



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

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#### MOVING TOWARD A BETTER CONCEPTUALIZATION OF “GRIEVING BEFORE A LOVED ONE DIES”

**“Grieving Before a Loved One Dies: A Real, but Overlooked Syndrome,”** an article in *Medscape*, **proposes a more precise way to define this pre-death grief.** The article shares about a study of this grief that was originally shared in *Palliative Medicine*. The study identifies two categories of pre-death grief. The researchers of the study hope the definitions “will inform therapeutic interventions to help those facing a life-changing loss.” Numerous studies show that pre-death grief may lead to more cases of prolonged grief disorder. The researchers propose that pre-death grief be divided into two categories in order to offer best help and therapeutic interventions to patients experiencing this grief.

**While pre-death grief has often been studied, “there have been conceptualization issues,”** says Jonathan Singer, PhD, visiting assistant professor of clinical psychology at Texas Tech University in Lubbock. These issues are problematic because they hinder “potential advancement of the field in differentiating typical grief from more impairing grief before the death.” The use of multiple terms to describe this kind of grief complicates “the picture.”

Researchers mined databases of articles that addressed “pre-death” grief. **Researchers limited their research to articles that used a “given term” within the article. Overall, they discovered that 18 different terms were used to describe this “pre-death” grief.** These include advanced grief as the most commonly used term; pre-death grief; pre-loss grief; caregiver grief; and anticipatory mourning. In the 18 terms identified, they found over 30 different definitions that were offered in the various studies—and the “definitions of these terms differed drastically.”

**From this review and analysis, the researchers chose the term “pre-death grief” and designated two categories within this broad designation. Anticipatory grief (AG) and illness-related grief (IRG),** says Singer, **provide “the field with uniform constructs to advance the study of grief before the death of an individual with a life-limiting illness.”**

IRG, says Singer, is “‘present-oriented’ and involves the ‘longing and yearning for the family member to be as they were before the illness.’ AG, on the other hand is “‘future oriented’ and is defined as ‘family members’ grief experience” while a loved one is still alive—but the grief is focused on the future loss of the loved one.

**The study hopes to advance this field of study by offering these definitions that can be consistently used to guide research and determine best interventions to address IRG and AG.** Applauding the study, Francesca Falzarano, PhD, concurs that researchers need “a consensus on an appropriate definition for pre-death that adequately encompasses its complexity and multidimensionality.”

(*Palliative Medicine*, February 2022,

[https://journals.sagepub.com/doi/10.1177/02692163221074540?url\\_ver=Z39.88-](https://journals.sagepub.com/doi/10.1177/02692163221074540?url_ver=Z39.88-)

[2003&rfr\\_id=ori%3Arid%3Acrossref.org&rfr\\_dat=cr\\_pub++0pubmed&";](https://journals.sagepub.com/doi/10.1177/02692163221074540?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed&) *Medscape*, 3/29,

[https://www.medscape.com/viewarticle/971180?sso=true&impID=4263100&uac=68861EJ&src=mk\\_m\\_ret\\_220521\\_mscpmrk\\_neuro\\_grief](https://www.medscape.com/viewarticle/971180?sso=true&impID=4263100&uac=68861EJ&src=mk_m_ret_220521_mscpmrk_neuro_grief))

#### HOSPICE NOTES

**\* NHPCO says it and the Hospice Action Network (HAN) applaud the introduction of the Palliative Care and Hospice Education Training Act (PCHETA) in the Senate on 5/19.** The bill, S. 4260, “would support research and education to develop hospice and palliative care medicine. Estimates have said that, without more investments,

the hospice and palliative care physician network “will grow a little over one percent in the next 20 years,” while the number of persons needing such care will grow by 20 percent. Enactment of PCHETA would address this gap and support patients served by hospice and palliative care. Though the bill has had support from both House and Senate in the last two Congresses, the bill has not yet passed. (NHCPO, 5/19, [https://www.nhpc.org/leading-hospice-and-palliative-care-organizations-laud-introduction-of-pcheta/?\\_zs=8kKKC1&\\_zl=1afj60](https://www.nhpc.org/leading-hospice-and-palliative-care-organizations-laud-introduction-of-pcheta/?_zs=8kKKC1&_zl=1afj60)).

