



What the Media Said about End-of-Life Care This Week March 1, 2021 A Service of Your State Association

EXPLORING ATTITUDES ABOUT DEATH AND END-OF-LIFE EXPERIENCES

Several recent articles explore the nature of death, how it is viewed and experienced, and how our attitudes about death and near-death experiences impact us. Each article addresses death from a different perspective and each brings issues and ideas for consideration.

Next Avenue recently published "[How our Attitude About Death Affects the Way We Age](#)." The subtitle asks: "Should we confront it, avoid it or something in between?" Gary M. Stern, a freelance writer, shares that he and his group of friends who are thinking more about death. Experiencing the pandemic, and watching friends die, Stern began wondering about what the healthiest attitude is to take toward death.

Stern interviewed palliative care specialists and they advised coming to terms with death and planning for it. Ethicist Arthur Caplan agrees that planning is helpful, and also suggested to him that dwelling too much on death is counterproductive.

BJ Miller, physician and author, talks about stages in facing death. The first stage is "coming gradually to accept the reality that one day you will die, not denying or fighting it." The second stage, Miller says, is a process of coming to terms with death. After these two steps, you have a feeling "of almost letting go." Miller adds that this "coming to terms with death is more important than ever." Otherwise the medical system will make your decisions for you, and the default will be to keep you on machines.

Physician and author Ira Byock says that failure to confront death comes with a price. "You rob life of its richness," he explains, by total avoidance. Byock suggests practical steps such as writing a will, pulling important documents together, and dealing with the underlying emotional issues. What needs to be said if you were to die suddenly?

While these leaders talk mostly about preparing for death, another leader has focused on patient's experiences. Hospice and Palliative Care Buffalo's CEO is Christopher Kerr, MD. Kerr researches the experience of death from the patients' perspective. He has written about and shared his work on patients' experiences including "vivid dreams that feature the patient's deceased loved ones."

He is also the author of “Death is But a Dream,” which was released a year ago. His TedxBuffalo talk, posted in 2015, has more than 3 million views on YouTube. And Netflix has a new documentary (also titled “Death is but a Dream”) in which he appears. Kerr recently offered an [*interview to Hospice News*](#) to talk about his research and to share how it informs the care that dying patients receive.

Over 20 years ago, Kerr says, he started paying more attention to “the non-physical dimensions of dying, the experiential piece of it from the perspective of the patient.” His medical students dismissed the idea saying there was no evidence. While there were many antidotes, surveys, and reports, there was no rigorous study. So he designed a series of studies, and eight manuscripts from these studies have been published thus far.

What Kerr has learned, he says, is that there is much more to dying than a “medical phenomena.” Kerr says, “Your perspective and your perceptions change as you’re nearing the end of life.” There are “profound inner experiences that either come out through conversation or through dreams, where there’s a reflection on the dying process” These dreams that patients report have an extremely high scale of being “strikingly vivid. And these experiences increase as patients draw closer to death. They’re recalled with clarity. They’re 100% distinct from confusional states.”

There are some patterns that patients report. As death draws closer, the dreams are “ever more populated by the people who you’ve loved and lost.” These experiences are, Kerr says, “incredibly common.” In their studies, “about 90% of patients relayed at least one experience, and about 88% of them were overwhelmingly positive” This finding offers a way to understand dying as more than physical, more than pain, and more than our anticipated grief

While Kerr conducted the work in order to help with medical education, he reports that the medical community has not had much interest. But now it has ended up in the “major media platforms in this country and around the world with a momentum that’s been absolutely stunning.” Kerr views the lack of interest from the medical community as “a lack of responsible oversight and ownership.” Our “cure-all” and “death-denying” system is uncomfortable with this subjective information. Patients and families, on the other hand, are drawn to, and seem to identify with, the findings.

In a somewhat similar exploration, *Geripal* has an article [*“It’s Time We Started Talking Openly About Near-Death Experiences and After Death Communication,”*](#) written by social worker Scott Janssen. *Janseen asserts that these phenomena “have positive impacts such as decreasing fear of death, bringing peace, or deepening one’s appreciation for important relationships.” Hospice and palliative care staff says Janssen, should take these experiences seriously.* Simply offering seriously-ill patients information about these kinds of experiences, regardless of whether they have had one, can decrease their fear of death and enhance comfort.” Professional caregivers can ask if patients have had any similar experiences Often this opens paths for deeper conversations. Some patients will have many questions and some will dismiss the idea.

Janssen offers a case study and numerous tips to professional caregivers on entering these conversations with patients. (*Next Avenue*, 2/25); (*Hospice News*, 2/22); (*GeriPal*, 2/22)

AFTERSHOCK OF THE PANDEMIC: GRIEF AND MENTAL HEALTH CONCERNS GROW

A number of experts are concerned about the growing and overwhelming grief and mental health concerns that are emerging as the pandemic has continued. A research study of survivors, an *ABC* news report, and a *CNN* opinion piece all add to the ongoing and growing awareness of these needs

Australia's Curtin University conducted research about COVID-related deaths and the needs of survivors. The lead author of the study, an Australian, worked with American researchers to interview people in the US who had experienced the death of a "close person" to COVID-19. The research is explored in "Family Caregiver's Preparations for Death: A Qualitative Analysis," in *Journal of Pain and Symptom Management*. Researchers found that mourners "would benefit from timely support and care to reduce the high risk of experiencing problems in important areas of everyday life."

