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# HOSPICE NEWS NETWORK

*Recent News on End-of-Life Care*

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## STUDY EXPLORES HOSPICES' ACCOUNTABILITY FOR PATIENTS' CAREGIVERS TRAINING

**The success of the hospice model relies on training and supporting primary caregivers to serve as the first line of care for patients dying at home.** Caregivers are empowered to monitor care, provide medications, and call on hospice professionals when necessary for further assistance. A new study published in *The Journal of Palliative Medicine* contends, **“Hospice should be held accountable for providing appropriate education and training that allows the caregiver to safely care for the patient at home, including administering medications.”**

**Unfortunately, researchers have found that caregivers often feel unsupported in their roles of managing pain, symptoms, and medication.** In their report, Eleanor L. DiBiasio, MPH, and co-authors outline the development of a new survey model that can reveal the degree to which caregivers feel supported in their role. In conducting their survey, researchers employed the Family Evaluation of Hospice Care (FEHC) instrument, which was developed and validated in 1999, to measure quality of care at the end of life. It provides a window into the experience of close family members and loved ones who provide the care for terminally ill patients in their last weeks of life.

**To develop the survey, the authors “relied on expert opinion, focus groups with bereaved family members, and existing guidelines to choose six key processes of care that family are required to do in safely caring for a patient at home.”** Based on this information, the team developed a series of measures that could gauge the extent to which caregivers felt supported and equipped for their role. The survey was conducted with small focus groups of 2-12 caregivers of individuals who died in hospice care. The study included 39 caregivers from 6 geographically diverse areas of the United States, including both rural and urban locations, as well as caregivers serving both Hispanic and African-American patients. Surveys were conducted in both English and Spanish.

A total of 262 individuals completed the written questionnaire (a 57.1% response rate). Most respondents were white, female, and had at least some college education. “Mean age of patient death was 76.2, and 55.2% had cancer. Mean age of respondents was 62.4. Of these caregivers, 45.0% were a spouse/partner, and 42.7% were a child of the deceased. The median length of hospice stay was 30 days, and 96.6% of respondents reported being the person involved in medical decision making for the patient. Thirty-five

percent of respondents previously cared for a dying patient, and 28.2% had previous experience with hospice.” **Overall, the researchers concluded that they had obtained a representative sample of the population, though they admit that Hispanic individuals were still underrepresented in the study.**

In the survey, **“Six questions focused on providing the caregiver with information, while another six focused on the training that hospice provided.”** Questions were asked as open-ended questions. Informational questions asked how caregivers were trained to utilize pain medication and to watch for side effects from pain medications. They were asked about how to deal with patients’ breathing issues, how to safely move patients, and what to expect as the patient neared death. In the training questions, caregivers were asked how much hospice trained them in watching for side effects from pain medication, how to titrate medication in order to gain better pain management, and how to give medications when the patient had difficulty swallowing. Caregivers were asked about hospice’s training them to help with breathing, how to help an agitated patient, and how to safely move the patient.

**The researches found the largest variances of responses in being trained to give extra medications and in caring for agitated patients.** The six informational items were dropped based on their poor performance. **“Our data support the use of one six-item composite score that measures how well hospice trains the primary caregiver for his or her critical role in patient care.”**

DiBiasio and her team conclude, “The proposed composite, which focuses on adequacy of caregiver training, is ready for further testing in a larger sample.” **The authors say, “Because of the inextricable link between safety and quality, the results of patient safety measures such as this module should be available with all publicly reportable data on hospice quality.”** (*The Journal of Palliative Medicine*, 6/9, [online.liebertpub.com/doi/abs/10.1089/jpm.2015.0185](http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0185))

## **IS RELIGION A KEY COMPONENT OF END-OF-LIFE CARE?**

**“From the very inception of modern day hospice, religion has been recognized as a key component of comprehensive care for the dying,”** writes Mark J. Stoltenberg in a book review for *The Journal of Palliative Medicine*. The book he reviews, “Religious Understandings of a Good Death in Hospice Palliative Care,” explores both the opportunities and pitfalls of interfaith dialogue as they relate to end-of-life issues. “Religious Understandings,” edited by Harold Coward and Kelli I. Stajduhar, offers a glimpse into the meaning and value of high-quality spiritual care at the end of life. **Above all, we are reminded of the power that religious expression can have in helping to make meaning out of traumatic events, especially when such expression “match the particularity and inculturated traditions of those it cares for.”**

