
HOSPICE NEWS NETWORK

Recent News on End-of-Life Care

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BYOCK SAYS THAT DOCTORS CAN LEAD THE WAY IN DYING WELL

Dr. Ira Byock, writing in *The New York Times*, asks, “At the end of Life, What Would Doctors Do?”

Byock comments that a number of emergent groups, books and projects demonstrate “that, as a culture, we are finally starting to come to terms with our mortality.” While not yet a national priority, this increasing awareness, says Byock, will lead us toward improvements in end-of-life care.

Byock calls on physicians to provide leadership in demonstrating how to live and die well. Byock says, “Doctors can be valuable guides in this process.” He shares a number of examples of physicians who have done this. Dr. Ken Murray, author of an online article, “How Doctors Die,” is one example. Murray’s article went viral and was viewed by millions. Byock also shares samples of the writing of Dr. Jane Poulson, who found greatest joy in spending time with family and friends as her life neared its end. Dr. Bill Bartholome wrote poignantly, as Byock shares, and talks about the time of living with his incurable esophageal cancer as a “gift.” More recently, neurosurgeon Dr. Paul Kalanithi wrote “When Breath Becomes Air,” where he shares of the decision to have a child with his wife, even when he knew he would not live to raise the child.

Clinical psychologist Peter Rodis, Byock’s friend, wrote about his dying. Rodis said, “Mostly, deep underneath, there is a quiet, joyous anticipation and curiosity; gratitude for the days that remain; love all around. I am fortunate.” And, neurologist Dr. Oliver Sacks, in his essay “My Own Life,” says, “Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure.”

From all of the examples, Byock summarizes, **“We can appreciate how dying and well-being can coexist. For all the sadness and suffering that dying entails, our human potential for love, gratitude and joy persist.”** With that conclusion, Byock imagines that physicians’ live and die in ways that “teach all of us about living fully for whatever time we have.” (*The New York Times*, 6/30, <http://well.blogs.nytimes.com/2016/06/30/at-the-end-of-life-what-would-doctors-do/>)

STUDY SAYS PATIENTS WITH CANCER AND DEMENTIA ARE MORE LIKELY TO RECEIVE BETTER END-OF-LIFE CARE

Does a terminally ill patient’s diagnosis determine the kind of care he or she receives at the end of life? A new study published in *JAMA Internal Medicine* suggests that physicians tend to be more

accommodating of the advance care wishes of patients with cancer or dementia than they are of those experiencing renal disease, congestive heart failure, pulmonary disease, or frailty. “There’s been a lot of focus on end-of-life care for cancer,” says Dr. Melissa Wachterman, lead author for the study. “But most people don’t die of cancer. And the quality of end-of-life care for those dying of other conditions... is not as good.”

To carry out the study, researchers looked at survey data from the families of approximately 34,000 patients who died in the VA health system between 2009 and 2012. They looked at how families rated the quality of care their loved one received – in particular, whether they had access to palliative care consultations, if they died in hospice or the ICU, and whether they had a do-not-resuscitate order at the time of death. **About 60% of families whose loved one died of cancer or dementia reported that their relative received excellent end-of-life care, and 80% said that their relative “always got the care he or she wanted.”**

The picture is less rosy for patients who died from other conditions. Only a little more than half (55%) of the families reported “excellent” end-of-life care for loved ones who died of renal, cardiovascular, or pulmonary conditions. When asked if doctors always gave desired care to their loved ones, 73% to 77% agreed. Patients with non-cancer/dementia conditions were notably less likely to receive palliative care consultations, and they died in much greater numbers in the ICU as opposed to hospice care. This can be viewed as a negative outcome, since studies have shown that “most people want to die comfortably at home, opting for fewer rather than more treatments.”

Based on the findings of the study, Wachterman says that there is “clearly room for improvement” in the way end-of-life care is handled by physicians who are attending patients of varying life-limiting conditions. And though the study was based on data from the VA, she expects that the trends of this study would be reflected in other settings as well. Despite the fact that the federal government has taken steps to make it easier for clinicians to accommodate the end-of-life wishes of their patients, many physicians say they feel uncomfortable with end-of-life conversations.

Often, non-cancer/dementia patients may suffer from the fact that their conditions are not understood to be as serious, likely leading to death. “Everybody gets that if you have advanced cancer, it’s very serious,” says Wachterman, but, “There isn’t always the recognition that these other conditions are also very serious.” **In order to ensure that end-of-life planning is taking place for all patients, regardless of prognosis, advance-care planning conversations should be integrated into routine care.** (*JAMA Internal Medicine*, 6/26, archinte.jamanetwork.com/article.aspx?articleid=2529496; *Lund Report*, 6/30, www.thelundreport.org/content/end-life-care-better-patients-cancer-dementia-study-finds; *Medline Plus*, 6/27, www.nlm.nih.gov/medlineplus/news/fullstory_159585.html)

HOW DO WE MEASURE SUCCESS IN END-OF-LIFE CARE?

