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Geography, Not Patient Preference, Determines Intensity of End-of-Life Care

Healthcare expenditures in the last months of life are known to vary considerably across U.S. geographic areas, with no link to improved outcomes. This variation is driven not by patient values, but by the types of healthcare services available and by the end-of-life care beliefs and knowledge of physicians, according to a report published in *Health Affairs*.

“We found that physicians’ beliefs and practice styles and area-level availability of services were the primary drivers of variations in intensity of care,” write the authors. “Patients’ beliefs, preferences, and supports did not contribute meaningfully to geographic variation in spending intensity.”

Investigators analyzed survey data from the prospective, multiregional Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) study linked to Medicare data on 1,132 Medicare patients diagnosed from 2003 to 2005 with advanced lung or colorectal cancer who had died by 2013 (female, 43%; white race, 79%; mean age at death, 75.6 years).

Hospital referral regions across the U.S. (n = 26) were stratified into quintiles according to the amount of Medicare spending in the last 30 days of life. Mean healthcare expenditures in the last month of life were \$13,663, but ranged widely, from \$10,131 in the lowest-spending quintile to \$19,318 in the highest-spending region.

HIGHER-SPENDING REGIONS HAD:

- Greater concentrations of physicians per capita than lower-spending regions
- A lower proportion of primary care physicians
- Fewer hospices per 10,000 people

PHYSICIANS IN HIGHER-SPENDING AREAS REPORTED FEELING:

- Less prepared to treat end-of-life symptoms than physicians in lower spending areas (33.4% vs 40.7%; $P < 0.001$)
- Less knowledgeable about discussing end-of-life options (49.5% vs 57.8%; $P < 0.001$)
- Less likely to discuss DNR status with a patient they estimated had four to six months to live (19.3% vs 30.3%; $P < 0.001$)
- Less likely to seek hospice care for themselves if terminally ill (54.4% vs 71.4%; $P < 0.001$)

In multivariate analysis, patient demographic and clinical variables had a negligible effect on the variation in end-of-life spending. However, availability of healthcare services explained 39% and physician beliefs explained 26% of expenditure variation in the final month of life.

“What we really need are interventions that help physicians feel more comfortable taking care of patients at the end of life, along with better training about the lack of efficacy and potential harms of some intensive treatments for patients with advanced cancer,” says lead author Nancy L. Keating, MD.

Source: “Factors Contributing to Geographic Variation in End-of-Life Expenditures for Cancer Patients,” *Health Affairs*; July 2018; 37(7):1136–1143. Keating NL et al; Department of Health Care Policy, Harvard Medical School and Division of General Internal Medicine, Brigham and Women’s Hospital, both in Boston, Massachusetts.

Early Pain-Specific Advance Care Planning and Directives Urged for Dementia Patients

To ensure that pain care will be provided in ways aligned with their wishes, a pain management plan for older adults with dementia should be discussed and developed early in the disease trajectory, while patients retain their decision-making capacity and can be reassured that their values will be honored, according to a forum article published in *The Gerontologist*, a journal of the Gerontological Society of America.

“Implementing advance care planning (ACP) prior to advanced stages of dementia may assist in developing a person-centered pain management plan and improve pain care for this population throughout the dementia trajectory,” write the authors.

Older adults with dementia are particularly vulnerable to under-assessment and under-treatment of pain, note the authors. Although dementia is not itself usually a cause of pain, these older patients often have accompanying multiple morbidities or injuries that do cause pain. As patients enter the advanced stages of the disease, it becomes increasingly difficult for caregivers and clinicians to determine the presence of pain, or to know without a written advance directive (AD) how the patient would want it treated.

ACP, used as an individualized, practical approach to managing and coordinating pain management for older adults with dementia, involves recurrent conversations with patients and their families regarding care preferences and should culminate in documentation of an AD.

PAIN AND DEMENTIA

Studies conducted within the past six years have found that 30% to 68% of older adults with dementia have persistent pain and that the prevalence of pain among these patients increases significantly in the last week of life, the authors explain.

Further, research shows that, despite the misconception that older adults with dementia are less sensitive to pain, they actually have higher than normal pain intensity ratings, perhaps due to neuropathological

changes in the brain associated with types of the disease, the authors suggest.

Adequate pain treatment can help prevent or alleviate some of the deleterious effects of pain, such as decreased immune response, impaired sleep, falls, and compromised mobility, note the authors. “Managing pain adequately can also reduce behavioral and psychological symptoms of dementia,” they write. “In fact, systematic, individualized pain management can significantly lower agitation levels in older adults with dementia,” thus perhaps allowing for reduction in the use of antipsychotic medications.

