



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

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A Service of Your State Association

OPPOSING VIEWS ON AID IN DYING OUTLINED IN *STAT*

As “right-to-die” legislation is debated in states across the U.S., many doctors and patients deal with the reality of painful deaths. *STAT* recently published two articles from doctors who laid out opposing arguments on such legislation. In their arguments, they looked at history, ongoing studies, and personal experiences to show the many sides of the debate.

Ira Byock is a palliative care physician and chief medical officer of the Institute for Human Caring of Providence St. Joseph Health in California. Byock’s article “Physician-assisted suicide won’t atone for medicine’s ‘original sin’” argues against aid in dying. Instead, Byock urges quality care that avoids suffering and refocuses on the fundamentals of caring. Roger Kligler, a Massachusetts doctor with stage 4 prostate cancer, draws from his personal and professional experiences to outline a contrasting perspective. His article in *STAT* is titled, “I’m a doctor with end-stage cancer. I support medical aid in dying.”

Byock writes that modern medicine’s “original sin” is “believing that we can vanquish death.” He sees a history of technological innovation—sanitation, vaccinations, and radiation treatments—as a powerful, but also detrimental, to the mentality of the profession. “When disease can no longer be kept at bay,” he writes, “modern medicine tends to give up altogether.”

Dying badly, he argues, is a crisis that is most evident and extreme in university-based referral centers. Byock cites one study that showed that UCLA’s cancer center referred only 23% of incurably ill patients to hospice before death. After embedding a palliative care nurse practitioner in selected clinics, this number rose to 53%. The study also found cancer patients receiving excess radiation treatments. This “overzealous treatment results in added revenue for doctors and the cancer center,” Byock writes, “but takes a disturbing toll on frail patients’ scant energy and fleeting time.”

Roger Kligler, on the other hand, believes terminally ill patients have the right to end intolerable suffering. Given the movement in state legislation to support assisted dying, he believes “that time is coming.” Kligler tells the story of watching his own mother and father-in-law suffer agonizing deaths from cancer when he was in his 40s. He thought then, “That’s not the way I want to die.”

As a palliative care doctor, Kligler says, he eased many patients pain, but he reflects on cases where he's "embarrassed to say that I declined to give [a particular patient] a lethal prescription, as I put my needs ahead of his. That is a morally compromised position."

Eventually, Kligler was forced to retire due to the progression of his cancer. He and his wife attended a lecture about medical aid in dying, and this led him to do something that was uncharacteristic of him. He decided to be less private about his illness and work to bring the assisted dying option to Massachusetts. He became an activist, worked as a volunteer for Compassion & Choices, a national nonprofit organization, testified in support of the End of Life Options Act, and involved himself in the effort to shift the medical society to drop opposition to medical aid in dying and establish a policy of "neutral engagement."

Soon after, he was experiencing pain "as the cancer ate away at my pelvis." He received palliative radiation and immunotherapy, but says that if the time comes that his pain is intolerable, he wants the ability to end that suffering. For both Byock and Kligler, the limits of medicine and technology play a role in that suffering, but they represent a divide in the doctors' positions towards patients' death. (STAT, 1/31) [Read more...](#) (STAT, 1/31) [Read more...](#)

END-OF-LIFE CARE AND PSYCHEDELICS EXPERIENCEING AN EVOLVING RELATIONSHIP

Palliative care researcher Dr. Ira Byock's "Taking Psychedelics Seriously," is a study that appears in the *Journal of Palliative Medicine*. He says that there is an expanding base of evidence regarding the safety and benefits of psychedelics. But issues like politics, regulation, and industry create challenges for legitimate use of psychedelics. Still, right-to-try laws in multiple states provide precedents for terminally ill patients to access treatments that have not yet gained FDA approval. Dr. Byock argues that, given the prevalence of suffering and growing acceptance of physician-hastened death, it's time to revisit the research into therapeutic use of psychedelics that began in the 1950s and 1960s.

Vice also includes an article that discusses the issue, titled "Can Magic Mushrooms Help Us Come To Terms With Death?" Researchers at New York University and Johns Hopkins University conducted experiments in 2016 to see how patients nearing the end of life responded to psychedelics." The central question being explored was whether people facing the crushing end-of-life anxiety could be helped by a psychedelic experience?

"This is a completely different way of working with people," clinical psychologist Dr. Stephen Bright tells *Vice*. "What we try to do in palliative care is to relieve pain and suffering as much as possible by giving people pain medication. But morphine's not going to take away their anxiety or their depression."

