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Joseph Puthumana, MD

Nicole Christenson, CRNP

Diane Ruckert, CRNP

For questions or referrals,
call Montgomery Hospice
Intake Department at
301-921-4400.

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Patients Involved in Hospice Decision Three Times More Likely to Die at Home

But study finds nearly half of patients do not participate in the final decision

Although patients are more likely to die at home and to live longer than seven days in hospice care if they participate in the decision to enroll, nearly one-half (49.1%) of patients are either not involved or are involved only peripherally in the enrollment decision, a team of Philadelphia researchers has found. More than one-third of patients in their study died within seven days of hospice enrollment.

“[P]atients so close to death may be either cognitively unable or emotionally unwilling to participate in decisions regarding their medical treatment,” write the authors. **“Educating patients and family caregivers on how to discuss health care preferences before the end of life is key.** This will help proxy decision makers, most often family caregivers, make end-of-life decisions based on what the patient would have wanted.”

The researchers analyzed survey responses from 165 family caregivers of patients who died in hospice care during an eight-month period in 2004.

KEY FINDINGS INCLUDE:

- 35.8% of study patients were enrolled in hospice < 7 days before death.
- 49.1% of respondents reported the patient was not involved in the hospice decision.
- 30.3% of respondents indicated that the patient made the decision, either alone or with advice from others.
- 78.7% reported that one or more people helped make the final decision to enroll the patient in hospice.

“These data indicate that some patients are not actively involved in the decision to enroll in hospice and that others, often physicians and family members, are making these decisions for the patient collaboratively,” the authors comment. **The most commonly reported health care profes-**

sionals participating in the decision were physicians (58.0%), social workers (25.5%), and nurses (20.4%). Also assisting in the decision to enroll in hospice were spouses (51.6%) and adult children/children-in-law (38.9%).

PATIENT INVOLVEMENT IN DECISION:

Patients involved in the decision to enter hospice are more likely to:

- Die at home (odds ratio [OR] = 3.3; $p = 0.006$).
- Enroll in hospice > 7 days before death (OR = 2.1; $p = 0.03$).
- Have a cancer diagnosis (OR = 2.3; $p = 0.02$).

Many respondents reported having discussed specific advance care planning topics beforehand with the patient, including mechanical ventilation (72.0%), cardiopulmonary resuscitation (68.4%), feeding tubes (64.7%), and antibiotics (59.6%).

“The differences between having an advance directive and discussing end-of-life care preferences listed in the advance directive are important, since without preference discussions many family caregivers find themselves without the knowledge, judgment, or courage to perform their responsibility as a proxy decision maker.”

Source: “Advance Care Planning and Hospice Enrollment: Who Really Makes the Decision to Enroll?” *Journal of Palliative Medicine*; March 4, 2010 [Epub ahead of print]; 13(5). Hirschman KB, et al; School of Nursing, Biobehavioral and Health Sciences Division, University of Pennsylvania; Philadelphia Veterans Administration Medical Center; and Wissahickon Hospice, University of Pennsylvania Health System, all in Philadelphia.

Kidney Disease Patients Report Lack of Support for Their End-of-Life Needs and Preferences

Patients with chronic kidney disease (CKD) do not receive the information they wish regarding their illness progression, prognosis, or the care options available to them as medical decisions are made, according to the results of a study published in the *Clinical Journal of the American Society of Nephrology*.

“Communication of prognosis and discussions related to planning for future death are lacking in the routine care of CKD patients,” writes Sara N. Davison, assistant professor of medicine, University of Calgary in Calgary, Alberta, Canada.

While 65% of patients in her study indicated they would prefer to die at home with comfort care or in a hospice facility, the vast majority of CKD patients in the U.S. die in acute care facilities without accessing palliative care services, notes Davison, who is also medical director of the university’s Peritoneal Dialysis Unit.

Davison measured survey responses of 584 patients with stage 4 or stage 5 CKD (mean age, 68.2 years; white race, 80.5%) presenting to dialysis, transplantation, or predialysis renal insufficiency clinics in Alberta, Canada, between January and April 2008.

KEY FINDINGS INCLUDE:

- 90.4% reported their nephrologist had not discussed prognosis with them.
- Only 38.2% of patients had completed an advance directive.
- 64.9% of patients preferred to die either at home with visits from a palliative care team (36.1%) or in an inpatient hospice (28.8%).
- 60.7% said they regretted the decision to initiate dialysis.

The majority of patients said they had chosen dialysis over conservative care because it was their physician’s wish (51.9%) or the wish of their families (13.9%). Only 34.2% reported that the decision to be treated with dialysis was their own personal choice. “This highlights the need to re-evalu-

Recommendations for Integrating End-of-Life Practices into Care of Patients with Kidney Disease

- **Enhance predialysis education** to include: conservative options, the relevance of advance care planning, and the availability of palliative care and hospice services.
- **Identify patients** who would benefit from palliative care interventions.
- **Routinely screen for and manage pain** and other symptoms. Screen for and manage distress.
- **Facilitate access** to specialist palliative care, including hospice.
- **Incorporate palliative care** into training for all nephrology fellows, emphasizing symptom management and advance care planning.

