

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

June 14, 2022

A Service of Your State Association

ARTICLE EXPLORES “THE LOSS OF A ‘GOOD’ DEATH”

An article in *Medpage Today* explores how COVID has changed both dying and grieving processes, and warns of long-lasting repercussions. With over a million deaths from COVID, says author Rebecca Morse, PhD, MA, “We are just now starting to see and feel the true cumulative ramifications of these deaths.”

Deaths from COVID have violated “our basic assumptions about what makes a ‘good’ death,” says Morse. Respect for human beings and their lives and a chance to say goodbye have long been associated with having a good death. Avoiding extreme suffering, pain and fear, and meeting goals of quality care near life’s end, have not often occurred during the pandemic. All of this means that these deaths are more traumatic than usual, and interrupt the “typical” grieving process.” Due to this, Morse believes, there are higher risks for prolonged grief disorders and higher demand for mental health resources. The cumulative loss leaves us on the “precipice of a potential public health crisis if not considered and adequately resourced.”

Morse offers Charles Corr’s proposal that a good death requires the completion of four key tasks: “physical, psychological, social and spiritual.” Addressing pain and other symptoms, as well as opportunity for physical touch, are important to meet physical needs. Minimizing fear and anxiety and offering presence and emotional support are critical to meet psychological needs. Socially, people need chances to say goodbye, make amends, and feel real human connection. Spiritually, we need time to make meaning of our lives and deaths, and we need chances for forgiveness. Death during a pandemic results in many of these human needs going unmet.

There are many risk factors when we grieve, and the circumstances of the pandemic amplifies these risks. Deaths were untimely, unexpected, and painful. Even among older adults, many were still living with some degree of health and were expecting more years in their lives. “That is partly why families may feel robbed; without the pandemic, their loved one would potentially be here today.”

No wonder then, says Morse, that so many “losses feel so traumatic – they were traumatic.” Survivors have been left with “guilt, anguish, and an intense sense of impotence.” And these traumatic experiences are leaving survivors with greater risks for “complicated or prolonged grief disorder.” (*Medpage Today*, 6/3, <https://www.medpagetoday.com/opinion/second-opinions/99033>)

HPCAHYS REPORTS LEGISLATIVE VICTORIES IN THE 2021-22 NEW YORK STATE LEGISLATION

The Hospice and Palliative Care Association of New York State (HPCANYYS) reports an unprecedented end to the 2021-22 State legislative session, raising the Association’s profile in advocacy and education on end-of-life care issues within the state. The Association recently updated its members on the Association’s legislative victories. The victories are aimed at improving hospice and palliative care awareness and utilization, and addressing disparities in care for those with a life-limiting illness in historically underserved populations.

The legislative trifecta raising the profile of hospice and palliative care providers in the State of New York and supporting patient access and quality is as follows:

- **A.8880-A (Wallace)/ S.8205 -A (Hinchey)** establishes a statewide advanced care planning campaign to promote public awareness of hospice and palliative care services.
- **A.8881-A/ S.8206-A (Hinchey)** will establish the Office of Hospice and Palliative Care Access and Quality at the New York State Department of Health.

- **A.8006 (Gottfried) / S.7626 (Rivera)** authorizes residents of assisted living programs to receive hospice services, and directs the Commissioner of Health to convene a workgroup of stakeholders to make recommendations as to coordination and division of services, responsibilities, and reimbursement of assisted living programs and hospice programs.

The three bills passed with overwhelming bipartisan support in both houses of the legislature and will be acted on by the Governor by the end of the year.

The Association also announced a fourth victory in increasing awareness, education, and recognition regarding end-of-life care. Prior to the end of the legislative session, the Senate and Assembly formally adopted a Resolution memorializing Governor Kathy Hochul to proclaim November 2022 as Hospice and Palliative Care Awareness Month in the State of New York.

