Death with dignity has improved end-of-life care nationwide.

The passage of death with dignity laws, starting with the Oregon Death with Dignity Act in 1994, has had an impact that extends far beyond providing a heretofore unavailable end-of-life option. It brought conversations about death and dying out of the shadows and into mainstream discourse in Oregon and nationwide.

In the process, the public began to explore the full range of end-of-life options to a greater degree and policymakers, clinicians, and health systems created policies and procedures to ensure patients' preferences for care were documented and honored.

BACKGROUND: THE SUCCESSFUL PASSAGE AND DEFENSE OF THE OREGON DEATH WITH DIGNITY ACT

The Oregon Death with Dignity Act [1] came about not as a novel idea but as a carefully considered policy whose authors learned from unsuccessful attempts to pass aid-in-dying legislation in other states.

The most significant difference between the Oregon Death with Dignity Act and ballot initiatives defeated in Washington and California in 1991 and 1992, respectively, was that it did not seek to legalize euthanasia. Indeed, the authors of the Death with Dignity Act and the founders of Oregon Right to Die, the political action committee that led the successful campaigns for the law's passage in 1994 and against its repeal in 1997, took special care to introduce a stringent series of safeguards designed to prevent abuse. [2]

Following its passage in November 1994, by a margin of 51 to 49 percent and the failure of its repeal in November 1997 by a margin of 60 percent to 40 percent, the Death with Dignity Act was subjected to a host of challenges at the state and federal level, from the Drug Enforcement Agency in the Clinton years to the Supreme Court during the George W. Bush presidency. [3]
Since its implementation began in 1998, the law has continued to work as its authors and champions intended, bringing peace of mind and autonomy to qualified terminally ill Oregonians. Researchers and clinicians alike recognize the Oregon Death with Dignity Act as a viable end-of-life option for terminally ill patients and contributing to wide-ranging improvements in end-of-life care.

DECADES OF DATA UNDERSCORE THE EFFICACY OF THE OREGON LAW

What has made the Oregon experience so instructive to advocates and medical professionals in other states is the abundance of data collected during the law's two decades of implementation.

The Oregon Death with Dignity Act requires the state's Health Authority to produce annual reports detailing, among other things, the number of prescriptions written under the law; the number of patients who ingest the medication; and the demographics of people who use the law. [4]

Patterns in the data have remained consistent over 20 years of reporting. The most recent annual report from the Oregon Health Authority, for 2017, shows that, as has been the case since the law's inception, the majority of patients who used the law to hasten their death were 65 or over, insured, well educated, and enrolled in hospice care. [5]

Since implementation began, 1,967 Oregonians have had prescriptions written for them under the law and 1,275 patients have died from ingesting the prescribed medication. In this time, the estimated rate of Oregon Death with Dignity Act deaths in the state averaged 40 per per 10,000 total deaths. The law is used sparingly: one third of all those who receive prescriptions do not take the medications, and Oregon Death with Dignity Act deaths are a minuscule proportion of all deaths in the state.

OREGON A MODEL FOR EXCEPTIONAL END-OF-LIFE CARE

Medical professionals in states across the country look to Oregon's continuum of care for patients at the end of life, reflected in state policy, the practices of clinicians, and the culture surrounding death and dying. What the data continue to show is that Oregonians die with the comfort and control desired by the majority of Americans.

A 2017 survey by the Kaiser Family Foundation asked respondents about their preferences for end-of-life care and their perception of how the U.S. healthcare system handles patients in their final stage of life. [6]

Consistent with a number of surveys and polls conducted in the past decade, the majority of Americans surveyed, 71 percent, said that, given the choice, they would prefer to die at home. The same percentage said the most important component of end-of-life care should be "helping people die without pain, discomfort, and stress"; however, 49 percent of respondents thought most patients did not have enough control over decisions about their own end-of-life care, indicating that patients' desires about pain management and medication may not always be honored.
Hospice care received high marks from respondents: 87 percent of Americans who had someone in their household utilize hospice care in the past year said they have a positive opinion of hospice.

**OREGON LEADS THE NATION IN HOSPICE AND PALLIATIVE CARE**

Hospice utilization in Oregon has continued to increase; a recent *New England Journal of Medicine* report found that more people die at home or in hospice in Oregon than in any other state. [7]

In a comprehensive study conducted with family members of 86 Oregonians who were participating in the Oregon Death with Dignity Act, researchers concluded [8]:

"...another concern regarding the legalization of PAD [physician aid in dying] is that PAD would become a substitute for quality end of life care... Insofar as family rating of the quality of a loved one's death is an indicator of end of life care, this study adds to the evidence that the choice to pursue PAD does not appear to be due to, or a reflection of, poorer end of life care."

