
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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WHY IS END-OF-LIFE CARE MORE EXPENSIVE FOR PEOPLE OF COLOR? A NEW STUDY INVESTIGATES

No matter who you are, dying in America can be a very expensive process. About a quarter of Medicare costs go to treat people who are in their last year of life. The last months of life are more expensive, however, for some than others. In particular, black and Hispanic Americans are more likely to incur greater expenses in the last year of life – far higher than those experienced by whites. Despite years of research and investigation, no one has yet been able to pinpoint the reason for this disparity.

One of the latest studies to emerge regarding this disparity comes from the University of Michigan Medical School. *Journal of the American Geriatrics Society* recently published the findings of this study. “Unlike other kinds of health cost disparities, they didn’t find that the difference could be explained by differences in patients’ income, education, medical conditions or other individual factors such as use of hospice. The differences also persisted after they took into account general health spending patterns in a dying person’s area.”

Researchers also considered the unique circumstances that surround death and dying, taking these factors into account for the first time. The University of Michigan team found, however, that even these specific end-of-life factors did not explain the disparities in care costs between whites and minority end-of-life patients. **Even after all other factors were calculated in, the authors found that blacks paid, on average, \$7,100 more than whites for care in the last year of life; Hispanics paid an average of \$6,100 more.**

Unable to pinpoint a single, simple cause for care cost disparities between whites and other racial/ethnic groups, researchers have concluded that there must be larger, systemic factors that can’t be reduced to simple demographic markers. “We need to look harder for the causes of disparities in end-of-life care costs, and look at factors on the provider level and health system level, including family dynamics that may come into play,” says Elena Byhoff, M.D., M.Sc., who led the study while she was a Robert Wood Johnson Clinical Scholar at U-M and is now at Tufts Medical Center.

Byhoff and her colleagues “hope that their study will add to the broader conversation about how to encourage good patient-provider-family interactions in patients’ final years, including the difficult but important questions about advance planning for end-of-life care. **Whites were twice as likely as blacks and Hispanics to have an advance directive document in place in the study.**” Byhoff believes that new Medicare coverage for end-of-life conversations may help

narrow the gap, “but providers must also act on patients’ wishes as spelled out in advance directives, and families must understand and honor those wishes when the patient can no longer speak for him or herself.” Previous research has demonstrated that costs are typically lower for patients who have spelled out their wishes ahead of time.

While patients’ preferences have long been viewed as key to understanding cost and outcome disparities, they are particularly hard to study. The team from the University of Michigan took them into account by using data from the Health and Retirement study (HRS), from the University of Michigan Institute for Social Research. They also interviewed “seniors’ survivors, which allowed them to find out if the death had been expected, if the patient had discussed their end-of-life treatment preferences with their survivor, and if they had a formal advance directive in place when they died.”

Using this data, researchers were able to match “each senior’s survey data with his or her Medicare data, from doctor visits and hospital stays to prescription drugs and home, hospice and nursing home care. HRS participants consented to this analysis as part of taking part in the study.” They used the End-of-Life Expenditure Index developed by the Dartmouth Institute to take regional variations in care costs into account.

While it was hoped that a full analysis of patient preferences might account for the disparities in cost of care, the UM team still found no clear link. “The persistence of disparities even after taking into account so many factors makes end-of-life care different from other types of care, where factors such as income, education and ZIP code explain much of the difference in outcomes and spending between racial and ethnic groups.” (*MedicalXpress*, 9/1, medicalxpress.com/news/2016-09-dying-people-deeper.html; *University of Michigan*, 9/1, www.uofmhealth.org/news/archive/201609/why-does-dying-cost-more-people-color-new-study-takes-deeper; *Journal of the American Geriatrics Society*, 8/2016, onlinelibrary.wiley.com/doi/10.1111/jgs.14263/full)

DEMENTIA CAN MAKE END-OF-LIFE CARE EVEN HARDER

A recently published article in *The Washington Post* explores the unique challenges that dementia poses to the end-of-life experience. The article raises the question: Is it possible to have a “good death” when dementia is present? Families often describe other patients’ last months as painful, but meaningful. Unfortunately, this is often not the case with patients experiencing dementia. Because of the way the disease affects memory, changes personality, and causes behavior issues, the last months of life with dementia can be anything but uplifting for both the patient and family members.

