



What the Media Said about End-of-Life Care This Week July 27, 2021 A Service of Your State Association

AMERICAN EXPERIENCE OF DEATH AND DYING CONTINUES TO CHANGE

An article in *The Pilot*, in Southern Pines, SC, offers “The Way We Process Death, Grief has Come a Long Way in History.” Columnist Michael Smith reflects on American cultural attitudes toward death and dying. He recalls a 2013 Twitter post saying, “Cremation is my last chance for a smokin’ hot body.” Fifty years ago, says Smith, fewer than four percent of US deaths chose cremation, while that number grew to 54.6 percent by 2019. Projections expect cremation to rise to 79.1 percent by 2035.

In 1939, “The American Way of Death,” written by British aristocrat Jessica Mitford, hit *New York Times* bestselling list for over a year. Mitford found Americans’ ways of dealing with death to be “bizarre.” The book explored the tactics of using pressure on bereaved persons to encourage increased spending on funerals. Mitford “dignified cremation and no-frills burials, which morticians dubbed the ‘Mitford service.’” The book broke through cultural taboos around death, and brought discussions into the open.

A century ago, most deaths occurred at home. The technology that now keeps us living for years longer was non-existent. Death was a more frequent and familiar experience. **Now, however, about 25% die at home, with most dying in nursing homes and hospitals.**

Sheldon Solomon, in 2016, authored “The Worm at the Core,” which labels death an “existential terror” that hides in the back of our minds. We avoid thinking about death and dying in what Solomon labels “terror management theory” or TNT. Ernest Becker, in his Pulitzer Prize winning book, “The Denial of Death, said, “We humans are burdened with juggling life around n existential dread—the knowledge of the End.”

Elizabeth Kubler-Ross noted the way that American hospitals were dealing with death. “Everything was huge and very depersonalized, very technical. Patients who were terminally ill were literally left alone, nobody talked to them.” But Kubler-Ross talked with these patients, and learned from them. Her book, “On Death and Dying,” offered stages of dealing with illness and grief. Her focus, says Smith, “was changing Western cultural resistance to dealing with death, and teaching us how to accept it.”

Smith adds the names and influence of a number of others, including physician Cicely Sanders, who founded hospice. Clearly, the rituals and attitudes around death and dying are continuing to evolved. (*The Pilot*, 7/25, https://www.thepilot.com/opinion/column-the-way-we-process-death-grief-has-come-a-long-way-in-history/article_5d22d92a-ebd5-11eb-837d-03486f18f6a4.html)

HOSPICE NOTES

* CMS will hold a webinar on 8/4 that will “share updates on the fiscal year (FY) 2022 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements Final Rule.” More details and a link to registration is available at the link below. (CMS, 7/21, <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Spotlight>)

* The Office of Inspector General (OIG) reports that Palmetto GBA correctly calculated cap amounts for hospice, but they failed to “collect all cap overpayments or pay refunds associated with lookback years due to

two internal policies.” Overall, says OIG, “Palmetto did not collect lookback overpayments totaling \$545,639 or send refunds to hospices totaling \$17,513.” Communications were also insufficient. OIG made recommendations to Palmetto and Palmetto agreed with the recommendations and will take action to remedy the issues. (OIG, 7-20, <https://oig.hhs.gov/oas/reports/region6/61908003.asp>)

*** The Massachusetts Office of the State Auditor reviewed payments for hospice services for dual-eligible members.** The audit was performed along with the US Department of Health and Human Services (HHS), and the Boston Office of the Inspector General (OIG). The audit covered the period between 1/1/15 to 7/31/19. The audit found that MassHealth lacked accurate information in its system of accounting. Additionally, MassHealth’s payment system paid for “professional services that were not coordinated by hospice providers.” DME was paid in error, as were ambulance and inpatient services for dual-eligible members. Hospices were reminded of their obligation to submit a MassHealth Hospice Election Form and a Medicare Hospice Election Form. Details, a summary report, and the full report are available at the links below. (Mass.gov, 7/1, <https://www.mass.gov/audit/audit-of-the-office-of-medicare-masshealth-payments-for-hospice-related-services-for-dual-eligible-members> <https://www.mass.gov/info-details/masshealth-did-not-ensure-that-it-had-accurate-information-in-its-medicare-management-information-system-about-dual-eligible-members-who-chose-to-receive-hospice-services>; Mass.gov, <https://www.mass.gov/audit/audit-of-the-office-of-medicare-masshealth-payments-for-hospice-related-services-for-dual-eligible-members>)

