HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

Volume 20, Number 41 November 8, 2016
A Service of State Hospice Organizations

JAMA INFOGRAPHIC PROVIDES SNAPSHOT OF END-OF-LIFE CARE

***Journal of the American Medical Association* created the Visualizing Health Policy infographic to provide insight and improve understanding of the current state of Medicare and end-of-life care.** Out of 2.6 million deaths that occurred in the United States in 2014, 2.1 million, the vast majority, were beneficiaries of Medicare. Though Medicare patients at the end of life incurred costs that greatly exceeded those of other patients ($34,529 per year for end-of-life patients vs. $9,121 for other beneficiaries), the total share of Medicare spending on end-of-life care has been trending downwards between 2000 and 2014 (from 18.6% to 13.5%). Medicare spending for people at the end of life varies based on age, with younger end-of-life patients incurring fewer costs than elderly patients.

During this same period, the proportion of Medicare beneficiaries receiving hospice care at the end of life grew to 46%. **Medicare spending on hospice increased dramatically, from $2.3 billion at the turn of the century to $10.4 billion in 2014.**

"**Surveys show that more than 7 in 10 people aged 65 years and older have not discussed end-of-life care with a physician and that 4 in 10 have not documented their end-of-life care wishes."** Before January of 2016, Medicare did not reimburse physicians for having end-of-life discussions with their patients. Perhaps as a consequence, 68% of physicians still report that they have not received any training for such discussions.

The data-rich information is online at the *Journal of the American Medical Association*. (*JAMA*, 11/1, jamanetwork.com/journals/jama/fullarticle/2576570; *Kaiser Family Foundation*, 11/1, kff.org/slideshow/medicare-and-end-of-life-care/)

PHYSICIAN OFFERS TIPS ON GIVING TERMINAL DIAGNOSES

Dr. Andrew Epstein doesn't sleep well. As an oncologist at the Sloan Kettering Memorial Cancer Center in New York, he spends his days having some of the most difficult conversations imaginable. *Quartz* shares about Epstein's experiences and his advice to other physicians.

Sometimes, Epstein is informing his patients of a very serious prognosis. Other times, he's letting patients know that their conditions have worsened, and that they are not likely to live. These conversations, when treatment has failed and end-of-life care is now the most viable option, are emotionally draining -- to such an extent that Dr. Epstein spends a significant portion of his week in recovery.

Having end-of-life conversations with patients who are just learning that they are terminally ill is one of the most difficult tasks for any physician. It's no wonder that they're so often avoided or delayed. **Most patients say they want to have this kind of frank, open end-of-life discussion, but many don't end up having them.** This is probably because most doctors feel unprepared to deliver such bad news, even if they've received some training in school. It's hard to feel like one is disappointing a patient and a family at such a profound level.

As hard as it is, there are always ways to be a better bearer of bad news, says Epstein. "It's all about self-awareness, preparation, respect for others and inquiry into [their] perspective." **Dr. Epstein lays out some pointers for how to conduct an effective, and emotionally sensitive, end-of-life conversation with a patient who is learning that they are almost certainly going to die soon.**

First, he says, it's important to call a meeting. It's important not to wait for the "right time" to deliver the news. "You want to have a comfortable, private setting, arrange for the meeting, and don't meet any later than necessary," says Jayson Dibble, a communication specialist at Hope College in Holland, Michigan. Delaying the news simply makes it more difficult for patients and families to grapple with the reality of their situation.

Setting an appointment for the meeting is key. Having a meeting shows the patient that they have their doctor's full attention. It provides the blocked-out time and space to fully hear the news and deal with its implications, with the supportive presence of the physician. It allows the patient time to prepare, too, for what they will implicitly know is major news about their health.

Once the meeting has been scheduled, it is important that physicians take the time to prepare themselves. "Epstein pours over his patients' charts and imagines himself in their shoes, trying to figure out the questions they are most likely to ask. He also makes sure that he's ready to translate medical jargon into practical facts the patient can use to make a decision about their care."

There is a tendency for doctors to over-explain, but Epstein warns against this. "Understandably, medical professionals don't want patients to lose hope, so they'll start going through all the additional tests they could run and explaining all the experimental treatments available the patient could try. This, though, is a form of stalling, and doesn't give the patients the information they actually need to hear."

Dr. Epstein encourages doctors to keep in mind the reason they are having this conversation. It is primarily to provide patients with the truth, so that they can take control over their end-of-life experience rather than being buffeted to and fro by a medical system that, ultimately, cannot save them. In this context, **the natural human tendency to hedge and present a more optimistic picture can actually damage the patient's ability to engage with the reality of their illness. And it can make preparations for the end-of-life experience that they truly desire.**

Epstein says that the key to providing the best care during these end-of-life conversations is to take the time to understand the patient's values. Patients have many objectives at the end of life, and many of these are often more important than prolonging lifespan. Patients often choose to focus on quality of life, making decisions for their own care, reaching life milestones,

and keeping up with hobbies. All of these can be more important than mere length of life.

