# HOSPICE MATTERS

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Montgomery HOSPICE

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# Frank Communication with Families Linked to Fewer End-of-Life Hospitalizations from Nursing Homes

Two behaviors were identified among nursing homes with the lowest rates of hospitalizations among seriously ill patients: decisions being made on a case-by-case basis rather than by algorithms, and staff members being encouraged to actively counsel families against transfers deemed unlikely to be beneficial, Yale researchers have found.

The staff at these facilities with low hospitilization "avoided decision-making algorithms and followed the 'enhanced autonomy' model recommended by experts, in which medical personnel do not remain neutral but explore disagreements with patients in an 'intense exchange of medical information, values, and experiences.' They acknowledged how hard this was to do," write the authors of a research letter published in *JAMA Internal Medicine*.

Investigators analyzed results of 31 indepth interviews conducted among key staff members (directors of nursing, physicians, administrators, advanced practice clinicians, social workers, and others) at eight Connecticut nursing homes in either the top or bottom 10% for hospitalization rates ("high-hospitalizing" or "low-hospitalizing") from 2008 to 2010.

All participants identified a common set of barriers faced in trying to avoid potentially burdensome hospitalizations. These included both family beliefs and facility structure, such as:

- Family guilt that if they did not "do everything" they would be giving up on their loved one
- Family belief that nursing homes provide inferior medical care
- Lack of on-site clinicians at night or on weekends
- Facing difficult decisions as a clinician in relative isolation

## SUCCESSFUL PRACTICES OF LOW-HOSPITALIZING FACILITIES

**Case-by-case decision making vs default hospitalization.** "One of the things we talk to them [families] about is, when you get to this end stage — because for many of our people it is the end stage — what's your goal?" said a social worker at a low-hospitalizing facility. "Is your goal treatment? Is your goal treatment with comfort? If your goal is comfort, then being treated in place is more likely to achieve that."

Persuading against potentially harmful hospitalization vs deferring to family's first decision. "We've worked as hard as we can to educate [families] and I wouldn't say influence them, but if we do genuinely feel like it's not in their best interest, we'll work really hard to discourage someone who is making a bad decision," said an administrator.

The authors recommend that future research be conducted to find the best ways to more broadly promote the successful behaviors found in their study.

Source: "Avoiding Hospitalizations from Nursing Homes for Potentially Burdensome Care: Results of a Qualitative Study," JAMA Internal Medicine; January 1, 2017; 177(1):137– 139. Cohen AB, Knobf MT, Fried TR; Department of Medicine, Yale School of Medicine; Division of Acute Care/ Health Systems, Yale School of Nursing, both in New Haven, Connecticut; and Clinical Epidemiology Research Center, VA Connecticut Health System, West Haven.

# Physicians Offered Guide to Timely Discussions of Care Goals for Patients with ESRD and Other Serious Illnesses

More than 400,000 patients in the U.S. with end-stage renal disease (ESRD) are on dialysis, yet fewer than 10% report having had a conversation about goals of care and preferences, "although nearly 90% report wanting this conversation," write the authors of a special feature article published in the *Clinical Journal of the American Society of Nephrology*.

"With nearly 60% of patients on dialysis regretting their decision, it is clear that a serious illness conversation should occur before a patient starts dialysis," write the authors. "Patients generally expect such conversations to be initiated by their clinician, but nephrologists, like many clinicians, do not routinely initiate in-depth serious illness conversations until late in the disease course, if at all."

#### BARRIERS TO SERIOUS ILLNESS CONVERSATIONS INCLUDE:

- Patients' incomplete understanding of disease and prognosis
- Inadequate clinician training and commitment regarding discussions
- Time constraints and uncertainty regarding discussion timing
- Focus on interventions and procedures rather than on patient-centered goals and preferences
- Fragmentation across care settings and in advance directive documentation

"In the last month of life, patients on dialysis over age 65 years experience higher rates of hospitalization, intensive care unit admissions, procedures, and death in hospital than patients with cancer or heart failure, while using hospice services less," write the authors. "In contrast, 65% of patients on dialysis would prefer to die at home or in hospice, and over 50% would choose care focused on relieving pain and discomfort rather than prolonging life."

The authors offer a step-wise conversation guide to support clinicians and help advance best practice in conversations with patients with ESRD and other serious illnesses. *[See sidebar.]* "Using a structured communication guide or checklist can help focus both patients and clinicians, improve quality, reduce variation, and ensure that critical issues and concerns are addressed while providing direction to challenging conversation," write the authors.

The article also includes two ESRDspecific practical tools: a table of clinical and time-based triggers for holding the initial and subsequent conversations with ESRD patients, and a table with extended samples of specific language to use under different scenarios.