One of the greatest challenges of dementia is the lack of ability to communicate. Central to a meaningful end-of-life experience is the expression of one’s wishes and the ability to have them carried out. Much of this is taken away from patients with dementia and their families – especially if they have not had end-of-life conversations before the onset of dementia.

A recent study in *The American Journal of Alzheimer’s Disease and Other Dementias* finds that concerns about communication are at the forefront for families facing the end of life with someone with dementia. How are we to understand our loved one’s wishes when, in the

haze of dementia, they resist taking medication that we believe they would – in their normal awareness – want to take? How do we care for pain when the patient is unable to clearly communicate it? How do caregivers cope with the psychological loss of their loved one, sometimes long before the physical loss of death?

Dying with dementia is, in many ways, as hard on families and caregivers as it is on patients themselves. “Caregivers who took part in the study said they worried that their loved ones were in pain but were unable to properly express it — and that possibility disturbed them, according to interviews with families taking care of dementia patients in their last stage of life.” Many participants expressed their frustration and sense of defeat at patient’s cognitive challenges and unpredictable emotional responses. Some described patients as being “prisoners within their own bodies.”

Caring for patients with dementia can be a huge challenge for hospice workers, too. Previous research has found that prescribing the appropriate levels of pain medication may be a challenge when caring for patients with dementia. **Patients with cognitive impairment are prescribed lower doses of opioids than patients with cancer, though they have similar pain scores.** Other research has found that caregivers must learn their loved one’s “signals” for when they are in pain. For some, it might be a gripping of the hand, for others a facial expression or gasping.

Eventually, the stress of caring for a family member with dementia can seem overwhelming. “You get to the point you want them to die because it’s hard,” says Jackie Mantua, 53, who provides care to her mother, who has dementia. “It’s hard to deal with. It’s a very helpless feeling.” For Mantua, the decision to bring in hospice care wasn’t easy. In many ways, she feels like her mother is already gone.

“There isn’t much for Mantua to do when she visits her mother. She chatters as her mother dozes, cradling a baby doll that is always with her. A staff member regularly changes the doll’s clothes, which amuses Mantua. For now, she keeps driving an hour once every other week from her home on Maryland’s Eastern Shore to [her mother]’s room in Rockville, where they wait for the end together.” (*The Washington Post*, 9/4, www.washingtonpost.com/national/health-science/how-dementia-makes-it-harder-to-offer-end-of-life-comfort/2016/09/02/4bb34b0c-6ed0-11e6-8365-b19e428a975e_story.html; *KHN*, 9/7, <http://khn.org/news/patients-with-dementia-create-communication-challenges-in-hospice-care/>)

HOSPICE AND END-OF-LIFE NOTES

* **CMS posted the FY 2017 Medicaid hospice rates.** (*CMS*, 9/1, <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/benefits/downloads/medicaid-hospice-rates-ffy-2017.pdf>)

* **Enrollment in hospice is shown to increase lifespans and improve quality of life for patients with advanced-stage, non-small-cell lung cancer.** “Prior research has shown that advanced stage nonsmall cell lung cancer (NSCLC) patients enrolled in hospice care receive less aggressive treatment at the end of life (EOL) without compromising survival. Our purpose was to profile the continuum of care of these patients, exploring the connection between hospice

enrollment and quality indicators for excellence in EOL cancer care.” (*Journal of Palliative Medicine*, 9/1, online.liebertpub.com/doi/pdfplus/10.1089/2016.0064)

