

Dear members of the Committee on Public Health,

My name is Lisa Honkanen. I am a physician of Geriatric Medicine, practicing in New York. I thank you for the opportunity to testify today AGAINST Bill 5326.

My concerns are that **BILL 5326 WILL:**

1. **Not give any new rights to patients.** Its purpose is to legally protect doctors who prescribe medications intended to cause death. Those who demand a "right to die" in this way relinquish to another the "power to kill" and thus, they take away from all terminally ill patients, the protection against abuses by doctors who can and will oblige death by a lethal prescription.
2. **Promote a more permissive attitude toward suicide in general.** The World Health Organization recognizes that promotion of suicide can lead to imitative suicidal behaviors, warning against normalizing suicide or presenting it as a solution to problems. (WHO, 2008) Changing the words used to describe the method of death in this bill is, at best, a naïvely ineffective safeguard against this. Suicide rates are increasing across the country in the last ten years, therefore we cannot afford to minimize the gravity of suicide by any method, especially at a time when other social and economic factors are increasing the known risk factors for suicide. (Parker-Pope, 2013)
3. **Contradict Connecticut's Comprehensive Suicide Prevention Plan 2005** which recommends "to identify particular needs of high-risk populations and high-risk situations." This document recognizes that those who are particularly vulnerable to suicide include those with major depression and that isolation and segregation are causal risk factors – which are very common during serious illness, most especially those terminal conditions that impair physical and cognitive function. (Connecticut Department of Public Health, 2005) So those most vulnerable are overlooked by the law because it specifically redefines the intent for suicide by terminally ill patients as not suicide but "aid in dying", and therefore exempts them from the means and services provided to all other depressed or suicidal individuals to ameliorate the very reasons one might seek a controlled death.
4. **Increase the possibility for coercion, or at least a perceived duty to die, in the most vulnerable populations** (the poor, aged, depressed) **and lead to abuses** (so-called safeguards can be difficult, if not impossible, to enforce) (Emanuel, 1999 – this is an objective analysis of the benefits vs. harms of physician-assisted-suicide in which he concludes that "*there is no compelling evidence*" that Physician Assisted Suicide (PAS) will significantly improve care, and that "*The benefits and harms of legalizing euthanasia and PAS are likely to reinforce inequities in the delivery of health care services and the disparities of wealth and power in our society.*"). Examples
 - a. **involuntary implementation** (e.g. a patient can be given the lethal medication covertly by someone else, before he has decided himself to use it)
 - b. **inadequate adherence to the "safeguards"** (e.g. bypassing a psychiatric evaluation by minimizing depressive symptoms, doctor shopping for two physicians to concur that a patient meets qualifying criteria for PAS)

- c. **offering this as a first line before exhausting true palliative measures**, because it is less expensive, less labor-intensive, etc.
- d. **inaccurate self-reporting could obscure unappealing details** of the death process; since there is minimal, if any, investigative scrutiny allowed over these cases, there is no transparency
- *Note that subjects of abuse cannot report the violation – they are conveniently dead.
5. **Discriminate against the terminally ill** because different “rules” apply to them with this proposed law. According to this bill, the law would deem that intentionally ending one’s life is not “suicide” if the individual bears a diagnosis of “terminal illness”, but the same act or intent without a terminal illness is correctly labelled “suicide” and warrants mental health and other resources to help heal one’s suffering and prevent the act. Indeed, most clinical and forensic psychiatrists agree that “the presence of major depressive disorder should result in an automatic finding of incompetence” to make decisions about PAS (Hinckle, 2010), yet an Oregon-based study confirmed that patients with major depression have died by lethal ingestion (they should have been excluded automatically). (Pereira, 2011) It is virtually impossible to prevent these circumventions of the “safeguards.” This policy suggests some individuals may be better off dead, and reinforces the idea that individuals who meet the criteria are not worth the resources to prevent suicide.
6. **Discriminate against even some subgroups of proponents** for physician provided prescriptions intended for lethal overdose, e.g. those who cannot swallow. Could this be the gateway for lethal self-injections? Will this encourage euthanasia, i.e. death at the hands of another who administers the lethal injection for someone who cannot swallow (which has happened in Oregon)? Why should someone who cannot swallow not have the same legal opportunities as his swallowing counterpart? Why should someone who fears being unable to swallow in the future, feel compelled to ingest the lethal overdose of prescribed pills “now” before the swallowing deteriorates? These cases highlight flaws inherent in the proposed law and the defective logic that supports it.
7. **Diminish the impetus for improving true palliative care** (palliative care meaning that care which respectfully manages symptoms, not an effort to disguise euthanasia). A leading hospice physician in the Netherlands has written that “Regulation has proved to be difficult if not impossible and is fraught with danger. It also serves to stifle creativity in palliative care and even to make proper care impossible to achieve.” (Zylicz, 2002)
8. **Undermine the physician – patient relationship, by eroding trust in the physicians’ duty to “first do no harm.”** It transforms the profession of medicine from a healing art to an exploitation of a doctor’s ability to provide material cooperation in homicidal opportunity.
9. **Advance an increasingly casual regard for the morals and ethics that historically have informed a prohibition of these types of acts.** This bill subverts centuries of moral thinking, dating back to 500 B.C. with the original version of the Hippocratic Oath which itself was an **attempt** to establish a set of ethical principles in response to physician directed euthanasia; opposes the 1997 U.S. Supreme Court unanimous decision that rejected assisted suicide as a constitutional right; violates the ethics policies of most major medical associations; and if we are

