

Physician Aid in Dying: The American Experience

Elizabeth Paulk, M.D.

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"It seems to me that, as with opposition based on whether the physician is 'active,' the argument that physicians should be only 'healers' focuses too much on the physician, and not enough on the patient. When healing is no longer possible, when death is imminent and patients find their suffering unbearable, then the physician's role should shift from healing to relieving suffering in accord with the patient's wishes. Still, no physician should have to comply with a request to assist a terminally ill patient to die, just as no patient should be coerced into making such a request. It must be a choice for both patient and physician."

Marcia Angell, M.D.

"The routine practice of physician-assisted suicide raises serious ethical and other concerns. Legalization would undermine the patient-physician relationship and the trust necessary to sustain it; alter the medical profession's role in society; and endanger the value our society places on life, especially on the lives of disabled, incompetent, and vulnerable individuals. The ACP-ASIM remains thoroughly committed to improving care for patients at the end of life."

Daniel Sulmasy, M.D. & Lois Snyder, M.D.

This is to acknowledge that Elizabeth Paulk, M.D. has disclosed that she does not have any financial interests or other relationships with commercial concerns related directly or indirectly to this program. Dr. Paulk will not be discussing off-label uses in her presentation.

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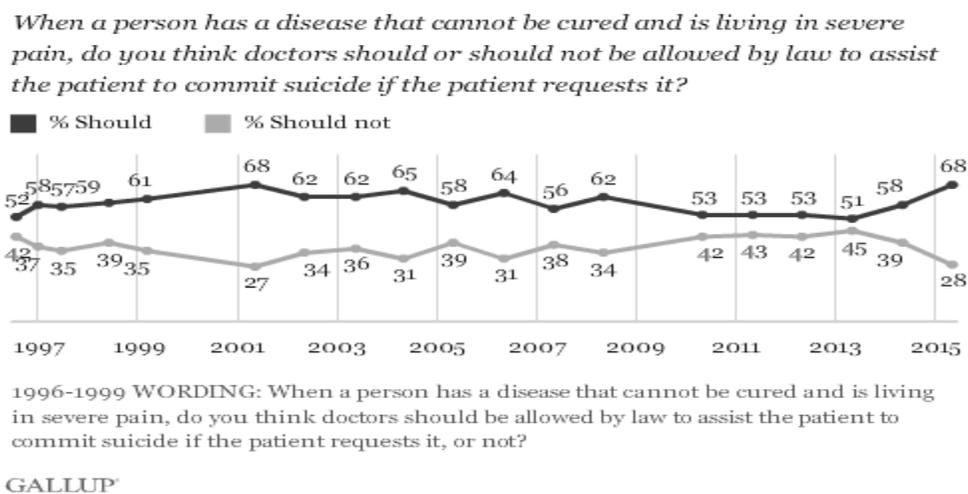
This Grand Rounds presentation is intended to leave the audience with an understanding of the history of Physician Assisted Suicide in the United States, the current legislative landscape, and what the experience with PAD has been in areas where it is legal. It will include a discussion of the how the practice is conducted, which patients are likely to request and receive the intervention, and what both proponents and opponents feel the nation should move in the future to ensure optimal end-of-life care.

Educational Objectives

- 1.) Learners will understand the process for requesting Physician Aid in Dying under the Oregon Death with Dignity Act
- 2.) Learners will be able to identify which patients are most likely to request Physician Aid in Dying
- 3.) Learners will be able to list at least one moral argument supporting Physician Aid in Dying and more moral argument against.

Physician Aid in Dying is a very controversial subject, and one that raises strong feelings for those on both sides of the argument. Some view it as a compassionate act on the part of a physician to alleviate intractable suffering. Others view it as a barrier to the improvement of end-of-life care and a slippery slope to euthanasia of the disabled, eugenics and ethnic cleansing. Still others hold moral or religious beliefs that make the taking of life under any circumstances unconscionable. The debate over this issue gets at the very core of what it means to be a physician: our rights, our relationships with and obligations to our patients, and how we as a profession prioritize the competing demands of relieving suffering and preserving life. Consequently, this topic carries great emotional valence. The purpose of this discussion is to advocate neither for nor against the practice of Physician Aid in Dying (PAD). The sole purpose is to inform the audience of the existing data regarding the practice after 16 years of experience with Death with Dignity Act in Oregon and review how that data can inform the debate.