**\* A study reported in the *Journal of Pain and Symptom Management (JPSM)* finds that patients with dementia (PWDs) who enroll in hospice receive improved end-of-life care that is similar to that received by patients who do not have dementia.** The study of 2,059 decedents, all aged 70 and older, provides evidence that encourages policies that “facilitate hospice enrollment and prevent live discharge for PWDs.” (*JPSM*, June 1, [https://www.jpmsjournal.com/article/S0885-3924\(22\)00499-7/pdf](https://www.jpmsjournal.com/article/S0885-3924(22)00499-7/pdf))

**\* An article in *Alzheimer’s News Today* offers ideas to help families prepare for the home death of loved ones.** “Treading Dark Waters” acknowledges that most people want to die at home, and hypothesizes that the desire for control is a core reason for this desire. Author Ray Burrow notes ways that hospice care can help, and offers ideas on how to be ready for a home death. The article discusses advance directives, and explores tasks that must be faced after death. (*Alzheimer’s News Today*, 5/16, <https://alzheimersnewstoday.com/2022/05/16/dying-home-how-prepare-yourself-loved-one-alzheimers/>)

**\* A study reported in *JAMA Network* evaluates changes in Medicare policy that were aimed to reduce long hospice stays.** But, say the study authors, an unintended consequence meant “there were immediate declines in the share of patients receiving hospice care with ADRD [Alzheimer disease and related dementias] and a slower growth in use of hospice care among patients with ADRD after implementation of the US Improving Medicare Post-Acute Care Transformation Act and the 2-tier payment system compared with prepolicy trends.” Results of the study indicate that reduction in hospice use by Alzheimer’s disease and related dementias (ADRD) may result in a poorer end-of-life experience for persons with ADRD. Study authors call for further research to “examine mechanisms through which hospices enacted change and consequences for quality of care.” (*JAMA Network*, 5/6, <https://jamanetwork.com/journals/jama-health-forum/fullarticle/27919630>)

**\* “Beating turnover with compassion in hospice care, Paradigm Health shines as a Top Workplace” appears in *IndyStar*.** Paradigm is one of the winners in Indiana’s 2022 Top Workplaces. Senior leaders work to be sure standards are met while listening to all staff to improve the organization. Bryan Smith, hospice chaplain for Paradigm Health, says the supportive culture at the organization makes staff want to stay. Employees describe Paradigm as having a “friendly, home-like environment, where they feel valued and are able to connect and have fun together.” Those who work with patients say the positivity of the organization carries through into the care they take to patients. Regardless of the difficulty of the work, says a team leader, “‘You never feel alone. There is always someone’ to help.” (*IndyStar*, 5/18, <https://www.indystar.com/story/news/2022/05/18/paradigm-health-indiana-shines-top-workplace-2022/7225117001/>)

**\* The Illinois Hospice and Palliative Care Organizations has posted its 2022 legislative priorities on its homepage.** The plan includes five pillars that address care for the seriously ill in nursing facilities; calls for increasing the nursing workforce; offer high quality community-based palliative care; seeks equitable access to quality care; and, honors patient’s wishes. The priorities are online in a PDF, found at the second link below. (IHPCO, <https://il-hpco.org/about-us/advocacy/>; [https://il-hpco.org/wp-content/uploads/2022/05/IL-HPCO-Policy-Priorities-2022\\_FINAL\\_5.5.22.pdf](https://il-hpco.org/wp-content/uploads/2022/05/IL-HPCO-Policy-Priorities-2022_FINAL_5.5.22.pdf))

**\* Sarah McSpadden, president and CEO of Elizabeth Hospice in San Diego, shares her thoughts about “bad actors” in hospice. Fraudulent billing and poor delivery of hospice care are being provided by some hospices. And hospices of higher quality are “being swallowed up by the bad actors and competing with them for patients,” says McSpadden.** Hospice fraud has been a huge issue in California, but that state is hardly alone. McSpadden says “national licensing, certifying, credentialing and accrediting bodies all play a part.” Hospices in California, she said, pushed for better regulatory oversight. These good hospices “are willing to take the hits from increased investigations and oversights.” Hospice referral sources may not see or understand hospices well enough to be sure that they are referring to “good” hospices. And some consumers think all hospices are “strung together.” McSpadden is disappointed that the recent California audit found the Department of Health Care Services has not done what it should have to address these issues, and the California Department of Public Health has not had adequate performance either. She calls on those in oversight to “step up, step together and do a better job of protecting people in hospice. (*Hospice News*, 5/12, <https://hospicenews.com/2022/05/12/bring-it-on-hospices-willing-to-take-hits>)

from-regulators-to-ensure-ethical-quality-care/?euid=c545e6d325&utm\_source=hspn-newsletter&utm\_medium=email&utm\_campaign=8652cd0fa8)

\* **A Pennsylvania hospice nurse has been sentenced to a “one year probation and a \$525 fine” for stealing patients’ medication and using for herself. She also “permanently surrendered her nursing license.”** The news was released by the Middle district of Pennsylvania. (Department of Justice, Middle District of Pennsylvania, 5/23, <https://www.justice.gov/usao-mdpa/pr/york-nurse-sentenced-stealing-prescription-drugs-hospice-patient>)