Dr. Bright, who is also vice president of Australia's Psychedelic Research In Science and Medicine association, says follow-up assessments are promising. Of the patients in the NYU trial, 70% rated the experience as one of the top five most spiritually significant experiences of their lives, and 87% reported increased life satisfaction overall. A research paper from the *Journal of Psychopharmacology* attributes this success to the "mystical experience," which is described as an encounter of profound unity, transcendence, and positive mood that is infused with a renewed sense of purpose and meaning.

Psilocybin disables the default mode network—what allows certain parts of the brain to communicate while cancelling out "cross talk" from other areas—and thus opens up new lines of communication. Dr. Bright says of the patients, "I guess they feel a sense that there's something else out there, and they're more likely then to talk heart-to-heart and have that meaningful conversation."

For palliative care doctors, this unlocking of emotional and spiritual pain could be profound. Dr. Byock writes that palliative care clinicians encounter patients with emotional, existential, or spiritual suffering that persists "despite optimal existing treatments." This can take away a sense of worth in life. Byock links this to data from Oregon that shows most terminally people obtaining prescriptions to end their lives are motivated by non-physical suffering.

"Taking Psychedelics Seriously" offers a history of this particular class of drugs and their therapeutic potential. It considers the potential in careful patient screening, preparation, and administration of such drugs. If the research is expanded, other patients could potentially experience the results that Dr. Bright has witnessed. "By having the psilocybin experience they can see death in a whole different way," he says. "They're much more comfortable with it." (*Journal of Palliative Medicine*, 1/22) [Learn more...](#) (*Journal of Psychopharmacology*, 11/30/2016) [Learn more...](#) (Vice, 1/29) [Read more...](#)

HOSPICE NOTES

* Hospices are learning from the lessons of 2017's hurricanes and wildfires. NHPCO's *Newsline* covers the issue, offering insights from interviews with hospice providers in California and the southern part of the U.S. who endured natural disasters. They stress the importance of knowing if patients plan to shelter in place or evacuate, considering coordination of services and supplies, planning medication needs, and thinking of all possible roadblocks—including such mundane things as tire repair. Every provider agreed that a well-developed and rehearsed emergency plan was essential. "Pearls of Wisdom" include providing real cash advances to staff before a disaster, taking care of staff, planning for those who may lose a home, coordinating with state and local emergency management agencies, and developing pre-disaster partnerships with providers outside your service area. (*NHPCO Newsline*, Winter 2017)

* The National Coalition for Hospice and Palliative Care (the Coalition) is comprised of nine national organizations representing clinicians from the full interdisciplinary team, researchers, and hospice and palliative care programs. They focus on the “Four C’s”: Cooperation, Communication, Coordination, and Collaboration. The Coalition addresses challenges in the field including the evolution of health care and health policy in the U.S., increasing the number of benefit recipients, achieving innovative designs to meet needs, addressing misconceptions, and creating new resources for those in the field. (*NHPCO Newslines*, Winter 2017)

* CMS will allow non-skilled home health care support as a supplementary benefit in Medicare Advantage plans beginning in 2019. “Our priority is to ensure that our seniors have more choices and lower premiums in their Medicare health and drug plans,” writes CMS Administrator Seema Verma, emphasizing the benefits of flexible plans. The change hopes to “compensate for physical impairments, diminish the impact of injuries or health conditions, and/or reduce avoidable emergency room utilization.” The announcement does not explicitly include plans to include hospice benefits as supplemental benefits, but the article notes the idea was “floated late last year” and this new change could signify more changes to come. (*Home Health Care News*, 2/1)

[Learn more...](#)

* Garth Brooks performed “If Tomorrow Never Comes” along with co-writer Kent Blazy at an iconic Tennessee cafe to benefit Alive Hospice. The performance coincided with the song’s 30th anniversary. (*WKRN*, 2/2) [Learn more...](#)

* A *NCP Stakeholder Summit Summary Report*, available for download, captures key themes, considerations, and ideas discussed during the Summit, held in June of 2017. The summit hosted 58 representatives from 43 national and regional organizations from a range of care settings, provider associations, accrediting bodies, payers, and community service organizations. [View the report here.](#)