honest about the facts, it violates all states' homicide laws. The American Medical Association (AMA), supported by the American College of Physicians, opposes PAS because it contradicts the fundamental tenet of the medical profession: "Primum nocere." First do no harm. The traditional Hippocratic Oath declares, "I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect." The AMA further states "permitting physicians to engage in euthanasia would ultimately cause more harm than good. Euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult to control, and would pose serious societal risks." (AMA; Washington v. Glucksberg, 1997; Vizcarrondo, 2013)

10. **Hinge brazenly on the accuracy and confidence of a physician's diagnosis and prognosis**, leaving no prospective alternatives in the case of error -- because the patient is dead. Physicians' diagnoses and prognoses are often wrong. In addition, the determination of "terminal" is difficult to predict in many cases. Ted Kennedy lived five times beyond his 2-4 month prognosis and he certainly had the smartest doctors on his team.
11. **Obscure reality**. By changing the language to more euphemistic terms, the underlying activity endorsed by this law is obscured. On first glance, the public agrees, the laws get passed, and then the truth is exposed – but it's too late. Voters and others favor expanded "choices" but often do not know the details. A recent Gallup Poll showed a 20 point discrepancy in support of doctors being allowed to "end the patient's life by some painless means" versus helping the patient "commit suicide" – same method but different words to describe it had quite a different level of support. If those same people knew the details about abuse potential, mishaps, etc. this gap in support would be even more dramatic. (Eckholm, 2014)
12. **Assumes that death is "The Solution" for suffering** and dismisses that the main reasons a controlled death is sought are psychosocial and existential in nature, not intractable pain – which with proper medical care can be quite well managed. (Hudson, 2006; Ezekiel, 1999). Indeed, earlier this year, an 85 year old Italian woman fearing fading beauty sought the assistance of Dignitas (an assisted suicide clinic) in Switzerland. Her unknowing family discovered her fate when her ashes were delivered! (Moran, 2014)
13. **Encourages financial incentives**. Death is cheaper than providing extended health care services. Insurance companies and others naturally will favor this.

ISSUES SPECIFIC TO THIS BILL:

1. There is no family notification required, only "recommended" (Sec. 9.1)
2. There is no direct supervision to enforce "safeguards" and detect/thwart abuses. For example
 - a. The voluntary, well-informed basis of consent is dubious – who will ensure that feasible options will be fully disclosed?
 - b. No longitudinal relationship with the physician is necessary – a physician cannot truly understand the motives let alone assist a patient's plan in the limited visits required to assess capacity to consent to this method of death.
 - c. Without direct physician supervision of the ingestion, how can a doctor know that the prescription is used for the patient or that there is not an attempt for a double suicide?

