



HOSPICE NEWS NETWORK

Recent News on End-of-Life Care

Volume 20, Number 10 March 15, 2016
A Service of State Hospice Organizations

60 MINUTES EXAMINES PHYSICIAN-ASSISTED SUICIDE

CBS'S 60 Minutes aired a segment titled **“Should the Terminally Ill Control How They Die?”** The story recounted the story of Brittany Maynard, the 29-year-old who moved to Oregon in 2014 in order to access “aid-in-dying,” or “assisted suicide.” Guests on the segment included her husband, Dan Diaz. Diaz shared how having access to the medications to end her life brought comfort to her. At the same time, they continued to seek treatment options that would help her “fight” her cancer.

The story also featured **Dr. Jon LaPook, who interacted with the guests. He spoke with Dr. Eric Walsh, an Oregon physician and the prescriber of the medication for Maynard and other Oregonians.** “You know, we categorize tears into a single adjective,” said Walsh. “Tears of joy, tears of sorrow, tears of regret. But actually in the physician aid-in-dying these are tears that contain all of those adjectives.”

Another guest of the show was Elizabeth Wallner, a Californian who has sued the state for her right to end her life with assistance. LaPook talked with Wallner and her 20-year old son, Nathaniel. Additionally, Dr. William Toffler, an Oregon physician who questions the practice, and the role of physicians in helping patients end their lives, shared about the use of palliative sedation. But, said the husband of another patient, it didn't work for her and he watched her die in terror. In addition to the video of the aired segment, the website includes segments on ethical concerns about the practice and about how the medicine works.

In response, *Forbes* published “What ‘60 Minutes’ Didn't Say About Why ‘Death With Dignity’ Is So Hard.” Regardless of where we live, all citizens do have power to impact their end-of-life care, says writer Arlene Weintraub. “Patients still have plenty of power to dictate how they want to spend their final days to their physicians, family members and other caregivers. So-called ‘advance directives,’ including living wills, allow anyone to choose whether they want life-saving measures to be taken, or whether they would prefer palliative care

to keep them comfortable until their illness runs its course.” The problem, says Weintraub, is that “60% of adults want their end-of-life wishes to be honored, but only 30% had completed advance directives.” And, the author contends, physicians do not do a good enough job at having these conversations with patients.

Weintraub identifies a list of major concerns that prohibit improved end-of-life care. These impediments.

* **“Everyone is so overwhelmed with decisions during medical crises they often make the wrong ones.”** Weintraub cites a 2015 study, from *Critical Care Medicine*, that found that physicians in academic medical centers “made a staggering 102 decisions per day.” Says Weintraub, “These researchers and others have questioned whether such ‘decision fatigue’ can lead to hastily made choices that patients regret later.”

* **“Doctors often opt to sustain life even when patients don’t want that.”** Weintraub cites one study, published in *JAMA* in 2015, which found that almost 25% of ICU patients with DNR orders still received CPR.

* **“Med schools spend precious little time teaching doctors how to help their patients make end-of-life decisions.”** She credits physician Ezekiel Emanuel, oncologist and professor of medical ethics and health policy at the University of Pennsylvania, as saying that this training “‘is not something you’re born with, but it is something you can be trained to do.’”

CHAIN HOSPICES PROVIDING HALF OF ALL CARE

Howard Gleckman, writing in *Forbes*, says, “Large multi-agency, multi-state hospices are fast becom[ing] the primary source of end-of-life care in the U.S.” A new study published in *Health Affairs* found that in 2011 almost half of all hospice patients received care from chain hospices. This is a significant increase from a decade before, when small, mostly non-profit, hospices provided care for three-fourths of patients.

“In 2000, a typical for-profit chain operated 5.6 agencies with 2,300 enrollees. By 2011, those firms owned an average of seven agencies with an average roster of 2,700 Medicare patients, according to the study. By contrast, a typical mom-and-pop for-profit cared for only one-tenth as many people—about 220.” The five largest for-profit chains owned 283 agencies, that together serve 190,000 patients. Larger corporations also often own these chains as well.

Gleckman points out that the study does not look at quality of care or the length of stay in different kinds of hospices, but does shed light on how hospice care is changing in the United States. This change is part of a large change in the healthcare industry, he says, and, “Hospices are scrambling to consolidate so they can benefit from the economies of scale and marketing advantages of being big.” (*Forbes*, 01/14, www.forbes.com/sites/howardgleckman/2015/01/14/hospice-is-becoming-a-chain-business/#6b4eca3e55c8)

ARTICLE EXAMINES USE OF LIFE-EXTENDING CARE FOR PATIENTS NEAR THE END OF LIFE

***The Washington Post* published an article supporting evidence that some common medical interventions near the end of life can, instead of improving patient life and length-of-life, decrease quality of life, and fail to give the patient significantly more time alive.** But refusing to order treatments or life-saving interventions is often difficult. Leslie Blackhall, an associate professor of internal medicine at the University of Virginia Health System in Charlottesville, explains “If we tell people, ‘Chemo isn’t going to help you,’ they still want it. We [all] want a peaceful, comfortable, dignified death. . . but not yet.”