PAD has been very prominently discussed and debated in the popular press and on social media over the last year after the well-publicized case of Brittany Maynard, a 29-year-old with Glioblastoma Multiforme who moved to Oregon from California so she could take advantage of the Death with Dignity Act, and receive Physician Aid in Dying (PAD). She and her husband, supported by the organization Compassion & Choices, released a series of videos explaining their motivations and were received, for the most part, very sympathetically by the American public. In the wake of this public discussion, a number of states have begun considering legislation to legalize PAD. Although it seems unlikely that this is a subject that will come before the Texas Legislature any time soon, it is a subject that our patients, friends, and families are aware of and likely to have questions about. As Academic Physicians, we have a particular obligation to keep ourselves informed about the debate and be prepared to discuss it with patients, students, and house officers.



Historical Context

As long as there has been human suffering at the end of life, others have been troubled by the question of how to address it. Since antiquity, there has been controversy about whether or not hastening death to mitigate suffering was within the purview of a healer. There is literature addressing the issue in religious and philosophical texts from many traditions, generally opposing any hastening of death. Unfortunately, literature clarifying how the Death with Dignity movement (which seeks legalization of PAD) evolved is relatively sparse, but generally it seems to represent the confluence of three separate but related streams of thought. First, during the 1900's, best sellers about mercy killings of terminally ill patients with intractable suffering (such as Death of a Man and Jean's Way) and suicides of famous people in the face of terminal illness (including religious leader Henry P. Van Deusen and author Arthur Koestler) generated a lot of publicity. Second, patient trust in physicians and medical institutions suffered significantly as a consequence of national scandals like the Tuskegee experiment and the hepatitis experiments at Willowbrook school. This information helped undermine the public's trust of physicians in general, seek to assert their own rights and to emphasize the importance of their autonomy in medical decision making.

Finally, the healthcare environment, particularly as it relates to care of the dying, underwent a huge revolution in the 1960's with the invention of chronic mechanical ventilation. Prior to the 1960's, aside from polio patients in an iron lung, patients who became critically ill were not able to survive in most cases. With the advent of mechanical ventilation, we became able to keep the bodies of dying people alive far longer than the natural course of their illness would have allowed. In the majority of cases, this is a miraculous thing. In some cases, however, physicians were like teenagers with an extremely powerful car. We really had not safely learned to use all the power we had, and very quickly it became clear that the ethical principles that had guided medicine for the previous 2000 years did not provide the guidance required to navigate the questions that came up. The principles of "do no harm" and "preserve life" increasingly became competing priorities. Patients and doctors found themselves troubled by how to find the most moral and ethical way to approach clinical situations such as persistent vegetative state and terminally ill patients who could not be weaned from or wished to refuse aggressive life sustaining therapies. The public observed that dying was increasingly medicalized and seemingly out of an individual's control.

Efforts to optimize the patient's right to self-determination caused a wave of changes to sweep through the U.S. legal system starting in 1967 with the Living Will. Other controversial (at the time) innovations were the first U.S. hospice agency in 1972 and The California Natural Death Act in 1976, which gives legal standing to living wills and protects physicians from being sued for failing to treat incurable illnesses. Perhaps the most influential change of all came with the

determination, in *Cruzan v. Director, Missouri Department of Health*, that patients have the right to refuse unwanted medical interventions, even if it means that their death may be the result. It also confirmed a patient's right to appoint a healthcare proxy to speak for him or her in the event that capacity is lost. Regarding the case, Justice William Brennan wrote, "An ignoble end steeped in decay is abhorrent. A quiet, proud death, bodily integrity intact, is a matter of extreme confidence." [1] The *Cruzan* decision solidified the right to refuse unwanted treatment, but did not solve all the problems surrounding End of Life (EOL) care in the United States. The Institute of Medicine issued a report in 1997 called, "Approaching Death: Improving Care at the End of Life" [2] which described many endemic problems, including poor pain and symptom management, lack of advance care planning, and deaths occurring most commonly in institutional settings.