PALLIATIVE CARE NOTES

*** Florida launched a Florida Palliative Care Coalition.** The group will work to unify the definition of palliative care within the state, and serve as advocate for Floridians “in the final phases of life.” The coalition is an effort of many organizations. Details and more information are available at the link below. (CTAC, 7/21, <https://www.thectac.org/2021/07/from-commitment-to-action-florida-launches-state-palliative-care-coalition/>)

*** An article in *American Journal of Managed Care* explores the “digital innovations in palliative care during COVID-19” and how these interventions have impacted patient palliative care.** The growth of telepalliative care programs could, say the authors, “transform the PC consult to address workforce shortages and expand access to PC services during and beyond the pandemic.” The article identifies key points for understanding, as well as securing sustainability. (*American Journal of Managed Care*, 7/21, <https://www.ajmc.com/view/reimagining-the-inpatient-palliative-care-consult-lessons-from-covid-19>)

*** AseraCare launched a palliative care program in Grand Island, NE.** The program, the first of its kind in the area, will serve chronically-ill persons who wish to continue treatment. (*KSNB-Hastings*, 7/23, <https://www.ksnbllocal4.com/2021/07/23/aseracare-starts-first-palliative-program-grand-island/>)

*** Patient populations have low knowledge about palliative care, with a small percentage “considered to have adequate knowledge of these services.** A survey by NCI Health Information National Trends reveals that “89% of all participants had inadequate knowledge of palliative care.” Even though palliative care has known benefits, the number of patients using palliative care has not significantly increased. (*cancer network*, 7/24, <https://www.cancernetwork.com/view/study-indicates-lacking-knowledge-of-palliative-care-in-the-general-us-population>)

END-OF-LIFE NOTES

*** An article in *cure* is titled “Study Analyzes Quality of Life Research on Patients with CLL and Their Caregivers.”** Chronic lymphocytic leukemia (CLL) impacts the lives of patients and those who love them. Trying to develop an education tool, researchers discovered a lack of information on how CLL impacts parents and caregivers of CLL patients. Spiritual well-being, say the authors, deserves more attention. Overall, patients need education and support in facing treatment, dealing with adverse symptoms and quality of life, and other aspects of life. More work is needed to understand the needs of patients and caregivers. (*cure*, 7/22, <https://www.curetoday.com/view/study-analyzes-quality-of-life-research-on-patients-with-cll-and-their-caregivers>)

* **An article in the *Atlanta Journal* explores the work of a Catholic nun, Sister Aletheia, whose mission is encouraging people to think about death.** “Memento mori” –remember your death—reminds us of the value of life each day. (*Atlanta Journal*, 7/23, <https://www.ajc.com/life/remember-your-death-is-good-slogan-to-live-by/DG5M4VINDVFEZL63MWFZJNJ64I/>)

* **Stephen Thewlis, author of an opinion column in *Desert Sun*, writes of the “needlessly cruel” death of his husband, Michael Mercil.** Mercil was a hospice patient dying with metastatic melanoma. In spite of his plans to use California’s End of Life Option, Mercil died before before the 14-day waiting period. This meant that “his last four days were filled with delusions, extreme agitation and hallucinations.” Though health professionals were “absolutely wonderful,” Thewlis writes that he supports proposed changes to the current California law that would make dying much less “barbaric.” (*Desert Sun*, 7/25, <https://www.desertsun.com/story/opinion/contributors/valley-voice/2021/07/25/death-dignity-under-end-life-law-not-coachella-valley/8071948002/>)