END-OF-LIFE NOTES

* Dozens of physicians, ethicists, and lawyers are urging Congress not to pass “right-to-try” legislation that would allow dying patients access to unapproved, experimental drugs. A letter drafted by Alison Bateman-House, associate professor of medical ethics at NYU Langone Health, and her colleagues addressed concerns. The letter was aimed at the House Committee on Energy and Commerce that is currently considering the bill. The over 40 signatories of the letter say, “This legislation sells vulnerable patients and families false hope at the expense of weakening the FDA’s critical role in making sure that all Americans can have confidence in the safety and effectiveness of our medical products.” (*STAT*, 2/1) [Read more...](#)

* Amy Levine shares what she has learned from working with those facing death. Levine runs the Doula Program to Accompany and Comfort, a non-profit that trains and matches those who visit people facing the end of life alone. Uncertainty can plague people, she says, and we worry about saying the “right thing.” She says we often wish to prevent, fix, or ignore death. “As illness progresses, loss increases,” she says. “We need help to care for ourselves — our personal needs. We lose the ability to join others, to meet new people, to seek connection.” H (*Huffington Post*, 2/1) [Learn more...](#)

PALLIATIVE CARE NOTES

* A new study from the *American Journal of Kidney Diseases* studies end-of-life care for patients with advanced kidney disease in the U.S. Veterans Affairs health care system. The authors found that patients treated with dialysis received more intensive patterns of end-of-life care. They also discovered that if “there had been a decision not to pursue dialysis therapy before death, [those individuals] were more likely to receive palliative care and hospice.” (*AJKD*, 1/10) [Learn more...](#)

* West Virginia’s House Bill 4035 was introduced in January with the hopes to create an Advisory Coalition on Quality of Life. This coalition would seek to improve quality and delivery of patient-centered and family-focused care in the state. The bill outlines its membership, power and duties, and sunset date at the end of December 31, 2021. (*West Virginia Legislature*, 1/12) [Learn more...](#)

* Mississippi is on its way to receiving its first palliative care facility, which could see medically vulnerable patients, including those who are now at the Children’s Hospital. The House passed a bill in January that would lease state-owned property in Jackson to a nonprofit that will pay for the new facility. Guy Giesecke, CEO of Children’s of Mississippi, says that these patients deserve to live in a more home-like facility where they can still receive the highly specialized care they require. (*U.S. News*, 1/29) [Learn more...](#)

* An article in the *Journal of Palliative Medicine* compares palliative care teams at two hospitals. One hospital has advanced practice nurses only model of palliative care delivery (APN model). The other hospital has implemented an interdisciplinary team—concluding that the team model reduces length of stay and saves money. Writing for *Pallimed*, Brianna Morgan and Elise Tarbin say the study warrants further scrutiny. They argue that the authors consider “a handful of variables” and that it is worth considering whether other contextual factors impacting the success of palliative care teams. They point to “gender, years of experience, feelings of autonomy and empowerment” and “environmental factors (e.g. disease-related characteristics of the patient population, systems-level signs of support for palliative care such as palliative triggers),” among other factors to consider. (*Pallimed*, 1/27) [Read more...](#) (*Journal of Palliative Medicine*, 12/1/17) [Read more...](#)

* *Medline Plus* and the *National Institute of Nursing Research* have collaborated to offer a new text-based service for those living with serious illnesses, their families, and caregivers who are interested in palliative care. Texting MP CARE to 468311 will sign users up for a weekly message on palliative care. (*Medline Plus*, 1/12) [Learn more...](#)

* A new study from the *Journal of Palliative Medicine* concludes, "There are significant unmet data needs for a comprehensive accountability system in serious illness care." The study set out to identify specific data needs and assess gaps. The researchers suggest, "These gaps can be prioritized and addressed through alignment and collaboration across stakeholders." (*Journal of Palliative Medicine*, Volume 21, 2018)

* What can chaplains do in outpatient palliative care? A recent pilot study conducted among 31 patients with advanced cancer looked at the feasibility of chaplain-delivered spiritual care in outpatient settings using the Spiritual Assessment and Intervention Model (Spiritual-AIM). The study contributes to an area of palliative care research, *Medscape* writes, which has not been well supported or studied. (*Medscape*, 1/26) [Learn more...](#)