These three streams were converging in the early 1990's, and there was a public sentiment that patients were getting sucked into a medical industrial complex at the end of life. Once inside it was almost impossible to escape - people who were dying didn't really have a way to take back their autonomy, and take control over how their deaths would go. The book *Final Exit*, by Derek Humphry, leader of the Hemlock Society, came out in 1991 [3]. It detailed how terminally ill patients can painlessly end their lives and spent 18 weeks on the New York Times bestseller list. The environment was also right for the public to consider the ideas of a very controversial pathologist by the name of Jack Kevorkian. Dr. Kevorkian had a variety of unorthodox ideas, one of which was that prisoners on death row should have the right to donate their organs for transplantation prior to execution. [4] The idea that struck a chord with the public, however, was the right of the terminally ill patient to commit suicide with the assistance of a physician. He invented two different machines, facilitating death by thiopental and carbon monoxide. His ideas went almost completely unrecognized by the medical community but were widely recognized by the American public.

Money from the sale of *Final Exit* was used by the Hemlock Society to fund the ballot measure in Oregon that came to be known as the Death with Dignity Act. It passed in 1994, but legal objections stood in the way of enacting the law until 1997. The Supreme Court, upon hearing the case, determined that, while patients do not have a right to Physician Assisted Suicide, there is nothing in the Constitution that forbids it, and the determination regarding legality should be made by each individual state. [5] About ten years later Washington State voters passed the Washington Death with Dignity Act. Vermont followed suit in 2013. In Montana, there was no legislative change – the state supreme court determined that the practice is legal under their existing laws. [6] There is also one county in New Mexico where PAD is currently legal. The practice is legal throughout Canada, in Holland, Belgium, and Switzerland.

The medical establishment has not embraced the concept of Physician Aid in Dying, although that may be changing, at least among younger physicians. A recent Medscape poll revealed that about 54% percent of physicians were in favor of patients having the right to physician assisted suicide[7]. In 2001, the American College of Physicians came out with a statement that they did not support the legalization of physician assisted suicide, citing ethical concerns, worry that the practice would erode the patient/physician relationship, and that vulnerable populations would be at increased risk[8]. Most state legislatures agreed with the ACP. In 45 states, physician assisted suicide is currently illegal.

In 2014, Brittany Maynard came into the public eye. She was a beautiful young woman diagnosed after one year of marriage with Glioblastoma Multiforme who moved from California to Oregon to use the Death with Dignity Act. After fairly public media campaign explaining her motives she decided to take the medication on November 1, 2014 and died at home in Portland with her husband and her family. The publicity surrounding her actions catapulted this debate back into the public eye but even so the medical literature is very quiet on the topic.

The Death with Dignity Act

The Oregon Death with Dignity (DwD) Act[9] legalized PAD for adult state residents of Oregon who are able to make and communicate informed health care decisions, and is fully outlined at the Oregon Health Authority website. It explicitly does not allow euthanasia, an act taken by another that ends the life of the patient. The practice of euthanasia, although the Greek roots of the word mean “good death,” has very strong associations for a lot of people because of its historical context and potential for abuse. Euthanasia, which can be voluntary (at the patient’s request) or involuntary, is illegal in either context in all 50 states (the practice is legal in Holland). Suicide is the act of killing one’s self because of a desire not to continue living. We generally think of suicide as the end of a life that would otherwise continue without the intervention. Proponents of PAD, and the Oregon Death with Dignity statute, argue that the name, “Physician Assisted Suicide” is inaccurate, because the patient will die regardless of the intervention.

The Death with Dignity act applies to adult Oregon state residents with decision making capacity who, in the reasonable judgment of two physicians, have an incurable and irreversible illness that will result in death within six months. The process is as follows:

- 1.) Patient makes an oral request to the primary attending.
- 2.) The primary attending and a consulting physician make a determination of eligibility. If there are any concerns about capacity, psychiatric consultation is sought.