Patients generally identify their nephrologist or primary care physician as the healthcare professional with whom they want to have such conversations, note the authors. Some patients have also indicated that they would trust their dialysis unit social worker for these talks. The authors suggest that a coordinated team approach can work well, with the nephrologist addressing the medical information and prognosis while a dialysis nurse or social worker can lead discussions on values, goals, and preferences.

"Conversations should occur at a time

when the patient is stable and able to consider goals, values, and preferences without the need to make healthcare decisions under duress and without the added stress of an acute illness," write the authors. Repeat conversations can be prompted by changes in patient status or other triggers. In addition, ongoing conversations might be incorporated into the routine series of careplan assessments mandated by the Centers for Medicare and Medicaid Services.

"[S]erious illness conversations should be conducted with all patients with advanced kidney disease who are considering whether to choose dialysis and/or their health care proxies," assert the authors. Such conversations will pave the way for the shared decision-making process recommended in guidelines from the Renal Physicians Association and the American Society of Nephrology.

Source: "Serious Illness Conversations in ESRD," Clinical Journal of the American Society of Nephrology; Epub ahead of print, December 28, 2016; DOI: 10.2215/CJN.05760516. Mandel E et al; Renal Division, Department of Medicine and Departments of Psychiatry and Medicine, Brigham and Women's Hospital, Boston.

## Step-Wise Guide to Serious Illness Conversation

- **1. Set up the conversation,** framing it as an opportunity to think in advance and be prepared. Ask permission to start the conversation. Emphasize that decisions do not have to be made immediately.
- **2. Explore the patient's understanding** of their illness and their preferences for information. Focus more on quality-of-life issues than on details of laboratory results and other parameters.
- **3. Share prognosis,** which can be framed as either a time-based or functional prognosis, always with an acknowledgment of uncertainty.
- 4. Explore key topics, such as the patient's health-related and personal goals, fears, and worries, along with personal strengths; levels of function and independence the patient considers critically important, and the trade-offs the patient is willing to make in weighing procedural burdens vs quality of life.
- **5. Facilitate family involvement**, where possible. Including family or proxies in discussions can help relieve patient anxiety, improve family outcomes, and reduce future end-of-life decision-making conflict.
- **6. Bring the conversation to a close.** Summarize what was said, make a recommendation for care, and assure the patient of your continuing commitment.
- **7. Document the conversation** in the patient's electronic medical record, share the conversation's content with the patient's primary care provider, and give the patient a written hard copy of the conversation.

- Adapted from Mandel et al, Clinical Journal of the American Society of Nephrology

# Hospice Provides 'Excellent' End-of-Life Care for Loved Ones, Majority of Families Report

Highest quality ratings given when hospice stay is more than 30 days

Bereaved family members of cancer patients who died while in hospice care were more likely to indicate that their loved ones received proper symptom relief, had their wishes followed, and died in their preferred place than were relatives of nonhospice patients. Further, the earlier patients were referred to hospice, the higher the families' approval ratings, according to a report published in the *Journal of Clinical Oncology*.

"Overall, longer hospice stays were associated with family perceptions that patients received 'just the right amount' of pain medication, greater patient-goal attainment, and higher rates of familyreported excellent quality of end-oflife (EOL) care, compared with short stays," write the authors. "Together, our findings suggest that encouraging hospice enrollment, particularly enrollment weeks before death, may improve EOL experiences of patients with cancer."

Investigators compared questionnaire responses of family members of 1970 patients (985 matched pairs) who had died either with or without hospice care. Data were derived from the Cancer Care Outcomes Research and Surveillance (CanCORS I and II) studies, in which nationally representative participants, who were patients newly diagnosed with lung or colorectal cancers, were enrolled from 2003 through 2005 and followed through 2011.

The total number of participants with an after-death family interview was 2307; 1257 were enrolled and 1050 were not enrolled in hospice. Overall, among all 1257 of hospice enrollees, the median length of hospice stay was 21 days (interquartile range, 7 to 56 days). More than one-third (36%) of patients were under 65 years of age, with a wide range of insurance types.

#### FAMILY REPORTS: KEY FINDINGS

• Patients enrolled in hospice were more likely to have their EOL wishes

followed "a great deal" than were those not in hospice (80% vs 74%; adjusted difference, 6 percentage points; 95% confidence interval [CI], 2 to 11 percentage points), families reported.

- Hospice patients more often received "just the right amount" of pain medicine than did nonhospice patients (80% vs 73%; adjusted difference, 7 percentage points; 95% CI, 1 to 12 points).
- A higher percentage of patients in hospice than of those not in hospice were given "just the right amount" of help with dyspnea (78% vs 70%; adjusted difference, 8 percentage points; 95% CI, 2 to 13 points).
- More hospice patients' EOL care was rated as "excellent" by their families (57% vs 42%; adjusted difference, 15 percentage points; 95% CI, 11 to 20 points).
- Hospice enrollees were more likely to die in their preferred place than were nonhospice patients (68% vs 39%; adjusted difference, 29 percentage points; 95% CI, 23 to 34 points).