* **The INN Between, in Salt Lake City’s Sugar House neighborhood, serves homeless adults needing end-of-life care.** The INN Between offers hospice, housing, meals, and activities. Volunteers offer other services. The INN Between has supported 87 people at life’s end, and 250 very ill persons have been cared for there. (*The City Journals*, 7/22, <https://www.mysugarhousejournal.com/2021/07/22/363124/the-inn-between-helps-adults-experiencing-homelessness-obtain-health-and-end-of-life-care>)

ADVANCE CARE PLANNING AND BEREAVEMENT NOTES

* **FAIR Health, a nonprofit organization, received a grant from The John A. Hartford Foundation to improve lives of older adults and “to pilot a new set of shared decision-making (SDM) and other healthcare engagement tools geared toward older adults with serious illness.”** First, FAIR Health will assess needs related to the project. Then, a new set of SDM tools will be developed, and decision aids will be created. An advisory board, including physician Diane Meier, will work with FAIR Health in its efforts. The project will “help older adults and their family caregivers understand cost information for treatment options based on clinical evidence while balancing risks and outcomes aligned with their preferences and values.” (*HomeCare*, 7/22, <https://www.homecaremag.com/news/fair-health-receives-grant-john-hartford-foundation>; The John A. Hartford Foundation, <https://www.johnahartford.org/grants-strategy/a-national-initiative-to-advance-cost-information-in-shared-decision-making-for-serious-health-conditions>)

* **“Being a Bereavement-Conscious Hospice and Palliative Care Clinician” explores the opportunities that nurses have “to prevent the devastating bereavement outcomes that some patients experience.”** Great bereavement care, says the article, begins before a patient dies. Family member worries and stress often surround a patient’s end-of-life experience. Nurses can help by offering education about the dying process, and assuring loved ones that a patient’s suffering is being cared for. Talking with families about what is ahead, and supporting decision-making is also helpful. Family is defined here as “for whom it matters.” Bereavement grief screening is one tool to be used, and the article says that this is best done before a patient’s death. The article includes practical tips and examples. (*Hospice and Palliative Nursing*, August 2021, <https://pubmed.ncbi.nlm.nih.gov/34185724/>)

* **PsychCentral shares “6 Coping Skills to Work Through Grief.”** The article notes several kinds of grief and offers coping skills. These include the use of positive reframing, humor, spirituality, acceptance, focusing perspective, and problem-solving. (*PsychCentral*, 7/21, <https://psychcentral.com/health/coping-skills-for-grief#coping-skills-for-grief>)

* **Cake, “the world’s largest online platform for end-of-life planning and navigating mortality,” received \$3.7 million from a significant number of investors.** The pandemic has added to the value of end-of-life planning and created more interest in creating consumer engagement. Called “the first company to use AI and NLP technology at scale to improved user experience in end-of-life planning.” Cake grew rapidly last year and serves over 30 million people annually. In addition to consumer-facing tools, “Cake also has a business line building custom advance care and end-of-life planning solutions for health systems, health plans, insurance companies, and banks, including one of the largest health systems in the US.” (*PR Newswire*, 7/21, <https://www.prnewswire.com/news-releases/cake-raises-3-7m-to-expand-end-of-life-planning-offerings-amidst-growing-demand-301338285.html>)

* **The University of Vermont has researched “what happens during a conversation between a health care provider and a seriously ill person.”** What is being learned may help clinicians—especially newer ones—learn how to engage in these conversations. What works for one may not work for another. Careful listening is key, with frequent verbal requests for patients to share what they are thinking, what they need, and what they are feeling. (WCAX, 7/22, <https://www.wcax.com/2021/07/22/uvm-research-focuses-approach-end-of-life-conversations/>)

