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# HOSPICE NEWS NETWORK

*Recent News on End-of-Life Care*

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## **MEDICARE NEEDS TO LOWER BARRIERS TO HOSPICE**

**An article in *The Journal of the American Medical Association* argues that the requirements that demand hospice patients to cease curative treatment and to be within six months of death create unnecessary barriers to hospice care.** This results in under-utilization of hospices, says Dr. Orefoe O. Odejide, MD, MPH, Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute, says that these barriers result in more hospitalizations of patients near the end of life.

**In “A Policy Prescription for Hospice Care,” Odejide says that the barriers are particularly true for patients with hematological malignancies. These patients have the lowest hospice utilization rate of oncology patients.** And, those patients with hematological cancers enter hospice three days before death on average. This short time in hospice often prevents patients and their families from benefiting fully from the care that hospice can offer. Additionally, these patients also have a high rate of intensive care, as well as frequent hospitalizations near death.

**Dr. Odejide presents several structural reasons why hospice is being particularly under-utilized by hematological cancer patients.** He explains, “The fact that reimbursement structure of the hospice benefit is insufficient for hospices to provide blood transfusions discourages patients with advanced hematologic cancers from receiving hospice care.” This is a result of the false dichotomy between hospice care and disease-directive care that is palliative, Odejide argues.

**The author believes that policy changes are needed in order to address these barriers to hospice care.** In some places this is already happening. A 2005 Aetna pilot program offered comprehensive case management and hospice accessibility to those within 12 months of death. The data from this program seems to point to better symptom management and less need for acute care in the hospital near the end of life. Other hospices are working for an “open-access model” in which patients receive both hospice care and procedures that palliate symptoms. For this to be adopted more widely, however, Medicare will need to change their flat per diem rate to something that more closely reflects the kinds of care given.

These changes, Odejide says, may result in neutral costs changes or even reduce costs, as intensive hospital care at the end of life is particularly expensive when compared to home-based care. Medicare seems to recognize this, and in 2014 started a pilot project in which patients can receive concurrent care. Odejide concludes, “Increasing hospice use will require such forward-thinking policies that make it easier for physicians to recommend hospice and for patients to choose it.” (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482339](http://jama.jamanetwork.com/article.aspx?articleid=2482339))

## **FAMILIES OF CANCER PATIENTS SAY HOSPICE IS BEST PLACE TO DIE**

**“Family Perspectives on Aggressive Cancer Care Near the End of Life,”** reports on research findings that **“earlier hospice enrollment, avoidance of ICU admissions within thirty days of death, and death occurring outside the hospital were associated with perceptions of better end-of-life care.”** The study, published in *The Journal of the American Medical Association*, reports on interviews of family members of advanced-stage cancer patients. The purpose of the interviews was to “assess the association of aggressive end-of-life care with bereaved family members’ perceptions of the quality of end-of-life care and patients’ goal attainment.”

**Family members who had loved ones enrolled in hospice for more than three days reported excellent care received by patients.** Fifty-seven percent of family members of cancer patients reported excellent end-of-life care for their family members in hospice. Only forty-two percent of those who had family members die in hospitals reported the same.

**“Families: Hospice Best for Dying Cancer Patients,”** from *WebMD*, says that **earlier hospice admissions would significantly increase the quality of end-of-life care.** Patients who have hospice care, says Dr. R. Sean Morrison, director of the National Palliative Care Research Center, have more peaceful deaths, as well as better quality of death, than those who die in hospitals. Morrison says that this is because hospice takes into account patients wishes and preferences, and is able to match care to these patient preferences. Family members also receive support from hospice. He argues “If 50 percent of Americans said they were unhappy with their hip replacement, that would be a national outrage. The same should be said of the care of people at the end of life -- we have to be able to do better.”

**“Among family members of older patients with fee-for service Medicare who died of lung or colorectal cancer, earlier hospice enrollment, avoidance of ICU admissions within 30 days of death, and death occurring outside the hospital were associated with perceptions of better end-of-life care,”** conclude the researchers. Our findings are a powerful argument for the importance of advance care planning,” said researcher Dr. Alexi Wright. (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482326](http://jama.jamanetwork.com/article.aspx?articleid=2482326); *WebMD*, 01/19, [www.webmd.com/palliative-care/news/20160119/families-say-hospice-better-than-hospital-for-dying-cancer-patients](http://www.webmd.com/palliative-care/news/20160119/families-say-hospice-better-than-hospital-for-dying-cancer-patients))

## HOSPICE AND END-OF-LIFE NOTES

\* ***The Journal of the American Medical Association's* January issue focuses on end-of-life care and related issues, including physician assisted dying.** The editors of the journal points out that this issue is urgent because of the high number of people who receive aggressive treatment close to their deaths and the large sum of money that is spent on end-of-life care. HNN Editor's Note: HNN will cover the individual articles in JAMA in this and subsequent issues. (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482307](http://jama.jamanetwork.com/article.aspx?articleid=2482307))