Ann Jackson, who led the Oregon Hospice Association during the campaign to pass and defend the Oregon law in the 1990s, wrote in 2008 [9]:

"*The Oregon Death with Dignity Act has been a catalyst...in efforts to improve Oregon's end-of-life care. Hospice workers, collectively and individually, strongly support the right of Oregonians to choose from among all legal end-of-life options.*

"*And hospice workers are unanimous in agreement that the ODDA facilitates meaningful and important conversations about the end of life.*"

Researchers comparing patterns of hospice use in various states have recognized Oregon's high rate of hospice use as exceptional. The authors of a 2015 *Journal of Palliative Medicine* report suggested a connection between the implementation of the Death with Dignity Act and the state's high quality of end-of-life care [10]:

"*It is possible that the Oregon Death with Dignity Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options, more appropriate palliative care training of physicians, and more efforts to reduce barriers to access to hospice care and has thus increased hospice referrals.*"

In the two decades since the enactment of the Oregon Death with Dignity Act, Oregon has developed a culture of collaboration among clinicians across disciplines and integration of educational resources that helps patients and providers work together to set goals for end-of-life care planning.

Susan W. Tolle and Joan M. Teno argue that other states, like California, should follow Oregon's lead to improve end-of-life care for all residents, not just those who express interest in obtaining a prescription under the state's aid-in-dying law [11]:
“Replication of the experience in Oregon requires the development and adoption of interventions at every step in this complex medical and social interaction. We must embrace the complexity, develop dynamic and multifaceted interventions, track the quality of care, and embed these interventions in the local and national health care culture.”

California’s largest health systems took the established medical standard of care and built policies and processes to integrate medical aid in dying into end-of-life care.

When drafting institutional policy for implementation of the End of Life Option Act, top administrators and clinicians at California’s regional and statewide health systems looked to Oregon's decades of data and to their peers in Oregon who had significant experience helping patients access the state’s Death with Dignity Act.

In December 2015, two months after California Governor Jerry Brown signed the End of Life Option Act into law, the University of California-San Francisco convened the End of Life Option Act Task Force, "to promote thoughtful deliberation on topics that will be relevant to healthcare systems as they create patient-centered policies to respond to the End of Life Option Act in California." [12]

The Task Force was similar in structure and purpose to Oregon Health and Science University's Task Force to Improve Care of Terminally Ill Oregonians, established in 1997 following the enactment of the Oregon Death with Dignity Act. [13]

The UCSF Task Force first convened in December 2015 to discuss strategies for developing policies related to the new law and again in September 2017 to debrief on processes and lessons learned from the first year of the Act's implementation.

CALIFORNIA’S END OF LIFE OPTION ACT AS PART OF HEALTHCARE

The End of Life Option Act clearly relates to health care and the calls in the Governor's Proclamation. [14] "Healthcare" includes end-of-life care, and the Act has provided eligible persons with access to another end-of-life care option beyond palliative care, hospice care, and other options of last resort.

Even a cursory review of the Act's provisions confirms that it incorporates reliable indicia of health care, such as requiring a medical diagnosis, a patient-physician relationship, a second medical opinion, a patient’s informed consent, and health-related regulatory oversight.

The fact that health insurers, including but not limited to Medi-Cal, provide coverage for medical aid in dying is further evidence that the Act relates to health care.

The Act also has resulted in more comprehensive conversations between patients and health care providers about end-of-life care in California. Significantly, as has happened in other states that have passed aid-in-dying laws, these broader conversations have led to better use of end-of-life health care options that pre-existed the Act.
Indeed, residents of states with aid-in-dying laws are better-versed in end-of-life care issues than of those with no such statutes. A poll by *National Journal* and The Regence Foundation has found residents in Oregon and Washington to be more knowledgeable and supportive of a variety of end-of-life options, including hospice and palliative care, than most Americans. [15]

A direct and foreseeable result of the Act is the relief it provides to many seriously ill Californians even if they do not take the prescribed medication. Indeed, the mere existence of the Act provides individuals with comfort that, should they qualify for medical aid in dying, they will be able to receive it, thereby maintaining control over their end-of-life care and decisions.

The implementation of the Oregon Death with Dignity Act demonstrates that medical aid in dying is not only an established component of palliative medicine, but it has improved the continuum of end-of-life care.

**IMPLEMENTING THE END OF LIFE OPTION ACT: AN INTERDISCIPLINARY APPROACH**

Representatives from California's largest health systems, including Sutter Health, Kaiser Permanente Northern California, Providence California, and the University of California-Los Angeles described the interdisciplinary approach each of their institutions undertook to create policies and practices that would inform how clinicians worked with patients to help them access the law.