—Adapted from Davison, *Clinical Journal of the American Society of Nephrology*

ate decision making around the initiation of dialysis and involving patients in discussions about prognosis and goals of care,” writes Davison, who strongly recommends that end-of-life care practices be integrated into CKD care. [See sidebar.]

APPLICATION OF FINDINGS TO U.S. PATIENTS

“The article by Davison serves as a clarion call to the broader nephrology community to be more sensitive to the end-of-life preferences of patients with CKD and end-stage renal disease (ESRD),” according to the American authors of an editorial accompanying the report.

“Care to improve the quality of life of patients with ESRD for each day of their lives is as important as optimizing their nutritional status or dosage of dialysis,” write Daniel Cukor, PhD, of the Department of Psychiatry and Behavioral Sciences, State University of New York, Brooklyn, and Paul L. Kimmel, MD, of the federal National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health.

Although the Canadian patient sample does not match the ethnic diversity of the wider U.S. population, note the commentators, the study findings highlight the lack of knowledge within the professional community about the informational needs and end-of-life preferences of these patients.

“A truly amazing, perhaps surprising, yet incredibly important finding of the article...is that more than 60% of the sample evaluated by Davison ‘regretted their decision to start dialysis,’” they state. Further, more than 90% of patients were found to have had no discussion of prognosis with their nephrologist. “Providing prognosis is a fundamental duty of physicians,” they assert.

The authors recommend that the renal care team identify patients in need of palliative and end-of-life care services, have the appropriate resources available, and encourage patients to seek additional help and to use referrals.

“While we labor to increase the quantity of life for our patients, we must be cognizant of its quality as well,” advise Cukor and Kimmel. “Both education of patients and families, as well as physicians and dialysis staff, will surely facilitate this goal.”

Source: “End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease,” *Clinical Journal of the American Society of Nephrology*; February 2010; 5(2):195-204. Davison SN; Department of Medicine, University of Alberta, Edmonton, Alberta, Canada. “Education and End of Life in Chronic Kidney Disease: Disparities in Black and White,” *ibid.*; pp. 163-166. Cukor D, Kimmel PL; Department of Psychiatry and Behavioral Sciences, Downstate Medical Center, State University of New York, Brooklyn; Division of Kidney Urologic and Hematologic Diseases, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Bethesda, Maryland.

Medical Students Feel Moderately Prepared to Deliver End-of-Life Care, But Negative 'Hidden' Curriculum Can Devalue Care Principles

A national survey of 1455 fourth-year medical students randomly sampled from all regions of the country in 2001 has found that students feel "moderately well prepared" for a majority of end-of-life care tasks, and have been taught "most aspects" of this care in both the formal and informal (clinical) curricula, according to a report published in the *Journal of Palliative Medicine*.

However, note the authors, there is a third or "hidden" curriculum, in which unintended messages are inferred by students while observing the behavior of residents and attending physicians. "Negative attitudes or poorly modeled behaviors may have detrimental effects on trainees' appreciation and delivery of care to dying patients...and may lead to 'ethical erosion' or an undermining of students' idealized values."

Negative messages inferred by students from the hidden curriculum included:

- Working with dying patients is "not at all" or only "a little" rewarding (60% of respondents).

- Dying patients are not good teaching cases for students (45%).
- Treating psychosocial needs of dying patients is not a core clinical competency (41%).
- Death is a medical failure (21%).

The messages received from this hidden curriculum were found to be negatively associated with students' perceived preparation for and attitudes toward caring for the dying, and with their perceptions of the quality of their medical education.

FINDINGS BOTH 'ENCOURAGING' AND 'TROUBLING'

Compared to data published over 12 years previously by members of this same research team, "the current study is notable for a dramatic increase in the amount of palliative care content included in medical school curricula," comments senior associate editor R. Sean Morrison, MD, in his accompanying commentary. While Morrison considers this improvement in the formal curriculum to

be "highly encouraging," the data concerning the implicit, negative messages received by medical students he deems "troubling." His article outlines several policy initiatives for strengthening support for palliative care educators and for encouraging young physicians to choose this career path.

"Whereas there is one cardiologist for 71 persons experiencing a myocardial infarction and one oncologist for every 141 patients diagnosed with cancer, there is only one palliative medicine physician for every 31,000 persons living with a serious and life-threatening illness."

Source: "Determinants of Medical Students' Perceived Preparation to Perform End-of-Life Care, Quality of End-of-Life Care Education, and Attitudes Toward End-of-Life Care," *Journal of Palliative Medicine*; March 2010; 13(3):319-326. Billings ME, et al; Division of Pulmonary and Critical Care Medicine, University of Washington, Seattle. "Bringing Palliative Care to Scale in Our Nation's Medical Schools," *ibid.*; pp. 233-234. Morrison RS, senior associate editor, *Journal of Palliative Medicine*.