The research revealed that grief from deaths that occurred during the pandemic were "felt more acutely than deaths before the pandemic, and deaths from other natural causes." This grows primarily because of the restrictions that lead to lack of access for caregivers to be with those who are dying. Researchers call for palliative care to integrate psychological care "to facilitate efficient and cost-effective means of supporting people who are grieving." The title of a media release reporting on the study, "Study suggests greater need for grief support due to COVID-19," is the essence of the findings. The article is available online.

A *CNN* opinion piece examines the complications when the loss of loved ones is also bare of rituals of memorials and burials. David Perry, the author, has experienced grief during the pandemic. Perry says, "We are left with the cold fact of imminent death surging throughout this brutal winter, without access to any of the rituals that might make it more bearable. And the continuing restrictions on gatherings extend the possibility of "communal grieving" into the future. "The road ahead," he writes, "is still grim and solitary." The numbers of losses of lives and bereaved persons, he says has become unfathomable. There is so much grief and loss to be faced, and so much pain.

How will all of this suffering be addressed? "Our mental health systems aren't ready," Perry says. "Our spiritual leaders may not be ready either. We'll have to be proactive both in building capacity to support mourning and encouraging people to take care of themselves in an era of post-Covid trauma." Additionally, there is a bureaucracy to be dealt with. Well before the pandemic, human resource systems "grudgingly yield a day or two of paid leave in the immediate aftermath of a death, and then only for an immediate family member." Our systems are not prepared for the coming and ongoing cycles of "delayed mourning."

A link on line with the *CNN* piece, offers a close, intimate video of those suffering at the loss of their loved ones. It vividly reveals their suffering and pain, and their lack of access to traditional grieving rituals. Perry's advice: "Build more space in our work, our families and communities to make space for a long process of grieving." And, he adds, "Assume that everyone is struggling with the trauma of living through a year of mass death, faced mostly alone.

Another looming crisis is the focus of a report by *ABC News*. They say there is a mental crisis being faced by healthcare workers. "Experts say some doctors, nurses and other [health workers on the frontlines](#) will have to face a mental [health](#) reckoning after being in the trenches fighting the global pandemic. *AMA* says that physician stress was high before the pandemic, and has now increased dramatically.

The article highlights the life, service and death of physician Lorna Breen. "Her family says the weight of the unrelenting pandemic crushed her seemingly indomitable spirit." Breen committed suicide. Physician Mona Masood started the Physician Support Line that offers confidential mental health support to physicians at no cost. The support has a team of over 700 volunteer psychiatrist and have already been engaged with more than 200 physicians and medical students.

Breen's family members are working with other organizations and members of Congress to pursue lasting change via a law that will remove "barriers to mental health care within the medical profession at the national level." (*Journal of Pain and Symptom Management*, 2/27) [Read more...](#) (*Eureka Alert!*, 2/25) [Read more...](#) (*CNN*, 2/11) [Read more...](#) (*ABC News*, 2/16) [Read more...](#)

HOSPICE NOTES

* *Geripal* hosts "So you want to be a hospice medical director?" Presenters include two medical directors who talk about being a hospice medical director, reasons to make this choice, training that is needed, and other topics. The podcast is online at the link below. (*Geripal*, 2/25) [Listen to the podcast here.](#)

* In order to "maximize their scale and negotiating power with payers' value-base payment models," five Wisconsin providers of hospice and palliative care have joined in a partnership and created a new organization. The five organizations formed the *Wisconsin Hospice and Palliative Care Collaborative (WHPCC)*, a 501c3 organization, whose joint services cover 80% of the state. *WHPCC* will partner with payers under a single contract. The plan is to work together in negotiation "quality management, compliance, policies and procedures. . ." (*WHPCC*, 2/24) [Read more...](#) (*Hospice News Network*, 2/24) [Read more...](#)

* NHPCO released “[Black and African-American Outreach Guide](#).” The guide includes such topics as “disparities in Black/African-American health, outreach as a standard of practice, and strategies for reaching out to Black/African-American communities. Marisette Hansan is President/CEO of the Carolinas Center and a member of NHPCO’s Diversity Advisory Council. Hansen calls for customizing our work with these communities. “So we have to create listening sessions we have to engage in partnerships. And that guide really gives you a roadmap of what you can do to be successful.” And NHPCO’s President and CEO Edo Banach points out that only 8.2 of Medicare beneficiaries who received hospice in 2018 were African American. Banach calls for a re-commitment to working harder to be sure equitable access is a reality for all diverse communities. The guide recognizes disparities, offers data, provides strategies for outreach, and offers further resources. The guide is available online at the second link. (NHPCO, 2/24) [Learn more...](#)

