
HOSPICE NEWS NETWORK

Recent News on End-of-Life Care

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DOCTORS STILL STRUGGLE WITH END-OF-LIFE CONVERSATIONS

A small study published in *JAMA Internal Medicine* confirmed that primary care physicians know that it is important for older patients to understand outcomes and consider life expectancy when making treatment decisions. Nevertheless, physicians say, they still often avoid bringing up the subject. **The twenty-eight doctors interviewed for the study explain that there were several barriers to conversations about long-term prognosis**, “including time constraints as well as a lack of confidence in tools commonly used to predict how many years patients have left.” One researcher explained the importance of considering life expectancy, saying, “Many decisions in primary care require a complex balancing of the potential benefits and potential harms of the decision. Since life expectancy may change that balance, it is one piece of information that can be considered to help tailor medical decisions to each individual patient.”

In another effort to address end-of-life issues, The John A. Hartford Foundation, the California Health Care Foundation, and Cambia Health Foundation have released the results of a poll of doctors about their one-on-one conversations around end-of-life care with their patients. **The report is entitled “Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning?”**

Nearly all the physicians interviewed in the survey felt that end-of-life planning discussions are important, and supported Medicare covering these services. But several barriers prevent them from following through on these convictions. Less than a third reported that they have formal training in how to talk to patients and their families about the topic. But training makes a significant difference. Physicians who have received explicit training in end-of-life conversations are more likely to find conversations about end-of-life care to be rewarding than those who have not. They are also less likely to feel unsure about what to say in these conversations. Another barrier takes the form of systemic issues and documentation. Few physician practices have formal systems in their practices for assessing patients’ wishes and goals of care, nor do they have in place a system of electronic records to indicate that patients have an advance care plan.

Interestingly, the survey found that seventy-five percent of the doctors say the conversations were initiated because Medicare reimburses for advanced-care planning, but only fourteen percent of the doctors report having to bill Medicare-eligible patients. Three-fourths of doctors believed that it was their job to initiate end-of-life discussions with patients, something that patients in an earlier study agreed with. **There were many doctors, however who expressed concern that their patients might feel like they were giving up on them if**

they brought up the subject of end-of-life planning. Peggy Maguire, Cambia Health Foundation President and Board Chair, explains, “Reimbursing doctors to have these conversations is only part of the equation. It's equally important that consumers are empowered by these conversations and feel their wishes are expressed and respected.”

Physicians often struggle to talk with their own healthcare providers about their personal end-of-life decisions. The survey found that only half had had these discussions. This is a much larger segment than the general population, which is at seventeen percent. **Doctors who had conversations with their own care providers were much more likely to have similar conversations with their own patients.**

“Too many people with serious illness, or at the end of life, still receive care that’s completely at odds with their own personal wishes,” said Terry Fulmer, president of the John A. Hartford Foundation. **Fulmer explains that advanced care planning is “not just an extra. Advanced care planning is an essential clinical intervention, just as important in its own way as chemotherapy or surgery.”**

An upcoming second phase of the polling project will include focus groups with physicians, nurse practitioners, and others on the health care team. The focus will be to explore barriers to pursuing end-of-life conversations with patients in more detail.

Fulmer notes that it used to be very difficult to ask about organ donations, and says that now this is routinely asked. In a *Forbes* article, Fulmer says, **“There are still people who see a discussion about end of life and advance care planning as ‘an unconscionable conversation.’”**

Drawing on the information from this survey, Mark Miller, writing for Reuters, feels that the low number of doctors who have billed Medicare for advance care planning reflects a slow start to the new Medicare program. Besides the lack of initiative from patients and doctors, the lack of adequate medical records systems hobbles the practice. Miller says, “The healthcare system is not ready to get this done on a large scale.” (*Medscape Multispecialty*, 04/14, www.medscape.com/viewarticle/861871; *The John A. Hartford Foundation*, 04/14, www.jhartfound.org/blog/talking-with-patients-about-end-of-life-care-new-poll-reveals-how-physicians-really-feel/; *Medscape Multispecialty*, 04/15, www.medscape.com/viewarticle/862040; *Medical Daily*, 04/18, www.medicaldaily.com/end-life-palliative-care-hospice-382383; *NPR*, 04/15, www.npr.org/sections/health-shots/2016/04/15/474267680/doctors-unsure-about-how-to-talk-with-patients-about-end-of-life-care; *MedPage Today*, 04/15, www.medpagetoday.com/PublicHealthPolicy/GeneralProfessionalIssues/57375; *MedCity News*, 04/14, medcitynews.com/2016/04/end-of-life-care-planning-and-ehrs/; *Market Wired*, 04/14, www.marketwired.com/press-release/national-poll-conversation-stopper-whats-preventing-physicians-from-talking-with-patients-2115067.htm; *The Boston Globe*, 04/15, www.bostonglobe.com/metro/2016/04/14/doctors-want-talk-about-end-life-care-but-often-don-know-how-survey-finds/TCud0bVVz1doYSCNuJVxSI/story.html; *Reuters*, 04/21, www.reuters.com/article/column-miller-medicare-death-column-pers-idUSL2N17M1M0; *Pulse Headlines*, 04/21, www.pulseheadlines.com/healthcare-system-ready-talk-endoflife-wishes/27138/; *Forbes*, 4/14, <http://www.forbes.com/sites/brucejapsen/2016/04/14/despite-medicare-coverage-barriers-remain-to-end-of-life-discussions/#1991717b6d58>)