When you actually deliver the news, it is important to be concise, polite, and clear. Above all, it's important not to fill the air with words in order to blunt the impact of the news. "After the bad news, we [tend to] fill the silence with a lot of words, and instead what we should do is shut up," says Epstein. Patients need time to process the news they are hearing, and to allow their emotions to run their course, before they can really engage with the facts. Speaking too soon can interrupt that process. "They need quiet, and then some phrase to address their emotion, to empathize," he says.

Being fully present in these conversations requires a deep empathy, continually imagining what the other person might be thinking and feeling. At the same time, it's important for doctors to recognize their own emotional limits. **"If you get too emotionally mired in it, the care of other patients will suffer and you'll burn out," he says.** (*Quartz*, 11/3, qz.com/823918/how-doctors-give-patients-bad-news/)

HOSPICE CHAPLAIN REFLECTS ON LIFE AND DEATH IN INTERVIEW WITH NPR

Hospice chaplain Kerry Egan says that her job is to help dying people come to terms with their own mortality. That means sitting with them as they express regrets and fears. It also means listening to their stories, and hearing their joy at life. "There's no time to preach or teach," Egan tells Terry Gross, of *NPR's Fresh Air*. "You have to use whatever tools that person already has in their spiritual toolbox to help them come to meaning in their lives."

Every person is unique, with his or her own sense of what is meaningful and what is most important. For some, that sense of meaning comes from religious faith. For others it is based more in family relationships, or even arts and literature. **"If you think about how different every single person who's living ... is, well, people are just as different in the dying process,"** says Egan, who lives in Columbia, South Carolina.

Egan has recently published a memoir entitled "On Living," which explores her work as a hospice chaplain, and shares the impact that the work has had on her own life. While many assume that working in hospice must be a sad job, she reveals that working in end-of-life care brings her great joy. "I'm constantly reminded of the strength of the human soul," she says. "I'm constantly reminded of ... how much love people have for each other, and the love that's all around us that we just don't necessarily take a moment to see."

In her interview with *NPR*, Egan discusses the practical work of a hospice chaplain, and shares what her work looks like on a practical level. She describes her role as that of helping the dying and loved ones grapple with issues of purpose and meaning. **Ultimately, she says, her job is to be a pastoral presence with those who need it most.**

Egan speaks about how many hospice patients feel about death. It's not what you'd expect. **"I think people would be really surprised to know that a lot of hospice patients aren't nearly as afraid of dying as you think they are,"** says Egan. "I think some of us who are healthy in the middle of life have a real fear and horror of death, and I think a lot of hospice patients don't.

They don't anymore. Some of them are downright curious."

Egan speaks about the common phenomenon experienced by end-of-life patients of seeing visions of their mothers. "It's not a necessary step, everybody doesn't experience it, but it happens a lot. ... They come to them, they wave at them, sometimes they talk to them, and it's really, really comforting to people."

She shares about her experience, as a hospice chaplain, of needing to "remain soft" while also cultivating inward strength. "If you're not willing to be soft on the outside, you're not going to get any work done. And if you have to be soft on the outside to be an effective chaplain, well then something's got to hold you up, and the only thing that can hold you up is sort of an interior strength. That's it."

For Egan, it all comes back to how much joy she finds in her work as a hospice chaplain. "Death is really sad. When someone dies, it's really sad, but there's also enormous joy to be had and funny times and happy times and everything. It's life, right? Dying is part of living, so everything you have in the course of a life you have in the course of dying." (*NPR*, 10/31, www.npr.org/sections/health-shots/2016/10/31/499762656/hospice-chaplain-reflects-on-life-death-and-the-strength-of-the-human-soul)

HOSPICE AND END-OF-LIFE NOTES

* **An Indiana hospice chaplain, Mike Mercer, helps dying patients and their families plan for the end of life.** "No one wants to have the tough talks about last wishes, do-not-resuscitate orders or funeral home choices. But one local chaplain wants to help change that." Mercer has published a book, "Walking Home Together: Spiritual Guidance and Practical Advice for the End of Life." (*Daily Journal*, 10/31, www.dailyjournal.net/2016/11/01/mike_mercer_story/)

*** Research reveals that one in four seniors aren't discussing end-of-life care.** "Despite decades of work to improve advance care planning, over a quarter of older adults have still not engaged in any type of discussion or planning for their end-of-life preferences or plans," says lead author Krista Harrison, a geriatrics research fellow at the University of California, San Francisco. (*Health Day*, 10/31, consumer.healthday.com/senior-citizen-information-31/misc-aging-news-10/advance-care-planning-jama-im-ucsf-release-batch-2943-716372.html; *JAMA Network*, 10/31, http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2575882)

*** House calls are coming back in a big way for seniors who need at-home assistance.** And, says an article in *McKnight's,* home visits might even reduce health care costs. (*McKnight's*, 11/2, www.mcknights.com/guest-columns/house-calls-coming-back-for-seniors-needing-care/article/570152/?DCMP=EMC-MCK_Daily&spMailingID=15801534&spUserID=NDI1OTM3MTEwNDES1&spJobID=900748276&spReportId=OTAwNzQ4Mjc2S0)