#### LOW PERCENTAGES OF 'TOO LITTLE' OR 'TOO MUCH' CARE WITH HOSPICE

- Families of hospice patients were less likely to report that "too little" pain medicine was given (8% vs 11%; adjusted difference, 3 percentage points; 95% CI, 0 to 6 points).
- Families were less likely to report that patients received "less help than wanted" with dyspnea when in hospice (12% vs 18%; adjusted difference, 6 percentage points; 95% CI, 2 to 11 points).
- In addition, families of patients in hospice were not more likely than families of nonhospice patients to report the receipt of "too much" pain medicine (10% vs 11%).

Although hospice patients had a higher symptom burden than those who did not die under hospice care, their symptoms were better controlled overall, note the authors. "Of note, the families of patients enrolled in hospice were not more likely to report that patients received 'too much' pain medicine, rather they were more likely to report that patients received 'just the right amount," they write.

### LENGTH OF HOSPICE STAY IMPACTS OUTCOMES

- Families of patients in hospice > 30 days more often reported that patients' EOL wishes were followed "a great deal" compared with patients enrolled  $\leq$  3 days (87% vs 79%).
- Families of patients enrolled for > 30 days were more likely to report that their loved ones received "just the right amount" of pain medicine compared with those enrolled  $\leq$  3 days (85% vs 76%) and more often rated the overall quality of care as "excellent" (65% vs 50%).
- The longer patients were enrolled in hospice, the more likely they were to die in their preferred place (> 30 days in hospice, 75%; 8 to 30 days in hospice, 67%; 4 to 7 days in hospice, 61%; ≤ 3 days in hospice, 48%).

The effect of the duration of hospice enrollment is important, note the authors, because so many patients with advanced cancer are enrolled within three days of death. "Families of patients who received more than 30 days of hospice care reported the highest quality EOL outcomes," they write.

"Although early hospice enrollment may not be possible for all patients, our data suggest that more attention should be focused on efforts to enroll patients with cancer into hospice earlier, because the median length of stay for patients enrolled in hospice care in the United States is only 17.4 days."

Source: "Family Perspectives on Hospice Care Experiences of Patients with Cancer," Journal of Clinical Oncology; Epub ahead of print, December 19, 2016; DOI: JCO2016689257. Kumar P, Wright AA, Hatfield LA, Temel JS, Keating NL; University of Pennsylvania, Philadelphia; Harvard Medical School, Boston; and Brigham and Women's Hospital, Boston.



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#### 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



# Physicians Urged to Help Patients with Correct Completion of POLST Forms to Avoid 'Decisions by Default'

Most older patients presenting to an emergency department (ED) had Physician Orders for Life-Sustaining Treatment (POLST) forms that were incomplete or contained contradictory choices, increasing their risk for receiving unwanted or invasive treatment, according to a report published in the *Journal of the American Medical Directors Association*.

"We called it 'Decisions by Default' to make patients aware that if they don't make a decision about a specific life-sustaining treatment, then in an emergency, they will most likely get the most aggressive treatment available," the authors state.

The brightly-colored POLST forms are accepted for use in more than 20 states, with programs under development in a further two dozen. The name of the orders can vary from state to state. In New York, where this study was conducted, the forms are called MOLST (Medical Orders for Life-Sustaining Treatment).

Investigators analyzed the content of directives contained in 100 MOLST forms collected from patients (median age, 79 years; female, 64%) presenting during a nine-month period to the ED of an urban tertiary care hospital. The forms addressed patients' wishes regarding such treatments as resuscitation, intubation, ventilation,

artificial nutrition and hydration, and future hospitalization and transfers.

#### **KEY FINDINGS**

- 69% of the forms had at least one section left blank.
- 14% of forms contained conflicting selections, such as a desire for "comfort measures only" with a wish also for a trial period of intravenous fluids (43%) or the use of antibiotics (43%).
- Among the 14% of patients who requested cardiopulmonary resuscitation, 14% also requested "limited medical intervention," and 5% requested a do-not-intubate order.

It is possible that patients and/or surrogates do not understand the meaning of some of the interventions when indicating their preferences, suggest the authors. "It is important that signing physicians review the patient's wishes with the patient (or surrogate), to ensure that any inconsistencies or incomplete information is addressed."

Source: "Decisions by Default: Incomplete and Contradictory MOLST in Emergency Care," Journal of the American Medical Directors Association; January 2017; 18(1):35–39. Clemency B, Cordes CC, Lindstrom HA, Basior JM, Waldrop DP; Department of Emergency Medicine, University at Buffalo School of Medicine, Buffalo, New York; Doctor of Behavioral Health Program, Arizona State University, Phoenix; University at Buffalo School of Social Work, Buffalo, New York.