OTHER NOTES

* The first annual report from the Colorado Department of Public Health and Environment regarding the End-of-Life Options Act shows that "it's working well," *Cision* reports that data show that 69 terminally ill adults utilized the option, 37 Colorado physicians wrote prescriptions for aid-in-dying medication, and 19 pharmacists dispensed them. "The data ... assures me that there are no problems with the Colorado End-of-Life Options Act as written," says Dr. Cory Carroll, a family physician in Fort Collins, who has participated in the law. The report includes tables illustrating: 1) Underlying terminal illnesses/conditions among patients prescribed aid-in-dying medication; 2) Categories of medications dispensed to patients prescribed aid-in-dying medication; and 3) A summary of patients who died following prescription of aid-in-dying medication, including by sex, age group, race/ethnicity, marital status, education, county of residence, place of death and hospice enrollment status. (*Cision*, 2/1) [Read more...](#)

* Two Utah measures, that would allow terminally ill people to use certain types of marijuana and would allow for farmers to grow it for research purposes, passed through their first legislative hurdle. The movement has its detractors on both sides—including advocate Christine Stenquist who argues that everyone with chronic pain, not just those who are terminally ill, should have access to marijuana for pain and symptom relief. Stenquist suffers from trigeminal neuralgia, a condition of the nerve linked to the face. Lawmakers have rejected this broad medical use in multiple sessions. The proposal will now move to a vote before the full house. (*The Kansas City Star*, 1/31) [Read more...](#)

* Apple has announced their plan to offer electronic medical records, bringing together records and providing a fuller snapshot of health. The iOS 11.3 release will debut these expansions in a Health Records section of the Health app that comes pre-installed. “Johns Hopkins Medicine, Cedars-Sinai, Penn Medicine and other participating hospitals and clinics are among the first to make this beta feature available to their patients,” Apple writes. Dr. Paul Sax suggests that Apple begin by building a universal immunization record. (*Apple*, 1/24) [Learn more...](#) (*NEJM*, 1/29) [Read more...](#)

* Amazon, J.P. Morgan, and Berkshire Hathaway announced that they intend to form an independent healthcare company, but offered few details. To David Vivero, CEO of the digital health startup Amino, the news “proves every business is a healthcare business,” as the companies’ unique incentives and influence highlight how pervasive healthcare challenges are to employers. With few details and similar claims of health care involvement being circulated in the past, the article says that the healthcare industry “isn’t holding its breath” on immediate market disruptions. (*Healthcare Dive*, 1/31) [Learn more...](#)

* Yale University Assistant Professor and health economist Zack Cooper responded on Twitter to the news that Amazon, JP Morgan, and Berkshire Hathaway aim to form a new health care company. He writes, “I do hope Amazon, JP Morgan, & Berkshire succeed. Health care is wildly inefficient. However, it’s a bit like Mayo Clinic, Cleveland Clinic, and Partners Health coming out and saying they don’t like their computers so they’re going to form a new IT company.” (*Twitter*, 1/30) [Read more...](#)

* Scrapbooking can serve as a way to share, remember, and help loved one’s cope with grief. Excelsa Health Frick Hospital in Mount Pleasant launched its scrapbooking bereavement group in April, which they say allows people to be creative and take away tangible projects. “(*Herald-Standard*, 1/29) [Read more...](#)

* “This is the wrong way to deal with the opioid epidemic,” writes Jeffrey A. Singer for *Newsweek*. He examines the passage of The Arizona Opioid Epidemic Act in late January, passed only three days after it was introduced. This means it was passed without testimony from medical professionals and experts. “Among the harmful features of the Act,” he says, “are strict restrictions on the amount and dose of opioids doctors can prescribe to new and postoperative patients.” Singer says this approach isn’t “just inhumane, it’s dangerous” because patients will turn to illegal markets or other drugs for relief. “This sloppy, ill-conceived, and hasty piece of legislation is best understood as a bipartisan act of political grandstanding by the Governor and the legislature in a year when the Governor and most lawmakers are up for re-election. They have until 2019 to fix it before its harmful effects begin to appear.” (*Newsweek*, 1/29) [Learn more...](#)

* Over 90 bipartisan Senators and Congressional leaders sent a letter to the FDA calling for their attention to drug shortages related to the impact of Hurricane Maria in Puerto Rico. Puerto Rico is the home of about 80 pharmaceutical companies, and these companies manufacture about 10 percent of all drugs that Americans consume. “The lack of medicines and medical supplies since Maria devastated Puerto Rico is creating immense anxiety for hospitals, providers, and, most importantly, the patients they serve,” say the authors of the letter. The leaders call on the FDA to answer a number of questions and to work on resolution of this concern. (U.S. Senate, 2/2) [Read more...](#)

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