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HOSPICE NEWS NETWORK

Recent News on End-of-Life Care

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DREAMS OF DYING CAN PLAY THERAPEUTIC ROLE

Dr. Christopher W. Kerr, a palliative care physician of Hospice Buffalo, researches the therapeutic role of patients' end-of-life dreams and visions. He and his team hope to demystify these experiences and understand their role and importance in supporting "a good death" — for the patient and the bereaved." Jan Hoffman, writing in *The New York Times*, takes an in-depth look at these phenomena in "A New Vision for Dreams of the Dying."

This approach to paying close attention to dreams and visions is a reversal from most of modern medicine, which does not put particular emphasis on the dreams of those who are dying.

Throughout history, and in many traditional cultures, however, the dreams, visions and last words of dying people are considered particularly important. In a study by Kerr, published in *The Journal of Palliative Medicine*, fifty-nine terminally ill people were interviewed about their dreams. The majority of people reported having dreams and finding them comforting. About one in five found the dreams distressing. While many said they often could not remember their dreams, they found the dreams particularly compelling.

Themes emerged among the dreams including loved one's waiting for them, opportunities to engage with those already deceased, and completing unfinished business. Many people were assured that they were loved, and that they had done well in their life. Some felt a sense of forgiveness or relief from the dreams. They were packed and ready for a journey. **Dr. Kerr explored some of these commonalities in a TED talk he gave in Buffalo.**

Processing emotions through dreams allows the dying to deal with death, whether positive or negative feelings emerge. "The motivation and pressure for these dreams is coming from a place of fear and uncertainty. The dreamers are literally helping themselves out of a tough spot," explains Tore Nielsen, a dream neuroscience researcher.

Dr. Timothy E. Quill, an expert on palliative care medicine at the University of Rochester Medical Center, explains the importance of the research this way. "The huge challenge of this work is to help patients feel more normal and less alone during this unusual experience

of dying. The more we can articulate that people do have vivid dreams and visions, the more we can be helpful.”

Dreams and visions, or “waking dreams,” are considered part of patient’s delirium as they approach death. But Kerr and his colleagues encourage caregivers to recognize the value in visions of loved ones in the room. Dr. Anne Banas explains that physicians should ask, “Is there meaning to the vision or is it disorganized? If there is meaning, does that need to be explored? Does it bring comfort or is it distressing?”

Not all the dreams reported were comforting. Particularly those who had experienced trauma were likely to relive it in their dreams. These kinds of dreams and visions can be particularly upsetting to patients and their families. Care providers should make sure to seek out information about the patient’s life to see how best to help. An example is given of a woman who was reliving the trauma of being sexually abused as a child. The doctors learned of this talking to the family and therefore were able to choose anti-anxiety drugs over antipsychotics.

Dr. Quill said, “Our job [as physicians] is witnessing, exploring and lessening their loneliness. If it’s benign and rich with content, let it go. But if it brings up serious old wounds, get real help — a psychologist, a chaplain — because in this area, we physicians don’t know what we’re doing.”

The Hospice Buffalo researchers have found that dreams, when positive and in context, can offer comfort not only for the dying, but also for those who live them. They may help them see that their loved one is at peace or feel connected to their ancestors.

In the original article in *Journal of Palliative Medicine*, the authors concluded that these experiences “are commonly experienced phenomena during the dying process, characterized by a consistent sense of realism and marked emotional significance. These dreams/visions may be a profound source of potential meaning and comfort for the dying, and therefore warrant clinical attention and further research.” (*The New York Times*, 02/02, www.nytimes.com/2016/02/02/health/dreams-dying-deathbed-interpretation-delirium.html?_r=0; *Journal of Palliative Medicine*, March 11, 2014, <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0371>; *TedXBuffalo 2015*, July 27, 2015, <https://www.youtube.com/watch?v=sUyknQuBTKc>)

BAD NEWS SHOULD BE REFRAMED AS SERIOUS NEWS

Doctors often struggle with the frequency at which they have to deliver bad news to patients. Often this is a terminal diagnosis, but it can also be other sorts of life altering losses and diagnoses. While it seems obvious that specialists like oncologists would often deliver bad news, the burden actually often rests with primary care physicians. They either make diagnoses themselves or have to explain the results of a patient’s visit to a specialist.