- (Although, this same risk applies to other medications prescribed, the intent of the lethal prescription here is far different than *any* medication a physician will prescribe for that individual.) How can the doctor know the medication was successful – was another means to “finish the job” necessary by a desperate observer?
- d. Second opinions will be directed to those who will agree – i.e. doctor shopping will be inevitable.
 - e. The determination of “terminal” diagnoses could be suspect – the “accepted” definition could be “stretched” (and how does a doctor “console” a patient suffering with a long term illness that is not expected necessarily to die in six months?)
 - f. Proper handling of medication – after it is dispensed, there is no tracking; and it is questionable how unused prescriptions will be managed (can a dead patient properly dispose of the pills he didn’t take?) (Sec. 12)
 - g. There is no requirement that observed abuses be reported – the cases are concealed from routine scrutiny (Section 11)
 - h. The death certificate obscures the truth. The proximate cause of death is SUICIDE BY POISONING no matter what terminal disease process impelled the individual to choose this and no matter what the State declares a legal activity by doctors. It is what it is and, in this doctor’s opinion, this is a grand deception to legalize a homicidal activity. Indeed, if the doctor has not determined the patient is “terminal” even the State would deem it homicide. (Sec. 9.b, Sec. 13.d, Sec. 16.c)
 - i. In addition, it is the utmost offense to codify suicide by physician facilitation and euphemize the term so it is more palatable to the general public. Suicide is suicide. Transparency by the crafters of this bill would at least have left the language in a familiar parlance, rather than insisting on using the new term, more favorable to social engineering of the subject: “aid in dying.” (Sec. 1.2, Sec. 13.d)
 - j. Finally, if this is such a pleasant way to die, why cannot it be done in public? Is the scandal too much for the public to know? A death manipulated to be compassionate should be better than a natural death, right? Why should another person be forced to be present (one who might be upset by a bad outcome), if the prescribing doctor cannot be required to take this responsibility? Who is to guarantee that a patient will not take the pills alone as the bill advises against? (Sec. 9.a.2)

You see, no bill, no matter how diligently legislators attempt to cover every scenario to manipulate a “good death” that does not invite harm, can be devised. **This is a Pandora’s Box. Please don’t open it!**

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What Is the Great Benefit of Legalizing Euthanasia or Physician-Assisted Suicide?

Ezekiel J. Emanuel

Euthanasia and physician-assisted suicide (PAS) are not ends in themselves with intrinsic value. At best, they are means to realize the end of a good death or, more accurately, a quality dying experience.¹ The current debate has tended to focus on whether euthanasia or PAS is appropriate for this or that individual, or whether passive is the same as active euthanasia, or whether providing morphine for pain relief with the risk of respiratory depression and premature death is the same as euthanasia. But the issue that has exercised this country for the past five to ten years is legalization—or otherwise publicly sanctioning a social practice²—of euthanasia or PAS. This issue is not about the morality of a specific decision regarding the care of an individual patient, but the ethics of having a particular social policy and practice. Ultimately, the ethical question we should consider is: Will legalizing—or permitting—euthanasia and PAS promote—or thwart—a good death for the 2.3 million Americans who die each year in the United States? Will people who die be helped or harmed by having euthanasia or PAS available to them?

In confronting this question, we must first acknowledge that figuring out the benefits and harms of permitting euthanasia or PAS is speculative, at best. As will become clear, we inherently lack some of the essential information we need for this assessment. But judgment under uncertainty and with incomplete data is precisely the type of ethical judgment that we—laymen and legislators—must make in deciding whether on balance it is better to legalize euthanasia or PAS or not. And, far

1. See Ezekiel J. Emanuel and Linda L. Emanuel, "The Promise of a Good Death," *The Lancet* 351, suppl. vol. 2 (1998): S21–S29.

2. By the "publicly sanctioning of a social practice of euthanasia or PAS" I have in mind what occurs in the Netherlands, where euthanasia and PAS are technically still illegal and can be prosecuted, but where there is social sanction for these interventions, and they have become accepted social practices. In the Netherlands there are specific guidelines and safeguards for the performance of euthanasia and PAS. Approximately 3.4 percent of all deaths occur by these interventions (Paul J. van der Maas, Gerrit van der Wal, Ilinka Haverkate, et al., "Euthanasia, Physician-Assisted Suicide, and Other Practices Involving the End of Life in the Netherlands, 1990–1995," *New England Journal of Medicine* 335 [1996]: 1699–1705).

from being neutral, this uncertainty needs to be considered in this ethical evaluation. Nevertheless, articulating and estimating the benefits and harms of legalization can be quite helpful in clarifying the stakes of the choice.