Multiple systems developed steering committees or working groups comprised of clinicians and experts from the disciplines of oncology, hospice and palliative care, pharmacy, psychology, and medical ethics. These groups met regularly in the months leading up to and following the implementation of the law to address the law's technicalities, the importance of preparing healthcare professionals across disciplines to speak with patients about the law, and the mechanics involved in integrating the law into a system's existing continuum of end-of-life care.

While specific strategies and policies differed by system, several key elements described by participants were consistent across multiple health systems:

- Every health system used the opportunity provided by the passage of the EOLOA to train and educate clinicians of all disciplines to have conversations with patients about the full range of end-of-life-care options, including medical aid in dying;
- Conversations between patients and providers about accessing the End of Life Option Act led to broader conversations about patients' wishes for end-of-life care [16];
- Most patients who made requests under the End of Life Option Act already were involved in hospice or had received palliative care consultations;
- Many patients who requested and received medication under the law seemed to view the medication as a last resort, as evidenced by the fact that they obtained a prescription for medication under the law but never filled it;
- Key decision-makers consulted regularly with clinicians, epidemiologists, medical ethicists, and other medical professionals in Oregon and Washington to gather data and guidance related to the implementation of those states' aid-in-dying laws.
DEATH WITH DIGNITY COMPLEMENTS HOSPICE AND PALLIATIVE CARE

The 2017 California Department of Public Health report on the End of Life Option Act shows that over 83 percent of persons who took medical aid-in-dying drugs were receiving hospice or other palliative care at the time. [17] This figure mirrors years' worth of data from Oregon and other states that have passed aid-in-dying laws and underscores that, rather than a substitute, medical aid in dying is a complement to hospice and palliative care.

These concerns as manifest in Oregon have been explored by Quill [18]:

"Will legalizing physician-assisted death undermine improvements in palliative care and hospice? Data from Oregon suggest that the opposite may be true. Compared to other states, Oregon appears to have a very high percentage of deaths at home (where most people would prefer to die), high rates of hospice referral, high opioid prescribing rates per capita, and a statewide [Do Not Resuscitate/Do Not Intubate] policy, which has been the model for much of the rest of the country.

"Legalization of PAD has also been a wake-up call for physicians, who now frequently attend palliative care and hospice training programs knowing that they must be experts at basic palliative care if they are to be responsive to the more challenging patients who want to discuss PAD."

In two short years, California health systems have adopted policies related to implementing the End of Life Option Act that require medical professionals across a wide range of disciplines to be skilled at conducting conversations with patients about their wishes for end-of-life care and provide them the tools and integrated support to do so on a large scale. Reports from those who were most intimately involved in the earliest stages of implementation suggest that the state of California is poised to create a culture around end-of-life care that champions an integrative approach to providing patients with information and access to a full range of end-of-life options, including medical aid in dying.

"AN UNFORESEEN BENEFIT" OF THE ACT

In his proclamation convening the 2015 California Legislature's extraordinary session on healthcare, Gov. Brown directed lawmakers to "consider and act upon legislation necessary to... improve the health of all Californians." [19]

The passage of the End of Life Option Act and its subsequent implementation has had what physicians interviewed by the Los Angeles Times described as "an unforeseen benefit" [20]:

"Physicians across the state say the conversations that health workers are having with patients are leading to patients' fears and needs around dying being addressed better than ever before. They say the law has improved medical care for sick patients, even those who don't take advantage of it.
'It really has created a new standard for how we ought to be helping people at the end of life,' said Dr. Neil Wenger, director of the UCLA Health Ethics Center."

Health systems and healthcare providers in California have used the opportunity afforded by the passage of the End of Life Option Act to learn more about patients' needs and priorities for end-of-life care. Given time, what is now novel could evolve into a new normal in which all Californians, regardless of their interest or ability to access aid in dying, explore and document their wishes for care at the end of life.

TOWARD IMPROVING END-OF-LIFE CARE

As the number of states with assisted-dying laws continues to grow, end-of-life care in these states is improving in tandem. The successful implementation of the Oregon Death with Dignity Act, and the state's status as a model of exceptional hospice and palliative care, paved the way for California and other jurisdictions to adopt similar policies. In the process, residents of six states and the District of Columbia have gained access to a vital end-of-life option, and all Americans have benefited from the ways medical aid in dying has improved the continuum of end-of-life care.

The beginning of a cultural shift within health systems catalyzed by the passage of the End of Life Option Act has the potential to create in California a healthcare environment similar to that of Oregon, where aid in dying has become an essential component of a comprehensive system of end-of-life care.

As members of the End of Life Option Act Task Force wrote in 2017, "Ideally, California providers will use the momentum of change to reach the same "silver lining" of improved end-of-life care achieved by Oregon providers since the Death With Dignity Act went into effect." [21]
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