

The Clinical, Ethical and Legislative Case for Medical Aid in Dying in New York

By David C. Leven and Timothy E. Quill

Introduction

Palliative care and hospice should be standards of care for seriously ill and dying patients.¹ Most, but not all, suffering can be adequately addressed with the skillful addition of palliative measures to a patient's treatment plan. Therefore, the first place to go if a patient makes a request for medical aid in dying is to ensure that his or her suffering is thoroughly understood and addressed with state of the art and science palliative care.² To be clear, medical aid in dying is not part of usual palliative care or hospice practice. It is the process by which an adult, mentally competent, terminally ill patient, who doctors determine is likely to die within six months, self-consumes prescribed medicines to end suffering and achieve a peaceful death.

Some patients making requests for medical aid in dying have witnessed bad deaths in their life experience, and are worried about going through a similar process in their own future. Such patients can benefit from a thorough exploration of what they have seen and are afraid of from their own lives, followed by a frank discussion about how one's doctor proposes to address such circumstances should they occur to the patient him or herself. In the vast majority of cases (but not 100 percent) such suffering can be addressed with the skillful provision of palliative treatments without resorting to treatments that intentionally hasten death. Experienced palliative care experts are increasingly available to help address the most challenging problems, making the need for direct assistance in dying because of immediate, intractable suffering relatively rare. However, if you happen to be one of those infrequent cases with intractable, unrelievable, severe suffering, you have a real problem that requires a direct medical response.

Of course, not all patients who request medical aid in dying do so because of severe immediate physical suffering that is refractory to treatment. The majority of patients making these requests do so because the dying process is going on too long for them to tolerate, and they are "tired of dying" or intolerant of the debility, which is so often a central part of the late stages of the experience.³ Such patients may be used to being in control of their own lives and of their own bodies, so becoming extremely dependent upon others is not something they want to accept or to which they can adjust. As a society we tend to admire similarly situated patients who choose to stop life supports to maintain their independence, but should there be no life support to stop in the presence of a similarly debilitating illness, we sometimes accuse patients of having an excessive "need to control" their future.

Every dying person should have a right to excellent palliative care and hospice no matter what other choices they make—be it requesting long shot, aggressive, disease-directed treatment, or treatment devoted entirely to palliation delivered with the help of a hospice program, or, if they are mentally competent and fully informed, treatments that might hasten death. As much as possible, given constraints imposed by one's disease process as well as limitations imposed by the law, patients should be able to die in a way that is consistent with their values and beliefs. Clinicians who care for seriously ill patients should facilitate palliative care for the dying, and they should also become aware of the full range of legally available "last resort" options to help address severe and intractable suffering.⁴ Ideally, in our opinion, medical aid in dying should be one of those legally available options of last resort.

Hastening death by medical aid in dying is ethically similar to other legal means of hastening death, including the withholding or withdrawal of life-sustaining treatment, voluntarily stopping eating and drinking, or palliative sedation to unconsciousness.⁴ Each of these options will result in death, and each requires some form of physician participation. Health care professionals are arguably more actively involved in the resulting deaths of their patients when withdrawing life-sustaining treatment such as a ventilator than when providing a potentially lethal medication that a patient can take at a time of his or her own choosing. If a clinician took someone off a life support without the permission of the patient or her surrogate decision maker and the patient died, the clinician would potentially be subject to murder charges. Similarly, providing palliative sedation to unconsciousness while not simultaneously providing life-sustaining treatment without permission from the patient or his surrogate decision maker would be both unethical and illegal. The intent and consent of terminally ill patients matter much more than the intent and willingness of health care professionals.