Furthermore, any reasonable commentator on this issue must acknowledge that no matter which social policy regarding euthanasia or PAS is adopted—legalization or maintaining the current policy of permitting them in individual cases—there will be both benefits and harms. Legalization would inevitably generate abuses, cases in which people's lives were intentionally ended when they should not have been because they were coerced, or because appropriate palliative measures were not provided, or because they did not consent. As Brock, a staunch proponent of legalizing euthanasia and PAS, has acknowledged, stringent safeguards can "not eliminate . . . the potential for abuse."³ Similarly, opponents must acknowledge that if neither euthanasia nor PAS is permitted, some patients experiencing unremitting pain will be prevented from ending their lives and will suffer needlessly. And other patients who might not use euthanasia or PAS but would receive some reassurance by knowing these are possible options would not have this psychological benefit if they remain illegal. The ethical question is how do the benefits and harms of legalization compare.

WHAT ARE THE LIKELY BENEFITS OF LEGALIZING EUTHANASIA AND PAS?

Proponents of euthanasia and PAS identify three main benefits to legalization: (1) realizing individual autonomy, (2) reducing needless pain and suffering, and (3) providing psychological reassurance to dying patients.

Benefit 1: Realizing Autonomy

Autonomy is an essential American value and should not be dismissed. Yet as this symposium makes clear, it is controversial whether permitting euthanasia or PAS is essential to realizing individual autonomy.⁴ I cannot enter this debate. But it is worth noting that polls suggest that most people do not find securing individual autonomy sufficient justification for legalizing euthanasia or PAS.⁵ Intentionally ending a person's life is

3. Dan W. Brock, "Voluntary Active Euthanasia," *Hastings Center Report* 22 (1992): 10–21, p. 20.

4. It may be worth noting that the autonomy justification does not distinguish euthanasia from PAS. The justification invokes the notion that as part of autonomy individuals should control the timing and manner of their own deaths. This train of thought justifies both euthanasia and PAS. The only reason to favor PAS rather than euthanasia must be based on either political expediency or on safeguards.

5. Survey data suggest that about one-third of Americans are against euthanasia or PAS no matter what the circumstances—including a patient with unremitting pain—while

an act that requires another person's participation, and requires giving that other person a good reason to participate. Without a good reason beyond preference or personal life plans, people would not permit it. Indeed, the notion that individual autonomy is not a sufficient justification is embodied in the safeguards incorporated into most proposals for legalization. The key safeguards require (1) that the patient initiate and freely and repeatedly request euthanasia or PAS; (2) that there be unremitting pain or uncontrolled physical suffering that cannot be relieved except by euthanasia or PAS; and (3) that a second physician consult on the case to be sure of the patient's prognosis and that the patient is acting voluntarily and understands his or her decision.⁶ Having more than the first safeguard acknowledges that autonomy is an insufficient justification for euthanasia or PAS, that these interventions must also realize a good besides autonomy, such as relief of unremitting and excruciating pain.

Benefit 2: Relief of Pain and Suffering

If we legalize euthanasia or PAS, how many people will have their needless pain and suffering relieved? To determine this number we need to know five factors: (1) how many dying people there are each year; (2) what proportion of these patients have a recognizable and distinct dying process during which they can request euthanasia or PAS; (3) what proportion of these patients would be competent to request euthanasia or PAS; (4) what proportion of these patients would have unremitting pain that would justify euthanasia or PAS; and (5) what proportion of these patients would actually want euthanasia or PAS.

In factor 4, I have limited intentionally the acceptable justifications to relief of pain and have not included suffering. Pain and suffering are clearly not the same thing. Pain is fairly objective: there is a shared notion of what constitutes pain; there are standardized measures for physicians to assess pain and how much there is; and there are well defined and codified interventions for the relief of pain. Of all the justifications

about one-third are for euthanasia or PAS no matter what the circumstances or reasons for the request. There is a key one-third of Americans whose views are more nuanced. They believe the morality of any particular act of euthanasia or PAS is not absolute but depends upon the particular circumstances of the case; that in some cases it may be appropriate, but in others it is not ethical. Interestingly, the only circumstance that commands a majority in favor is when the patient has unremitting pain. See Ezekiel J. Emanuel, Diane Fairclough, Elisabeth Daniels, and Brian Clarridge, "Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences of Oncology Patients, Oncologists, and the Public," *The Lancet* 347 (1996): 1805–11; and Daniel Callahan, "When Self-Determination Runs Amok," *Hastings Center Report* 22 (1992): 52–55.