- 3.) The patient makes a second oral request no sooner than 15 days later.
- 4.) The primary attending provides a full description of the Death with Dignity act. The attending physician must also inform the patient of alternatives including Palliative Care, Hospice and pain management options.
- 5.) The patient must submit a written request, no sooner than 13 days after the initial request, signed and dated by the patient in the presence of two witnesses, at least one of whom is not a family member or potential beneficiary of the patient's estate, who corroborate that the patient is capable, acting voluntarily, and not being coerced to sign.
- 6.) Physician must offer patient the opportunity to rescind the offer.
- 7.) The attending physicians must request that the patient notify the next of kin of the prescription request.
- 8.) 15 days after the first oral request and 48 hours after the written request, a prescription may be given to the patient.
- 9.) The patient uses the prescription at home usually with the guidance of a volunteer from a non-profit.
- 10.) The request can be rescinded at any time for any reason "without regard to his or mental state."

The shortest possible time between request and receipt of medication is 15 days, though most patients use more time.

Capacity is defined by the state of Oregon as, "the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available." The law also stipulates that this must be an informed decision: "based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) his or her medical diagnosis; (b) his or her prognosis; (c) the potential risks associated with taking the medication to be prescribed; (d) the probably result of taking the medication to be prescribed; (e) the feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control."

Using DwD data to evaluate concerns about PAD

The most recent report available from the Oregon Health Authority includes data from 1998 – 2012.[10] 1050 prescriptions have been written, and 673 patients have died by ingesting lethal medication prescribed by their physicians. Complications are uncommon. 22 patients regurgitated some or all of the medication, and 6 regained consciousness. Both the number of

requests and the number of patients using the medication has increased over time, although deaths using DwD act still remain at about 0.2% of total deaths in the state.

Although these numbers are very small for statistical analysis, they still help provide information to address the numerous concerns expressed about potential for abuse of this legislation. The speculation, prior to institution of the law, was the “patients may be motivated to pursue PAD to avoid poor quality of dying caused by symptom distress and impaired function, psychological variables such as depression and hopelessness, lack of or conflicted social support, existential or spiritual distress, and perception of self as a burden.”[11]

Vulnerable populations

Of the 673 patients who died using a prescription obtained through the DwD act, 51.6% were male, the median age was 71 (ranging from 25 to 96), and 97.6% were white (Oregon’s population is 80% white). 71% had at least some college education, and 64.6% had private insurance. The primary diagnosis was cancer (80.3%), followed by ALS (7.3), chronic lung disease (4%) and heart disease (1.8%). One of the primary concerns expressed about legalization of PAD is that vulnerable populations would be disproportionately affected. Although it is still possible that the trend will creep in that direction moving forward, those using this legislation now are well-educated, well-insured, and dying of a terminal illness rather than suffering with a chronic disabling disease.

Some interesting work has been done to help identify the characteristics of patients who are likely to request PAD. The figure below compares 55 Oregonians who either requested PAD or contacted a PAD organization with 39 terminally ill patients who did not.[12]

Table 2
Comparison of Oregonians Who Did and Did Not Pursue PAD

Predictor	Did Not Pursue PAD	Pursued PAD	t	df	P
	(n = 39)	(n = 55)			
	Mean (SD)	Mean (SD)			
Depression ^a	4.7 (2.7)	6.2 (3.8)	2.19	91.99	0.03
Hopelessness ^a	2.4 (2.6)	5.9 (4.4)	4.79	89.16	<0.001
Pain	2.5 (2.2)	2.8 (1.2)	0.75	92	0.46
Dismissive attachment	3.3 (0.8)	3.7 (0.7)	2.64	93	0.01
Support ^a	36.1 (3.8)	35.3 (7.6)	-0.67	83.68	0.51
Spirituality	39.4 (7.1)	31.3 (9.3)	-4.60	92	<0.001

PAD = physician-assisted death; Depression = Hospital Anxiety and Depression Scale, Depression subscale; Hopelessness = Beck Hopelessness Scale; Pain = Wisconsin Brief Pain Inventory; Dismissive attachment = Relationship Scales Questionnaire, Dismissive Attachment subscale; Support = Duke-University of North Carolina Functional Social Support Questionnaire; Spirituality = Functional Assessment of Chronic Illness Therapy-Spirituality Well-Being.

