
HOSPICE NEWS NETWORK

Recent News On End-of-Life Care

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IS END-OF-LIFE SUFFERING GETTING WORSE?

In 1997, the Institute of Medicine published a groundbreaking report detailing the suffering experienced by many Americans at the end of life. The report offered broad-stroke recommendations on how to improve care, which hospice and palliative care organizations have been working to implement since that time. Yet, despite the meteoric growth of the hospice care industry throughout the United States, it's not clear that dying in America has become any less painful.

“The number of Americans experiencing pain in the last year of life actually increased 12% between 1998 and 2010,” according to a recently released study in *The Annals of Internal Medicine*. At the same time, end-of-life depression has risen by more than 26%. All this, despite the fact that guidelines and quality measures for end-of-life care that have been developed, even as the number of hospice and palliative care programs has risen and hospice use doubled between 2000 and 2009.

“We’ve put a lot of work into this and it’s not yielding what we thought it should be yielding,” says study author **Dr. Joanne Lynn**, who directs the Center for Elder Care and Advance Illness at the Altarum Institute. The study surveyed family members about their recently deceased loved one’s end-of-life experience, including whether the person suffered pain, depression, or confusion. All three of these symptoms have grown in prevalence over the last ten years.

Why should this be? One reason, according to Lynn, is the steady increase in high-tech medical interventions at the end of life. Despite the growth in hospice care and palliative medicine, high-intensity curative care has grown faster. **“We’ve increased the number of people put on ventilators and kept in hospitals, and we simply have more treatments that are possible to offer.”**

In a recently published article for *The New York Times*, **Dr. Ira Byock describes the dying process experienced by many Americans as “brutal,”** concurring with Dr. Lynn’s observation that state-of-the-art medical treatments often take a heavy toll on the quality of life of those who receive it. Describing a friend who was dying from cancer, Byock says, “As he became sicker, the treatments got more intense. Each decision came with more difficult trade-offs and uncertainties. Each step to stay alive risked making things worse.”

Byock notes that hospice was, unfortunately, effectively unavailable to his friend because of Medicare rules limiting other forms of treatment that can be received simultaneously.

“Hospice care could have vastly improved the quality of his waning life, and eventually it did. But those rules mean that dying patients enrolled in Phase I studies, which aren’t intended to be treatments, are routinely denied access to hospice services.”

Despite the best efforts of hospice and palliative care advocates in recent decades, our health care system is still much better equipped to fight disease than it is to meet the basic safety and comfort needs of dying patients and their families. Byock insists that both are essential and that both aspects of patient care must be addressed.

“People who are approaching the end of life deserve the security of confident, skillful attention to their physical comfort, emotional well-being and sense of personal dignity,” says Byock. **“Their families deserve respect, communication and support. Exemplary health systems and healthy communities deliver all of this today. But they are few and far between.”**

According to Dr. Lynn, one part of the solution is to consider how much we invest in treatments that improve quality of life. **Curative treatments receive high priority - as they should - but unfortunately this often leaves potential palliative treatments under-studied and under-developed.** “Think about how much we invest in curing Alzheimer’s disease, and how little we put into making the course of Alzheimer’s better.” (*Kaiser Health News*, 2/3, kaiserhealthnews.org/news/study-suffering-at-end-of-life-getting-worse-not-better/; *The New York Times*, 1/31, opinionator.blogs.nytimes.com/2015/01/31/dying-shouldnt-be-so-brutal/; *Medscape*, 2/4, www.medscape.com/viewarticle/839181; *MedCity News*, 2/4, medcitynews.com/2015/02/arent-hospice-palliative-care-cutting-amount-end-life-suffering/; *NPR*, 2/3, www.npr.org/blogs/health/2015/02/03/383522954/pain-and-suffering-at-lifes-end-are-getting-worse-not-better; *The Washington Post*, 2/3, www.washingtonpost.com/blogs/wonkblog/wp/2015/02/03/its-only-getting-worse-to-die-in-america/; *HealthDay*, 2/2, consumer.healthday.com/senior-citizen-information-31/misc-death-and-dying-news-172/many-americans-face-pain-depression-in-their-final-year-696087.html)