OTHER NOTES

* **Close to sixty groups are calling for mandated vaccines for all healthcare workers.** The groups include the American Medical Association, American Nurses Association, American Academy of Pediatrics, Association of American Medical Colleges, National Association for Home Care and Hospice, Mayo Clinic and the VA. In the joint statement, the groups say they hope to set an example for other employers. The last link below includes a copy of the joint statement. (*Washington Post*, 7/26, https://www.washingtonpost.com/health/2021/07/26/mandatory-vaccinations-urged-health-workers/?wpisrc=nl_sb_smartbrief; *Medpage Today*, 7/26, <https://www.medpagetoday.com/infectiousdisease/covid19vaccine/93747>; *CNN News*, 7/26, <https://www.cnn.com/2021/07/26/health/vaccine-mandate-health-care-workers/index.html>; *AMA*, 7/26, <https://www.ama-assn.org/press-center/press-releases/ama-support-covid-19-vaccine-mandates-health-care-workers>; *American College of Surgeons*, 7/26, <https://www.ama-assn.org/press-center/press-releases/ama-support-covid-19-vaccine-mandates-health-care-workers>)

* **Geripal features a podcast focused on the use of cannabis by older adults.** The free online podcast explores numerous aspects of cannabis and shares about interactions with other medications. (*Geripal*, 7/22, <https://www.geripal.org/2021/07/cannabis-in-older-adults-podcast-with.html>)

* **“Almost 9 in 10 physicians (87 percent) reported that data interoperability should be a high priority at their healthcare organization right now.”** So says a Harris Poll of about 300 physicians. Similarly high numbers show that physicians think increasing that electronic medical data (EHR) interoperability will improve diagnosis of patient illnesses and improved patient outcomes. And, 96% say that more and easier access to patient data may save lives. “However, the survey found that while EHR aims to improve patient care, burdensome clinical documentation processes within EHR hinders physicians’ ability to deliver high quality, patient-centered care.” (*EHR Intelligence*, 7/20, <https://ehrintelligence.com/news/google-9-in-10-docs-say-interoperability-data-exchange-top-priority>)

* **A *New York Times* article, written by author Michael Pollan, asks, “How Should We Do Drugs Now?”** The article explores the increasing legalization of cannabis, as well as decriminalization of heroin and cocaine. Oregon has legalized psilocybin therapy and is in a process to “train facilitators to administer them beginning in 2023.” More and more plant medications are included in a reform movement on drug policies, including “plant medicines” such as psilocybin, ayahuasca, iboga and the cactuses that produce mescaline.” As we move away from the “drug war,” asks Pollen, what is drug peace? He explores that question in depth. The article is online at the link below.” (*New York Times*, 7/9, https://www.nytimes.com/2021/07/09/opinion/sunday/drug-legalization-mdma-psilocybin.html?mc_cid=2a0dbf4fc7&mc_eid=d67266dfca)

* **An article in *Stanford Social Innovative Review* explores the values of leadership efforts of nonprofit organizations that engage those they serve as a critical part of the organization.** A research project by author Lehn M. Benjamin found that staff of nonprofits engage boards, staff, volunteers and others. But engagement with the beneficiaries of the nonprofit is often lacking. But, he notes, being “*motivated to make a difference for participants is not the same thing as placing participants at the center of managing and leading.*” Benjamin explores this situation and examines how “managing nonprofits might be different if participants were more central to our approaches.” From management practices, to donor engagement, to numerous other aspects of the organization, he examines management strategy, and notes examples of how some organizations are engaging participants more fully. (*Stanford Social Innovation Review*, 7/15, https://ssir.org/articles/entry/putting_participants_at_the_center_of_managing_and_leading_nonprofits#)

* **A *Medscape* commentary examines “The Peculiar Timing of Death.”** Physician Mark E. Williams recalls an important lesson about death that he learned in his early career, and how it reinforced his value and celebration of each day of life. (*Medscape*, 7/14, <https://www.medscape.com/viewarticle/954024>)

* **Healio News features an article that suggests that digital connectivity is becoming the sixth vital sign.** The barriers to connectivity, says physician Dr. David. C. Kohoff, are diminishing. Kohoff, in the transcript of a *Healio* interview, addresses the issues of connectivity and its impact on medicine and health care. (*Healio*, 7/23, <https://www.healio.com/news/endocrinology/20210723/connectivity-digital-tools-becoming-the-sixth-vital-sign-in-health-care>)

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