Because of the progressive loss of ability to verbalize their treatment wishes, adults with dementia should be engaged in ACP discussions early in the disease trajectory, urge the authors, adding that the recent change in billing codes for reimbursement for ACP discussions by the Centers for Medicare and Medicaid may help encourage earlier and ongoing conversations.

TOPICS TO DISCUSS FOR AN ADVANCE PAIN-MANAGEMENT CARE PLAN INCLUDE:

- Goals of care, both overall and specific
- Procedures to be avoided or minimized
- Risk/benefit assessments for possible proposed treatments
- Types of acceptable treatments: nonpharmacological, pharmacological, or none
- Treatment routes and frequency

The article includes a table with pharmacological and nonpharmacological pain management options as well as a list of sample questions that patients/proxies can ask their clinicians about pain management.

ADDRESSING COMMON CHALLENGES TO ACP IN DEMENTIA

“Although older adults with dementia are presumed to have the capacity to make healthcare decisions unless proven otherwise, there is no consensus for determining decision-making capacity,” the

authors write in their article.

There is also little guidance on holding conversations to determine preferences and needs for geriatric pain management prior to cognitive incapacity, note the authors. Drawing upon research on pain and aging, they offer components of a practical approach to conducting such conversations.

APPROACH TO PAIN-SPECIFIC ACP DISCUSSIONS

Optimize decision making.

- Have a designated healthcare proxy documented and present for decision-making support at each clinical visit.
- Introduce conversations about ACP for pain management early in the disease course.

Identify goals, values, and preferences.

For many older adults with progressive, terminal illness and their families, pain relief and symptom management are the chief goals, the authors note.

- Use the patient’s experience of past health events to guide the conversation.
- Offer example scenarios in which pain management and palliative care would be called for.

Align values with treatment options.

- Assess caregivers’ capacity to implement a pain management plan.
- Provide and discuss a checklist of pharmacological and nonpharmacological options for pain management, and ask the patient and proxy to select the most appealing or acceptable options.

Ensure continuity with documentation.

“Pain is a common reason why older adults are transferred from nursing homes and skilled nursing facilities to acute care settings,” write the authors. Nevertheless, information about pain assessment and treatment preferences rarely accompanies patients in these transfers.

- Ensure that the patient’s pain management preferences are entered in the

Continued on Page 3

Clinical Trial Patients: An Overlooked Population for Palliative Care Delivery

Barriers to the initiation and delivery of palliative care (PC) to patients enrolled in cancer clinical trials include a lack of shared understanding of PC among members of the trial team, a lack of clarity concerning the delivery process, and the conflation of PC with care for dying patients, according to a report published in the *Journal of Palliative Medicine*.

“Our research suggests great variability in how multidisciplinary providers conceptualize and deliver PC, which is further complicated by the apparent conflation between PC and hospice or end-of-life care,” write the authors.

Despite growing evidence for the benefits of PC, few studies have explored its concurrent provision with trial-delivered therapy, note the authors. “This is an important deficit, given that many patients enrolled in clinical trials may have failed standard treatments, have advanced cancer, experience high symptom burden, and consequently, have potentially life-threatening diagnoses.”

The benefit of integrating PC concurrently into the care of patients in clinical trials is noted in the 2017 update to the American Society of Clinical Oncology’s PC clinical practice guideline, point out the authors.

Investigators analyzed interview responses of key members of two multidisciplinary teams (n = 19) caring for patients with advanced hematologic and prostate cancer enrolled in phase I and II clinical trials. Seven additional, non-research par-

ticipants were also interviewed, including palliative medicine experts and clinical nurses. The research was conducted as part of a larger qualitative study at a U.S. teaching hospital with a dedicated PC team.

Four major themes were identified regarding the meaning that respondents from the clinical trial teams assigned to the term “PC;” in addition, three key themes emerged related to participants’ experiences with the delivery of PC in the clinical trial context.

KEY PERCEPTIONS OF PC

- **Its holistic nature.** Respondents believed that PC treats the whole patient, and includes having a keen awareness of patients’ values and quality of life, acquired through listening.
- **The importance of symptom care.** Participants involved in direct patient care stressed that managing symptoms, especially pain, was key in PC. Management of psychosocial symptoms was also deemed an important element of PC.
- **Perceived conflict between palliative and curative goals of care.** Initiating PC could send patients and the team the wrong message, respondents said, believing that PC’s aims conflict with the goals of active research treatment.
- **The conflation of PC and end-of-life care.** Although most respondents acknowledged that PC is more than care for patients close to death, many nevertheless used “hospice” and “PC” interchangeably, or said that other team

members viewed them as synonymous.