HOSPICE NOTES

* **The Medicare Payment Advisory Commission found that over half of Medicare payments for hospice services are for patients who are in hospice for longer than six months.** Another concern, says an article in *My Palm Beach Post*, is the higher number of people leaving hospice without dying. The article says, “More than 17 percent of U.S. hospice discharges in 2014 were living people.” Jonathan Keyserling, senior vice president and counsel for the National Hospice and Palliative Care Organization explains, “This eligibility for hospice is not a limit on how long a patient and their family may receive end-of-life services, but rather an ongoing test to determine coverage for hospice services.” (*My Palm Beach Post*, 04/08, www.mypalmbeachpost.com/news/business/six-months-to-live-most-us-hospice-spending-goes-f/nq2Lf/)

* **Perinatal hospices are providing care for parents of newborn babies who have low life expectancies. The popularity of such services has grown as more people find out in advance that their child, yet to be born, is unlike to survive.** Perinatal hospice offers pain relief to the infants, and helps family members both connect to and let go of the newborn. Many mothers and fathers find this particular kind of hospice a lifeline in a time of grief and loss. The work of such programs has become entangled with the issue of abortion in Indiana, where a law requires mothers seeking to end a pregnancy to be told about perinatal hospice. (*The Washington Post*, 04/17, www.washingtonpost.com/news/wonk/wp/2016/04/16/perinatal-hospice-care-prepares-parents-for-the-end-at-lifes-beginning/)

* Health and Human Services Inspector General Daniel Levinson spoke at Health Care Compliance Association's Compliance Institute. **Levinson says, “Kickbacks between physicians and hospice providers are an ‘alarming’ concern for the office.”** (*McKnight's*, 04/19, www.mcknights.com/news/hospice-fraud-in-oig-crosshairs/article/490922/)

* **A study published in *The American Journal of Medicine* considered how much hospice eases common end-of-life symptoms in older adults.** The researchers found that symptoms such as fatigue, depression, and anxiety decrease significantly when individuals begin hospice care. The findings suggest that earlier referrals to hospice may be beneficial. (*The American Journal of Medicine*, 03/08, [www.amjmed.com/article/S0002-9343\(16\)30205-4/fulltext](http://www.amjmed.com/article/S0002-9343(16)30205-4/fulltext))

* **Rosemary Baughn, Senior Vice President of VNSNY Hospice and Palliative Care, writes in *Huffington Post*.** Baughn says, “Among our goals in hospice care, which brings quality of life to end of life for both patient and families, is to understand each individual’s goal for the final months and final moments, including place of death. We then bring all the resources, expertise and support of our hospice team to focus on helping people achieve those goals.” (*Huffington Post*, 04/20, www.huffingtonpost.com/rosemary-baughn/observing-the-wish-to-die-at-home_b_9731950.html)

* **CMS has posted for comment the FY2017 Hospice Wage Index rule. The rule calls for a 2% increase in hospice wage index.** “The new reporting requirements include two new quality measures: Hospice Visits When Death is Imminent and Hospice and Palliative Care Composite Process Measure. The first will assess hospice staff visits to patients and caregivers in the last week of a patient’s life. The palliative care measure will assess the percentage of hospice patients

who received care processes consistent with current guidelines.” Comments on the proposed rule, which is available at the first link below, are due June 20, 2016. (*Department of Health and Human Services*, 04/2016, s3.amazonaws.com/public-inspection.federalregister.gov/2016-09631.pdf; *Home Care Health News*, 4/21, <http://homehealthcarenews.com/2016/04/cms-to-increase-hospice-payments-by-2-in-2017/>)