Resuscitation is designed to keep a person alive so that an underlying medical condition can be treated. However, when there is no effective treatment, such as with late stage cancer or dementia, conducting CPR on a patient can seriously impact the quality of their remaining time, and may not significantly extend it. CPR can often result in broken ribs, the patient being moved to the ICU, and additional interventions such as a catheter and feeding tube. A 2009 analysis in the *New England Journal of Medicine* found that, of people older than 65 years who received in-hospital CPR, only 18 percent survived long enough to be discharged -- and the survival rate dropped as age increased.

Dialysis is another treatment that was developed for otherwise healthy people, but has begun to be used on older patients who are often in late-stage renal failure. Most dialysis patients are now older than sixty-five, with those older than seventy-five the fastest growing group. According to 2013 research in *Aging Health*, dialysis is used in approximately ninety percent of elderly people with end-stage renal disease. Sharon Kaufman is author of the book “Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line.” Kaufman says, “People aren’t ‘choosing’ dialysis — they are being directed toward what is available, and what is available is more. Patients are not getting better; they are just hoping not to get worse.” Kaufman also talks about a physician friend who chose not to have dialysis because for him “the hours attached to a machine and the treatment’s side effects — including fatigue, low blood pressure, blood poisoning and muscle pain — were not worth it.”

Feeding tubes also often extend life, but seriously impact its quality. This is particularly true for dementia patients who often lose appetite, choke, or resist being fed. According to a 2010 article in *JAMA*, nearly one third of people with cognitive impairment, who live in US nursing homes, are given feeding tubes at some time.

Often, Muriel Gillick, director of the program in aging at the Harvard Pilgrim Health Care Institute, says people want to offer feeding tubes “because feeding someone we love is our way of nurturing and showing we care.” Instead, experts encourage that we keep people comfortable. “Ice chips can be offered to assuage thirst, and reading to people, holding their hands, keeping them warm and dry are all sustaining activities that improve quality of life.” (*The Washington Post*, 03/07, www.washingtonpost.com/national/health-science/in-the-last-months-or-days-these-treatments-can-make-things-worse/2016/03/07/a2a53722-a5d1-11e5-ad3f-991ce3374e23_story.html)

HOSPICE NOTES

*** According to an article in *Pittsburgh Post-Gazette*, Medicare fraud by hospice providers is a problem that the new Medicare payment reforms do little to address.** Aggressive enrollment of those who are not really dying has been the trademark of several recent cases of fraud. The article expresses concern about “ballooning” hospice costs. “Hospice costs shot up because an increasing number of seniors used the program,” says the article, “but also because the time that patients spend in hospice has been rising.” In a related editorial, *Pittsburgh Post-Gazette*’s editorial board expressed their belief, saying, “There’s no question that hospice care can be a godsend to patients and their families. It is equally true that better oversight and regulation of this growing industry is warranted.” (*Pittsburgh Post-Gazette*, 03/06, www.post-gazette.com/business/healthcare-business/2016/03/06/Hospice-fraud-estimates-at-65-billion/stories/201603060044; *Pittsburgh Post-Gazette*, 03/11, www.post-gazette.com/opinion/editorials/2016/03/11/Terminal-fraud-Unscrupulous-operators-tarnish-hospice-care/stories/201603310030)

*** A new study published in *The Journal of the American Geriatrics Society* finds that many hospice patients experience multiple transitions (being moved from one facility to another) during their time in the program.** This change often disrupts their routines and places them at heightened risk for medical errors. The researchers found that 10.2 percent of patients experienced at least one health care transition after their hospice enrollment, but, in some states, the number exceeded twenty percent. “A total of 6.6 percent of hospice patients had between 2 to 19 care transitions, 53.4 percent of which were transitions to a hospital.” The lead author of the study explained, “The provider- and state-level variation in the proportion of hospice users who had care transitions suggests that provider and market factors and not solely individual and family preferences may influence transitions.” Additionally, says the lead author of the study, Shiyi Wang, M.D., Ph.D., an assistant professor in the Department of Chronic Disease Epidemiology and a faculty member in the Cancer Outcomes, Public Policy, and Effectiveness Research Center at Yale School of Medicine, “This matters because such transitions may place hospice users at risk of discontinuity of care and medical errors, while also increasing the level of stress for their caregivers and family members.” (*Yale School of Public Health*, 02/18, publichealth.yale.edu/news/article.aspx?id=12146)