John Leifer, CEO of the health care strategy firm, the Leifer Group, recently examined the evolution of end-of-life care in the 19th century and considered the changes that are needed now. His article, “How to Measure the Success of End-of-Life Care,” appeared in *Hospitals and Health Networks*.

It was not too long ago, Leifer notes, that hospitals took the place of personal homes as the site for life’s beginnings and endings. Hospitals provided advanced medical care, where births could be

conducted more safely, and for death to be fought up until the very last. The role of the hospital provided economic incentives, as well as humanitarian ones. "From the hospital's perspective, meeting all the needs of its patients was like an annuity. It would pay consistent returns throughout the patient's lifetime, with a kicker at the end as the patient's utilization often soared. Savvy health care marketers picked up quickly on the opportunity to position their organizations as 'cradle to grave' providers."

At the time, few people saw any problem with such thinking. Hospitals were bringing so much benefit to our lives, why wouldn't we want to benefit from these scientific gains at all stages of life -- and death? **But beginning in the early 1970s, a new perspective began to emerge. A small group of physicians, nurses, and educators "began to question whether the health care field was properly managing end-of-life issues."** They asked whether the hospital was always the best place to care for patients -- particularly those experiencing terminal conditions. They wondered, "Might not many of us be happier dying at home, rather than in a hospital?"

Predictably, many physicians objected, insisting that it was a moral obligation to always do everything possible to prevent death. **"A dynamic tension arose between those who sought to heal the body and those whose definition of healing was not simply biological but included concepts such as quality of life, finding meaning and purpose at life's end, holding on to hope and achieving closure. It is a tension that continues today despite significant changes in end-of-life care."**

In the midst of this tension, the goal of many hospice advocates has primarily been to increase enrollment in hospice care while decreasing deaths that occur in hospital settings. Thanks in large part to these efforts, that's exactly what's happened. Between 2000 and 2009, the percentage of deaths in hospitals declined from 32.6% to 24.6%, while use of hospice at the time of death increased from 21.6% to 42.2%.

But rather than simply celebrating the increase of hospice enrollment and decrease in hospital deaths, Leifer says, **it may be time to ask more difficult questions about what constitutes dignified quality care for people at the end of life. Some questions to consider:** Is hospice an option that is selected proactively, or best utilized "only after potentially unnecessary, ineffective, or inappropriate interventions have failed?" Can emergency room admissions prove beneficial to end-of-life patients? When and why? What are the financial motivations behind end-of-life care, and how does this interact with what is in the best interests of patients? Are medical personnel appropriately trained in end-of-life techniques? If not, how is this being addressed? What are the quality measures that are being used to establish and encourage the use of end-of-life care in hospitals? Are they working?

Leifer argues that now is the time to proactively manage the evolution of end-of-life care, from a simplistic, pro-hospice admissions/anti-hospital deaths viewpoint. "The efforts made by health care leaders to improve end-of-life care have the power to speak volumes about the moral imperatives of hospitals and their stewards. Gains will be realized only if improving end-of-life care becomes one of a handful of strategic initiatives guiding your institution through the difficult times ahead." (*H&HN Magazine*, 6/27, www.hhnmag.com/articles/7390-end-of-life-care-a-work-in-progress)

HOSPICE NOTES

*** Personally meaningful rituals can help increase compassion and decrease burnout among hospice staff and volunteers, according to a study published in *The Journal of Palliative Medicine*.**

“Organizations may benefit from providing training and support for personalized rituals among team members, especially new staff who may be at greater risk for burnout.” (*JPM*, 6/23, online.liebertpub.com/doi/abs/10.1089/jpm.2015.0294)

*** World Hospice and Palliative Care Day posters and other materials for promoting the day are now available for download. World Hospice and Palliative Care Day will take place on Saturday, October 8th, 2016.** “It is a unified day of action to celebrate and support hospice and palliative care around the world.” (*eHospice*, 6/30, www.ehospice.com/southafrica/ArticleView/tabid/10689/ArticleId/19852/language/en-GB/View.aspx)

*** *The Huffington Post* features “4 Things You Should Know About Hospice Care.”** These four things include: “Hospice doesn’t mean you’ve given up.” “Hospice is not a place you go to die.” “Insurance covers hospice care.” “Hospice is not just for the elderly.” (*Huffington Post*, 6/29, www.huffingtonpost.com/john-whyte-md-mph/4-things-you-should-know-3_b_10740842.html)