* **CMS has finalized emergency-preparedness rules that will impact providers, including hospices, who participate in Medicare/Medicaid.** “CMS issued this new rule to create a consistent foundation of emergency preparedness across the health care system, ensuring that providers across the spectrum are better positioned to respond to disasters and to ensure continuity of care for some of our most at-risk populations.” **Hospices will need to be in compliance by November 2017.** (*CMS*, 9/8, www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2016-Press-releases-items/2016-09-08.html; *ASPR Blog*, 9/8, www.phe.gov/ASPRBlog/pages/BlogArticlePage.aspx?PostID=205)

* **Should patients be able to video the moment of their deaths? Art Caplan at the Division of Medical Ethics at NYU Langone Medical Center considers the ethical dimensions of this question.** “What should you say if someone approaches you and says, ‘I’m thinking about putting something on television; I want to record my death; I want to make sure that my family understood it; I want to make sure that I leave a memory’?” Caplan stresses the importance of being sure “proper permission” is given for these videos. (*Medscape*, 9/6, www.medscape.com/viewarticle/866572)

* **Live discharges from hospice represent a potential vulnerability to the Medicare Hospice Benefit.** A recent study says, “Live hospice discharges and burdensome transitions increased between 2000 and 2012. For-profit hospice programs demonstrated larger increases than nonprofit hospice programs.” (*JPM*, 9/1, online.liebertpub.com/doi/full/10.1089/jpm.2015.0383)

* **The Visiting Nurse Association of America (VNAA) is advocating for the passage of the Care Planning Act of 2015, “which would establish Medicare reimbursement for health care professionals to provide a voluntary discussion about the treatment options and goals for patients with serious illness...”** VNAA also plans to advocate for the passage of the Palliative Care & Hospice Education and Training Act (PCHETA), and the Compassionate Care Act. (*Home Health Care News*, 9/6, homehealthcarenews.com/2016/09/vnaa-details-home-health-and-hospice-policy-goals/)

* **Caring for high-need, high-cost (HNHC) patients is an urgent priority, says Dr. David Blumenthal.** “At least three steps are essential to meeting the needs of these patients: developing a deep understanding of this diverse population; identifying evidence-based programs that offer them higher-quality, integrated care at lower cost; and accelerating the adoption of these programs on a national level. Although we are making progress in each of these areas, much work remains.” (*NEJM*, 9/8, www.nejm.org/doi/full/10.1056/NEJMp1608511?query=TOC)

* **Does Western culture have a mistaken understanding of grief?** “We are a culture of emotionally stunted individuals who are scared of our mortality and have mastered the concept of stuffing our pain,” says Michelle E. Steinke. (*Huffington Post*, 6/3, www.huffingtonpost.com/michelle-e-steinke/stifled-grief-how-the-wes_b_10243026.html)

* **Does America have a drug problem? More than one, actually!** An article in *California Health Online* exams the public health issues being created by the overwhelming array of prescription drugs being administered to the hospitalized elderly. (*California Health Online*,

8/31, californiahealthline.org/news/americas-other-drug-problem-copious-prescriptions-for-hospitalized-elderly/)

*** The well being of patients and caregivers may be linked, according to a new study published in *The Journal of Clinical Oncology*.** The study finds, “The well-being of patients’ informal caregivers is associated with perceived quality of care among patients with cancer.” (*Oncology Nurse Advisor*, 9/1, www.oncologynurseadvisor.com/general-oncology/cancer-caregiver-well-being-perceived-quality-care/article/519860/)

*** NHPCO has partnered with Rory Feek to promote “To Joey with Love.”** The documentary “follows the musical and reality TV stars over the course of an extraordinary journey – one that brought them home to their farming roots, celebrated the birth of their daughter, and followed Joey on her incredible journey as she battled and ultimately succumbed to cervical cancer. Through this loving tribute to his wife, Rory Feek hopes to help families who face difficult end-of-life decisions, and will be sharing information and resources about hospice care, including a preview from the award-winning ‘Moments of Life’ campaign.” The documentary will air in theaters on September 20 and October 6. (*NHPCO Newsbriefs*, 9/1; *USA Today*, 8/31, www.usatoday.com/story/life/movies/2016/08/31/rory-feek-joey-documentary-trailer-premiere-exclusive-interview/89541470/; <http://tojoeywithlove.com/>)

