

What the Media Said about End-of-Life Care This Week

June 21, 2022

A Service of Your State Association

AUTHORS EXAMINE THE WORK OF PALLIATIVE CARE IN NURSING HOMES

“Palliative and End-of-Life Needs of People Receiving Care in Nursing Homes: Answering the Call” appears in the *Journal of Hospice and Palliative Nursing*. The article is written by Mary Ersek, PhD, RN, FPCN, and Betty Ferrell, PhD, FAAM, FPCN. About 25% of Medicare beneficiaries die in nursing homes (NH). And 33% to 33.5% of these persons “have an NH stay in the last 90 days of life, often receiving post-acute care.” We also know that the quality of end-of-life care in NH, as in other places, is lacking.

Many studies have shown that this population experiences “high rates of hospitalization, potentially burdensome treatments, and undertreated symptoms. . . .” Covid, of course, found NHs in particularly difficult situations. Though NH deaths account for about .5% of deaths in the US, 18% of Covid deaths happened in NH. Media attention highlighted the problems and brought further attention to end-of -life care in NHs.

Because of these deficits, the National Academies of Sciences, Engineering, and Medicine got sponsorship from several organizations to explore how the U.S. “delivers, finances, regulates, and measures the quality of NH care and to propose strategies to improve care.” The committee, which included both Ersek and Ferrell, recently released the report, “The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff,” for external review. The report highlights the needs for both resources and funding to address these need. Issues to be faced include staffing, quality improvement, finances, health information technology and regulations.

“Palliative and end-of-life care is woven throughout the report and is seen as a key component to the delivery of high-quality NH care.” Most of these providers serve as “external teams” from both hospices and healthcare systems as they interact with NH staff. **So, says the article, “hospice and palliative care nurses should commit to accessing and reading the report and, in particular the sections that explicitly discuss palliative and end-of-life care.”** Via broad dissemination of the report, all can work together to improve quality of life at end of life for NH patients.

NH staff interact more than most with patients, including those at the end of life. And they are often the most direct connection with residents’ families. They feel the loss when their residents die, and they need and deserve grief support. By exercising the expertise of hospice and palliative care nurses, both NH staff and families can be supported. “We should provide education and support to increase NH staff’s confidence, knowledge, and skills in delivering high-quality palliative and end-of-life care.” And we can value and support the expertise of NH nurses and staff.

Covid has been hard on all, and “our colleagues in long-term care settings, including NHs, have been devastated.” The report shares more about these needs and “should convince all of us of the work left to be done.” And hospice and palliative care nurses should “lead the way.”

The first link below is to the article in *Journal of Hospice and Palliative Nurses*. The second link is to the 2022 paper from the National Academies of Science, Engineering and Medicine, which is online as a full download. (*Journal of Hospice and Palliative Nurses*, June 2022, https://journals.lww.com/jhpn/Fulltext/2022/06000/Palliative_and_End_of_Life_Needs_of_People.1.aspx; National Academies of Science, Engineering, and Medicine, 2022, <https://nap.nationalacademies.org/download/26526>)

HOSPICE NOTES

*** While the value of hospice care has “strong evidence base” for patients and families, less has been known about outcomes of hospice care for dementia patients.** Krista Harrison, et al, wrote, “Hospice improves Care Quality For Older Adults With Dementia In Their Last Month of Life,” which is published in *Health Affairs*. Harrison joined a *Health Affairs* podcast to share what has been learned about the “higher quality last month of life care” for dementia patients who enroll in hospice when compared to dementia patients who do not access hospice. The first link below leads to the podcast. The second link below leads to the paper which is available for purchase. (*Health Affairs*, 7/14, <https://www.app.com/story/news/health/2022/06/14/nj-aid-dying-law-legal-challenge-end-of-life-care/7616767001/>; *Health Affairs*, https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2021.01985?utm_medium=podcast&utm_source=a+health+p+odyssey&utm_campaign=june2022issue&utm_term=harrison)

*** North Carolina’s Rockingham Now shares the story of Chaplain Marcia McQueen, her planning for end-of-life care, and her experiences with palliative care and hospice.** McQueen served as chaplain for Hospice of Rockingham County for four years, and later as chaplain at a hospital for fourteen years. In her work, McQueen often worked with advance care planning, and she was an advocate for herself as she faced her diagnosis of a brain tumor. The story shares her journey, her months of care with palliative care, and her move into hospice with the hospice where she had served as chaplain. McQueen died on June 7. (*Rockingham Now*, 6/10, https://greensboro.com/community/rockingham_now/news/chaplain-embodied-living-dying-well/article_84068fd2-e8e1-11ec-bf4c-33659d382170.html)

