Factors Identified That Influence Patients’ Desire for End-of-Life Discussions with Physicians

Patients with serious illness who were concerned about being a burden, worried about their future quality of life, or who were not sure which of their physicians would be responsible for their care were more likely than others to desire an end-of-life care discussion with their clinician, according to a report in the *Journal of Pain and Symptom Management*.

In addition, patients with higher levels of anxiety were more likely to want future discussions, as were those with symptoms of moderate to severe depression who had discussed end-of-life care in the past.

“Understanding how these factors influence patients’ preferences for communication about end-of-life care may help facilitate improved discussions about goals of care and advance care planning and provide directions for future interventions,” write the authors.

Investigators analyzed questionnaire responses from patients with serious illness (n = 473; mean age, 73.5 years; non-Hispanic white, 79.3%) enrolled in an ongoing randomized trial of an intervention to improve delivery of care concordant with patient wishes. Participants, who were diagnosed with one of 17 chronic, life-limiting conditions, were cared for by their primary or specialty care clinicians (n = 128) in one of 53 different clinics within two large healthcare systems with no formal system for promoting advance care planning or goals-of-care communication.

Overall, 29% of respondents had had a previous end-of-life care discussion with their physician; 57% desired either an initial discussion or further discussion, with 19% being unsure.

**PREDICTORS OF NO PAST DISCUSSION**

- Patient did not feel sick enough to talk about end-of-life care (*P* = 0.000)
- Patient was not sure which doctor would be providing care (*P* = 0.006)
- Patient would rather concentrate on staying alive than talk about death (*P* = 0.046)

**PREDICTORS OF WANTING A FUTURE DISCUSSION**

- Patient was concerned about becoming a burden (*P* = 0.000)
- Patient was worried about future quality of life (*P* = 0.000)
- Patient was not sure which doctor would be providing care (*P* = 0.037)

Although depression and anxiety were unrelated to having had prior discussions, patients with higher anxiety were more likely to desire future discussions (*P* = 0.001), as were patients with more depressive symptoms who had had discussions in the past (*P* = 0.001).

Video Decision Aid May Help Heart Failure Patients Make Well-Informed Choices

Patients with advanced heart failure who were shown a short video depicting scenes of different levels of care were better informed about their end-of-life care options, more likely to forgo invasive interventions and choose comfort care, and more likely to have advance care planning (ACP) discussions with their physicians than were those who did not view the video, according to a report published in the journal *Circulation*.

“Because the course of heart failure is uncertain, in part because of improved therapies, doctors may be reluctant to initiate a conversation with their patients about advance care planning,” says lead author Areej El-Jawahri, MD, of the Massachusetts General Hospital Cancer Center in Boston. “We found that when patients were better informed, it’s easier for them and their doctors to discuss end-of-life issues.”

Participants were 246 patients with advanced heart failure (mean age, 81 years; male, 61%; white race, 85%) enrolled between 2012 and 2015 from seven U.S. teaching hospitals. All patients listened to a reading of a verbal description of the three levels of goals of care (life-prolonging care, limited medical care, and comfort care). The randomly-assigned video intervention group (n = 123) then watched a six-minute physician-narrated video depicting each of the three levels of care.

**DEPICTIONS OF LEVELS OF CARE**

- **Life-prolonging care:** includes images of simulated cardiopulmonary resuscitation (CPR)/intubation and a ventilated patient being tended in an intensive care unit.
- **Limited care:** shows, among other hospital ward scenes, a patient receiving medication through a peripheral intravenous catheter and one wearing a nasal cannula.
- **Comfort care:** depicts a patient at home receiving oral medications, being assisted with eating, and with a nasal cannula on oxygen.

At baseline and following the intervention, both the verbal (control) and video intervention arms completed questionnaires on goals-of-care choices, CPR/intubation preferences, and knowledge of goals of care (possible score, 0 to 6). Preferences for goals of care and use of CPR/intubation were similar in both arms at baseline, as were knowledge scores.

**OVERALL FINDINGS**

Compared with the control group, those who watched the video:

- Were less likely to choose life-prolonging care (22% vs 41%)
- Were more likely to choose comfort care (51% vs 30%)
- Were almost twice as likely to forgo CPR (68% vs 35%)
- Were more likely to forgo intubation (76% vs 48%)
- Had higher mean knowledge scores of care options in a six-item test (4.1 ± 1.4 vs 3.0 ± 1.5)
- Were four times more likely to discuss their end-of-life choices with their physician within three months (61% vs 15%; all comparisons, *P < 0.001*)

**CHANGES IN PREFERENCES, BEFORE AND AFTER INTERVENTION**

- In the video intervention arm, preference for life-prolonging care dropped from 37% to 22%, limited care choice rose from 11% to 25%, and selection of comfort care rose from 36% to 51%. Knowledge of care options increased from 2.7 at baseline to 4.1.
- Control arm choices rose from 31% to 41% for life-prolonging care and from 14% to 22% for limited care, while the selection of comfort care dropped from 37% to 30%. Knowledge of level of care options rose slightly, from 2.8 at baseline to 3.0.