KEY ASPECTS OF PC DELIVERY EXPERIENCES

- Dynamics among providers were complex, often with disagreement or uncertainty surrounding who should be responsible for initiating, delivering, and coordinating PC.
- Discussing PC with patients and families was considered challenging, sometimes involving reluctance among both patients and key informants.
- The timing of PC delivery can be complicated by the apparent conflict between the clinical trial and palliative goals, frequently resulting in a lag in delivering needed PC.

The authors advocate for improved care delivery models that would routinely integrate PC into clinical trials and a reform of cancer care systems that currently force a choice between quality of life and curative treatment.

“As clinical trials remain a backbone of scientific discovery for the advancement of cancer diagnosis and treatment, it is imperative to support patients by appropriately integrating palliative services into their care regardless of curative or research goals,” they write.

Source: “*Perspectives on Palliative Care in Cancer Clinical Trials: Diverse Meanings from Multidisciplinary Cancer Care Providers*,” *Journal of Palliative Medicine*; May 2018; 21(5):616–621. Mollica MA et al; National Cancer Institute, NIH, Bethesda, Maryland.

Early Pain-Specific Advance Care Planning (from page 2)

- medical chart.
- Preferences for hospitalization for new onset pain should also be clearly documented.

Conduct ongoing discussions.

- Schedule for regular ACP discussions — perhaps annually — to update for any changing preferences.

- Take note of any changes in treatment preferences indicated by behavior in patients who can no longer articulate their wishes.

The authors caution clinicians that, while it is important to have a documented written directive, “advance directives are not absolute, and ambiguities and dilemmas may still arise as health status changes.

Thus, decisions and preferences should be re-evaluated throughout the dementia trajectory.”

Source: “*Shifting Paradigms: Advance Care Planning for Pain Management in Older Adults with Dementia*,” *The Gerontologist*; May 8, 2018; 58(3):420–427. Booker SS, Booker RD; *College of Nursing, Iowa City, Iowa; LifeCare Hospitals of Shreveport, Shreveport, Louisiana*.

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- Physical / functional decline
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- Multiple comorbidities

When life expectancy can be measured in weeks or months, hospice is usually the best option. For patients with **pulmonary disease (COPD)**, look for the following indicators:

- Dyspnea at rest
- Poor response to bronchodilators
- Recurrent pulmonary infections
- Right heart failure
- Unintentional weight loss
- Bed to chair existence

Call us any time, any day.

Geoffrey Coleman, MD
Medical Director
Montgomery Hospice



Educational Video Helps Clinicians Understand Patients' Faith-Based Views of End-of-Life Care

An educational intervention using a video podcast significantly improved healthcare professionals' understanding of values and customs of three major religions concerning medical care at the end of life, and was deemed clinically useful by all participants, according to a report published in the *Journal of Palliative Medicine*.

"Patients' religious and spiritual values impact their goals and perception of illness, especially at the end of life," write the authors. "Improved awareness may better equip clinicians to consider patients' religious consideration, hold religious/spiritual discussion, and account for the diverse perceptions around suffering, pain relief, grief, treatment preferences, preparation for death, and rituals before and after death."

Investigators conducted a literature review and consulted with faith leaders to develop survey tests and a one-hour video podcast in which clinically relevant religious teachings regarding end-of-life care were addressed by a Protestant Christian pastor, a Jewish rabbi, and a Muslim imam.

Pre- and post-podcast tests, with 10 questions on each religion, were administered to participating clinicians (n = 73; physicians, 41%).

KEY FINDINGS

- Median test scores for questions on each of the three religions improved significantly post-podcast, ($P = 0.0001$), with overall median pre- and post-test scores rising from 17 (range, 10 to 24) to 27 (range, 16 to 30) out of a possible 30.
- All participants agreed, either strongly (73%) or somewhat (27%), that the podcast was clinically useful.
- Improvements in understanding did not differ by participant medical specialty, years of service, educational level, or self-reported religious beliefs.

The authors note that the intervention is easily reproducible, but their small sample size limits the findings' generalizability, so additional research to determine longitudinal impact and the impact of the educational intervention on patient outcomes is recommended.

Source: "Educational Intervention Enhances Clinician Awareness of Christian, Jewish, and Islamic Teachings around End-of-Life Care," Journal of Palliative Medicine; Epub ahead of print, July 13, 2018; Moale AC et al; Department of Medicine; and Department of Internal Medicine, Morsani College of Medicine, University of South Florida (USF) Health, Tampa, Florida; Department of Medicine, Johns Hopkins School of Medicine, Baltimore, Maryland.