END-OF-LIFE NOTES

*** Dr. Jessica Nutik Zitter writes in *The New York Times* about having to resist her training as an ICU doctor to intervene when a patient is clearly dying from multiple causes. Instead, she chooses to use her knowledge of palliative care to help the patient.** She writes “And so often, when a patient is actively dying, I must hold myself and my residents back, quiet our itchy fingers, and acknowledge that we find ourselves in the uncomfortable position of waiting for nature to take its course.” (*The New York Times*, 04/14, well.blogs.nytimes.com/2016/04/14/in-the-hospital-letting-nature-takes-its-course/?emc=eta1&_r=1)

*** Ric Baxter, director of palliative care services for St. Luke's University Health Network, writes about how baby boomers are moving away from keeping a loved one alive at all costs.** Instead, they are considering what a “good death” looks like. He encourages families to talk about end-of-life wishes “as soon as end-of-life frailty becomes evident, and the conversation needs to be ongoing because what constitutes the quality of life changes from year-to-year, month-to-month even day-to-day as life winds down.” (*The Morning Call*, 04/18, www.mcall.com/opinion/yourview/mc-hospice-care-baxter-yv-0418-20160417-story.html)

*** A Rutgers-Eagleton poll found that nearly two-thirds of New Jersey residents have thought about their end-of-life care and talked to their physicians or family members about it.** However, few have taken steps to make those choices binding with an advance directive or a living will. More than three-quarters of those polled said they were familiar with hospice care, though New Jersey has some of the highest rates of medical intervention at the end of life. (*NJ.com*, 04/14, www.nj.com/healthfit/index.ssf/2016/04/most_nj_residents_avoid_end-of-life_planning_poll.html)

*** New Jersey patients can spell out what kind treatments they are willing to accept in their final months, weeks or days by using the POLST (Practitioner Orders for Life-Sustaining Treatments) form.** It is a “one-page form completed by a doctor or nurse practitioner with the patient’s help.” The form accompanies a patient's medical records and is available wherever the patient receives care. However, few New Jersey residents seem to be aware of POLST or choose to use it. The Goals of Care project, in collaboration with Bridgeway Care and Rehabilitation Centers, Care Associates Network, and the Health Care Association of New Jersey have created a series of six videos that teach patients and families and guide them through the decision-making process. (*NJ.com*, 04/21, www.nj.com/healthfit/index.ssf/2016/04/state_law_allows_dying_go_out_on_their_own_terms.html; *Goals of Care*, <http://www.goalsofcare.org/njpolst-video-series/>)

*** Eric J. Hall, President & CEO of HealthCare Chaplaincy Network, argues that the time at the end of life should not be thought of as just waiting to die, but rather a time in which**

the spirit can be enriched and enlivened. Hospices and nursing homes are addressing this need in patients to help meet the spiritual need of patients for transcendence, friendship and affection. (*Huffington Post*, 04/18, www.huffingtonpost.com/eric-j-hall/the-body-may-weaken-but-t_b_9695428.html)

*** Internal medicine resident Ravi Parikh writes about his experience of gaining better understanding of a patient’s wishes by asking the important question “What matters to you?” instead of just confirming the code status.** Parikh says that patients he has talked with wanted to know the prognosis they face and “also wanted to know whether their symptoms — pain and nausea, for example — would ever go away, and what options would allow them to be at home during their final days.” He writes, “End-of-life discussions are opportunities to learn more, to start a conversation that we as doctors have been missing out on for quite a while. Once we listen enough to learn, maybe those ‘goals of care’ discussions will start focusing on the goals of the patient, not the doctor.” (*The Washington Post*, 04/18, www.washingtonpost.com/national/health-science/when-a-doctor-and-patient-disagree-about-care-at-the-end-of-life/2016/04/18/eb82f0c2-c51d-11e5-8965-0607e0e265ce_story.html)

*** According to a study published in the *Journal of Clinical Oncology* family-focused therapy during palliative care and into bereavement reduces the severity of complicated grief and risk of prolonged grief disorder in high-risk families.** (*Oncology Nurse Advisor*, 04/19, www.oncologynurseadvisor.com/general-oncology/prolonged-grief-disorder-reduced-by-family-therapy-during-palliative-care/article/490810/)

*** Seven years ago, MedStar Washington Hospital Center, in DC, sought to understand the stress of medical residents.** Nneka Sederstrom, director of the Center of Ethics at the hospital, said that when residents were asked the primary cause of stress, they “told her it came from being required to offer care to terminally ill patients that they believed was overly aggressive.” Physician Joanne Lynn notes that this also creates stress for patients and families. Lynn says, “Most patient distress is caused when physicians encourage unnecessary testing and hospitalizations. She also noted that patients and their families often express feeling that that their end-of-life wishes are not heard or respected by physicians.” Sederstrom believes that the new generation of physicians that are being trained “will practice better medicine because they now have the tools to know how to say no.” (*Modern Healthcare*, 4/19, <http://www.modernhealthcare.com/article/20160419/NEWS/160419902/teaching-young-physicians-how-to-say-no-to-aggressive-end-of-life>)