*** The Stanford Friends and Family Letter Project uses letter templates to encourage people from a wide variety of backgrounds to write a final letter to their loved ones.** “The letter template, which is available in eight languages, allows writers to express gratitude, forgiveness and regret.” (*New York Times*, 9/7, www.nytimes.com/2016/09/07/well/family/writing-a-last-letter-before-you-get-sick.html?_r=0)

*** “I was my husband’s caregiver as he was dying of cancer. It was the best seven months of my life.”** Tracy Grant shares about her experience caring for her dying husband, and the transformative effects it had on her life. (*The Washington Post*, 8/30, www.washingtonpost.com/news/inspired-life/wp/2016/08/30/i-was-my-husbands-caregiver-as-he-was-dying-of-cancer-it-was-the-best-seven-months-of-my-life/?wpisrc=nl_sb_smartbrief)

*** Who has the best access to quality end-of-life care? One study says that patients with cancer or dementia do.** “An American research group compared the quality of end-of-life care in patients with different terminal diseases and found that the quality and accessibility of end-of-life care was higher in patients with cancer and dementia than in patients with different terminal illnesses.” (*Medical News Bulletin*, 9/7, www.medicalnewsbulletin.com/quality-end-of-life-care-different-terminal-diseases-september-7-2016/)

*** A new survey finds that most physicians overestimate both the benefits and harms of common treatment interventions.** “Overall, physicians overestimated the benefits 79% of the time, and the harms 66%; attending physicians and residents were equally inaccurate.” The report, by Mona Krouss, MD, from the University of Maryland Medical Center, Baltimore, and colleagues was published online on August 29 in *JAMA Internal Medicine*. (*Medscape*, 8/29, <http://www.medscape.com/viewarticle/868079>)

*** The Do Not Resuscitate order turns 40 this year.** Drs. Jeffrey P. Burns and Robert D. Truog give an overview of the history of DNRs and hospitals’ treatment of end-of-life care in the last four decades. “The DNR order... represented an important advance in decision making at the

end of life. But the concept has undergone considerable evolution over the past 40 years.” (*NEJM*, 8/11, www.nejm.org/doi/full/10.1056/NEJMp1605597)

*** The Coalition to Transform Advance Care (C-TAC) announced the launch of C-TAC Innovations, and a long-term partnership with Gundersen Health System’s Respecting Choices program.** As a non-profit affiliate of C-TAC, C-TAC Innovations will help to implement Gundersen’s Respecting Choices program and the C-TAC Advanced Illness Care Model. (*C-TAC*, 9/8, www.thectac.org/2016/09/c-tac-launches-service-affiliate-c-tac-innovations-includes-respecting-choices/; *Lacrosse Tribune*, 9/8, lacrossetribune.com/news/local/respecting-choices-transferring-to-d-c--based-group-hq/article_eface1ed-0021-5e13-b836-7c01f6892740.html)

PALLIATIVE CARE NOTES

*** A new article in the *Journal of Palliative Medicine* explores the rise of online advance care planning tools.** “Although technology does not replace human interaction, there is potential for decision-aid tools to help guide the patient and their loved ones on how to approach ACP. We are beginning to see an emergence of innovative online decision-aid tools.” (*JPM*, 9/1, online.liebertpub.com/doi/abs/10.1089/jpm.2016.0266)

*** Palliative care legislation would benefit cancer patients and survivors, says Dick Woodruff, vice president of Federal Relations of the American Cancer Society Cancer Action Network (ACS CAN).** “We can make significant strides against cancer and other life-threatening conditions through patient-centered care that treats the person as well as the disease. We’re hopeful the Energy and Commerce Committee will hear testimony on the PCHETA bill when Congress returns and begin the process of enacting this smart legislation into law.” (*The Hill*, 8/31, thehill.com/blogs/congress-blog/healthcare/293870-palliative-care-legislation-would-help-cancer-patients-and)

