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 COVER STORY TWO

Medical aid in dying

A complex ethical dilemma

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regon's 1994 Death with Dignity Act was the nation's first law authorizing medical aid in dying, allowing mentally capable, terminally ill adults with six months or less to live the option to request, obtain, and self-ingest medication to die peacefully in their sleep if their suffering becomes unbearable. Since then, eight more states—Washington, Montana, Vermont, California, Colorado, Hawaii, New Jersey, Maine and the District of Columbia (DC)—have authorized medical aid in dying.

In my role as Doctors for Dignity Program Manager at Compassion & Choices, I speak with physicians across the country, some in authorizing states who have written prescriptions for terminally ill patients and others who

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are just beginning to incorporate medical aid in dying into their practices. I also hear questions and concerns raised by colleagues who live in states where medical aid-in-dying legislation is being considered. Here are a few of the common themes that have emerged.

Safeguards ensure proper application of medical aid in dying

While specific state laws vary, Oregon's Death with Dignity Act and every other medical aid-in-dying statute requires that a terminally ill patient who requests medical aid in dying be fully evaluated by two physicians who must concur that the patient qualifies. They must agree on a six-month prognosis and that the patient is capable of making medical decisions and understanding the consequences of those decisions. Both doctors are obliged to ensure that patients are fully informed of all the alternative options, including hospice care and pain control, and that patients are volitional and free from coercion. If either physician questions the patient's capacity, a mental health consultant makes the final determination.

Annual reports from the Oregon Health Authority indicate that the vast majority of terminally ill patients who request medical aid in dying are suffering from an advanced disease with a predictable trajectory; the most common diagnoses are cancer and ALS. Most patients are enrolled in hospice care at the time of the request, which ensures another level of protection as hospice enrollees are evaluated by an interdisciplinary team of health professionals on a regular basis.



Fears of abuse are unsubstantiated

Opponents of medical aid in dying often express concerns that legalizing medical aid in dying could lead to abuse by physicians, families, or insurers. They particularly cite fears that underserved communities or people living with disabilities could be pressured to forgo care or be denied care if medical aid in dying were an option. More than 45 years of cumulative data in authorizing states belie these concerns. No physician has been disciplined, and not a single instance of abuse or coercion has been substantiated. In fact, Disability Rights Oregon, the nonprofit whose mission is to protect the rights of people living with disabilities, has not had a single complaint of abuse of the state's Death with Dignity law.

Regardless of whether a state has authorized medical aid in dying, insurance providers cover treatments that are deemed effective and proven, and not those considered unnecessary or experimental. A research article published in the New England Journal of Medicine concludes that insurers have no financial incentive to pressure patients to accelerate their deaths.

Medical aid in dying does not undermine hospice or palliative care

Since Oregon's Death with Dignity law was enacted, hospice use in Oregon has grown and is now double the national average. Oregon consistently

ranks high in hospice quality indicators and appropriate usage. More people in Oregon die at home (80%) than nationally (20%) and fewer experience invasive medical procedures in the last month of life. Ann Jackson, the former CEO of the Oregon Hospice Association and a former opponent of the Death with Dignity law, declared publicly that the law led to more open conversations, improved the ability of hospice programs to address fears, and had been implemented responsibly.

Pain is not the main concern

Requests for medical aid in dying do not reflect a failure of palliative medicine. The reasons most patients give for choosing medical aid in dying are related to a desire for control, loss of quality of life, preserving autonomy, and avoiding unnecessary suffering. Physical pain is a less common factor (25%), as are economic concerns (5%).

Suffering can take many forms and personal values play an important role. According to ethicist Eric Cassell, MD, while physicians agree that relief of suffering is central to our role, diagnosing suffering requires an understanding of the person, not just the disease. Suffering is not a mental affliction, but a complex interplay of disease symptoms with values, personality, and spiritual meaning. According to Cicely Saunders, founder of the modern hospice movement, total pain is the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.