For all scales, higher scores represent higher levels of the construct measured.
^aEqual variances not assumed.

Smith, K.A., et al., 2015.

These numbers are very small, but overall PAD requesters had higher levels of depression, hopelessness, and dismissive attachment, and lower levels of spirituality (“Meaning, purpose,

and hope. Desire to transcend immediate hardship and suffering and make sense of or find meaning in the experience”). The relationship between hopelessness and realism can be difficult to clarify in a terminally ill population. In a hopeless situation, realism can masquerade as hopelessness. The strongest correlation of all was an inverse correlation between spirituality and propensity to seek PAD. The authors conclude that those who pursue PAD lack an expectation of meaning in the dying process and consequently view it as a manner to circumvent suffering that has no value. There is a separate discussion of the role of attachment style in Oldham & Ganzini[13], in which the authors speculate that a request for PAD “may be the culmination of a person’s life long pattern of concern with issues such as control, autonomy, self-sufficiency, distrust of others, and avoidance of intimate relationships and communications.”

There remains concern some patients with depression are receiving prescriptions for lethal doses of medication.[14] Of patients who died using PAD in 2012, only 2 were referred for psychiatric evaluation. About 50% of those with persistent desire for PAD have some evidence of clinical depression. Diagnosis is complicated in terminally ill patients because so many diagnostic features of depression overlap with symptoms of advanced illness (e.g., fatigue, sleep disturbance, thoughts about death). With modification for these symptoms, the rate of depression among those with persistent desire for PAD is 13% (26.1 without modification).[15] In another study, 17% of the patients approved for a prescription met criteria for depression and ingested lethal medication. None were evaluated by mental health professional at the time of the request, and “whether the depressive disorder influenced the judgment of the three individuals who received PAD is unknown.”[16].

Unmitigated suffering

The Oregon Health Department has physicians submit with the written request for PAD the reasons that the patient is seeking it. One of the primary concerns, particularly among the Palliative Care community, was that patients would elect PAD because of inappropriately managed symptoms. In the Dwd experience, however, the major drivers were not symptom control.

Table 1. Characteristics and end-of-life care of 673 DWDA patients who have died from ingesting a lethal dose of medication as of January 14, 2013, by year, Oregon, 1998-2012

Characteristics	2012 (N=77)	1998-2011 (N=596)	Total (N=673)
End of life concerns⁹	(N=77)	(N=592)	(N=669)
Losing autonomy (%)	72 (93.5)	538 (90.9)	610 (91.2)
Less able to engage in activities making life enjoyable (%)	71 (92.2)	523 (88.3)	594 (88.8)
Loss of dignity (%) ¹⁰	60 (77.9)	386 (82.7)	446 (82.0)
Losing control of bodily functions (%)	27 (35.1)	318 (53.7)	345 (51.6)
Burden on family, friends/caregivers (%)	44 (57.1)	214 (36.1)	258 (38.6)
Inadequate pain control or concern about it (%)	23 (29.9)	134 (22.6)	157 (23.5)
Financial implications of treatment (%)	3 (3.9)	15 (2.5)	18 (2.7)

The end of life concerns most commonly expressed were losing autonomy, loss of ability to enjoy activities, and loss of dignity. Concern about being a burden was present in 38.6%, and inadequate pain control or concern about it was 23.5%. Furthermore, 90.4% of patients were enrolled in hospice at the time they used the prescription. Ostensibly, this means that they were receiving optimal Palliative Care. Unmitigated suffering does not appear to be a major driver of these requests.

Quality of Death

When the DwD act was first legalized, there was concern that patients and their families would experience lower quality end of life care. In fact, when compared to patients who requested and did not receive PAD or did not request it at all, those receiving PAD prescriptions had higher quality ratings on items measuring symptom control (e.g., control of surroundings and control of bowels/bladder) and higher ratings on items related to preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not pursue PAD or in some cases, those who requested but did not receive PAD.[11]

Slippery Slope

Another frequently cited concern is DwD act will be the top of a slippery slope, resulting in euthanasia when patients who are not able to administer the medications themselves claim unfair discrimination and sue for the right to take advantage of the legislation, or that the law would be expanded to include anyone who wanted die. In fact, this has not been the case in the 21 years the law has been on the books.