## PALLIATIVE CARE NOTES

\* **Targeted Oncology offers “Intervention Tool STEP Displays Feasibility in Identifying Patients Benefitting From Early Palliative Care.”** “Researchers determined it feasible to distinguish between patients with advanced cancer who remain stable without and with early palliative care by utilizing the novel intervention tool Symptom screening with Targeted Early Palliative care.” The efficacy of the tool, developed in Canada, was shown in a study to successfully identify patients who need early palliative care. The article explores the various aspects of the tool, and says ““a multicenter randomized trial of STEP versus standard palliative care in patients with advanced cancer is underway.”” (*targetedonc.com*, 5/12, <https://www.targetedonc.com/view/intervention-tool-step-displays-feasibility-in-identifying-patients-benefitting-from-early-palliative-care>)

\* **Geriatrician and palliative care physician Santiago Lopez reflects on lessons that were reinforced during COVID-19.** Sharing stories of personal patients, Lopez calls for physicians to listen carefully to patients; assess the real need of patients; and “respond with kindness and compassion.” (*Medpage Today*, 5/18, <https://www.medpagetoday.com/opinion/second-opinions/98784>)

\* **Illinois State Senator Laura Fine (D-Glenview) led the effort to require private insurers to “cover specialized care for children living with serious illnesses while allowing the child to seek additional treatments.”** Under the new law, private insurers will cover pediatric palliative care. Often this care leads to fewer emergency room visits, shorter hospital stays and improved quality of care. In spite of these benefits, only one percent of the 2800 children living with chronic illness in Illinois have access to such treatment. SB 3819 became law on 5/13 and will go into effect on 1/1/23. (Illinois Senate Democrats, 5/13, <https://www.illinoisenedemocrats.com/caucus-news/28-senator-laura-fine-news/4002-fine-s-new-law-increases-access-to-specialized-care-for-children-living-with-serious-illnesses>)

\* **New York’s Calvary Hospital is launching a “first-of-its-kind palliative and end-of-life care residence program” in July.** The hope is to simultaneously expand the reach of palliative care and to address the city’s nursing shortage. According to AAHPPM, there will be 83.7 million adults in the US by 2050, and there is a major need for an increased nursing force. The new residency will start with a minimum of eight nurses. The nurses “will learn at Calvary Hospital and within the organization’s New York metropolitan area home-based hospice program.” The nurses’ focus on palliative care will help to bolster the available nurses. The program will serve as an effort to both recruit and retain nurses. New York’ Department of Health predicted in 2001 that New York will face a shortage of 39,000 nurses by 2030. (*BronxTimes*, 5/16, <https://www.bxtimes.com/calvary-hospitals-new-palliative-care-residency/>)

## END-OF-LIFE NOTES

\* **Katie Couric Media shares “All Your Questions About Physician-Assisted Suicide, Answered.”** The article explores why it is so difficult to talk about end of life. Even when faced with terminal illness, people are reluctant to talk about death and dying. Twenty percent of Americans live in a state where assisted dying is legal. The bulk of the article explores the process of assisted dying, the reasons people choose it, and fears, costs and benefits of assisted death. (*Katie Couric Medica*, 5/16, <https://katiecouric.com/health/what-is-physician-assisted-suicide/>)

\* **Literary Hub shares the story of the illness and road to death of Tallu Quinn, written by her husband**

**Robbie.** The moving details of their journey are honest, and provide a glimpse into their lives as Tallu lived the last of her life. Tallu's book, "What We Wish Were True," was released last month. From her slow loss of faculties due to her glioblastoma, the article shares poignantly about the engagement of Robbie, their two young children, and friends, as they work to support Tallu with her unyielding determination to continue writing. (*Literary Hub*, 5/23, <https://lithub.com/a-liturgy-a-great-release-on-becoming-my-wifes-writing-partner-at-the-end-of-her-life/>)

\* **"I'm an end of life doctor—here's what really happens when you die" appears in *The Sun*.** Palliative care physician Kathryn Mannix calls death a "process," and says it is not as bad as many people expect. ER doc Thomas Fleischmann offers five states of dying and has offered these in a TED Talk. The article shares about the brain waves of a patient hooked up to EEG and what happened with his brain waves the 15 minutes before and after death. Gamma oscillations increased during this period. This suggest, says the article, "We might see a sort of film reel of our best memories as we die.' We might 'enter a dreamlike state that feels similar to meditation.'" (*The U.S. Sun*, 5/19, <https://www.the-sun.com/health/5373545/end-of-life-doctor-deaths-process/>)