*** Genesis Healthcare Inc. announced that it has agreed to sell the majority of its home health and hospice operations for \$84 million to Compassus.** This move is “part of a strategy to shed businesses that are not central to its nursing home operations and to pare down its huge debt load.” Genesis acquired the home health and hospice businesses when it merged last year with Skilled Healthcare. Genesis already sold Skilled Healthcare’s assisted living facilities as a part of a debt reduction plan. (*Philly.com*, 03/09, www.philly.com/philly/business/20160310_84_million_for_Genesis_Healthcare_hospice_business.html)

*** American Academy of Hospice and Palliative Medicine is participating in the Choosing Wisely campaign, “a national effort led by the American Board of Internal Medicine Foundation to help physicians, patients, and other healthcare stakeholders think and talk about the overuse of healthcare resources.”** AAHPM hopes that the initiative will help increase awareness about hospice and palliative care options. “Five Things Physicians and Patients Should Question in Hospice and Palliative Care” is available online in a printable

format. (*American Academy of Hospice and Palliative Medicine*, 03/2016, aahpm.org/outreach/choosing-wisely)

END-OF-LIFE NOTES

* **Ann Neumann, visiting scholar at the Center for Religion and Media at New York University and a hospice volunteer, has written a new book entitled “The Good Death: An Exploration of Dying in America.”** In the book, Neumann takes “a close-up look at end-of-life issues and how they are both helped and hindered by faith.” She encourages readers to examine their own wishes about what role they want their faith and the faith of their caregivers to play in end-of-life decisions. Neumann expresses concern that faith often limits peoples’ options at the end of their life. She argues, ““A good death is whatever a patient wants. It is not up to me, to their legislators, to their priests, to their families. That is true informed consent. A good enough death is as close as we can get because humans are not perfect. We can get so much closer, but we will never have a perfect death.” (*Desert News*, 03/07, www.deseretnews.com/article/865649519/The-Good-Death-Hard-to-find-and-religions-role-may-be-to-blame.html?pg=all)

* ***New England Public Radio* produced a segment focused on examining whether talking about death can lessen the fear of it.** The program interviewed Harvard researcher Michael Norton and medical ethicist Lynn Pasquerella. The recording, in its entirety, can be heard on NEPR’s website. (*New England Public Radio*, 03/03, nepr.net/news/2016/03/03/does-facing-death-lesson-fears-of-dying/)

* ***Journal of Palliative Medicine* published a study that examines how the communication between physicians, nurses, and families improves high-quality end-of-life care.** The study was conducted within the ICU units of numerous hospitals, and relies on surveys completed by nurses in these ICU units. Surveys revealed a positive collaboration between physicians and nurses talking about family questions, family dynamics, spiritual/religious issues, and cultural issues and a higher quality of death. However, there was a negative association with discussions between nurses and physicians about nurses’ concerns for patients or families. Since support of family decision-making is so important, researchers suggest this is a “potential target for interventions to improve end-of-life care.” (*Journal of Palliative Medicine*, 02/19, online.liebertpub.com/doi/full/10.1089/jpm.2015.0155)

PALLIATIVE CARE NOTES

* **A study published in *Journal of Palliative Medicine* examines the “feasibility, acceptance, and potential beneficial effects” of music therapy for terminal ill cancer patients in a palliative care ward.** After two sessions, they found that music therapy was well received by the patients, based on questionnaires given after each session. Several kinds of music therapy were offered, and receptive methods accompanied by therapeutic conversation were particularly appreciated and feasible. The researchers also found that “frequency and duration of music therapy, previous experience with music and music therapy, as well as sociodemographic factors influence positive effects of music therapy.” (*Journal of Palliative Medicine*, 03/2016, online.liebertpub.com/doi/pdf/10.1089/jpm.2015.0384)

* **Country music singer Joey Feek recently died.** Her husband, Rory, wrote a blog about her decision to suspend cancer treatments and continued to write until after Joey's death. Joey's life and death and Rory's blog have garnered media attention. (*In Focus*, 03/2016, www.abc2news.com/news/in-focus/country-singers-blog-about-dying-wife-opens-the-conversation-on-palliative-care; *People*, 03/09, www.people.com/article/joey-feek-death-rory-book; *This Life I Live*, 03/04, thislifeilive.com/)

* ***Cure*, a new book by science journalist Jo Marchant, explores whether the mind can heal the body.** Marchant tries to find the middle ground between medical professionals who dismiss a mind/body connection and New Age alternative medicine practitioners who may overstate it, Marchant says, "Terminal cancer patients who talked with palliative care specialists focused on quality of remaining life, rather than medical care, had less depression and better experiences than patients who didn't get such care, a small study found." And, furthermore, these patients lived several months longer. (*Science News*, 03/06, www.sciencenews.org/article/minds-healing-powers-put-test-new-book)