Medical Aid in Dying Should Not Be Considered "Assisted Suicide"

Patients who choose medical aid in dying determine the manner of their deaths just as do many patients who choose other last resort options. They should be carefully evaluated for their decision-making capacity, but they are

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not by definition “suicidal” unless their decision is distorted by associated mental illness. Stark differences exist between dying patients who are making a life-ending decision in the context of a severe, irreversible terminal illness, and those with primarily mental illnesses who die by suicide.⁵ Mental illness-related suicide is committed by those who usually do not have a terminal illness and could continue to live but choose not to, usually because of some distortion in their thinking based on potentially treatable mental illness. Such suicides are usually done in isolation, often impulsively and violently, and are tragic. We should do everything in our power, including potentially involuntary hospitalization, to prevent them. To the contrary, in the U.S. states where medical aid in dying has been legalized, it is available only to terminally ill patients who will soon die; it is the result of a carefully thought out process that usually takes several weeks; and it requires consultation from two physicians who must document their findings and almost always includes support of immediate family. The term “assisted suicide” is rejected by the American Public Health Association, American Academy of Hospice and Palliative Medicine, American Medical Women’s Association, among others, and in state laws which permit aid in dying. Most recently, the American Association of Suicidology issued a comprehensive statement, “SUICIDE” IS NOT THE SAME AS “PHYSICIAN AID IN DYING” (<http://www.suicidology.org/Portals/14/docs/Press%20Release/AAS%20PAD%20Statement%20Approved%2010.30.17%20ed%2010-30-17.pdf>)

Medical Aid in Dying Laws Have Worked as Intended as an Ethical Practice in U.S. States Where It Has Been Legalized

There is a growing body of evidence, compiled over two decades from Oregon and Washington, which demonstrates that aid in dying is beneficial to some terminally ill patients by allowing them to escape unwanted suffering, and that it causes no significant harm to patients, families, or the medical profession. It has not undermined efforts to improve hospice and palliative care within these jurisdictions, and in some cases may even improve delivery of palliative care and hospice services.⁶ No major problems have emerged as expected by opponents.

Medical aid in dying is thought about frequently but rarely used. In Oregon, one out of six terminally ill patients talk to their family members about the option, and one out of 50 talk to their doctors about it, but it accounts for only about one in 300 deaths.⁷ Furthermore, one-third of patients who obtain the medications do not take them, but such dying patients are probably comforted knowing that this option is available.

In U.S. states where the practice is legal, there is no evidence of disproportionate impact on vulnerable populations, nor is there evidence of related coercion or abuse.⁸

There is evidence that family members of those who request aid in dying may feel better prepared and accepting of their loved one’s death.⁹ There is also evidence that patients who access aid in dying have at least as good, and in some cases better, deaths than others.¹⁰ About 90 percent of those who end their lives by using aid in dying in Oregon are receiving hospice care, so the issue of more palliative care resolving the issue is irrelevant (<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>). Almost all patients who choose aid in dying have health insurance and most are college educated, as indicated in the above report.

There is no evidence of any slippery slope in the US. Medical aid in dying is only for the terminally ill, mentally competent adults. There is no serious or concerted movement to extend medical aid in dying to those who are not terminally ill. And, there is no evidence that where medical aid in dying is permitted the reputation of the medical profession has suffered in any way.

Seventy-seven percent of New Yorkers support aid in dying, according to a 2015 poll, including large majorities of Democrats, Republicans, Conservatives, and Catholics. Physicians support aid in dying by an almost 2 to 1 margin, 57 percent to 29 percent per a 2016 Medscape poll, though some of those physicians who support the practice in general terms would not want to provide medical aid in dying themselves. Where legal, physicians who do not want to participate are not required to do so.

Medical Aid in Dying Legislation in New York

Legislative efforts to establish medical aid in dying as a right began in New York in 2015. The current bills, A. 2383 (Paulin) and S. 3151 (Savino), also called the Medical Aid in Dying Act, are comprehensive and patterned after laws in other states which permit aid in dying and which have worked as intended.

Although there are no statutory safeguards and protections pertaining to other decisions by patients (or their agents or surrogates) where death results, such as withdrawing life-sustaining treatments, or voluntarily stopping eating and drinking, or palliative sedation, there are numerous safeguards and protections in the Medical Aid in Dying Act. Some of the key provisions are summarized below.

1. To legally request medical aid in dying (MAID), a patient must be at least 18 years of age and have a terminal illness as defined, confirmed by an attending physician and a consulting physician.
2. A patient must make an oral and a written request (on a form provided in the law) for MAID. The written request must be witnessed by 2 adults who attest that the patient: 1) has capacity; 2) is acting voluntarily; and 3) is not being coerced.