Attending physicians for each of the participants were asked at baseline to report what code status they would prefer for themselves if they were in their patient’s situation. Most physicians reported they would choose to forgo CPR (87%) and intubation (81%). Preferences of the video intervention arm for code status were in higher concordance with their physicians’ choices than were those of the verbal arm.

“In this case, a picture is worth a thousand words,” says El-Jawahri, who is also a member of the Video Images of Disease for Ethical Outcomes (VIDEO) Consortium, which develops and assesses decision support tools. “After watching the video, patients have a much better sense of what procedures and therapies align with their own preferences and values.” Further, 99% of participants who saw the video said they were comfortable watching it; 96% said they would recommend it to others.

The video creators took care in its production to portray an unbiased representation of end-of-life care options, note the authors. Although the study included a disproportionate number of white participants, thus perhaps limiting the generalizability of the findings, the authors believe that this type of video tool, which is designed to support — not to replace — physician/patient communication about end-of-life care, could be offered inexpensively to patients everywhere.

The video, which was produced specifically for this study, can be viewed solely as an accompaniment to the published report at https://vimeo.com/165643630.

Source: “Randomized, Controlled Trial of an Advance Care Planning Video Decision Support Tool for Patients with Advanced Heart Failure,” *Circulation*; July 5, 2016; 134(1):52–60. El-Jawahri A, Paasche-Orlow MK, Matlock D, Warner Stevenson L, et al; Massachusetts General Hospital, Boston; Harvard Medical School, Boston; Boston University School of Medicine, Boston; University of Colorado School of Medicine, Aurora; Brigham and Women’s Hospital, Boston; Newton-Wellesley Hospital, Newton, Massachusetts; Tufts University School of Medicine, Boston; and Vanderbilt University Medical Center and Nashville Veterans Administration Medical Center, both in Nashville, Tennessee.
Surrogates’ Prognostic Expectations Differ from Those of Physicians More Than Half the Time

More than half of surrogate decision makers for critically ill, incapacitated patients hold a different — and generally more optimistic — prognostic view of the patients’ ability to recover than do the patients’ physicians, researchers have found. Further, many surrogates who say they understand the physician’s prognosis still choose to believe differently, for personal and/or emotional reasons, according to a study published in the Journal of the American Medical Association.

“Clinicians cite unrealistic expectations by surrogates as one of the most important barriers to high-quality end-of-life care in seriously ill patients,” write the authors. “The findings suggest that interventions are needed not only to improve the comprehensibility of prognostic information, but also to attend to the emotional and psychological factors that influence surrogates’ prognostic expectations.”

A 2010 U.S. study found that nearly half of adults nearing the end of life were unable to make their own decisions about life-prolonging interventions, the authors note. Surrogates need to have a clear understanding of the probable outcomes of these interventions, because overly optimistic expectations of surrogates have been “associated with more use of invasive treatments in dying patients and delayed integration of palliative care,” they write.

Investigators analyzed results of a mixed-methods study (both quantitative surveys and qualitative interviews) involving 229 surrogate decision makers (median age, 47 years; non-Hispanic white, 57%) for 174 incapacitated patients at high risk of death (median age, 60 years; non-Hispanic white, 56%) and their 99 physicians (median age, 40 years; non-Hispanic white, 66%) at four intensive care units of a major medical center from 2005 to 2009.

On day five of the patient’s receipt of mechanical ventilation, physicians and surrogates were independently asked the same question: “What do you think are the chances that the patient will survive?” Surrogates were also asked for their “best guess” of the physician’s prediction and for reasons that their estimate might differ from the physician’s.

**Key Findings**

- Physician-surrogate discordance about prognosis occurred in more than half (53%) of instances (95% confidence interval [CI], 46.8% to 59.7%).
- 43% of surrogates were more optimistic than physicians; 10% of surrogates were more pessimistic.
- In 28% of all instances, discordance was related to both misunderstandings by surrogates and differences in belief about the prognosis.
- While surrogates’ prognostic estimates were much more accurate than chance alone, physicians’ estimates were significantly more accurate than surrogates’ (C statistic, 0.83 vs 0.74; absolute difference, 0.094; 95% CI, 0.024 to 0.163; P = 0.008).