\* **Roger Rustad, a chaplain at Sonoran Winds Hospice, has repurposed a motorized wheelchair that was originally built for a 700-pound man. The chair is now used for taking dying patients on their last trip outdoors.** Rustad modified the chair to be more comfortable, accommodate medical equipment, and play music as it rolls along. Patients enjoy getting to go outside on this unique vehicle. The article includes photos of one patient's travels with Rustad. (*The Orange County Register*, 01/10, [www.ocregister.com/articles/rustad-699221-butcher-chaplain.html](http://www.ocregister.com/articles/rustad-699221-butcher-chaplain.html))

\* **Dr. Louis M. Profeta, an emergency physician in Indianapolis, blogs about how end-of-life care often means that people die in pain in nursing homes rather than in the comfort and familiarity of their own homes.** He says, "We have accumulated so many options, drugs, stents, tubes, FDA-approved snake oils and procedures that there is no way we can throw a blanket over all our elderly and come to a consensus as to what constitutes inappropriate and excessive care. We cannot separate out those things meant to simply prolong life from those meant to prolong quality life." (*LinkedIn*, 01/16, [www.linkedin.com/pulse/i-know-you-love-me-now-let-die-louis-m-profeta-md](http://www.linkedin.com/pulse/i-know-you-love-me-now-let-die-louis-m-profeta-md))

\* **The *Dance to Death Afterlife Podcast* interviewed registered nurse Barbara Karnes about her new twenty-five minute film, "New Rules for End of Life Care."** The film explains the dying process, the changes the dying person goes through, and the role of pain management. Karnes previously wrote "The Little Blue Book," which gives families of dying people much needed information in easy to understand language. The full two part interview can be heard on the podcast's website. (*Dance to Death Afterlife Podcast*, 01/17, [dancetodeathafterlife.com/new-rules-for-end-of-life-care-with-registered-nurse-barbara-karnes/](http://dancetodeathafterlife.com/new-rules-for-end-of-life-care-with-registered-nurse-barbara-karnes/))

\* **Dr. Mark Taubert, a palliative care consultant in Cardiff, Wales, writes on the *British Medical Journal's* blog about his positive responses to the death of David Bowie.** In an open letter, shared on Bowie's son's Twitter account, Taubert addresses Bowie saying "Many people I talk to as part of my job think that death predominantly happens in hospitals, in very clinical settings, but I presume you chose home and planned this in some detail. This is one of our aims in palliative care, and your ability to achieve this may mean that others will see it as an option they would like fulfilled." (*USA Today*, 01/19, [www.usatoday.com/story/life/music/2016/01/19/david-bowie-son-shares-open-letter-from-doctor/78996806/](http://www.usatoday.com/story/life/music/2016/01/19/david-bowie-son-shares-open-letter-from-doctor/78996806/))

\* **The *Journal of the American Medical Association* published the results of a study that examines where people die.** Drawing on the data in the "National Longitudinal Mortality Study

between 1979 and 2011,” they tracked where physicians, other health professionals, other highly educated people, and everyone else died. **Researchers found that physicians, other health professionals and educated people died in hospitals at a lower rate than the general public.** The study also showed that many people still die in ways against their expressed wishes. (*Time*, 01/19, [time.com/4185691/doctors-death-hospice/](http://time.com/4185691/doctors-death-hospice/); *The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482317#Discussion](http://jama.jamanetwork.com/article.aspx?articleid=2482317#Discussion))

**\*PBS, in their Religion and Ethics Newsweekly covers the Stanford Letter Project, a program created by Dr. VJ Periyakoil, director of palliative care education and training at Stanford University School of Medicine. The goal is to help patients express to their doctors what their wishes for end-of-life care are.** The full transcript and video of the program can be found on PBS’s website. (*PBS*, 01/16, <http://www.pbs.org/wnet/religionandethics/2016/01/14/january-15-2016-doctors-and-end-of-life-discussions/28640/>)

**\* “When and Why People Die in the United States, 1990-2013,” appears in the latest issue of *The Journal of the American Medical Association*.** In the US, life expectancy continues to grow for both men and women, though the increase is at a slower pace than in other high-income countries and globally. (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482313](http://jama.jamanetwork.com/article.aspx?articleid=2482313))

**\* Atul Gawande, writing in an editorial in the January *Journal of the American Medical Association*, speaks about the American medical community’s response in dealing with death. Says Gawande, the American medical community’s “fundamental error has been to split the primary responsibilities for treatment of serious illness from providing care enabling the best possible quality of life in the face of such illness.”** This is most dramatically illustrated by the fact that those in hospice have to give up curative treatment, but Gawande sites other examples. He reframes end-of-life care issues, saying, “The vital goal almost all people want from medicine is not having a good death but having as good a life as possible all the way to the very end.” (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482308](http://jama.jamanetwork.com/article.aspx?articleid=2482308))