*** New York Post shares about Penny Smith, a hospice nurse in Washington state and her sharing on Tik Tok.** Smith, who has 432,000 followers on Tik Tok, shares often about her “conviction that there is life after death—something she said she came to believe in after seeing the spiritual epiphanies experienced by patients in their dying days.” The article shares patient stories that Smith has witnessed. Embedded within the article is a video of one of Smith’s posts. (*New York Posts*, 6/13, <https://nypost.com/2022/06/13/im-a-hospice-nurse-heres-why-im-convinced-theres-life-after-death/>)

*** A recent study examined how the presence of pain and depression in NJ inpatients with metastatic cancer patients in NJ in 2018 impacted the patients’ referrals to hospice.** Patients without pain and/or without depression were less likely to be referred to hospice upon discharge. Furthermore, Blacks and Hispanics “had significantly lower odds of receiving a hospice referral.” And, patients whose primary language is not English had fewer referrals to hospice. “Patients with pain and depression had increased hospice referrals.” (*Journal of Hospice and Palliative Nursing*, June 2022, https://journals.lww.com/jhpn/Fulltext/2022/06000/Hospice_Referral_in_Advanced_Cancer_in_New_Jersey.5.aspx)

*** Edo Banach, after serving NHPCO as President and CEO for five years, is leaving NHPCO at the end of August.** Banach says his time with NHPCO “has been one of the most fulfilling chapters of my career.” NHPCO Board Chair Norman McRae says the organization will use the summer to work on transition plans. Ben Marcantonio, NHPCO’s COO will serve as interim President and CEO. (NHPCO, 6/17, <https://www.nhpco.org/edo-banach-stepping-down-from-nhpco-leadership-role/>)

PALLIATIVE CARE NOTES

*** A podcast, “Grief, Loss, and a Brighter Path Forward,” features an interview with Stephanie Harman, MD, who is the founder of Stanford’s palliative care services.** In the podcast, Harman shares her own journey into palliative care via the death of someone close to her. She shares her advocacy for palliative medicine, and offers a future vision for palliative care. A transcript of the interview is offered by accessing the link below. (*Medpage Today*, 7/14, <https://www.medpagetoday.com/podcasts/thedoctorsart/99218>)

*** Last year, WHO’s Director-General called for strengthening palliative care services, calling on countries to “face this global challenge on palliative care with collective compassion...”** Information sent back to WHO offers some encouragement. Uganda, for example, first started offering palliative care in 1983, and now “79% of its health districts provide palliative care services.” Portugal now has laws that say citizens have a “right to access palliative care within primary health care.” Still, palliative care is guessed to be available to only about 10%

of the world's people." These and other feedback are online at the link below. (WHO, June 9, <https://www.who.int/news/item/09-06-2022-feedback-from-member-states-in-response-to-who-director-general-s-call-to-strengthen-palliative-care-services>)

* **An article in *Healthline* explores the benefits that palliative care can offer to Parkinson's patients.** And that help can begin as soon as diagnosis, as providers can help people "learn about Parkinson's, manage their symptoms, plan for the future, and more." Palliative care becomes even more important as the disease progresses. Palliative care providers can help patients "minimize symptoms, adjust medications, recommend therapies and assistive devices, and provide mental health care." The article describes palliative care, compares it with hospice, shares the benefits, and encourages patients to start palliative care as soon as possible. (*Healthline*, 7/16 <https://www.healthline.com/health/parkinsons/palliative-care-parkinsons-disease#takeaway>)

* **Wilke-Barr Pennsylvania's *Times Leaders* features an article by of Dr. Alfred Casale, a cardiothoracic surgeon and chief medical officer for surgical services and chair of the Geisinger Heart Institute.** Casale writes to describe and support palliative care. He also explains advance directives, as well as hospice. Casale writes that their region needs "expanded palliative care," and says this is one of the reasons that "Geisinger is designing a new cancer center in Dickson City." (*Times Leader*, 6/13, <https://www.timesleader.com/features/1560834/to-your-health-understanding-palliative-care>)

END-OF-LIFE NOTES

* **A geriatrician, who is also an Orthodox Jew, and a Hindu pharmacist challenged New Jersey's Medical Aid in Dying Law.** The Appellate Division of the Superior Court, however, upheld the law, saying that "the constitutional and religious arguments of the doctor and pharmacist who challenged the law were 'meritless.'" The judge said that, to his knowledge, not "a single family member or interested party" of those who have utilized the law have objected, and the law has not been used illegally. (*app*, 6/14, <https://www.app.com/story/news/health/2022/06/14/nj-aid-dying-law-legal-challenge-end-of-life-care/7616767001/>)

