians’ communication behaviors may play an important role in explaining the very low rate of prognostic understanding we observed among patients with incurable cancers,” comment the authors.
Taking the Initiative (from page 4)

However, physician communication style may be only one of the possible factors influencing patient awareness of prognosis, they suggest. The other half of the communication dyad — the patient — may sometimes misinterpret what has been said, fail to absorb imparted information, or prefer to delay or evade any mention of prognosis.

“Nevertheless,” they write, “the association between most-important-doctors’ propensity to discuss prognosis and patients’ prognosis awareness was robust to several sensitivity analyses where we reclassified these responses.”

The authors suggest that efforts be made to identify health care professionals with important roles in patients’ medical decision making and help them to enhance their communication skills. Further research is also needed regarding styles and content of prognosis discussions, to determine approaches that can maximize patient understanding.

PATIENTS WILLING TO RESPOND TO PHYSICIANS’ PALLIATIVE CARE REFERRALS

Patients with advanced cancer and self-identified unmet care needs are likely to agree when interviewed that they could use the services of a palliative care team, but say they are unlikely to ask for a referral. However, most patients report they would be very likely to see a palliative care specialist if their oncologist recommends it.

“One of the challenges in efforts to improve the quality of life for patients with advanced cancer is matching provision of subspecialty palliative care to the patients who need it most,” write the authors. “These findings signal the importance of ensuring that oncologist referrals reflect patient needs.”

Investigators analyzed survey data gathered on 169 patients (mean age, 62 years) with advanced cancer who were receiving ongoing care at one of two Pittsburgh academic cancer centers between December 2011 and April 2012. The most common cancer diagnoses were breast (32%) and lung (18%). Median length of time since cancer diagnosis was 46 months.

OVERALL FINDINGS

- 82% of patients identified at least one unmet need.
- The most commonly cited unmet palliative care needs were related to symptoms (62%) and psychological/emotional distress (62%).

KEY FINDINGS

- In adjusted analysis, unmet needs were associated with higher patient-perceived need for subspecialty palliative care services, especially for psychological/emotional distress (odds ratio [OR], 1.30; 95% confidence interval [CI], 1.06 to 1.58; P = 0.01) and symptom needs (OR, 1.27; 95% CI, 1.01 to 1.60; P = 0.04).
- No significant association was found between patients’ reports of unmet needs and their likelihood of requesting palliative care services.
- However, patient-reported willingness to see a palliative care specialist if their oncologist recommended it was rated as high overall (8.6 on a scale of 1 to 10).
- “Easily administered screening tools may help oncologists identify and refer their patients who would most benefit from palliative care services,” suggest the authors. Targeting education concerning the benefits of palliative care to oncologists may also help increase appropriate referrals, they add.
- “Finally, this data highlights the importance of facilitating and improving delivery of palliative care within oncology practices.”

A CALL FOR DECISION-MAKING SUPPORT FOR PHYSICIANS

“Patients with advanced cancer identify many unmet palliative care needs because they are waiting for their doctor to initiate it,” writes Journal of Palliative Medicine editor-in-chief Charles F. von Gunten, MD, PhD. “We know that physicians are willing to tell patients their prognosis if asked; patients want to know their prognosis if their doctor brings it up.” And “if the doctor does discuss prognosis, the patient remembers it.”

Traditionally, the practice of medicine is three-pronged: diagnosis (“What’s wrong with me?”); prognosis (“What will happen to me?”); and treatment (“What can be done to help me?”). But modern medicine struggles to incorporate prognosis into standard practice by helping physicians know when and how to tell their patients what is likely to happen to them, observes von Gunten.

What is needed is the same level of information technology used to enhance the delivery of quality care in other facets of medicine, applied to providing aids to physicians in predicting survival, discussing prognosis, and facilitating end-of-life care plans. For example, von Gunten speculates about a computer-driven decision-making tool with a pop-up box saying, “Your patient has a prognosis of three months.” “When physicians are engaged, given the right tools and the right systems, we do the right thing,” states von Gunten. “We have the information technology. We are now in a period when systemization of care is acknowledged to improve care at lower cost. Why wait?”

Experts Outline Drug-Free ‘DICE’ Approach to Managing Dementia Behavioral Symptoms

Behavioral symptoms, which are among the most difficult aspects of caring for people with dementia, occur in all types of dementia and affect nearly 98% of these patients at some point. These noncognitive neuropsychiatric symptoms (NPS) are associated with poor outcomes for both patients and caregivers, and account for about 30% of the cost of caring for community-dwelling individuals, according to an article published in the Journal of the American Geriatrics Society.

“Innovative approaches are needed to support and train the front-line providers for the burgeoning older population with behavioral symptoms of dementia,” says lead author Helen C. Kales, MD, director of geriatric psychiatry at the University of Michigan Health System, Ann Arbor. “We believe that the DICE approach offers clinicians an evidence-informed, structured clinical reasoning process that can be integrated into diverse practice settings.”