“The Legislature has made it clear we are entering a new era for hospice and palliative care providers, patients, and their families in the State of New York,” said Cheryl A. Kraus, Esq., Director of Federal and State Government Relations for HPCANYS. “Our lead legislative sponsors and co-sponsors are passionate regarding the work our members provide and have vowed ongoing support to address the issues that impact health care access and choice for New Yorkers with a life-limiting illness.” The Association expressed profound appreciation for its legislative allies and stakeholder supporters. “Hospice and palliative care providers have earned their recognition and rightful place on the larger healthcare continuum in New York State.” (HPCANYS, 5/24, Members’ only memo: BREAKING NEWS: LEGISLATIVE & REGULATORY UPDATE)

HOSPICE NOTES

*** “Seniors Matter” shares an article that identifies essential non-medical items that comfort hospice patients.**

Author Dianne Gray is a grief specialist and doula. Recognizing that patients have different needs, Gray identifies practical items that often add comfort to those receiving hospice care. Preferred music choices are important, because “music accesses a part of the brain that connects neurological synapses in a way not much else can.” Audio books can help patients when it is physically more difficult to read books. Small water features and fountains are enjoyed by many because the sound of water is soothing and can help create a sense of being close to nature. Scents are enjoyed by many, though not all, patients. Gray suggests that the patient always be consulted before adding scents as some may be nauseated by these. Cozy blankets and soft items of clothing worn by loved by family members may be of comfort. Photos of loved ones kept where the patient can view them keep these special people in the mind of the patient. The loving presence of family and friends is critical, as this can be a lonely place for patients. Listen to the stories and conversation—even if you have heard them many times before. (*Seniors Matter*, 6/5, <https://www.seniorsmatter.com/what-are-essential-items-to-comfort-a-loved-one-in-hospice/2606392/>)

*** Net Health offers a no cost on-demand webinar titled “Finding Gold in Change: Home Health and Hospice Challenges Reimagined.”** The webinar explores staffing retention and the use of tech tools. Registration is required and is available at the link below. (Net Health, https://go.nethealth.com/HH_hospice_gold_webinar-gated)

*** End of Life University offers “The Hospice Journey: A Step-by Step Guide with Barbara Karnes RN.”**

Karnes is a speaker, author and expert on end-of-life care. She shares in this podcast about knowing the right time to consider hospice, how to find a good one, caring for a loved one at home, what hospice does and does not provide, talking to someone about hospice, what to watch for as death is near, and how hospice provides pain and symptom management. (*End of Life University*, 6/6, <https://eolupodcast.com/2022/06/06/ep-354-the-hospice-journey-a-step-by-step-guide-with-barbara-karnes-rn/>)

*** NHPCO and AAHPM are offering a complementary two-part webinar series geared to helping participants “advance diversity, equity, and inclusion.”** The series, on July 7 and July 21, includes programmatic and clinical perspectives, and will create opportunity for interdisciplinary teams to explore ways to improve diversity, equity, and inclusion. Registration is available at the first link below. Additionally, NHPCO is inviting hospice and palliative care providers to complete a “Health Equity and Inclusion Needs Assessment Survey.” The survey helps providers “evaluate their currently existing programs geared towards underserved populations as well as organizational governance structures that promote health equity.” The link to the survey is at the second link below. (NHPCO, <https://www.nhpc.org/webinar/nhpc-aaahpm-2022-diversity-equity-and-inclusion-webinar-series/>;

NHPCO *Newsbriefs*, 6/9, https://nhpco1.az1.qualtrics.com/jfe/form/SV_0rpCcFfqzZ60JnL)

* **A *Stateline* article, published by Pew Charitable Trust, asks, “What if Hospice Services Weren’t Just for the Dying?”** The article examines outcomes from the Medicare Care Choices Model. An independent evaluation of the project “provided its most robust data so far: The results found that participants were able to stay out of the hospital and live longer at home than a comparison group while also saving Medicare money.” In fact, says the article, the good results of the project have led many hospice experts to hope for an important policy change that will allow all patients to receive curative treatment while receiving “hospice-style benefits.” Hospice and end-of-life care has evolved, and hospice leaders hope that change will come that means patients may need to choose from a wide array of medical intervention. The article is available online at the link below. (Pew *Stateline*, 6/9, <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2022/06/09/what-if-hospice-services-werent-just-for-the-dying>)