6. Even among the justices of the Supreme Court it was clear that the only justification acceptable was when a patient had uncontrolled pain and also wanted euthanasia or PAS. Just wanting it was not a sufficient reason for legalizing euthanasia or PAS.

for euthanasia and PAS, pain is one most agreed upon and publicly endorsed. When it comes to suffering, mental anguish, or other symptoms, there are many more complicating factors that make them problematic as a justification for euthanasia or PAS. A full examination of this issue of justification is beyond this article. However, it is worth noting several points. Suffering—like mental anguish—is a vague and controversial notion; there is no shared interpretation of what constitutes suffering. Consequently, there are no agreed upon and validated standards or measurement instruments for health care providers to assess suffering and to discriminate how much there is. Similarly, there are no clear interventions that should be instituted and no clear understanding of when adequate palliative measures for suffering have been tried and failed. Ultimately, using these reasons as justification borders on relying exclusively on the patient's wants and wishes, and so collapsing the justification into the autonomy justification. Thus, because there is shared agreement that if euthanasia or PAS are justified in any cases they are ones of extreme, unrelievable pain, and because other justifications are controversial and problematic, I have excluded them from factor 4.

Current data do not—and probably never will—allow a precise estimate for each of these five factors. Using several different techniques, however, we can come up with some reasonable estimates. While there may be quibbles about the precise numbers, the overall conclusions about the benefits of legalizing euthanasia or PAS should be the same.

Factor 1: Each year approximately 2.3 million Americans die.

Factor 2: Many deaths are sudden and acute, leaving no time for euthanasia or PAS. It is unclear precisely what proportion of the 2.3 million deaths lack a recognizable and distinct dying process of several months in which euthanasia or PAS could occur. My own crude estimate is that 50 percent of all deaths in the United States occur quickly without warning, and 50 percent have a distinct dying phase in which patients could request euthanasia or PAS.⁷

Factor 3: In many deaths patients would not be competent to request and consent to euthanasia or PAS. Some deaths—0.2 percent—occur in children under eighteen years of age. Many adult deaths—although we do not know how many—occur in people who have been mentally in-

7. For my estimates see Ezekiel J. Emanuel, "The Future of Euthanasia and Physician-Assisted Suicide: Beyond Rights Talk to Informed Public Policy," *Minnesota Law Review* 82 (1998): 983–1014. In brief, I estimate that of the 2.3 million deaths, fifty thousand are in children under age eighteen; seventy thousand are accidents in adults (such as car accidents); thirty thousand are suicides; and fifteen thousand are homicides. In addition, there are illnesses that cause sudden deaths including strokes, heart attacks, mistaken insulin overdoses, pneumonia, and other infections. I estimate that these illnesses causing sudden death account for slightly under half of all deaths. My colleagues in the Netherlands, Paul van der Maas and his group, estimate that approximately 70 percent of deaths in the Netherlands have a distinct dying process before death. Both are estimates. Reality may be somewhere in between.

competent for more than six months.⁸ These patients would not have the mental capacity to request or consent to euthanasia or PAS. Combining factors 1–3 suggests that approximately one million Americans who die each year are mentally competent, have a distinct dying process, and would be competent to request and receive euthanasia or PAS.⁹

Factor 4: According to most authoritative sources, in the months prior to death, optimal palliative care should be able to relieve pain in all but 5 percent of patients.¹⁰ (Clearly, euthanasia or PAS would be unjustified if done in cases where patients had pain that was not adequately treated; in such cases the proper intervention would be to institute proper pain relief measures, not to end a life.)