* OIG released an audit report saying that Florida’s Tidewell hospice should return \$8.3 million dollars to the Federal Government. “Tidewell did not comply with Medicare requirements for 18 of the 100 claims in our sample,” says the report. Tidewell hospice disagrees with this action. Tidewell’s President and CEO Jonathan Fleece “vehemently” disagrees with the action. An attorney for the hospice “disagreed with the findings but did not disagree with two of the three recommendations made by the inspector general.” A statistical expert, employed by Tidewell, felt the sampling method “used by the Inspector General’s Office was flawed, as well as its extrapolated conclusion.” “Tidewell Hospice stands by our practices and our principles,” says Fleece. (OIG,2/18) [Read more...](#) (Sarasota Herald-Tribune, 2/25) [Read more...](#)

* A hospice nurse at the Veterans Affairs Medical Center in Bedford, MA, was sentenced to 40 months in prison for diverting patients’ morphine during January 2017. She admitted mixing water from the sink and diluting the patients’ medication. She then “ingested a diluted amount of the remaining drug.” (Boston25NEWS, 2/24) [Read more...](#)

* “On February 22, 2021, the United States Supreme Court denied a petition to review the decision of the Third Circuit Court of Appeals in the case *United States ex rel. Druding v. Care Alternatives*, 952 F.3d 89 (2020), thus declining to resolve a split among the federal appellate courts on the issue of the standard for proof of falsity under the False Claims Act.” The issue revolves around the desire for clarification on “proof of falsity under the false claims act.” As recent as 10/23/20 NHPCO, NAHC, AHCA, AAHPM, and AMA submitted an amicus brief supporting this review of the *Care Alternative Case*. (Lathrop GPM, 2/25) [Read more...](#)

PALLIATIVE CARE NOTES

* Colorado's Department of Public Health and Environment has released a new study titled "[Palliative Care in Colorado: Trends, Gaps, and Opportunities to Improve Care](#)." The report shares results of a statewide survey of all palliative care providers in Colorado. The Executive Survey says, "The goal of this survey was to measure growth in palliative care and to identify opportunities to improve care for Coloradans suffering from serious illness." Feedback for the survey was inclusive, including feedback from all Colorado hospitals, 76 hospices, and known community-based palliative care providers. This study was a collaboration effort of the *Colorado Department of Public Health & Environment*, the *Colorado Department of Health Care Policy & Financing*, the *American Cancer Network's Cancer Action Network*, and the *Center for Improving Value in Health Care*. The study was conducted by *Hospice Analytics*. The report is extensive, data rich, and inclusive of survey measures and other information. The top recommendations include: "1) additional funding mechanisms for palliative care; 2) ongoing statewide education, networking and mentoring; and 3) development of palliative care data collection and reporting tools." Based on results of the above study, the Colorado Department of Public Health & Environment and the Center for Improving Value in Health Care also released an *online interactive map* of Colorado Palliative Care Providers. (*Colorado Department of Public Health and Environment*) [Learn more...](#)

END-OF-LIFE NOTES

* An oncology nurse tells of her anxiety about death and how the poetry of Mary Oliver supported her. The personal story is available online. (*LIT HUB*, 2/18) [Read more...](#)

* "Giving Voice to Grief Through Poetry" is the latest episode of *End of Life University*. The podcast features Bruce Sterling, an author and poet. Sterling shares his own story of grief and how poetry has supported him. The podcast is online at the link below. (*End of Life University*, 2/22) [Access the podcast here.](#)

* Minnesota State Senator Chris Eaton shares an opinion piece with *StarTribune* titled "Now more than ever, Minnesotans need end-of-life aid." Eaton, and House Representative sponsored a bill to allow "mentally capable, terminally ill adult Minnesota residents with six months or less to live the option to request a doctor's prescription they could choose to take if their suffering becomes unbearable and they wish to die peacefully in their sleep." Eaton, who first sponsored the bill in 2015, says citizen support is strong. In 2016, 73% agreed this should be a legal option. (*Star Tribune*, 2/23) [Read more...](#)

* Connecticut legislators are considering a bill to offer physicians' help to terminally ill patients who ask for assistance in ending their lives. The public health committee had a hearing on 2/25 and heard from more than 100 advocates and opponents of the bill. Previous efforts have not become law. (*NBC TV*, 2/26) [Read more...](#)

* *Compassion and Choices* offers a webinar focused “on end-of-life education and planning from a faith perspective.” Led by leaders of faith communities, the webinar explores the issues. The webinar, titled “Black History Month Webinar: End-of-Life Empowerment and the Faith Community,” is available online. (*Compassion and Choices*, 2/18) [Learn more...](#)

Hospice Analytics is the national sponsor of Hospice News Network for 2021. 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.

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