Lack of oversight and regulation

Given the experience in Holland, where euthanasia was already been practiced complicitly and physicians do not report 100% of events, there was concern the same would occur in the United States, but so far it has not. Based on review of requests between 1998 and 2012, that

physicians are compliant almost 100% with the request criteria[16]. Very few concerns have been expressed to the Oregon State Medical Board about failure to comply with the very strict standards the law requires. The most notable exception has been a complaint about improper witnessing of one document.

Barrier to Palliative Care

The Death with Dignity Act also does not appear to be a barrier to the development of high quality Palliative Care. In fact, as noted in Ganzini's 2000 article, physicians made an effort to improve their abilities, and availability of the act has increased the impetus to have discussions about goals of care and end of life decisions.[17] Oregon is notable as the home of the POLST document (Physician Orders for Life Sustaining Treatment) to help ensure autonomy and optimize end of life care for nursing home residents, and probably is one of the most "Palliative Care" friendly states in the Nation.

The Debate

Moral Truth

There are many factors in the debate about legalization of PAD that are not, and cannot be, resolved by review of the data from Oregon. The first is that, for many, taking of a life is simply wrong. St. Thomas Aquinas wrote, "But the passage from this life to another and happier one is subject not to man's free-will but to the power of God. Hence it is not lawful for man to take his own life that he may pass to a happier life, nor that he may escape any unhappiness whatsoever of the present life, because the ultimate and most fearsome evil of this life is death...therefore, to bring death upon oneself to escape the other afflictions of this life, is to adopt a greater evil in order to avoid a lesser." [18] For those who believe that a man's life is not his to forgo, PAD is simply not a consideration. This is a view widely held among world religions and one not likely to be changed by time or legislation.

Many argue that Oregon is not like other places and hence the data cannot be extrapolated. The population is very homogenous, well educated, and with excellent healthcare access. They also have a uniquely competent public health infrastructure to ensure compliance with the existing laws. The other states that have legalized PAD (Washington State, Vermont, Montana) are not likely to expand the data significantly as they are demographically very similar.

Another argument is that PAD should be legalized because it is already going on other places without adequate regulation. This places vulnerable populations at greater risk by failing to ensure that their autonomy is protected. Two well-done studies about the secret practice of physician-assisted suicide report a lifetime physician participation rate of about 5%. Subgroups, such as AIDS physicians in San Francisco, California, show participation rates as high as 50%.[15]

There are those who argue that legalizing PAD would undermine the patient-physician relationship, and that prognostic uncertainty would lead to errors that would damage the credibility of the profession. They assert that physicians cannot be responsible for the alleviation of all suffering. Conversely, others argue that failure to legalize PAD damages the patient-physician relationship, and that we have an obligation to relieve all the suffering we can. There is very little, if any, data on this based on the Oregon experience and little to speak of regarding the more extensive experience in Holland. [19]

Palliative Care can eliminate all Suffering

Among the most vocal opponents of the legalization of PAD is Dr. Ira Byock, a Palliative Care physician. His argument is that PAD addresses concerns that would be mitigated by access to good Palliative Care. Although the reasons provided by patients seeking PAD were not primarily related to symptom control, at least a quarter either had pain or were worried about having pain. The reality is that Palliative Care and hospice cannot eliminate all suffering. 2-35% of hospice patients describe pain in the final week as severe or intolerable, 35% describe their shortness of breath as unbearable. Informants for 17% said they would have wanted PAD. As Dr. Quill observes in his 2003 article proposing that the ACP take a position of studied neutrality to PAD rather than open opposition, "These data speak to a more complex reality of dying patients, even those in hospice, than is ordinarily acknowledged." [15] My own clinical experience has been that there is a significant minority of patients for whom adequate symptom control cannot be achieved at home. Those patients are now forced to choose between death unconscious in an institutional setting or without adequate symptom management at home. This is a miserable situation for all involved.