DICE (Describe, Investigate, Create, Evaluate) is the acronym for the pragmatic, step-wise approach to managing NPS developed in 2011 by a specially convened multidisciplinary panel of clinical and research experts. It aims to treat NPS effectively while reducing the unnecessary use of psychotropic medications.

TREATING THE PATIENT-CAREGIVER UNIT

Because the behavioral symptoms of dementia affect the quality of life of both patients and their family caregivers in the home, the DICE approach addresses NPS management by evaluating patient, caregiver, and environmental perspectives.

“The approach is inherently individual- and caregiver-centered, because concerns of individuals with dementia and their caregivers are integral to each step of the process,” write the authors.

Behavioral symptoms of dementia can include aggression, agitation, anxiety, depression, sleep disturbances, delusions, hallucinations, and disinhibition. These can trigger hospitalization and early nursing home placement of the patient, caregiver stress and depression, and reduced caregiver employment.

The authors use a case example to illustrate a scenario that could typically result in psychotropic medication rather than behavioral and environmental interventions. The article includes two tables: one outlines patient, caregiver, and environmental considerations for each DICE step; the other lists behavioral and environmental modification strategies organized by general domains and specific targets.

THE DICE APPROACH

Describe. Characterize the NPS. Ask the caregiver to describe the problematic behavior and the context in which it occurs. If possible, elicit the patient’s perspective. Determine which aspect of the symptom is most distressing to each. This will help in evaluation of the caregiver’s knowledge of dementia and NPS.

Investigate. Examine, exclude, and identify possible underlying and modifiable causes. Consider patient factors, such as current medications and the presence of undetected medical conditions or pain. Evaluate the caregiver’s understanding of dementia, communication style, and expectations. Assess the home environment for under- or over-stimulation and safety.

Create. Collaborate with the caregiver and team members to create and implement a treatment plan. Address first any physical problems the patient may have. Develop strategies for improving caregiver skills and well-being. Ensure the safety and enhancement (or simplification) of the environment.

Evaluate. Assess whether the recommended interventions have been implemented by the caregiver safely and effectively. If the caregiver did not attempt an intervention, try to understand why and find solutions.

“Because NPS change and fluctuate over the course of dementia, ongoing monitoring of behaviors is essential, and removal of interventions, especially medications, should be considered from time to time,” suggest the authors.

The Centers for Medicare and Medicaid Services has reviewed the DICE approach, and plans to include it as an official part in its toolkit promoting nonpharmacological approaches in dementia.

**POLST Forms Found Effective in Honoring Patients’ End-of-Life Wishes**

Seriously ill patients whose preferences concerning hospitalization near the end of life are documented in a POLST (Physician Orders for Life-Sustaining Treatment) form in the medical record are likely to have their wishes respected, according to a report published in the *Journal of the American Geriatrics Society*.

“Because emergency medical service protocol is to provide full treatment including resuscitation and transport to a hospital, Americans who prefer otherwise need to plan in advance and make their wishes known,” write the authors. “In this study, we found striking differences in how many patients died in hospitals versus at home depending on how their POLST forms were completed.”

POLST forms, usually printed on brightly colored paper, are medical orders signed by the patient’s physician, nurse practitioner, or physician assistant following a discussion of the patient’s preferred treatment plan. The forms are valid across settings, and designed to be quickly understandable by medical professionals in emergency situations. For instance, the comfort measures only (CMO) order states, “Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location…. Maximize comfort through symptom management.”

In the largest research project to date on the outcomes of a POLST program, investigators analyzed data from the Oregon Center for Health Statistics on 58,000 people who died of natural causes in 2010 and 2011. Nearly 18,000 (30.9%) of these had a POLST form in the state’s POLST registry. Orders for scope of treatment included: comfort measures only (66.1%); limited interventions (26.7%); and full treatment (6.4%).

**KEY FINDINGS**

- 44.2% of patients who specified full treatment died in the hospital, a greater percentage than among those who had no POLST orders (34.2%).
- 22.4% of patients who requested limited interventions died in the hospital.
- Only 6.4% of those with CMO orders died in the hospital.

“Although it is probably more important how you die than where you die, where you die can strongly affect how you die,” comment the authors. “Dying in the hospital involves different treatment options, support, personnel, and challenges” than does dying in long-term care or at home with hospice.

The programs are implemented by individual states and regions, and must be endorsed by the POLST task force. (Levels of program status are: mature [number of state programs = 2], endorsed [n = 13], developing [n = 28], and no program [n = 8].) To date, only the programs in West Virginia and Oregon have achieved “mature” status.

The POLST online site provides a list of all U.S. states and the District of Columbia, with information on each state’s program status, links to individual state program websites, and local contact information. Visit www.polst.org.

*Source: “Association between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and In-Hospital Death in Oregon,” Journal of the American Geriatrics Society, Epub ahead of print, June 9, 2014; DOI: 10.1111/jgs.12889. Fromme EK et al; Division of Hematology and Medical Oncology, Oregon Health & Science University, Portland, Oregon.*
Our medical director, nurse practitioner and team physicians are available for consultation as you plan your patient’s end-of-life care.

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