*** Is a doctor's estimate of life expectancy a "clinical judgment" or an "opinion"?** "If the testimony of a single physician who did not have face-to-face consultations with the patients, but rather formed a judgment based solely on written documents is allowed to overturn the testimony

of several physicians who did meet with the patients and created the written documents, hospice benefits for future terminally ill patients could be denied." (*AMA Wire*, 11/1, wire.ama-assn.org/practice-management/judgment-life-expectancy-issue-medicare-fraud-case)

*** A new crop of tech start-ups are hoping to capture a slice of the end-of-life market, reports the *New York Times*.** "As baby boomers become more comfortable shopping online, these start-ups are finding a highly engaged audience. And those in their 20s and 30s, hitting major life events like marriage, the birth of a child or the loss of a parent, also require planning services." (*New York Times*, 11/2, http://www.nytimes.com/2016/11/03/business/start-ups-for-the-end-of-life.html?_r=0)

*** What does it mean to "die with dignity"?** Catholic patients at the end of life explore what it means to experience peace and joy at the end of life**.** (*St. Louis Review,* 11/3, stlouisreview.com/article/2016-11-03/dignity-happy-death)

*** Should some regular medications be discontinued towards the end of life?** "Medications that focus on prevention and treatment of illnesses should be reconsidered when life expectancy is only months or weeks," say authors. (*Medscape*, 10/27, www.medscape.com/viewarticle/871029?src=wnl_mdplsnews_161028_mscpedit_wir&uac=68861EJ&impID=1224287&faf=1)

*** What steps can you take to get the end-of-life care that you want? An article in the *Boston Globe* addresses this question.** "New data show that Massachusetts residents spend many of their final days in the hospital, instead of at home or in hospice care. Planning ahead can make it more likely that people get the care they desire." The article gives steps individuals can take to engage in end-of-life planning. (*Boston Globe*, 11/3, www.bostonglobe.com/metro/2016/11/03/how-get-care-you-want-end-life/LHSfxTbmcUvl7QEX8OPFMM/story.html)

*** Hospice care is under-used in Massachusetts, according to recently released data.** "A quarter of Massachusetts Medicare patients who used hospice care did so for six days or less in the year before their death, a statistic that prompted one member of a state health care watchdog agency to call for more education around end-of-life care." (*South Coast Today,* 11/2, www.southcoasttoday.com/news/20161102/data-hospice-care-underused-in-mass)

*** *HealthStream* is offering a free webinar on demand.** "The Future of Healthcare at Home: Value Based Purchasing, Quality and Hospital Based/Affiliated Agencies" can be viewed online, and registration is required. (*HealthStream*, hs.healthstream.com/l/152971/2016-07-14/2n4wvr

PALLIATIVE CARE NOTES

*** The *Journal of Palliative Medicine* is recognizing National Hospice and Palliative Care Month by providing free access to a variety of articles through 11/15/16.** A list of the articles, and a link to read each one, are online. (*Journal of Palliative Medicine*, http://view.liebertpubmail.com/?qs=b3550375791558a44a9bfe25137220b8aba8b432eeebd8208b644377a1d201f91b7047c16e0da4e211828ebcb7f8772409e897ac05e97d9dbf80a6f11da18228352a65a96b47ae94)

*** As access to opioids is reduced for those dealing with pain, access to marijuana is increasing.** "Unless the nation develops an increased tolerance to chronic pain, reduction in opioid prescribing leaves a vacuum that will be filled with other therapies. Enter cannabis." (*JAMA*, 11/1, jamanetwork.com/journals/jama/article-abstract/2576617)

*** CMS should not remove pain questions from payment calculations, some doctors argue.** "Pain control has been recognized internationally as a 'fundamental human right.' If we stop measuring pain control, we essentially dehumanize the patients we are under oath to serve." (*Pain Medicine News*, 10/13, www.painmedicinenews.com/Commentary/Article/10-16/Why-CMS-Should-Not-Remove-Pain-Questions-From-Payment-Calculations/38004/ses=ogst?enl=true)

OTHER NOTES

*** Please, don't call older adults "sweetie" or "honey."** An article in *Next Avenue* says this is ageism, and asserts that people want to be called by their names. "It's a fairly common practice for health care professionals and even families to interact with elders as if they've somehow moved to the other end of the age spectrum. Most will tell you they believe it conveys a sense of caring or nurturing when they lapse into using child-like vocabulary or refer to those adults..." (*Next Avenue*, 10/27, www.nextavenue.org/older-adults-called-sweetie/)

*** What are the clinical criteria for physician-assisted suicide?** In an article published the *Journal of Palliative Medicine* (available to read in its entirety until 11/15/16), researchers provide some suggestions for such criteria. "For physicians who are willing to provide [aid in dying], it is important that they be medically knowledgeable doing so. These criteria are designed to provide that knowledge and guidance." (*Journal of Palliative Medicine, Online 11/5*, online.liebertpub.com/doi/full/10.1089/jpm.2015.0092)

Thanks to Don Pendley for contributions.