Few doctors are trained, however, in how to deliver bad news in a caring and sensitive way. Poorly shared news can “inadvertently undermine patient trust and satisfaction by communicating news bluntly in a detached, mechanistic manner; creating false hopes through

use of excessive optimism; withholding adverse information, such as a poor prognosis, from the patient; and giving the family—but not the patient—information.” Bad news told well, however, can help the patient more quickly reorient and take needed action.

Reframing bad news as serious news is an important shift towards more compassionately giving patients difficult information. Says oncologist Anthony L. Back, MD, a professor at the University of Washington and the Fred Hutchinson Cancer Research Center in Seattle, how the message is shared makes a difference. “For this reason, after years of telling his patients, and teaching his students to tell their patients, ‘Mr. Smith, I’m afraid I have some bad news to tell you,’ Dr. Back now substitutes the word ‘serious’ for the word ‘bad.’”

Some medical schools are now training their students in better communication techniques for hard conversations. The American Medical Association’s *Education for Physicians on End-of-Life Care Participant’s Handbook* includes a module on communicating bad news. The model employs the **SPIKES protocol, where S stands for setup, P for patient’s perception, I for invitation, K for knowledge, E for empathy, and S for summarize and strategize.** The article includes tips for how to talk with patients, questions to ask to encourage dialogue, and a thorough description of each letter (or step) of SPIKES. (Medscape Multispeciality, 01/27, www.medscape.com/viewarticle/856955_1)

HOSPICE NOTES

*** After a decline in home health and hospice acquisitions earlier last year, Irving Lewin Associates report that merger and acquisition activity steadied itself in the third and fourth quarters of 2015.** “The large, publicly traded home health and hospice providers are just getting bigger in this market, and post-acute providers still search for home health and hospice business in their markets,” stated Lisa Phillips, Editor of the Health Care M&A Report. (*Irving Lewin Associates*, 01/25, www.levinassociates.com/pr2016/pr1601hhh)

*** Professor Elizabeth Bergman of Ithaca College led a study of people’s knowledge about palliative and hospice care. The study found that half of the respondents didn’t know the difference between palliative and hospice care.** “That means that there is quite a lot of community education that needs to go on. And it is important because to know about options means the greater likelihood that people will be able to access them,” Bergman said. (*Star Gazette*, 02/01, www.stargazette.com/story/news/local/2016/02/01/what-you-should-know-palliative-care/79532248/)

*** CMS comment period for “Medicare Spending Per Beneficiary – Post-Acute Care (MSPB-PAC) Resource Use Measures” ended on February 2, 2016.** NHPCO says that staff “reviewed the proposed set of resource utilization measures, the episodes of care, and how hospice utilization is included as a part of the episode.” After this review, **“NHPCO has serious concerns that the inclusion of hospice as an associated services provider may result in patients who are eligible for hospice and could benefit from hospice care being denied timely and appropriate access to hospice services.”** Specific concerns include that: **“PAC providers may not refer patients who are terminally ill to hospice.” “PAC providers may wait to refer patients to hospice until death is imminent.” “PAC providers may also delay**

referral to hospice until after the 30 day associated services period has elapsed.” Some services are excluded from the measure and **NHPCO argues that hospices should be excluded as well, saying, “Hospice patients have complex care needs and we are concerned that the MSPB-PAC measure creates a disincentive for PAC providers to refer to hospice if hospice is categorized as an associated service and therefore part of the episode of care window.”** This exclusion, they say, will “will ensure that patients and their families will receive the right care at the right time at end-of-life.” (*NHPCO*, nhpco.org, 02/04)

*** Neurologist and popular writer Dr. Oliver Sacks chronicled the end of his life after he was diagnosed with terminal cancer. Many of those observations have now been published in his new posthumous book *Gratitude*. According to his friend and editor Kate Edgar, Sacks’ end of life was made easier by his decision to enroll in hospice.** “At the very end of life, we were able to call one number and get advice and answers at any time of day. Having not been through the process before, we had many questions: What’s normal? What’s coming next? How will we know if he is in pain? It was very reassuring, medically and also logistically, to have someone who could calmly advise us on those things, so we could stay focused on Oliver and do the right thing for him.” (*Huffpost Healthy Living*, 02/02, www.huffingtonpost.com/rosemary-baughn/gratitude-for-dr-oliver-sacks-insights-at-the-end-of-life_b_9134650.html)