* **NHPCO has created a “Chinese American Resource Guide: 2022 Edition.”** The publication identifies cultural beliefs and explores collaborations and coalitions as tools to address the needs of this population. The guide also includes resources for engaging the community. The resource is free to both members and non-members and can be found online at the link below. (NHPCO, 2022, <https://www.nhpco.org/education/tools-and-resources/diversity>)

* **A “Supreme Court review of Rule 9(b)’s application in False Claims Act cases may finally be coming whether the Executive Branch likes it or not,”** says an article in *Health Industry Washington Watch*. Three false claims act include “Johnson v. Bethany Hospice and Palliative Care, LLC,” “United States ex rel. Owsley v. Fazzi Associates,” and “Molina Healthcare of Illinois, Inc. v. Prose.” The Supreme Court “asked the Solicitor General to weigh in on whether the Court should accept” the Bethany Hospice and Palliative Care, LLC. The Solicitor General “argued that the Supreme Court should not grant plenary review.....” The court is waiting for the feedback from the Solicitor General on the Fazzi case. It will take four Supreme Court Justices to move forward with the Bethany case against the recommendation of the Solicitor General. The article details other specifics of the cases, saying, “Only time will tell” if the cases are heard by the Supreme Court. (*Health Industry Washington Watch*, 5/25, <https://www.healthindustrywashingtonwatch.com/2022/05/articles/fraud-and-abuse-developments/scotus-review-of-rule-9b-in-false-claims-act-cases-may-be-on-the-way/>)

PALLIATIVE CARE NOTES

* ***Pharmacy Times* interviewed physician Ajeet Gajra at the 2022 American Society of Clinical Oncology.** The discussion focused on research “that found that utilizing an augmented intelligence-based system can improve the timeliness of referrals to palliative care and hospice services in community oncology environments.” These early referrals, says Gajra, are “a quality benchmark in oncology.” Early referral to palliative care serves patients and families better, says Gajra, and it also helps to avoid “traumatic treatments close to end of life.” The early referrals also help to avoid frequent hospitalizations and/or visits to ER. They also help create an easier transition into hospice when appropriate. Obstacles to these early referrals may include patient and family perspectives, clinician perspective and system-imposed obstacles. Gajra elaborates on each of these three obstacles. (*Pharmacy Times*, 6/4, <https://www.pharmacytimes.com/view/expert-recognizing-the-importance-of-early-palliative-care-referrals-is-essential-to-patient-care>)

* **CAPC addresses issues of health equity in “Acknowledging Barriers and Implementing Strategies to Reach Black People with Serious Illness.”** CAPC began Project Equity as “an initiative to create tools for meaningful change in the case of those in traditionally oppressed communities with a serious illness.” The first work of the Project, found at the first link below was an introductory paper titled “Equitable Access to Quality Palliative Care for Black Patients: A National Scan of Challenges and Opportunities.” In an environmental scan of the issues, “CAPC staff conducted 25 interviews with 27 subject matter experts (SMEs) in health equity and serious illness.” Those interviewed included clinicians, researchers, and payment and policy leaders. Six of the interviewees were patients or caregivers. The online paper gives an update on what has been learned so far, feedback on what needs to be improved, ideas for conquering obstacles, and the importance of timing and messaging of introduction of palliative care. The findings provide “critical context for the larger project...” “Understanding the historical basis of present-day inequity helps clinicians to recognize the disparities around them, and to take action,” says the paper. “Without this understanding, we risk perpetuating the cycle of harm.” (CAPC, <https://www.capc.org/project-equity-improving-health-equity-for-people-with-serious-illness/equitable-access-to-quality-palliative-care-for-black->

patients-a-national-scan-of-challenges-and-opportunities/; 5/27,<https://www.capc.org/blog/acknowledging-barriers-and-implementing-strategies-to-reach-black-people-with-serious-illness/>)