Factor 5: Not all dying patients with unremitting pain desire or would request euthanasia or PAS. Data from HIV patients in New York indicates that 53 percent of patients with significant pain have considered PAS.¹¹ (“Considered” is much less than “desired and repeatedly requested” PAS.) People who die of HIV infection are a small proportion of total deaths (less than 2 percent) and for a variety of reasons, especially because of their age, are unrepresentative of all dying patients. A more general survey of dying patients indicates that slightly over 10 percent of terminally ill patients with significant pain have “seriously thought” about euthanasia and PAS for themselves and about 4 percent have discussed these interventions.¹²

Combining all five factors, I estimate that each year, of the 2.3 million Americans who die, approximately 5,000 to 25,000 patients might have a distinct dying process with significant and unremitting pain, desire euthanasia or PAS, and be competent to repeatedly request and consent to euthanasia or PAS. (This is 0.5 percent to 2.5 percent of the

8. It is worth noting that about two-thirds of people who die each year are over sixty-five years of age, and dementia increases with age such that at the very least, 5 percent of the people over sixty-five years of age and 47.5 percent of those over eighty-five years of age are not mentally competent and cannot request or consent to euthanasia or PAS (D. A. Evans, H. H. Funenstein, M. S. Albert, et al., “Prevalence of Alzheimer’s Disease in a Community Population Higher than Previously Reported,” *Journal of the American Medical Association* 262 [1989]: 2251–56). In addition, many illnesses, especially terminal conditions, also transform people who were mentally alert to mentally incapable, undermining their ability to request and provide informed consent for euthanasia or PAS.

9. I believe this is an overestimate. I have hardly incorporated the factor of mental incompetence.

10. K. M. Foley, “The Treatment of Pain,” *New England Journal of Medicine* 313 (1985): 84–95.

11. William Breitbart, Barry D. Rosenfeld, and Steven D. Passik, “Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients,” *American Journal of Psychiatry* 153 (1996): 238–42.

12. D. Fairclough, J. Slutsman, E. Omandsun, L. L. Emanuel, and E. J. Emanuel, “Interest in Euthanasia and Physician-Assisted Suicide Among Terminally Ill Oncology Patients: Results from the Commonwealth-Cummings Project,” *Journal of Clinical Oncology* 17 (1998): 48a.

1 million people who have a dying process and are competent to request euthanasia or PAS. These proportions are based on the 5 percent who have unremitting pain with optimal pain control therapy combined with only 10 percent to 50 percent of patients with pain who desire euthanasia or PAS.)

An alternative method to calculate the proportion of dying patients who might benefit from euthanasia or PAS is to use available Dutch data to estimate those who might benefit from euthanasia and PAS. This method is based on two factors: (1) the proportion of all decedents that would use euthanasia or PAS and (2) the proportion that would do so for reasons of unremitting pain. *Factor 1:* According to the latest data, approximately 2.4 percent of all Dutch decedents had a distinct dying process, were competent to request euthanasia or PAS, and died from euthanasia or PAS.¹³ *Factor 2:* According to these same data, in only a third of cases did pain play any role in the patient's decision to seek euthanasia or PAS. These and other Dutch data have suggested that pain was the sole or dominant reason for euthanasia or PAS in 11 percent or fewer cases.¹⁴ Recent studies in the United States have suggested that among euthanasia and PAS cases in the United States pain also plays a relatively minor role in requests for euthanasia and PAS.¹⁵ Interviews with physicians suggest that in about one-third of cases pain is the motivating factor for the request for euthanasia or PAS. A recent survey of physicians indicated that 24 percent of patients who received euthanasia and 54 percent of patients who received PAS were experiencing pain. Combining these data suggests that if euthanasia or PAS were legalized fewer than 20,000 dying Americans might use these interventions to end

13. See Gerrit van der Wal and Paul J. van der Maas, *Euthanasie en Andere Medische Beslissingen Rond Het Levensende—De Praktijk en de Meldingsprocedure* (The Hague: Staatsuitgeverij, 1996); and van der Maas, van der Wal, Haverkate, et al., "Euthanasia, Physician-Assisted Suicide, and Other Practices Involving the End of Life." In the Netherlands in 1995, 3.4 percent of patients died by euthanasia or PAS. However, fully 0.7 percent did not consent to the procedure because they were incompetent at the time, and another 0.3 percent were not terminally ill, that is, did not have six months or less of life to live. Thus, overall, 2.4 percent of people who died in the Netherlands consented to euthanasia or PAS and were in a dying process.

14. See Paul J. van der Maas, Johannes J. M. van Delden, Loes Pijnenborg, and Casper W. N. Looman, "Euthanasia and Other Medical Decisions Concerning the End of Life," *The Lancet* 338 (1991): 669–74; and M. T. Muller, G. van der Wal, J. Th. M. van Eijk, and M. W. Ribbe, "Voluntary Active Euthanasia and Physician-Assisted Suicide in Dutch Nursing Homes: Are the Requirements for Prudent Practice Properly Met?" *Journal of the American Geriatric Society* 42 (1994): 624–29.