* **Kaytee Moyer writes in *Penn Live* that the legalization of medical marijuana in Pennsylvania will help address the misuse and abuse of opioid painkillers.** She argues that "legalizing medical marijuana in Pennsylvania gives those who suffer from chronic pain conditions the opportunity to cope with their pain through an organic herb, rather than a highly addictive opioid pain medication." (*Penn Live*, 03/02, www.pennlive.com/opinion/2016/03/heres-how-medical-marijuana-wi.html)

* ***Medscape Multispecialty* interviewed Dr. Diane Meier, professor of medicine at the Icahn School of Medicine at Mount Sinai and director of the Center to Advance Palliative Care, about palliative care and the benefits and can provide patients.** The entire video interview is available on *Medscape's* website. (*Medscape Multispecialty*, 03/10, www.medscape.com/viewarticle/859377#vp_1)

OTHER NOTES

* **Compassion & Choices, an advocacy group for physician-assisted suicide, released a statement praising the California legislature for closing the special session on healthcare.** This act triggers the End of Life Option Act going into effect in ninety-one days, on June 9. Governor Jerry Brown signed the bill into law in October, after the legislature passed it in September, but its implementation was tied to the close of the legislative session. (*PRNewswire*, 03/10, www.prnewswire.com/news-releases/california-medical-aid-in-dying-law-to-go-into-effect-in-91-days-300234365.html)

* **Spouse caregivers who are stressed are at a significantly higher risk of stroke than those of the same demographics who were not caring for their spouse.** Dr. Michael Albert, speaking at the American Heart Association meeting in Phoenix, explains, "Chronic stress boosts blood levels of the hormone cortisol and heightens inflammation in the body. This can cause arteries to harden and narrow and, ultimately, restrict blood flow to the brain, resulting in a stroke." Stroke is one of the top reasons for disability among adults. (*Health Day*, 03/04, consumer.healthday.com/senior-citizen-information-31/caregiving-news-728/stress-of-caring-for-sick-spouse-can-raise-stroke-risk-708715.html)

* **"Case Western Reserve University nurse scientists have received a \$2.37 million grant from the National Institute of Nursing Research to explore linking cancer patients with their families through videoconference."** The goal will be to link distant caregivers to their family members and the medical

professionals who are treating them. Assistant dean for research Sara Douglas says, “Many distance caregivers become distressed over not receiving enough medical information or knowing when is best for them to come home for an in-person visit. Videoconferences that connect doctors, nurses, patients, and distant caregivers have the potential to address many of these problems.” (*Crain’s Cleveland Business*, 03/04, www.crainscleveland.com/article/20160304/NEWS/160309897/cwru-nurse-scientists-receive-2-37-million-grant-to-study)

* **“I Understand Everything Better” is a multi-disciplinary performance created choreographed and directed by David Neumann.** The performance focuses on the death of his parents around the time of Hurricane Sandy. Neumann processed his grief in developing the work. He also spoke with a palliative care nurse at Sarasota Memorial Hospital about the process of dying. The play is being performed at the Historic Asolo Theater in Sarasota, Florida. (*Herald-Tribune*, 03/07, ticket.heraldtribune.com/2016/03/06/processing-death-through-dance/)

Thanks to Melanie Ramey for contributions.

Hospice News Network is published 45-47 times a year by a consortium of state hospice organizations. *Copyright, 2016. All rights reserved to HNN subscribers, who may distribute HNN, in whole or part, to provider members of the subscribers’ state organizations.* If readers need further information, they should consult the original source or call their state association office. HNN exists to provide summaries of local, state and national news coverage of issues that are of interest to hospice leaders. HNN disclaims all liability for validity of the information. The information in HNN is compiled from numerous sources and people who access information from HNN should also research original sources. The information in HNN is not exhaustive and HNN makes no warranty as to the reliability, accuracy, timeliness, usefulness or completeness of the information. HNN does not and cannot research the communications and materials shared and is not responsible for the content. If any reader feels that the original source is not accurate, HNN welcomes letters to the editor that may be shared with HNN readers. The views and opinions expressed by HNN articles and notes are not intended to and do not necessarily reflect views and opinions of HNN, the editor, or contributors. Only subscribing state hospice organizations have rights to distribute HNN and all subscribers understand and agree to the terms stated here.

ILLINOIS HOSPICE AND PALLIATIVE CARE ORGANIZATION
847 441 7200
pcramer@thepmcgroup.com
www.il-hpco.org