What makes for a good death? This is the focus of the authors as they examine what the world’s major religious traditions have to say, and how this relates to the evolution of

hospice care. The authors note the role of Cicely Saunder's Christian faith in the birth of the modern hospice movement. **"From the outset it was always clear that there would be no 'forcing of religion' on any patients, and openness to all religions would always be encouraged. However, in regards to the practice of hospice from the side of the providers, was this a new medical model for care, or was this rather a new form of Christian community?"**

Saunders would struggle with this question for the rest of her life, but in practice the dilemma would be answered pragmatically. "The City Parochial Foundation wanted to offer financial support, but under its terms of trust, it could not give to a purely Anglican venture. In hopes of helping more patients, Saunders accepted the offer, and hospice took its first step towards secularization." **Nevertheless, Saunders remained deeply rooted in her own Christian faith throughout these changes.**

**Moving on from the particular circumstances of hospice's origins in the UK, Coward and Stajduhar examine the "complex ways in which theology, local culture, and the changes of modernity impact perspectives on how to best care for the dying."** The book explores the way specific religious traditions impact and shape the mission of hospice. Christianity, Islam, Judaism, Hinduism, and Buddhism each have their own chapters in the book. Following these, subsequent chapters focus on particular geographical/cultural locations, including China, Thailand, Uganda, India, and Canada. The last two chapters explore what it means to care for children at the end of life, and the role of interfaith chaplains in hospice care.

**The authors conclude that, despite the rapid diversifying of the religious landscape, religious and cultural specificity are still important.** They say, "The automatic reduction of centuries of history and culture into a focus on a purely generic spirituality 'does a disservice to patients and can lead to the alienation of truly religious hospice patients.'" The authors mention the growing trend of religious non-affiliation, especially among younger generations. In response to this development, they have already committed to writing a second book that addresses this trend. **However, for the vast majority of patients around the world who do identify with some traditional form of religion, hospice care is strongest when it is rooted in a specific expression of those traditions.** (*The Journal of Palliative Medicine*, 6/9, [online.liebertpub.com/doi/abs/10.1089/jpm.2016.0114](http://online.liebertpub.com/doi/abs/10.1089/jpm.2016.0114))

## HOSPICE NOTES

**\* Does knowing your terminal prognosis eliminate hope? Quite the opposite says a study published in *The Journal of Palliative Medicine*.** The study indicates that transparency in communicating prognosis can be beneficial to patients and their families. "While upsetting, prognostic information engenders hope by helping parents feel prepared to do their best for their children in the difficult days to come." (*The Journal of Palliative Medicine*, 6/9, [online.liebertpub.com/doi/abs/10.1089/jpm.2015.0472](http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0472))

\* **Kindred hospice wins against a whistleblower in False Claims case.** The “outcome echoes similar recent cases where judges sided with hospice providers on the basis that physicians’ opinions on hospice eligibility can differ.” (*McKnight’s*, 6/22, [www.mcknights.com/news/kindred-hospice-wins-against-whistleblower-in-false-claims-case/article/504948/](http://www.mcknights.com/news/kindred-hospice-wins-against-whistleblower-in-false-claims-case/article/504948/))

\* **“I didn’t like it, but this was the death she chose.” Cindy Schweich Handler tells the story of her mother-in-law’s death in home hospice care.** “What she wants is to not treat her symptoms, to voluntarily stop eating and drinking, and to die.” Handler says, “Helping her reach this goal isn’t necessarily the gift I would choose to give her, but it’s the one she wanted to receive, and that’s what matters most.” (*The Washington Post*, 6/20, [www.washingtonpost.com/national/health-science/i-didnt-like-it-but-this-was-the-death-she-chose/2016/06/20/5ed57ad0-025a-11e6-9d36-33d198ea26c5\\_story.html?postshare=1361466464550242&tid=ss\\_fb-bottom2016-6-21number23.docx](http://www.washingtonpost.com/national/health-science/i-didnt-like-it-but-this-was-the-death-she-chose/2016/06/20/5ed57ad0-025a-11e6-9d36-33d198ea26c5_story.html?postshare=1361466464550242&tid=ss_fb-bottom2016-6-21number23.docx))