Where Dr. Byock has a very strong case, however, is that the discussion of PAD is a probably distraction from the much larger problem surrounding end of life care in the United States. Despite the passage of nearly 20 years, very little has changed since the 1997 Institute of Medicine report. He passionately argues, in the New York Times:

It's high time we boomers shook off our post-menopausal and "low T" malaise and reclaimed our mojo. Remember Howard Beale, the fictional news anchor brilliantly portrayed by Peter Finch in the 1976 film "Network"? Fed up with the inequities of modern life, one night Beale exhorts viewers to go to their windows and yell, "I'm as mad as hell and I'm not going to take this anymore!" We'll figure out the details later, he says; right now it's time to yell. And, across the country, they do. The persistently unsafe state of dying in America should provoke a Howard Beale moment. [20]

He outlines a number of necessary changes in End of Life Care that have already been proposed but remain unimplemented because, he asserts, of a lack of consumer demand. Much of the energy going into the PAD debate might be better spent pursuing improvement in End of Life

care across the board. Palliative Care has been shown over and over to improve care and reduce costs. These arguments are true regardless of your perspective on PAD.

A note on the Hippocratic Oath

Many opposed to legalization of PAD argue that it goes against the Hippocratic Oath, which states, “I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect.” The historical context here is very important. At the time when the oath was written, doctors were sometimes used as political assassins. As a consequence, there was fear of the physician as a poisoner. The oath is intended to reassure the public against that possibility.[21] It should be noted, regardless of one’s interpretation of that passage, that the Hippocratic Oath was lost for 1500 hundred years, and not employed widely by physicians until after Columbus had come to the New World. It is an excellent philosophical guide, but there are also elements of the oath we no longer take literally. The oath was originally sworn to Apollo, forbade surgery, and exhorted oath-takers to treat their teacher as equal to their parent and train other physicians for free.

The really big questions*

How one ultimately responds to the idea of legalization of PAD depends on some very weighty ethical arguments around the most fundamental building blocks of medical ethics – autonomy, beneficence, and the relative importance of effect vs intent.

Autonomy

Proponents of legalization of PAD argue that the right to self-governance is absolute. Your life is your own to do with as you please, and as part of that right, you must have access to the ultimate autonomous act of choosing when and how to die. Eugene Debs summed up this argument beautifully when he said, “Human life is sacred, but only to the extent that it contributes to the joy and happiness of the one possessing it, and to those about him, . . . and it ought to be the privilege of every human being to cross the River Styx in the boat of his own choosing, when further human agony cannot be justified by the hope of future health and happiness.”[22] On the other hand, it can be argued that autonomy is not the final word. We as a society do not recognize the right of a person to sell oneself into slavery. Others argue, as does St. Thomas Aquinas, that man belongs to God and as such does not have the purview to end his life. The position one takes on this argument is very personal.

Beneficence

Those who support legalization of PAD argue that, in the face of unmitigated suffering, the most beneficent act is to kill the patient. Dr. Adina Blady Szwajger killed babies and children in

the Warsaw Children's Hospital to prevent them from falling into the hands of the Nazis or starving to death alone because killing them was, in that context, the kindest action. Proponents of PAD argue that physicians should be willing to do the same for terminally ill people now. One hitch in that argument is that most of the patients requesting Dwd act assistance are not actually experiencing intractable suffering, or, if they are, it is of primarily an existential nature or fear of dependence. Whether existential suffering about the future, no matter how uncomfortable, warrants an intervention as ethically extreme as ending a life may be a very different question from how to manage a patient in intractable physical pain, depending on your perspective. Those on the other side of the argument assert that the most beneficent act one can perform in this context is to provide excellent, comprehensive palliative care. They do not deny that rare cases of unmitigated suffering may occur, but argue they do not justify changing medicine's historic rules.