\* **Crestone, CO has the nation's "only public open-air funeral pyre."** A story in *New York Times* shares the story of the life, death and outdoor cremation of Dr. Philip Incao. The practice of outdoor fire cremation using a pyre is, according to the article, "a defiant upending of American death rituals." The article mixes a telling of Incao's and his family's experience along with telling the history of the use of pyres for cremations. Incao's body lay in the front room of his home for three days, covered in flowers. Then his body was taken by the family to the pyre. The ritual was attended by about 70 people and Incao's cremation is one of about 70 pyre cremations since it opened over a decade ago. It can only be used by those who own land or live in Saguache County. Hospice chaplain Angela Lutzenberger purchased 73 acres of land in Dresden, Maine. She hopes to open a pyre site there. (*New York Times*, 5/18, <https://www.nytimes.com/2022/05/18/us/olorado-funeral-pyre.html>)

\* **An Australian study, covered in *The Atlanta Journal-Constitution*, is titled "Study: Older adults support the right to die, regardless of health."** The study, published in the *OMEGA Journal of Death and Dying*, revealed that most of the Australian participants aged 65 and over supported volunteer assisted dying (VAD), but the participants also "stressed a need for safeguards." (*The Atlanta Journal-Constitution*, 5/23, <https://www.ajc.com/life/study-older-adults-support-the-right-to-die-regardless-of-health/XUR4GOHRNJH6JAWYS3BPW5F3VM/>)

## GRIEF AND ADVANCE CARE PLANNING NOTES

\* **"End-of-life planning app helps you prepare for mortality" appears on *Freethink*.** In failing to prepare for death, we leave families to struggle with the logistics when "emotions are high." Izumi Inoue, founder of an end-of-life planning app called Bereev says this lack of planning "causes friction, additional trauma, and it tears families apart." Bereev is designed to help people prepare for death, leave instructions for after death, upload important documents, and leave messages and/or videos for loved ones. (*Freethink*, 5/15, <https://www.freethink.com/technology/end-of-life-planning>)

\* **A first-ever study evaluated the use of "a mindfulness intervention to ease grief."** Lindsey Knowles, PhD, with University of Washington School of Medicine, Seattle, Washington, and VA Puget Sound Health Care System, served as the study investigator. Both muscle relaxation and mindfulness training show efficacy in improving grief severity, says Knowles. "With replication, progressive muscle relaxation could be a standalone intervention for non-disorder grief or a component of treatment for disordered grief." An article in *Medscape* offers an overview of the study. The findings surprised Knowles who "hypothesized that mindfulness training" would be the more effective intervention. But muscle relations has a significant advantage in that it is a "relatively simple technique" that is easy to learn. (*Medscape*, 3/28, [https://www.medscape.com/viewarticle/971192?ss=true&impID=4263100&uac=68861EJ&src=mk\\_m\\_ret\\_220521\\_mscpmrk\\_neuro\\_grief](https://www.medscape.com/viewarticle/971192?ss=true&impID=4263100&uac=68861EJ&src=mk_m_ret_220521_mscpmrk_neuro_grief))

## OTHER NOTES

\* **An article in Fort Worth's *Star-Telegram* shares an AP story about the rise in the numbers of Buddhist chaplains in the U.S.** Training opportunities for Buddhist chaplains have burgeoned in recent years. "They include the Buddhist Ministry Initiative at Harvard Divinity School and the Buddhism track at Union Theological Seminary, an ecumenical Christian liberal seminary in New York City. Colorado's Naropa University, a Buddhist-inspired

liberal arts college, recently launched a low-residency hybrid degree chaplaincy program.” Programs continue to emerge and opportunities for Buddhist chaplains continue to expand. There are approximately 425 Buddhist chaplains throughout the U.S., Canada and Mexico. About two-thirds of these have Master of Divinity degrees. “Most of those working as staff chaplains also completed clinical pastoral education internships and residencies in health care and other settings.” Most of these chaplains, says the article, are from white families with a Christian background. Providence Health and Services, a Catholic nonprofit in Washington state, has hospitals in seven Western states. Providence employs ten Buddhist chaplains in order “to ensure patients get good spiritual care however it suits them.” (*Star-Tribune*, 5/16, <https://www.star-telegram.com/news/nation-world/national/article261461952.html#storylink=cpy>)

\* **“Reforming CON laws is a matter of life and death” is an article from Pacific Legal Foundation.** The article encourages states to remove these “burdensome laws” that “stifle competition and consumer access to quality services.” After explaining CONs, the article gives examples of times that CONs created a threat to health. The article shares the story of a young woman whose baby died at birth due to not being able to access the one ambulance that could have helped the mother make it to a nearby specialty hospital. The article also cites the problems of a non-emergency medical transport agency that transports patients from Ohio or Kentucky across the border of their states. The CON laws in Kentucky prevent patients from using the agency’s service. The article argues that all businesses should be free to compete, saying the laws cause suffering for human lives. (Pacific Legal Foundation, 5/19, <https://pacificlegal.org/reforming-con-laws-matter-life-death/>)

*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](http://www.HospiceAnalytics.com).*

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