LAWSUIT COULD BRING ASSISTED-SUICIDE TO NEW YORK

A group of doctors and terminally ill patients in New York have filed a lawsuit to overturn over that state’s ban on physician-assisted suicide (PAS). Physicians in New York can presently be prosecuted for participating in PAS under the state’s manslaughter statute, which covers anyone who “intentionally causes or aids another person to commit suicide.” **Those bringing the lawsuit contend that the manslaughter statute was not intended to prevent terminally ill individuals from hastening their own deaths, but rather to prevent mentally ill or distressed individuals from committing suicide.**

“The lawsuit, filed against New York Attorney General Eric Schneiderman in Manhattan Supreme Court, claimed that a New York law making it a crime to cause or aid another person to commit suicide does not apply to doctors who prescribe fatal drugs to mentally competent, terminally ill patients who ask for them.” The plaintiffs are asking the court “to clarify whether a

physician would be liable for helping someone die under New York law, and if so, to rule that piece of the law unconstitutional because it violates the equal protection clause.”

Those bringing the lawsuit argue that, because doctors are already allowed to help terminally-ill patients die in some circumstances - such as removing feeding tubes, switching off ventilators, and ceasing nutrition and hydration - “the fact that they cannot hasten death for other terminally ill patients violates the equal protection clause of the State Constitution.”

State senators Brad Hoylman (D-Manhattan) and Diane Savino (D - 23rd District) are planning to introduce a bill that would allow terminally ill patients to end their lives through the self-administration of physician-prescribed drugs. Another version of the bill has already been introduced in the New York Assembly, and has been referred to the health committee. The law would require an examination from two physicians and that the patient reiterate their request 15 days after first making it. **As this lawsuit proceeds, right-to-die activists are also pursuing a legislative route. Other groups oppose the effort.** (*The New York Times*, 2/4, www.nytimes.com/2015/02/04/nyregion/lawsuit-seeks-to-legalize-doctor-assisted-suicide-for-terminally-ill-patients-in-new-york.html; *Capital New York*, 2/4, www.capitalnewyork.com/article/albany/2015/02/8561573/suit-challenges-states-ban-assisted-suicide; *Forward*, 2/4, forward.com/articles/214142/jewish-end-of-life-activists-sue-new-york-over-law/; *National Catholic Reporter*, 2/6, <http://ncronline.org/blogs/ncr-today/ny-lawsuit-filed-declaring-physician-assisted-suicide-legal>)

PALLIATIVE CARE GROWS IN CULTURAL SENSITIVITY

An emerging approach to palliative care focuses on cultural sensitivity as a way to bridge the gap between palliative medicine and ethnic communities that have been traditionally under-served by the medical establishment. The *Associated Press* reports that the culturally sensitive model embraced by groups like *Familias en Acción* in Portland, Oregon has potential to improve care and reduce costs for individuals and families of all cultures and backgrounds who are facing serious illness.

Pilar Alcantara was devastated when she was diagnosed with advanced stage breast cancer. She felt lost and intimidated by her illness and by the whole medical process that she now found herself enmeshed in. Growing up in Mexico, she had learned to cope with illnesses using home remedies and prayer. She was taught to relate to doctors as unquestionable authorities, and she preferred not to know the details of her illnesses or plans of treatment.

Alcantara was feeling hopeless until she connected with *Familias en Acción*, a Portland-based nonprofit that takes cultural beliefs and habits into account while providing comfort care and improving quality at the end of life. Alcantara says that this approach saved her. “A few years ago, because of the pain and uncertainty, I wanted to bail on life,” she says. But thanks to the culturally sensitive model of palliative care she has received, she is feeling empowered to manage her illness. **“Palliative care gave me more control over my cancer.”**

This culturally sensitive methodology is growing quickly in the Pacific Northwest - Seattle and Portland in particular - and it is being taught to nursing students in California as one means of improving patient care and reducing treatment costs. Dr. Woody English, former medical director of palliative care at Providence Health and Services in Portland, says that this multi-faceted approach “has the ability to transform the usual health care system.”