3. One witness shall NOT be: 1) a relative; 2) a person entitled to a portion of the patient's estate; 3) an owner, operator or employee of a health care facility where the patient resides or is being treated; or 4) the patient's attending physician, consulting physician or mental health professional, if applicable, who determines capacity.
4. If either the attending or consulting physician believes the patient lacks capacity, the physician must refer the patient for evaluation by a mental health professional. Only patients subsequently found to have capacity may proceed.
5. A patient may rescind his or her request for medication at any time without regard to capacity.
6. Patients must be able to self-administer the medication.
7. An attending physician must have primary responsibility for the care of the patient requesting MAID and the treatment of the patient's terminal illness.
8. Attending physician responsibilities: 1) determine that the patient has a terminal illness; 2) determine that the patient has capacity, made an informed decision, and made the request for aid in dying voluntarily and without coercion; 3) inform the patient of the need for a consulting physician's confirmation, and refer if requested; 4) refer the patient to a mental health professional for evaluation if the physician believes the patient lacks capacity; 5) provide information and counseling regarding palliative care; 6) ensure the patient is making an informed decision by discussing with the patient the patient's diagnosis and prognosis, the potential risks associated with taking the medication, the probable result of taking the medication, the possibility that the patient may choose to obtain the medication but not take it, the feasible alternatives or additional treatment options including hospice and palliative care; 7) discuss with the patient the importance of taking the medication with someone else present and not taking the medication in public; 8) inform the patient that he/she can rescind the request for medication at any time; 9) document in the patient's medical records all MAID actions as specified; 10) ensure that all appropriate steps have been carried out in accordance with the MAID act; 11) offer the patient an opportunity to rescind the patient's request prior to writing the MAID prescription.
9. The consulting physician must: 1) examine the patient and medical records; and 2) confirm in writing that the patient i) has a terminal illness, ii) has capacity, iii) is making an informed decision, and iv) is acting voluntarily and without coercion.
10. A mental health professional asked to determine the capacity of a patient must, in writing, report to the attending and consulting physicians his/her conclusions whether the patient has capacity. If the mental health professional determines that the patient lacks capacity, the patient may not receive MAID.
11. A patient requesting MAID shall not be considered "suicidal," and a patient who self-administers aid in dying medication shall not be deemed to have committed suicide.

Conclusion

The lessons from Oregon or Washington where medical aid in dying has now been legal for a combined total of almost 30 years are that their laws have functioned as intended, there have been no abuses, there is no evidence that such laws in any way undermine progress in promoting palliative care and hospice care as standards of care for seriously ill and dying patients, and there are currently no concerted efforts in those states to repeal or amend those laws. We are confident that the provisions, safeguards, protections and restrictions outlined above ensure that, if enacted, the Medical Aid in Dying Act will work well in New York and provide another needed, albeit infrequently used, last resort option for terminally ill New Yorkers.

Endnotes

1. Morrison RS, Maroney-Galin C, Kralovec PD, Meier DE. The growth of palliative care programs in United States hospitals. *J. Palliat. Med.* 2005;8:1127-34.
2. Quill TE. Doctor, I want to die. Will you help me? *JAMA* 1993;270:870-3.
3. Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State. Patient requests and physician responses. *JAMA* 1996;275:919-25.
4. Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA* 1997;278:2099-104.
5. Ganzini L, Beer TM, Brouns M, Mori M, Hsieh YC. Interest in physician-assisted suicide among Oregon cancer patients. *J. Clin. Ethics* 2006;17:27-38.
6. Lee MA, Tolle SW. Oregon's assisted suicide vote: the silver lining. *Ann. Intern. Med.* 1996;124:267-9.
7. Tolle SW, Tilden VR, Drach LL, Fromme EK, Perrin NA, Hedberg K. Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide. *J. Clin Ethics* 2004;15:111-8.
8. Battin MP, van der Heide A, Ganzini L, van der Wal G, Onwuteaka-Philipsen BD. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *J. Med. Ethics* 2007;33:591-7.
9. Ganzini L, Beer TM, Brouns MC. Views on physician-assisted suicide among family members of Oregon cancer patients. *J. Pain Symptom Manage* 2006;32:230-6.
10. Smith KA, Goy ER, Harvath TA, Ganzini L. Quality of death and dying in patients who request physician-assisted death. *J. Palliat. Med.* 2011;14:445-50.