*** *Journal of Palliative Medicine* has released a systematic overview of populations and interventions for palliative and end-of-life care.** The overview says, “Palliative care improves cancer, CHF, COPD, and dementia outcomes. Effective models include nurses, social workers, and home-based components, and a focus on communication, psychosocial support, and the patient or caregiver experience. High-quality research on intervention costs and cost outcomes in palliative care is limited.” (*JPM*, 9/1, online.liebertpub.com/doi/full/10.1089/jpm.2015.0383)

*** What does palliative care look like for an unborn baby with no chance of surviving?** “The field of pediatric palliative care has been growing to meet the special needs of seriously ill children and their families. A component of this care, perinatal palliative care, is also now evolving to serve a vulnerable population in need of support when a pregnancy is affected by a life-limiting diagnosis. Congenital anomalies account for 20% of neonatal and infant deaths in the United States; thus, this is an area of tremendous need.” (*Medscape*, 8/30, www.medscape.com/viewarticle/867788)

*** Is suicide a consequence of the CDC opioid guideline?** “A growing number of reports suggest that the guideline is responsible for people with chronic pain throughout the country being tapered or withdrawn from opioids or dropped entirely from physicians’ practices, even if

the patients have been on stable doses of opioids for years with attendant improved pain and quality of life” (*Pain Medicine News*, 8/11, www.painmedicineneeds.com/Commentary/Article/08-16/Is-Suicide-a-Consequence-of-the-CDC-Opioid-Guideline-/37442/ses=ogst)

*** A “mystery shopper” approach allowed a recent study to reveal how difficult it can be for patients to access palliative care at major cancer centers.** A team of researchers, called cancer centers for information and found that “patients may face challenges when trying to access them [palliative care programs].” (*MedicalXpress*, 9/7, medicalxpress.com/news/2016-09-mystery-shopper-barriers-palliative-major.html)

*** It is broadly recommended that patients with cancer receive palliative treatments as soon as possible. A study published in the *Journal of Palliative Medicine*, however, finds a significant gap between physician recommendations and the actual practice of palliative care and hospice for cancer patients.** “There remains a gap between recommended timing of supportive services and real-world practice of care. Results suggest that difficulties in prognosticating death are not fully responsible for underexposure to hospice.” (*JPM*, 9/1, online.liebertpub.com/doi/full/10.1089/jpm.2015.0514)

*** The KB Group provides some FAQs about hospices providing community-based palliative care.** Questions include: “Do state laws prohibit hospices from providing non-hospice palliative care?” and “Can we use hospice staff in our palliative care program?” (*KB Group*, 9/8, www.the-kb-group.com/single-post/2016/09/07/FAQs-Providing-Palliative-Care-as-a-Hospice)

OTHER NOTES

*** States that have legalized medical marijuana are seeing a reduction in the use of Medicare prescriptions – and an associated cost savings - according to a study published in *Health Affairs*.** “The study found that prescription drug use fell in those states by an amount that represented an overall reduction in expenditures of about 0.5%, with an estimated savings of \$165.2 million in 2013 alone.” (*Pain Medicine News*, 9/1, www.painmedicineneeds.com/Policy-Management/Article/09-16/Medical-Marijuana-State-Laws-Associated-With-Reduced-Medicare-Prescriptions/37747/ses=ogst)

*** A letter to the editor of the *Journal of Palliative Medicine*, expressed concern over a *JPM* article on physician-assisted suicide in Hawaii and California. (See HNN, June 14, Volume 20, Number 22).** In “Selection of Respondents Creates Fatally Flawed Study,” authors argue that the self-selection of survey respondents is fatally flawed, and say that the respondents do not actually reflect the population. (*Journal of Palliative Medicine*, 8/8 (online ahead of print), <http://online.liebertpub.com/doi/full/10.1089/jpm.2016.0314>)

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