* **“Correcting the misperception of palliative care,”** written by **Andrew Esch, MD**, appears in *McKnight's Long-Term Care News*. While palliative care is relatively young, observes Esch, it has grown tremendously during the past 20 years. By 2019, 72.5% of all U.S. hospitals with more than 50 beds established a palliative care program. Compare that to 7.0% in 2001. And palliative care outside of the hospital is growing. Nevertheless, there is evidence that patients and providers, even though they think they understand palliative care, have misunderstandings....and these can “prevent patients from getting the care that they need when they need it.” Esch then defines and describes palliative care, and calls on palliative care providers to continue to intervene more quickly, even at the time of diagnosis. (*McKnight's Long-Term Care News*, 6/1, <https://www.mcknights.com/blogs/guest-columns/correcting-the-misperception-of-palliative-care/>)

END-OF-LIFE NOTES

* **Physician Steven Lin asserts that “AI can actually predict pretty accurately when people are gonna die.”** Stanford hospital’s “sophisticated computer model” is good at predicting if a patient will die within a year. But would you want to know? A program on WBUR explores the algorithm, explains how it works, and examines how the information should be used. A transcript of the show is online at the link below. (WBUR, 6/3, <https://www.wbur.org/onpoint/2022/06/03/smarter-health-the-ethics-of-ai-death-predictor>)

* **Lisa Vigil Schattinger, MSN, RN, is founder and Executive Director of Ohio End of Life Options.** The group “advocates for and provides education on medical aid in dying laws.” Schattinger has a professional perspective that has been informed by her personal experiences. An article in *Oncology Nursing News* shares about her experiences and her work as an advocate. It also explores the state of medical aid in dying and how it works. The American Nurses Association, says Schattinger, has a statement saying “that they feel nurses are ethically bound to be knowledgeable about it [aid in dying]” because so many people now have access to MAiD (medical aid in dying). (*Oncology Nursing News*, 6/2, <https://www.oncnursingnews.com/view/what-oncology-nurses-should-understand-about-medical-aid-in-dying>)

* **Bloomberg Law shares the story of Erinn Baldeschwiler, who is dying and wants to try psilocybin to help relieve her anxiety and depression.** Two terminally ill patients are seeking access to psilocybin under the Right to Try law, “a federal law and an array of state laws meant to grant people facing death access to experimental drugs outside of a clinical trial.” Sunil Aggarwal, Baldeschwiler’s Seattle-based palliative care physician, “suggested psilocybin to treat her anxiety and depression related to her terminal diagnosis.” Aggarwal and a group of attorneys have petitioned the DEA to get access to the drug for Baldeschwiler under Right to Try. And they have asked that the drug be supplied to them if DEA approves. They have been rejected by the DEA, and failed to get an appeal. Aggarwal was told she could apply for a research project of her own. Reps. Earl Blumenauer (D-OR) and Andy Biggs (R-AZ) wrote DEA, saying they are concerned that DEA is “obstructing access to psilocybin for therapeutic use consistent with the letter and intent Right to Try (RTT) laws.” Baldeschwiler traveled to D.C. and met with her Washington Senator Patty Murray (D-WA), who is chair of the Health Education, Labor, and Pensions Committee. Baldeschwiler continues to seek treatment to help her. (*Bloomberg Law*, 6/2, <https://news.bloomberglaw.com/us-law-week/hunt-for-psychedelic-mushrooms-faces-dea-hurdle-to-right-to-try>)