The most common reasons for surrogate over-optimism include:

- A conviction that maintaining hope would be beneficial to both the patient and themselves
- A belief that the patient had unique strengths unknown to the physician
- Religious belief that a higher power could save the patient

The most common reasons for surrogate pessimism include:

- A belief that the physician is predisposed to be overly optimistic
- A belief that the patient has unique weaknesses unknown to the physician
- A need to be braced or prepared for the patient’s death

**Clinical Implications**

Misperceptions about prognosis by surrogates have been well documented, but less has been known about the causes of these misperceptions, note the authors. In light of their findings, the authors suggest that clinicians check routinely with the surrogates of incapacitated patients to determine their perceptions of the patient’s prognosis, especially prior to engaging in goals-of-care decision making. When clinicians perceive that surrogates’ expectations diverge from their own, they should explore for causes other than the surrogate misunderstanding the information that was given.

“This is important because interventions to reconcile discordance about prognosis may differ for misunderstandings compared with differences in belief,” the authors observe. “Our findings raise the possibility that standard informational interventions may be insufficient, because they do not attend to the emotional and psychological sources of optimism that influence surrogates’ prognostic expectations.”

**The Importance of Listening**

The current study shows that “families are internally conflicted about prognostic information, both seeking and avoiding the information, struggling to integrate realism and hope,” write the authors of an accompanying editorial, led by Elie Azoulay, MD.

The physician’s task is not merely to relay information, notes Azoulay, but “to optimize the ability of surrogates to hear, absorb, integrate, and use information.”

Ideally, the physician begins a discussion by asking the family their understanding of what the clinical team expects to happen, notes Azoulay. If the answer includes prognostic expectations that differ from the team’s, an open-ended inquiry may help identify the source of the discordance, “including factors identified in this study.” In the discussion that follows, states Azoulay, “listening is as important as talking.”

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 dementia, look for the following indicators:
• FAST Score stage 7
• Urinary and fecal incontinence (intermittent or constant)
• No consistently meaningful verbal communication
• Requires assistance with ADLs
• History of aspiration pneumonia or UTI, sepsis or decubiti within the past 12 months

Call us any time, any day.
Geoffrey Coleman, MD
Medical Director
Montgomery Hospice

Hospice Use in Nursing Homes Results in Medicare Savings

Long-stay nursing home (NH) residents who used hospice incurred lower Medicare costs in the last six months of life than did non-hospice users, according to a report published in the *Journal of the American Geriatrics Society*. “The avoidance of costly inpatient and post-acute care appears to offset hospice payments, even when made over a prolonged period of time,” write the authors. “Coupled with a body of research that describes better quality of care for NH hospice users, findings of lower or even neutral costs appear to bolster the case for the value of hospice for NH residents.”

While the use of hospice in NHs has grown in the past decade, many residents still die without hospice services, experiencing lower quality end-of-life care — such as unrelieved pain, family dissatisfaction with care, and burdensome transitions, note the authors. But because NH residents tend to have longer lengths of hospice stay than non-residents (a mean of 20 days longer), concerns have been raised about possible higher costs to Medicare.

Investigators analyzed healthcare system data from 1999 to 2009 merged with Medicare claims, state Medicaid claims, and assessments from the Minimum Data Set for 2510 long-stay (> 90 days) nursing home decedents (mean age at death, 83 years; white, 63%).

FINDINGS
• 35% of nursing home decedents received hospice care.
• The median length of hospice stay was 34 days (mean length of stay, 103 days).
• Hospice users were less likely than non-hospice residents to be hospitalized in the last year of life (P < .001).
• Hospice users had lower total Medicare costs for all time periods measured, from two days prior to death, up to and including 90 days before death.
• For dually eligible decedents, hospice costs were lower for all time periods ≤ 90 days, and similar at 180 days.

“[H]ospice appears to be a ‘good deal’ or at least cost neutral for Medicare,” the authors write. “Financial and regulatory policies that inhibit access to or discourage use of the Medicare hospice benefit run the risk of further reducing access to palliative and end-of-life care for a very vulnerable population.”

Source: “Effect of Hospice Use on Costs of Care for Long-Stay Nursing Home Decedents,” *Journal of the American Geriatrics Society*; April 2016; 64(4):723–730. Unroe KT, Sachs GA, et al; Center for Aging Research; Regenstrief Institute, Inc.; School of Medicine; RESPECT Signature Center; and School of Nursing, all at Indiana University—Purdue University, Indianapolis, Indiana.