PALLIATIVE CARE NOTES

*** Part of the 2016 National Comprehensive Cancer Network Annual Conference focused on “more effective ways to encourage and deliver palliative care services across a variety of settings in oncology, with an eye toward introducing these services earlier in the cancer care trajectory, facilitating better provider–patient communication, and improving overall patient and caregiver quality of life.”** (*Cure*, 04/07, www.curetoday.com/articles/teambased-crucial-in-addressing-palliative-care)

*** New Hampshire Public Radio recently aired a discussion on the opioid epidemic and how physicians are dealing with prescribing medications in light of new guidelines from the**

CDC. Guests include Gil Fanciullo, Director of the Pain Management Center at Dartmouth-Hitchcock Medical Center; Andrew Kolodny, Chief medical officer at Phoenix House, a nonprofit drug and alcohol rehabilitation organization; Cindy Rosenwald, Democratic Representative from Nashua; and David Strang, Chairman of the New Hampshire Prescription Drug Monitoring Program Advisory Council. The program can be heard in its entirety online. (*NHPR*, 04/14, nhpr.org/post/prescribing-opioids-during-addiction-epidemic)

CDC GUIDELINES ON OPIOID USE NOTES

*** The Centers for Disease Control and Prevention recently updated the 2014 review on opioid use.** A *JAMA* article describes and reviews the guidelines, and this article is available online for free. The guidelines say that nonopioid treatments should be preferred for chronic pain and opioids should only be used when the risks have been weighed against the benefits. The guidelines encourage “evidence-based treatment, such as medication-assisted treatment with buprenorphine or methadone” for those who are addicted to opioids. CDC gives a full description of their process and an explanation of their 12 recommendations. (*Journal of the American Medical Association*, 04/19, jama.jamanetwork.com/article.aspx?articleID=2503508)

*** Dr. Yngvild Olsen wrote an editorial about the CDC guidelines for use of opioids. The editorial appears in *Journal of the American Medical Association*.** Olson says, “The CDC guideline for prescribing opioids for chronic pain is an important and essential step forward. With support from physicians across the country, as well as from policy makers at all levels, implementation of the recommendations in this guideline has the potential to improve and save many, many lives.” Olsen feels that the CDC listened to early critics of their plan, and tried to address those concerns. After hearing dissenting viewpoints, the agency, Olsen feels, substantially revised their guidelines. (*Journal of the American Medical Association*, 04/19, jama.jamanetwork.com/article.aspx?articleID=2503503)

*** According to *The New England Journal of Medicine* there are three key principles underlying the CDC’s new guidelines on opioid prescriptions.** First, nonopioid therapy is preferred for chronic pain outside the context of active cancer, palliative, or end-of-life care. Opioids should be added to other treatments for chronic pain only when their expected benefits for both pain and function are likely to outweigh the substantial risks inherent in this class of medication. (*The New England Journal of Medicine*, 04/21, www.nejm.org/doi/full/10.1056/NEJMp1515917?query=TOC&)

PHYSICIAN ASSISTED SUICIDE NOTES

*** Hospice advocates Jennifer Ballentine, MA, Cordt Kassner, PhD, and Ira Byock, MD, FAAHPM, sent a letter to the editor of *Journal of Palliative Medicine*.** They argue with a recent *JPM* article that suggested that Oregon hospice utilization is high because Physician Aid in Dying is legal in the state. They claim that the opposite is true, and say that the use of Physician Aid in Dying is low in Oregon because of high quality hospice care being available. The authors point to the lack of an increase in hospice enrolment after the passage of the Oregon’s Physician Aid in Dying law to support their case. (*Journal of Palliative Medicine*,

03/31, online.liebertpub.com/doi/abs/10.1089/jpm.2016.0035)

*** An editorial in *The Hill* argues that while other countries, like Canada, are dealing with end-of-life issues, Americans continue to be uncomfortable talking about personal decisions and public policy around the end of life.** Because of this, advance care directives are often ignored, and millions do not have access to palliative care and hospice. The authors say, “Despite what we think, the United States does not have the full continuum of end-of-life care available, especially for a terminally ill but mentally competent person, unless you live in one of the five states granting permission to hasten death.” (*The Hill*, 04/20, thehill.com/blogs/pundits-blog/healthcare/276947-myths-and-misconceptions-about-end-of-life-care-and-laws)

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