**\* Physician Orders for Life-Sustaining Treatment (POLST) are critiqued in a Viewpoint article in *The Journal of the American Medical Association*.** The authors say there is a “dearth of evidence that POLST programs, as currently designed, improve care for the dying.” Given this lack of evidence, they call for a clear plan for evaluation of “effects and outcomes of care” for POLST. They also call for “any plans to consider POLST completion as a quality metric be halted.” The authors argue, “Rapid expansion of programs that protect patients from unwanted resuscitation has outpaced the evidence supporting the programs and may compromise patient-centered decision making more broadly.” The authors conclude by saying, “While it is reasonable for terminally ill patients hoping to avoid resuscitation or hospitalization to indicate those preferences in POLST forms, the use of more expansive documents in different populations should not be advocated unless or until the problems with POLST can be convincingly surmounted.” (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482337](http://jama.jamanetwork.com/article.aspx?articleid=2482337))

**\* Authors of a study comparing the costs and care of cancer patients across the developed**

**world found that end-of-life care in the US is strong in some areas and weak in others.** The study, “Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries, appeared in *JAMA* and is online free at the link below. In an opinion piece published in *The New York Times*, Drs. Ezekiel Emanuel and Justin Bekelman write about the study. They say palliative care needs to become the default in the US and that end-of-life costs are not as high as many think they are. They say, “The good news is that, despite perceptions, the United States is actually not the worst when it comes to caring for these patients. In fact, on some important measures, we provide the best in end-of-life care.” In response to coverage of this same study, an article in *Mother Jones* encourages readers to read carefully, pointing out the headlines about the quality and cost of end-of-life care in the US often are misleading and unreflectively mimic the study’s authors’ viewpoint. (*The New York Times*, 01/19, [www.nytimes.com/2016/01/20/opinion/is-it-better-to-die-in-america-or-in-england.html?emc=edit\\_th\\_20160120&nl=todaysheadlines&nid=36525767&\\_r=1](http://www.nytimes.com/2016/01/20/opinion/is-it-better-to-die-in-america-or-in-england.html?emc=edit_th_20160120&nl=todaysheadlines&nid=36525767&_r=1); *Mother Jones*, 01/19, [www.motherjones.com/kevin-drum/2016/01/study-end-life-care-us-about-average](http://www.motherjones.com/kevin-drum/2016/01/study-end-life-care-us-about-average))

**\* The authors of a viewpoint article in *The Journal of the American Medical Association* consider arguments for and against “intensive care for patients at the end of life and proposes strategies to ensure the delivery of appropriate and optimal patient-centered care.”** The article proposes five strategies for improvement in ICU use at the end of life. They include reducing inappropriate ICU admissions; reevaluating the goals of care during the ICU stay; improving shared decision making; improving consensus decision making within the clinical team; and making ICUs more humane. (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482340](http://jama.jamanetwork.com/article.aspx?articleid=2482340))

**\* The American Medical Association released comments on the Centers for Disease Control and Prevention's proposed opioid prescription policy.** While the AMA applauded the CDC for treating the epidemic of opioid overdose deaths seriously, and agreed with many of the CDC’s proposals, the AMA also hopes that changes will be implemented in a patient-centered fashion. They point out, “**Evidence is lacking to support some of the proposals, and some conflict with existing federal or state policies.**” AMA hopes that many of these issues will get worked out in the upcoming comment period and with the help of an advisory panel. (*American Medical Association*, 01/13, [www.ama-assn.org/ama/pub/news/news/2016/2016-01-13-cdc-policies-opioids.page](http://www.ama-assn.org/ama/pub/news/news/2016/2016-01-13-cdc-policies-opioids.page))

## PHYSICIAN ASSISTED SUICIDE NOTES

**\* During this year’s legislative sessions, New York lawmakers will be giving consideration to two bills that would allow physicians to prescribe lethal doses of medications to terminally ill patients with less than six months to live.** Patients would have to be mentally competent, and two different doctors would have to agree that their illness is terminal in the next half a year. (*WXXI News*, 01/19, [wxxinews.org/post/ny-legislature-consider-assisted-suicide-bill](http://wxxinews.org/post/ny-legislature-consider-assisted-suicide-bill))

**\* A Viewpoint article in *The Journal of the American Medical Association* argues that physician-assisted death is sometimes justifiable.** The authors point out that physicians already are involved on a continuum in the very end of life from managing symptoms to withdrawing care, and say that PAD is just further along that spectrum. They also encourage doctors to

recognize that enquiries about PAD are an opportunity to reevaluate palliative care techniques, discuss the patient's feelings and goals and to address the patient's fears and concerns. (*The Journal of the American Medical Association*, 01/19, [jama.jamanetwork.com/article.aspx?articleid=2482334](http://jama.jamanetwork.com/article.aspx?articleid=2482334))

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