*** Palliative care provides an extra layer of support for the seriously ill, writes Paul Tatum for the *Columbia Daily Tribune*.** “If you are very sick and hope to remain at home, hospice might be the best way to get palliative care. Hospice also can help patients in nursing homes who do not want to return to the hospital when their prognosis is shortened.” (*Columbia Daily Tribune*, 6/5, www.columbiatribune.com/arts_life/pulse/palliative-care-provides-added-layer-of-support-for-seriously-ill/article_0856672c-d659-5d48-9656-080c4d6b0a01.html)

*** Atul Gawande says,** “The quality measures currently in place in skilled nursing facilities and hospice settings are too focused on safety and health to promote effective palliative care.” Gawande recently testified before the Senate Special Committee on Aging as part of an NHPCO-sponsored hearing on person-centered care for people with serious illnesses. (*McKnight’s*, 6/23, www.mcknights.com/news/gawande-good-palliative-care-blocked-by-quality-measures-lack-of-communication/article/505261/)

PALLIATIVE CARE AND END-OF-LIFE NOTES

*** Does advance-care planning result in surrogate decisions that reflect the patient’s goals of care?** A study published in *The Journal of Palliative Medicine* suggests that more study is necessary to “understand consistency between preferences and end-of-life care.” (*JPM*, 6/9, online.liebertpub.com/doi/full/10.1089/jpm.2015.0349)

*** Dr. Jay Marion of Louisiana State University believes that medical marijuana could help improve quality of life for patients in his home state.** “As a palliative care doctor, I welcome having as many tools in my toolbox as possible,” Marion said. (*Shreveport Times*, 6/30, www.shreveporttimes.com/story/news/2016/06/30/dr-jay-marion-medical-marijuana-could-improve-quality-life-louisiana-patients/86516426/)

*** What does it mean when death becomes a trendy topic? Conversations about the best way to do end-of-life care are everywhere these days.** “Joining other voices in these talks, the Hospice Foundation

of America has just mounted a yearlong awareness campaign, screening "Being Mortal" -- the 2015 PBS Frontline documentary based on Atul Gawande's best-selling book -- in 300 U.S. communities." (*HT Health*, 6/17, health.heraldtribune.com/2016/06/17/what-does-it-mean-when-death-becomes-a-trendy-topic/)

*** In the face of the destruction caused by dementia, health care providers are learning to give better care for those facing its ravages.** "Too often, families . . . have to wait until the ravages of Alzheimer's and other forms of dementia do great damage before the health care system brings in its full firepower." There is growing "effort designed to help patients live healthier, crisis-free lives at home, ease stress on families, and potentially reduce costs for insurers." (*Boston Globe*, 6/22, www.bostonglobe.com/metro/2016/06/21/ray-light-dementia-long-shadow/8NUpZa6HPYaN950tJWkC7N/story.html)

*** What do your aging parents want you to do for them?** Nearly 2 in 5 families disagree on the role children should play as their parents age. *Money* magazine published an article about the issue, and explored the value of parents and adult children talking about money. (*Money*, 6/28, <http://time.com/money/4373207/family-finance-adult-children-aging-parents/>)

*** Watching a video about end-of-life care options could help patients with advanced heart failure choose the best approach for themselves, according to a new study published in the journal *Circulation*.** "Because the course of heart failure is uncertain, in part because of improved therapies, doctors may be reluctant to initiate a conversation with their patients about advance care planning," said study lead author Dr. Areej El-Jawahri. (*US News*, 6/30, health.usnews.com/health-care/articles/2016-06-30/video-may-aid-end-of-life-decision-making)

*** Finding emotional healing and closure at the end of life can be a challenge, especially when cultural reservations about expressing feelings get in the way.** Writing for *The Huffington Post*, Rosemary Baughn explores the journey of a Chinese-American family to express love and find meaning at the end of life. (*Huffington Post*, 6/27, www.huffingtonpost.com/rosemary-baughn/help-for-emotional-healin_b_10701538.html)

*** In need of spiritual care?** A New York area Alzheimer's home agency has begun offering "virtual" spiritual care to its clients, allowing them to connect with HealthCare Chaplaincy Network chaplains via phone, email, or video conference. (*eHospice*, 6/30, www.ehospice.com/usa/ArticleView/tabid/10708/ArticleId/19862/language/en-GB/View.aspx)

*** New Mexico's Supreme Court has ruled against physician-assisted suicide for the state's citizens.** Advocates vow to continue the quest for passage of the bill, saying, "A strong majority of New Mexicans support aid in dying, and we are confident that they will ultimately prevail." (*Santa Fe New Mexican*, 7/1, http://www.santafenewmexican.com/news/health_and_science/new-mexico-supreme-court-rules-against-physician-assisted-suicide/article_6fee621d-e689-520d-a51f-974d08ec5ec2.html)

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