END-OF-LIFE NOTES

*** Barbara Jean O’Brien is a harpist who plays musical vigils at the bedsides of dying people.** In the forty-five to sixty minute session, she places music in response to the person’s vital signs, creating music unique to each patient. She sees her work as both for the dying person and their family. O’Brien explains, “It can deepen connections and hold them together as they prepare for the next step. I feel like it really exploits the incredible power of music in a way that’s so profound. It’s amazing work. The power of music to be assisting in people’s lives when they’re in such a fragile, vulnerable time is a powerful gift.” (*BDN Maine*, 02/5, bangordailynews.com/2016/01/28/next/a-beautiful-way-to-exit-this-life-musician-offers-end-of-life-care/)

*** Following up on their earlier Physician Misery Index, Geneia, a company that creates analytic and technology solutions to improve healthcare, surveyed an additional three hundred emergency room physicians. They found that advanced directives greatly reduce the stress of emergency room physicians, saying, “Ninety-three percent of those surveyed said they are less frustrated in cases where an advance directive is easily accessible.”** Geneia’s president and CEO says, “By having advance directives readily available to emergency physicians, the physicians would feel empowered. They would feel that they were giving better and more appropriate care to patients, and that they would be better aligned with [the patient’s] values and the values of their family members.” (*Physicians’ Money Digest*, 02/01, www.hcplive.com/physicians-money-digest/columns/financial-health-check-up/02-2016/emergency-medicine-physicians-look-for-solutions-to-burnout)

*** Florence Isaacs writes *Sincere Condolences* and *Widow in the World* for *Legacy.com*.** The two are advice columns on death-related issues. In her columns, which are growing more and more popular, she covers a wide range of issues related to death and its aftermath including funeral dress, condolences and eulogies. She also writes about widowhood and tries to help

others through sharing her own experiences. (*The New York Times*, 01/29, www.nytimes.com/2016/01/31/nyregion/the-dear-abby-of-death.html?_r=0)

* **Liz Bryant writes in *Richmond Times-Dispatch* about the process she and her father went through of slowing getting rid of his possessions.** He was aging and preparing to move from his home to an apartment, then to a nursing home and, finally, the hospital. She reflects about how her grief at her father's passing and his own experience of death was tied up in the objects of his life. (*Richmond Times-Dispatch*, 02/01, www.richmond.com/life/article_3e3d0ee9-9d89-5bdb-affa-0b6e1277a891.html)

* **Paul Kalanithi, a neurosurgeon who died of lung cancer last year, has posthumously published a memoir *When Breath Becomes Air* about his experience of terminal illness.** Considering the mass of data medical research produces, Kalanithi writes in his book about "why humans cling to these numbers and whether survival statistics, with their imprimatur of scientific rigor, distract us from the deeper meanings of life." (*The New England Journal of Medicine*, 01/13, www.nejm.org/doi/full/10.1056/NEJMms1516444?query=aging-geriatrics&)

* **End-of-life care for diabetes patients who may be receiving palliative or hospice care is an area that has only recently begun to be addressed.** American Diabetes Association recommendations include relaxing glycemic targets, simplifying regimens and respecting the patient's right to refuse diabetes treatment. (*EurekAlert!*, 02/02, www.eurekalert.org/pub_releases/2016-02/jdc-apg020216.php)

* **Kimberly Callinan, Chief Program Officer for Compassion & Choices, wrote in response to the opinion piece "Is It Better to Die in America?" by Ezekiel J. Emanuel and Justin E. Bekelman in *The New York Times*.** Callinan suggests that there are two policy changes that would improve end-of-life care. She writes that "Two federal policy reforms would help: Establish federal payment and referral to palliative-care consultations provided by trained palliative-care professionals who will advocate for and support the values and choices of the patient for every person with an advanced illness or nearing the end of life. Second, allow patients the option of enrolling in hospice while still continuing to receive disease-specific and restorative treatments if they choose." (*The New York Times*, 02/01, www.nytimes.com/2016/02/01/opinion/access-to-palliative-care.html?_r=0)