* **A study of 117 nursing students examines their communication skills in having difficult conversations with patients near the end of life.** Researchers noted one major theme: "*delivering bad news is difficult.*" Students expressed "fear, sadness, stress, feeling awkward, and a general lack of self-confidence in communicating bad news." While they knew these conversations are important, their anxiety about impending death made it difficult. Four subthemes emerged: Unsure about what to say and unsure about their own abilities; Feeling uncomfortable; Need for more exposure to these types of conversations; and, Need for help in creating a supportive environment for families. (*Journal of Hospice and Palliative Care*, June 2022, https://journals.lww.com/jhpn/Fulltext/2022/06000/Nursing_Student_Perceptions_of_End_of_Life.9.aspx)

* **"Some good news about end-of-life options" appears in *Santa Fe New Mexican*.** The article is written by Barak Wolfe, who has worked on end-of-life issues for many years, and is also a founder of End of Life Options of NM. The article shares about the implementation of New Mexico's End-of-Life Options Act which passed last spring. The law, which "came after four years in the courts followed by five years and three 60-day legislative sessions," makes medical aid in dying available "to qualified individuals at the end of life." While much remains to be done, says the article, "the new law is being utilized." The article clearly says that End of Life Options of NM honors and respect all end-of-life choices and consider their work "inclusive and nonjudgmental." (*Santa Fe New Mexican*, 6/17, https://www.santafenewmexican.com/opinion/commentary/some-good-news-about-end-of-life-options/article_8e6e78fc-ee5b-11ec-b653-87458cc6d116.html)

* **David White is a hospital chaplain, member of the C-TAC board, and an author.** His experiences with patients and loved ones, and with his own family members, built his base for writing "We Need to Talk – Conversations to Ease Fear and Suffering Surrounding End of Life." The book, according to a C-TAC book note "is a compassionate guide for people who recognize their mortality and are coming to terms with it." (C-TAC, 6/1555, <https://thetac.org/asset/blog/c-tac-individual-member-david-white-releases-book-we-need-to-talk/>)

* **An article in *New York Post*. Says "Mushrooms may help ease the elderly and terminally ill into afterlife.** "The article advocates for the use of psilocybin for people who are nearing life's end. David Luke, an associate professor of psychology at Greenwich University, "studies the psychological effects of psilocybin," and cites studies that have shown how psilocybin helps patients who are suffering with "anxiety, depression, and post-traumatic stress

disorder.” Luke says that palliative care therapists “would be really well suited” to guide people through the experiences. (*New York Post*, 6/14, <https://nypost.com/2022/06/14/mushrooms-may-help-ease-the-elderly-and-terminally-ill-into-afterlife/>)

*** Nursing homes (NH) are a frequent site for dementia patients, including those who die there.** A study, shared in *Journal of Hospice and Palliative Nursing*, examines staff perceptions about “where end-of-life care should be delivered, the role of Medicare hospice care, and the experiences providing end-of-life care to resident with advanced dementia.” The multisite study found that “most NH staff endorsed the NH as a better site of death for residents with advanced dementia compared with a hospital.” NH staff shared “mixed perceptions about hospice care.” NH staff report that they experience “difficult emotions” when they are providing end-of-life care to dementia patients. With the close ties they make with these patients, watching their decline is difficult. The study show that NH staff are strongly attached to their dying dementia patients and would rather care for them at the end of life rather than send them to the hospital.

(*Journal of Hospice and Palliative Nursing*, June 2022,

https://journals.lww.com/jhpn/Fulltext/2022/06000/Nursing_Home_Staff_Perceptions_of_End_of_Life_Care.3.aspx
)

OTHER NOTE

*** An article in Connecticut’s *Hartford Courant* says that the need for nurses in Connecticut is so serious that the state’s “colleges and universities can’t keep up” with the demand.** The pandemic has exacerbated what were already “significant shortages” before COVID. “Weeks ago, the U.S. Surgeon General issued an advisory about health care worker burnout, warning that ‘the public’s ability to get routine preventive care, emergency care, and medical procedure’ is at risk. The link to the article is below and a second link leads to the earlier warning by the Surgeon General. (*Hartford Courant*, 6/12, <https://www.courant.com/news/connecticut/hc-news-nurses-shortage-connecticut-20220612-u7zndkx35beqpfhdhxdegef2ilu-story.html>; U.S. Department of Health and Human Services, Office of the U.S. surgeon General, <https://www.hhs.gov/surgeongeneral/priorities/health-worker-burnout/index.html>)

NOTE: Some URL links require subscription, membership and/or registration.

Hospice Analytics is the national sponsor of Hospice News Network for 2022. Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of- life care. For additional information, please call Dr. Cordt Kassner, CEO, at 719-209-1237 or see www.HospiceAnalytics.com.

Hospice News Network is published 43-44 times a year. Copyright, 2022. 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.