Studies have clearly demonstrated the powerful impact that palliative care can have on the quality of life that patients experience. By reducing patient misery, palliative care also cuts down on medical costs associated with unnecessary trips to the emergency room. “A patient who is not having a crisis does not call 911,” observes Dr. Diane Meier, director of the Center to Advance Palliative Care.

By adding a cultural emphasis, the health care system is able to take into account patient needs that would be otherwise overlooked. “Until we understand a patient's drivers and concerns - the social, emotional, religious and historical contexts - we can't begin to help the person,” says Meier.

***Familias en Acción* began its program in 2011 with a \$260,000 grant from the Portland-based Cambia Health Foundation.** The organization provides “patient navigators who help chronically ill Latinos access doctors, fill out insurance forms and find financial assistance.” *Familias* also helps individuals get connected with support groups and health literacy sessions that can ease stress and reduce the emotional burden that Latinos in particular face in the course of serious illness.

In addition to the direct quality-of-life benefits for patients and families, *Familias* has already demonstrated that their model results in dramatic cost savings for the medical system. The group has shown a 62% reduction in inpatient, outpatient, and ER costs among a sample of their 90 patients who were tracked over two years. Advocates hope and expect to see this culturally-sensitive methodology expanded, so that it can be brought to bear on the needs of the growing population of aging minorities. (*ABC News*, 2/1, abcnews.go.com/Health/wireStory/culturally-sensitive-palliative-care-represents-approach-28642855)

HOSPICE NOTES

*** Former US Senator Mark Begich has joined the staff of the National Association for Home Care & Hospice as Vice President for Policy and Development, President and CEO of the Foundation for Hospice and Homecare, and Dean of NAHC's Homecare University.** (*NAHC*, 1/31, www.nahc.org/senator-mark-begich-joins-nahc-team/)

*** Hearing loss is a frequent, and often-overlooked, problem for hospice patients.** Despite the fact that 80% of Americans over 85 have hearing impairments, Medicare and the Medicare Hospice Benefit do not cover hearing aids, which can cost thousands of dollars. (*Reuters*, 2/4, www.reuters.com/article/2015/02/04/us-hearing-loss-hospice-idUSKBN0L82BT20150204)

* **“Is this hospice pitch legit?” asks Knight Kiplinger of *Kiplinger Personal Finance*.** Knight explains that some hospices engage in “aggressive enrollment practices” designed to scoop up healthier patients and help boost their earnings. While “such practices are not **the norm... they have sullied the reputation of classic hospice care, a valuable and honorable system.**” (Kiplinger, 2/2015, www.kiplinger.com/article/insurance/T027-C013-S002-is-this-hospice-pitch-legit.html)

* ***PBS News Hour* explains why hospice care is of benefit, and why it might be helpful sooner than many people think.** The article examines the “generous Medicare [hospice] benefit for those caring for a family member or friend.” (*PBS*, 1/29, www.pbs.org/newshour/updates/hospice-care-might-benefit-loved-one-sooner-think/)

END-OF-LIFE AND PALLIATIVE CARE NOTES

* **New Jersey Lt. Governor Kim Guadagno spoke recently about the growing and changing role of end-of-life care under the Affordable Care Act.** Speaking at the New Jersey Hospital Association’s annual meeting in Princeton, Guadagno spoke about the need to re-examine how end-of-life care is provided in New Jersey. “You are in the middle of reinventing yourselves.” (*NJBIZ*, 1/30, www.njbiz.com/article/20150130/NJBIZ01/150139982/At-hospital-association-event-Guadagno-talks-Obamacare-end-of-life-treatment)