For the vast majority of dying patients, hospice provides much needed support and relief from pain. But for some, prolonging the suffering that accompanies an inevitable death inflicts further suffering.

Doctors are free to follow their conscience

Medical aid in dying is an ethical dilemma because it presents tension between two competing goods: the desire to prolong life and the desire to alleviate suffering. In the face of such a dilemma, the patient must decide what is best for them. Medical ethics require physicians to respect patient autonomy, act in the interest of the patient, and to do no harm. But who decides?

Health care professionals who find that medical aid in dying conflicts with their religious or moral views are under no legal obligation to provide these services. However, a licensed physician is bound by professional ethics that precludes withholding medical information. Requests for medical aid in dying are an opportunity for all physicians to explore the meaning behind the request and better meet the patient's needs. Ethically, clinicians who choose not to participate in medical aid in dying should, at a minimum, provide patients with a reliable source of information about medical aid in dying and transfer medical records upon request.

Language matters

The medical community is grappling with appropriate language to describe and define medical aid in dying. A growing number of authoritative sources have discontinued use of the term “physician-assisted suicide” in favor of language that distinguishes a request by a terminally ill patient to hasten an inevitable death from the suicidal ideation that results from cognitive impairment. The American Academy of Hospice and Palliative Medicine uses the term “Physician-Assisted Dying,” while the American Academy of Neurology coined the term “Lawful Physician-Hastened Death.”



The lens through which we view requests for medical aid in dying can impact the care that patients receive and have implications for suicide-prevention strategies. Interpreting a request for medical aid in dying as “suicide” can trigger an inappropriate response and miss the opportunity to explore the deeper meaning behind the request.

Legally, in all jurisdictions where medical aid in dying is authorized, statutes emphasize that: *“Actions taken in accordance with [the Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.”* Assisting a suicide, which would occur outside the boundaries of the law, remains illegal.

Support for medical aid in dying is strong

Since 1997, Gallup polls have consistently shown support for medical aid in dying at between 64% and 74%. Public polls (<https://tinyurl.com/mp-thoman01>) show that more than two-thirds of Minnesota’s voters support medical aid in dying. That support is bipartisan and diverse, and spans every demographic group. Minnesota State Fair Surveys from 2016 showed support among fairgoers at 68% (<https://tinyurl.com/mp-thoman02>).

In a 2018 Medscape poll of 5,200 physicians across 29 specialties (<https://tinyurl.com/mp-thoman03>), nearly six out of 10 (58%) said that “‘physician-assisted suicide’ or ‘physician-assisted dying’ should be made legal for terminally ill patients.” As a result, a growing number of national and state medical societies have endorsed or adopted neutral positions regarding medical aid in dying in order to respect and protect both members who participate in medical aid in dying and those who opt out.

The Minnesota Medical Association created a task force to study physician aid in dying, which resulted in a position of conditional neutrality. As long as adequate safety parameters are met, the MMA will not oppose medical aid-in-dying legislation (<https://tinyurl.com/mp-thoman04>).

The growing movement in Minnesota

Legislation modeled after Oregon's Death with Dignity law was first introduced in Minnesota by Sen. Chris Eaton and Rep. Mike Freiberg in 2015. Feedback from legislative hearings and regional listening sessions resulted in the current End-of-Life Option Act. In September 2019, over 120 Minnesotans packed an informational hearing in support of the End-of-Life Option Act, which is likely to be revisited during the 2020 session.

As public awareness grows, physicians will have a unique opportunity to engage in the conversation. Becoming educated about medical aid in dying and separating fact from fiction will prepare physicians to answer questions that may arise. Compassion & Choices offers peer-to-peer resources for physicians, including Doctors for Dignity and Doc2Doc, which helps physicians provide unbiased information and better care to patients who ask about available end-of-life options. Up To Date provides clinical guidance in dealing with patient requests for medical aid in dying.

The grassroots movement to expand access to medical aid in dying is led by terminally ill individuals and the families of those who suffered unnecessarily at the end of life. Their mission is to empower every patient to chart their own end-of-life course.

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