\* **California’s Hospice by the Bay is using “quirky ads” to promote advance care planning and hospice care.** “A lot of attention is being given to the End of Life Option Act, and while it could potentially impact a small percentage of patients, end-of-life planning impacts 100 percent of us,” said Kitty Whitaker, CEO of Hospice by the Bay, one of the region’s largest hospice providers, with locations in Marin, San Francisco, San Mateo, Sonoma and Napa counties. One message, for example, is “Your dad doesn’t want to be resuscitated. Also, he wants to be buried ... in his birthday suit. Start talking about end-of-life planning. Too much information is good.” “We believe the most important thing any of us can do is to ‘have the conversation’ regarding end-of-life issues. As a hospice provider for more than 41 years, we know first-hand that the more prepared one is, the better the outcomes for everyone.” (*North Bay Business Journal*, 6/21, [www.northbaybusinessjournal.com/northbay/sonomacounty/5732574-181/hospice-by-the-bay-end-of-life-ads2016-6-21number23.docx](http://www.northbaybusinessjournal.com/northbay/sonomacounty/5732574-181/hospice-by-the-bay-end-of-life-ads2016-6-21number23.docx); *Hospice by the Bay*, [http://hospicebythebay.org/tmiisgood/?utm\\_campaign=tmiisgood-2016&utm\\_medium=print&utm\\_source=printad](http://hospicebythebay.org/tmiisgood/?utm_campaign=tmiisgood-2016&utm_medium=print&utm_source=printad))

\* **Palliative care is “value based care,” says Kathy Brandt of The KB Group.** Brandt highlights recent articles that demonstrate the emergence of value-based reimbursement. Brandt tells hospice providers, “This is the moment to build, launch and get paid for community-based palliative care.” (*The KB Group*, 6/21, [www.the-kb-group.com/#!/Palliative-Care-is-Valuebased-Care/o1vab/5769431a0cf2710e3e67fdb52016-6-21number23.docx](http://www.the-kb-group.com/#!/Palliative-Care-is-Valuebased-Care/o1vab/5769431a0cf2710e3e67fdb52016-6-21number23.docx))

\* **NHPCO says that the Congressional screening of the documentary, “Being Mortal,” based on Dr. Atul Gawande’s best selling book, was a success.** An article in *The Washington Post* says that Rory Feek, country singer and songwriter, brought the audience to tears when sharing about his wife, Jody, who died earlier this year. (NHPCO, 6/23; *The Washington Post*, 6/23, <https://www.washingtonpost.com/news/reliable-source/wp/2016/06/23/cause-celeb-rory-feek-brings-capitol-hill-audience-to-tears/>)

## END-OF-LIFE NOTES

\* **Several websites are working to make end-of-life conversations and planning more accessible.** An *ABC News* story cites several examples of these ventures. (*ABC News*, 6/22, [abcnews.go.com/Business/wireStory/click-die-sites-lay-plans-loved-40044952](http://abcnews.go.com/Business/wireStory/click-die-sites-lay-plans-loved-40044952))

\* **Faced with a rare and terminal cancer, one artist is using creativity to find acceptance and peace.** A story in *Huffington Post* shares about Kaylin Andres. “Eight years ago, at 23 years old, Andres was diagnosed with Ewings Sarcoma, a rare and often terminal form of bone cancer.” The story includes photos of her art and describes her experiences. “Andres described her work as a modern day memento mori, a symbolic reminder of the inevitable mortality that affects us all.” (*Huffington Post*, 6/21, [www.huffingtonpost.com/entry/diagnosed-with-rare-terminal-cancer-artist-finds-healing-and-acceptance-through-art\\_us\\_57682495e4b0fbbc8beb1bf62016-6-21](http://www.huffingtonpost.com/entry/diagnosed-with-rare-terminal-cancer-artist-finds-healing-and-acceptance-through-art_us_57682495e4b0fbbc8beb1bf62016-6-21) number 23.docx)

\* **“As oncologists, we should keep in mind that our goal is to provide care that prolongs patients’ lives, and not their deaths,” says Aaron Falchook in a reflection for *Oncology*.** (*CancerNetwork*, 6/23, [www.cancernetwork.com/asco-2016-street-team/reflections-caring-patients-cancer-end-life2016-6-21](http://www.cancernetwork.com/asco-2016-street-team/reflections-caring-patients-cancer-end-life2016-6-21) number 23.docx)