* **Do you know what you will do with your parents’ Facebook after they die?** In an article for *The Atlantic*, Jake Swearigen explores what it means to dispose of a departed loved one’s digital remains. (*The Atlantic*, 1/28, www.theatlantic.com/technology/archive/2015/01/what-my-parents-want-done-with-their-facebook-profiles-after-they-die/384886/)

* **Many clinicians in a hospital setting consider human concerns to be a greater barrier to communication than difficulties arising from clinical or system factors.** According to a new study published in *JAMA Internal Medicine*. “The clear take-home message for hospital-based clinicians is that we need really strong communication skills.” (*Medscape*, 2/3, www.medscape.com/viewarticle/839133)

* **Carolyn McClanahan writes for *Forbes* about how to ensure quality at the end of life.** “In this article, I discuss measures you can take to ensure a better quality of life at the end of life when you can no longer speak for yourself.” (*Forbes*, 2/4, www.forbes.com/sites/carolynmcclanahan/2015/02/04/how-to-ensure-quality-at-the-end-of-life/)

* **A mobile chalkboard is traveling through six counties in North Carolina as an outreach by Lower Cape Fear Hospice.** Persons are invited to share what they would like to accomplish before they die. The hospice goal for the effort is to increase conversations about end of life. (*JD News*, 1/24, www.jdnews.com/news/local/mobile-chalkboard-appears-in-area-1.428837?page=0)

* **Loss of daily living functions can serve as a marker for end-of-life care and hospice eligibility.** A recently published study has found that, for nursing home patients, comorbid diagnoses were better predictors of 6-month mortality than the patient’s functional status.

*(The Journal of Palliative Medicine, 2/2015,
online.liebertpub.com/doi/abs/10.1089/jpm.2014.0130)*

PAS NOTES

*** As an assisted-suicide bill is introduced in California, physicians and faith leaders are lining up on both sides of the debate.** State Senator Bill Monning (D-Carmel) explains the name of the bill, The End of Life Option Act. “Some will describe this as physician-assisted suicide. We strongly disagree with that characterization. As Brittany Maynard said, ‘I don’t have a suicidal bone in my body. I want to live, but I have a terminal cancer condition that will kill me.’” (*Monterey County Weekly*, 1/29, www.montereycountyweekly.com/news/cover_collections/after-sen-bill-monning-introduces-end-of-life-option-act/article_b988409e-a74c-11e4-b8be-d304d4812f0a.html)

*** The Travel, Recreation, Wildlife and Cultural Resources Committee of the Wyoming House of Representatives has voted unanimously to postpone consideration of legislation that would legalize PAS in that state.** As part of the decision, representatives recommended that the issue be subject to further study by an interim committee. (*Casper Star Tribune*, 1/29, trib.com/news/state-and-regional/govt-and-politics/committee-tables-wyoming-death-with-dignity-bill-recommends-interim-study/article_884e2a79-cfd3-5c43-b57b-186038a239b3.html)

*** Physician Ira Byock says we should “think twice” about assisted suicide.** “As someone who supports [many] other liberal causes, yet opposes physician-assisted suicide, I’d ask my fellow progressives to shine a cold hard light on this issue. We have been the target of a decades-long branding campaign that paints hastening death as an extension of personal freedoms. We should bring the same skepticism to physician-assisted suicide that we do to fracking and genetically modified food.” (*Alex Schadenberg*, 2/3, alexschadenberg.blogspot.com/2015/02/ira-byock-we-should-think-twice-about.html)

*** Oncologist James C. Salwitz writes about “The line between comfort care and murder.”** Salwitz examines the “double effect,” professional caregiver tasks, and consumer understandings and misunderstandings. “While there are many sound arguments for physician-assisted suicide, the legion of medical murder does not belong in that discussion,” he concludes. (*KevinMD*, 2/6, <http://www.kevinmd.com/blog/2015/02/line-comfort-care-murder.html>)

*** Megan Mann writes why she supports “death with dignity” legislation now being considered in California.** (*The Orion*, 2/3, theorion.com/blog/2015/02/03/dying-with-dignity-a-patients-choice/)

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