Intent vs effect

Those who argue in favor of legalizing PAD assert that, when treating a terminally ill patient, the end result is death, with PAD or without it. How we get there is less important than the suffering prevented given that the outcome does not change. They also argue that it is disingenuous to argue that death is not the intent in cases of withdrawal, withholding or terminal sedation. The vast majority of the time, we know, when performing a terminal extubation, that death is likely to result. Those on the other side of the argument counter that morally, intent and action are what matter. The intent of withdrawal is to allow nature to take its course. Even though we suspect that the course nature will take is toward death, we do not know that conclusively and are not acting with the intent of causing that to happen.

The View From the Edge

This debate about the right to end one's life prematurely is a strange one. In most of the world, and in fact, among most of the patients I see, there is no hurry at all die. The vast majority of people would give almost anything for a few minutes more of life, even in the face of significant physical symptoms. After months of contemplation on this topic, I remain conflicted about the appropriate response to public demand for legalization of PAD. I have seen profound physical suffering that medications administered in the home could not ameliorate, and remain haunted by those tortured deaths. At the same time, I have seen patients who feared dependence and loss of function almost to the point of panic find the last weeks of their lives profoundly meaningful as they discover new ways to relate to their families and a greater acceptance of their mortality. I believe there is a great deal to enjoy in life, even at the end. On balance, perhaps if a patient is fully informed regarding what he would be missing by ending life a bit prematurely, an autonomous decision to avoid emotional suffering is not egregiously wrong. I would probably want the choice myself, although it would be very uncomfortable ethically for

me to write a prescription in the absence of profound physical suffering that had failed all other means. Perhaps the main takeaway is that those who fear loss of control and dependency are likely to consider suicide. Any request for PAD should trigger an investigation of the degree to which inadequate symptom management, depression or challenges to long-standing difficulties relinquishing control might be causing discomfort.

Conclusion

It appears that at least some of the fears expressed prior to the legalization of PAD in Oregon can be laid to rest: regulatory compliance has been strict, there has been no extension of the policy to include euthanasia, vulnerable populations are not at increased risk, and PAD has not taken the place of Palliative Care. In fact, unrelieved symptoms do not appear to be a major driver of requests. For those who receive it, the practice is associated with an improvement in quality of death, and provide peace of mind. It is not clear that depression is being fully assessed or accounted for.

What the Oregon data does not, and cannot tell, is whether this practice is ethically right or wrong. Hegel wrote that, “Genuine tragedies in the world are not conflicts between right and wrong. They are conflicts between two rights.” In this case, the right of the terminally ill patient to avoid suffering that is not considered meaningful conflicts with the physicians right to adhere to long-standing traditions of preserving life. How one ultimately decides to resolve this dispute is deeply personal. Regardless of legislation, physicians must reserve the right to practice in a manner consistent with their ethics. Biller-Andorno writes in NEJM, “Even in societies with broad public support for physician-assisted suicide, a certain uneasiness and ambivalence remain, particularly among physicians who have to carry the emotional burden and moral responsibility of having enabled someone to end his or her life.”[23]

Perhaps the most important conclusion to draw from the Oregon experience is that the energy around legalization of PAD is driven by a fear of dying in a manner beyond one’s control. Legalization of this avenue helps only an extremely small numbers of people (0.2% of deaths in Oregon). The other 99.8% of dying patients are not significantly better off now than they were in 1997. Although fewer Medicare beneficiaries are dying in acute care hospitals, more are dying in nursing homes (which are generally understaffed) and ICU use in the last month of life has increased to 29.2%. Despite the wish of most Americans to die at home, the majority still die in institutional settings where end of life care has been demonstrated to be of lower quality. [24] **Our obligation as physicians in regard to PAD may be ambiguous, but the obligation to advocate for improved end-of-life care is very straightforward and is of benefit to us all.** The Institute of Medicine has issued a revised report entitled, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, in which they observe, “For the millions of Americans who work in or with the health care sector—including clinicians, clergy,

caregivers, and support staff—providing high-quality care for people who are nearing the end of life is a matter of professional commitment and responsibility. Health system managers, payers, and policy makers, likewise, have a responsibility to ensure that end-of-life care is compassionate, affordable, sustainable, and of the best quality possible.”[25]

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