* **Jessica Nutik Zitter, an ICU doctor, argues that our hospitals and culture need a "Code Death" to accompany "Code Blues" in which patients are resuscitated.** She writes that she was not really trained to help patients die, but she thinks that acceptance would be better for doctors and patients. This will mean doctors must recognize when to shift care from lifesaving to care of a dying person. They also will need to learn the technical skills to do this well. (*The New York Times*, 04/10/2014, well.blogs.nytimes.com/2014/04/10/a-better-way-to-help-dying-patients/?mwrsm=Facebook)

OTHER NOTES

* **"The state of California implemented a demonstration project to evaluate palliative care provided concurrently with disease-focused care for children with serious illness."** Analysis

of the program, Partners for Children, found that it greatly reduced caregiver stress and worry. It also helped facilitate better communication between caregivers and physicians by creating a family-centered action plan. (*Medscape Multispecialty*, 02/01, www.medscape.com/viewarticle/857800)

* **Salt Lake City Representative Rebecca Chavez-Houck (D) sponsored the End of Life Options Act in Utah.** “The bill is based on similar laws in Oregon and California, which have faced stiff opposition from critics who view life-ending prescriptions as medically unethical and morally tantamount to suicide.” The article in *The Salt Lake Tribune* takes a deeper look into the issue as viewed by citizens of Utah. (*The Salt Lake Tribune*, 02/05, www.sltrib.com/home/3473065-155/no-one-can-choose-if-they)

* **Dan Diaz, Brittany Maynard’s widower, has been in Colorado lobbying for physician assisted dying there.** Similar legislation failed there last year, but, this session, both the Colorado House and Senate have bills before them that would legalize the practice. Polls show that sixty-five percent of Coloradoans support the legislation. (*The Durango Herald*, 02/02, www.durangoherald.com/article/20160202/NEWS01/160209943/Brittany-Maynard%E2%80%99s-widower-fights-for-Colorado-end-of-life-bill-)

* **Eighty-one year old Jim Kinhan, who has colon cancer, asked presidential candidate Hillary Clinton about her views on “death with dignity” at a town hall event last Wednesday.** Clinton responded that she had not been asked that before and then seemed to have trouble formulating an answer. She did acknowledge that it is an important issue and one that individuals need to consider. (*The Washington Post*, 02/04, www.washingtonpost.com/news/morning-mix/wp/2016/02/04/meet-the-cancer-patient-who-challenged-clinton-about-death-with-dignity-on-cnn/)

* **“A Democrat-led state House committee has approved a Colorado right-to-die bill that would provide a legal option for the terminally ill to end their lives.** The House Judiciary Committee passed the bill on a 6-5 party-line vote late February 4 after hearing 10 hours of testimony. The legislation now goes to the full House for consideration, but faces an uphill battle if it reaches the Republican-controlled Senate. A committee there rejected the bill on a party-line vote on Wednesday [2/3].” (*SFGate*, 02/05, www.sfgate.com/news/article/Colorado-right-to-die-backers-try-again-before-6807260.php)

OTHER NOTES

* **According to *Valuing the Invaluable*, a new AARP Public Policy Institute report, says that, in 2013, “About 40 million family caregivers in the United States provided 37 billion hours of unpaid care, worth an estimated \$470 billion.”** Support for overtaxed caregivers has improved, according to the report, thanks to “Medicare and Medicaid changes, respite care organizations, workplace flexibility, and federal and state policy revisions.” (*Philly.com*, 01/24, articles.philly.com/2016-01-24/news/70038687_1_caregivers-nursing-mother)

* **The Hastings Institute, a nonpartisan research institution in bioethics, has released a list of issues for their readers to watch in 2016.** Included on that list are new end-of-life care

options due to the change in Medicare payments and the pilot program allowing patients to be enrolled in hospice and receive curative treatment. Legalization of physician aid in dying also made the list. (*The Hastings Institute*, 02/2016, www.thehastingscenter.org/News/Detail.aspx?id=7720)

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