Careful Assessment of End-of-Life Care Antimicrobial Therapy Urged

A retrospective review of all patients receiving initial palliative care consults during a five-month period in 2008 at a large tertiary care facility suggests that, among these terminally ill patients, "antimicrobials were frequently given empirically when the infection is not documented, but presumed," according to a report published in the *American Journal of Hospice and Palliative Medicine*.

KEY FINDINGS INCLUDE:

- 53.4% of all patients screened at the initial consult (n = 131) were receiving antimicrobials.
- Therapy for 58.7% of infections was empiric, while therapy for only 39.1% of infections was based on microbiologic cultures.

- Piperacillin/tazobactam (37.1%) and vancomycin (32.9%) were the most frequently used antibiotics.
- 67% of patients were either subsequently enrolled in hospice care (44.3%) or died prior to discharge (22.9%).

"Antimicrobial therapy is frequently viewed as usual care and not 'aggressive' care," the authors point out. "However, antimicrobial use, particularly the use of broad-spectrum, parenteral agents, is not therapeutically neutral." Particularly among patients nearing the end of life, "treatment burdens, including the maintenance of intravenous access for administration of parenteral agents, are important considerations."

Given the burdens of treatment, adverse effects, and the public health risks associated with the increased prevalence of

multidrug resistant organisms, they continue, "we believe it behooves clinicians to view antimicrobial use as an aggressive modality of care.

"As such, we advocate for careful assessment of potential benefits and treatment burdens of antimicrobial therapy in each individual patient, especially in those where palliation is the goal. Candid discussion of these issues with patients, their families, and other health care providers involved in the patient's care is imperative."

Source: "Antimicrobial Use among Patients Receiving Palliative Care Consultation," *American Journal of Hospice and Palliative Medicine*; December 3, 2009 [Epub ahead of print]; DOI:10.1177/1049909109352336. Chun ED, et al; Department of Internal Medicine, Division of Geriatric Medicine, University of Michigan Health System, Ann Arbor.

MONTGOMERY HOSPICE CORE VALUES:

- **UNCONDITIONAL COMPASSION:** Compassionate care, partnered with professional excellence, is the heart of our service.
- **DIGNITY OF THE DYING:** We affirm the right of our patients to be treated with respect, and to be honored as unique individuals.
- **DEDICATION:** We are committed and privileged to ease the burdens and challenges that our patients and families face.
- **COLLABORATION:** Mutual respect, empathy and trust unite us in providing care.



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Likelihood of Receiving Antipsychotic Medication in Nursing Homes Linked to Facility-Level Prescribing Rates

One-third of users had no clinical indication for this therapy, national study finds

The proportion of long-stay residents in U.S. nursing homes receiving at least one antipsychotic prescription in a year varies widely by facility, ranging from 0% to 100%. Regardless of clinical indication, residents entering facilities with the highest prescribing rates are 1.37 times more likely to receive antipsychotic medication, relative to residents entering nursing homes with the lowest rates, according to a report published in the *Archives of Internal Medicine*.

“We found that the likelihood of a newly admitted nursing home resident to receive an antipsychotic medication was strongly and independently related to the facility-level prescribing rate, even after adjustment for clinical and sociodemographic characteristics,” write the authors.

The researchers examined antipsychotic prescribing patterns among 16,586 residents newly admitted to 1257 nursing homes in 2006. Key findings include:

- Nearly 30% (n = 4818) of study residents received at least one antipsychotic prescription.
- Of these, 32% (n = 1545) had no dementia, psychosis, or any other clinical indication for this therapy.
- “The influence of the facility-level prescribing rate was most apparent in resi-

dents without psychosis, who have the weakest indication for antipsychotic medication use,” comment the authors.

Furthermore, “the risk of receiving antipsychotics steadily increased with higher facility-level prescribing rates, but only for residents with dementia and normal/mild behavior problems,” they note. “This suggests that managing behavioral problems plays an important role in facility-level decisions about antipsychotic prescribing.”

In 2005, the federal Food and Drug Administration issued an advisory and subsequent warnings regarding increased mortality associated with the use of antipsychotic agents for behavioral disorders among elderly patients with dementia. Nonetheless, conclude the authors, “safety concerns continue to persist in the use of antipsychotic medications in nursing home residents whose benefits from these agents are unclear,” and whose risk for adverse effects is elevated.

Source: “Unexplained Variation Across U.S. Nursing Homes in Antipsychotic Prescribing Rates,” Archives of Internal Medicine; January 11, 2010; 170(1):89-95. Chen Y, et al; Division of Geriatric Medicine and Meyers Primary Care Institute, University of Massachusetts Medical School, Worcester; Department of Medicine and Buehler Center on Aging, Health & Society, Feinberg School of Medicine, Northwestern University, Chicago.