* **Hospice and palliative care physician Daniel Miller, MD, authored “A Couples-Focused Approach to Terminal Illness” which appears in *Psychology Today*.** When one partner receives a terminal diagnosis, says Miller, the most crucial question is “how does the *couple* navigate the terminal illness?” Miller writes, “The trials of being a partner to a loved one with a terminal illness are severe and wrenching. It will leave no part of you untouched and in the end, will consume both of you.” While there are books and counselors and other guidance for the journey, says Miller, “You two are on your own.” During the coming months Miller will write articles that address a myriad of challenges a couple must face. (*Psychology Today*, 5/31, <https://www.psychologytoday.com/us/blog/end-life-matters/202205/couples-focused-approach-terminal-illness>)

GRIEF AND ADVANCE CARE PLANNING NOTES

*** When North Carolina's Beaufort Elementary School's music teacher, Alice Cashwell, was advised to enter hospice, Heather Boston, the director of student support services for the Carteret County Public Schools, worked to prepare students for the death of Cashwell.** Boston worked with the school's counselor, Candace Hunt, to "quickly design a curriculum for pre-teaching grief." Teachers began teaching the lessons three times a week to the students of the school. The lessons explored dealing with feelings and introducing the concept of loss. Teachers were given grieving strategies to share with students, and students shared their own experiences with loss and what brings them comfort. Hunt collected the ideas and "compiled a spreadsheet of student-centered strategies" that was given to the whole staff. This became a "toolbox filled with tools that students and teachers could pull out and use as needed." When Cashwell died in April, Boston and Principal Karen Wood shared a guide to teachers for how to tell children that someone has died, as well as a video reading of "The Goodbye Book." (*EdNC*, 5/19, <https://www.ednc.org/2022-05-19-beaufort-elementary-students-teaching-learning-grieving-coping/>)

*** Nurse Martie L. Moore writes "The finality of saying yes," which appears in *McKnights Long-Term Care News*.** Engaging in advance care planning, she says, is one thing when we help others with these conversations. But it is very different when we face the enactment of them with our personal loved ones. Moore has provided palliative care, and is a palliative care advocate. What she learned first-hand, through her end-of-life experiences with her mother-in-law and parents, is the difficulty of saying "no" to further medical interventions and "yes" to the finality of death. She calls for practitioners to "expand our actions from checklists to think about how we include the designated decision maker(s) to understand" the guilt they may face, the second-guessing of their decisions, and the fear of making the wrong decisions. (*McKnights Long-Term Care News*, 6/3, <https://www.mcknights.com/blogs/guest-columns/the-finality-of-saying-yes/>)

OTHER NOTES

*** *The Hastings Center* has created a special report on the work of a collaboration of bioethicists, established in 2020, that worked to address "underrepresented issues within bioethics such as racial and health justice."** The report "A Critical Moment in Bioethics: Reckoning with Anti-Black Racism Through Intergenerational Dialogue," includes numerous articles on anti-Black Racism in health care, anti-Black racism and health equity research and practice, anti-Black racism and bioethics, and "Braver, Bolder, Broader Bioethics." The paper also honors Dr. Marian Gray Secundy, the first director of the National Center for Bioethics in Research and Health Care. (*The Hastings Center Report*, March-April 2022, <https://onlinelibrary.wiley.com/toc/1552146x/2022/52/S1>)

*** IRS announced an increase in the standard mileage rate for the second half of 2022.** The rate will increase by four cents per gallon, and the standard business travel rate will be 62.5 cents per mile. The new rates go into effect on 7/1. (IRS, 6/9, <https://www.irs.gov/newsroom/irs-increases-mileage-rate-for-remainder-of-2022>)

*** *JAMA Network Open* shares a study that projects that by 2034 there will be "a racial and ethnic representation deficit of between 37,800 and 124,000 physicians."** The rates of "Black, Hispanic, and American Indian or Alaska Native medical school matriculation" have increased at a rate slower than other groups and there is increased underrepresentation. The data indicate that disparities of physicians will worsen what is already visible. (*JAMA Network Open*, 6/1, <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2792848>)

Thanks to Kimberly Ryan, Cheryl Kraus, Marisette Hansen and Don Pendley for contributions.

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.