\* **What happens when doctors “forget to feel”?** “So much has been written in recent years about shifting patient attitudes toward death and dying and how physicians can support these decisions through palliative care. But often ignored is the other half of the emotional coin: How do these conversations, and ultimately their outcomes, make the physician feel?” (*WBUR*, 6/23, [www.wbur.org/commonhealth/2016/06/23/doctor-emotional-burdens](http://www.wbur.org/commonhealth/2016/06/23/doctor-emotional-burdens))

\* **Standardized forms are now available to facilitate end-of-life conversations, but are physicians using them?** Researchers note the need to educate physicians and advance practitioners, in order to facilitate goals of care conversations and the use of standardized forms. (*The Journal of Palliative Medicine*, 6/9, [online.liebertpub.com/doi/abs/10.1089/jpm.2015.0424](http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0424))

\* **Bedside nurses have a critical role to play in the delivery of palliative care to patients in the ICU.** Interventions are needed to overcome barriers to nurses providing this care and conduct end-of-life conversations, concludes a report published in the *Journal of Pain and Symptom Management*. (*Medscape*, 6/2016, [www.medscape.com/medline/abstract/26596882](http://www.medscape.com/medline/abstract/26596882))

\* **One-third of Americans report that they are open to using cannabis for pain management.** *Prevention* magazine published a study that revealed, “A third of Americans say they would be ‘extremely or very likely’ to use medical marijuana for pain relief with a doctor’s recommendation. Of 1,025 U.S. adults surveyed, 20 percent said they would be interested in using medical cannabis to manage chronic pain as well. The survey also found that 75 percent of Americans believe marijuana should be legal for medical use.” (*Extract*, 6/21, [extract.suntimes.com/news/10/153/20924/a-third-](http://extract.suntimes.com/news/10/153/20924/a-third-)

americans-would-use-medical-marijuana-pain-relief)

**\* This November, voters in Colorado could decide to join Oregon and several other states in allowing physician-assisted suicide.** “The measure would allow terminally ill, mentally capable adults to access medication that would allow them to ‘shorten the dying process if suffering becomes unbearable,’ according to the ‘Yes on Colorado End of Life Options’ campaign.” (*Denver Post*, 6/21, [www.denverpost.com/2016/06/21/end-of-life-right-to-die-colorado/](http://www.denverpost.com/2016/06/21/end-of-life-right-to-die-colorado/))

**\* An article in *US News* says that there are four things that should never be said to a caregiver.** “Let me know if you need anything”; “You’re exhausted. Have you thought about placing your loved one?”; “Why do you do that when you can do this?”; “You’re a saint.” The article explores better options for responding to caregiver needs. (*US News*, 6/17, [health.usnews.com/health-news/patient-advice/articles/2016-06-17/4-things-you-should-never-say-to-a-caregiver](http://health.usnews.com/health-news/patient-advice/articles/2016-06-17/4-things-you-should-never-say-to-a-caregiver))

**\* Dennis McCullough, called “A Pioneer In End-Of-Life ‘Slow Medicine’” has died at age 72.** “Slow medicine advocates for adding quality of life rather than quantity of years for sick and elderly people.” The online article shares more about McCullough’s interactions with his patients. (*VPR*, 6/21, [digital.vpr.net/post/dennis-mccullough-pioneer-end-life-slow-medicine-dies-72#stream/0](http://digital.vpr.net/post/dennis-mccullough-pioneer-end-life-slow-medicine-dies-72#stream/0))

**\* Hospital deaths cost seven times more than home death.** “A recent analysis by Arcadia Healthcare Solutions finds that spending on those who die in the hospital is about seven times that of those who live out their last days at home. Much of that money comes from the estate of the deceased, but most of it is paid for by U.S. taxpayers through Medicare.” (*Benefits Pro*, 6/17, [www.benefitspro.com/2016/06/17/hospital-deaths-cost-7-times-more-than-home-deaths2016-6-21-number-23.docx](http://www.benefitspro.com/2016/06/17/hospital-deaths-cost-7-times-more-than-home-deaths2016-6-21-number-23.docx))

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