15. See studies by Anthony L. Back, Jeffrey I. Wallace, Helene E. Starks, and Robert A. Pearlman, "Physician-Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician Responses," *Journal of the American Medical Association* 275 (1996): 919–25; and Diane E. Meier, Carol-Ann Emmons, Sylvan Wallenstein, Timothy Quill, R. Sean Morrison, and Christine K. Cassel, "A National Survey of Physician-Assisted Suicide and Euthanasia in the United States," *New England Journal of Medicine* 338 (1998): 1193–1201.

their lives for reasons of unremitting pain. (This is based on noting that 2.4 percent of all dying patients in the United States is 55,000 people and that one-third of this is less than 20,000 people.)

Thus, through two different, albeit crude estimates, I believe we can say that, at best, legalizing euthanasia or PAS would benefit by relieving unremitting and excruciating pain 25,000 or fewer of the 2.3 million Americans who die each year.¹⁶

Benefit 3: Psychological Reassurance

No one has directly asked sick, let alone terminally ill, patients whether having euthanasia or PAS available as an option would be reassuring. The closest available data revealed that 41.6 percent of cancer patients—not all of whom were terminally ill—and 44.4 percent of the public thought discussions with their physicians about end-of-life care that included discussion of euthanasia and PAS would increase their trust in their physicians.¹⁷

Overall, the firmest benefit of legalizing euthanasia and PAS would be to relieve the excruciating and unremitting pain of 25,000 or fewer dying Americans each year. To put this into proper perspective, 1 percent or fewer deaths would be improved by legalizing euthanasia and PAS. In addition, approximately 40 percent of Americans might get some psychological reassurance knowing that euthanasia or PAS were possible alternatives if their dying was too painful.

WHAT ARE THE LIKELY HARMS OF LEGALIZING EUTHANASIA OR PAS?

What are the potential harms of legalizing euthanasia or PAS? Opponents identify six potential harms: (1) undermining the integrity of the medical profession; (2) creation of psychological anxiety and distress in patients from the possibility of euthanasia or PAS; (3) coercion of patients to use euthanasia or PAS against their wishes; (4) provision of euthanasia or PAS to patients prior to implementing optimal palliative care interventions; (5) provision of euthanasia or PAS to patients without their full informed consent because of either mental illness or mental incompetence; and (6) psychological distress and harm to surviving family members of the patient.

For almost all these harms there are few firm data. These harms are much harder to empirically evaluate; they require studying many deaths for the smaller proportion that occur by euthanasia or PAS and then assessing them for coercion, less than optimal palliative interventions,

16. The net benefit of legalization would be lower since we know some Americans currently receive euthanasia or PAS despite their being illegal. Currently there are no data on how many people who die do so by euthanasia or PAS.

17. Emanuel, Fairclough, Daniels, and Clarridge, "Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences," pp. 1808–9.

mental competence of the patient, and so forth. No research group has been able to assemble a representative and reasonably large enough number of cases to study and to do so would require enormous resources. (Small numbers of cases are likely to be unrepresentative and very deceptive.) Furthermore, determining how many of these harms might occur depends upon knowing how many dying patients might use euthanasia and PAS if they became legal or socially sanctioned. And for this we only have the Dutch data, and must guess about how well they translate to the United States.

Harm 1: Undermining the Medical Profession

Whether euthanasia or PAS harms the medical profession is an interpretive issue and probably depends upon other factors, such as the social role of the profession, that vary over time. While the data indicate that in the majority of cases physicians do not regret having performed euthanasia and PAS and would do so again in similar circumstances, a significant minority have regret and more. In a study my colleagues and I did, we found that about 25 percent of physicians regret having performed euthanasia or PAS in some cases because it did not lead to a good death for the patient or family. (This regret was not associated with fear of prosecution, which was also asked about.) Other physicians reported significant emotional burden from having performed euthanasia and PAS that, in some cases, even led to changes in practice patterns.¹⁸ Meier and colleagues reported that 18 percent of physicians who performed PAS and 12 percent who performed euthanasia were uncomfortable with having assisted in ending a patient's life.¹⁹ In addition, at least 7 percent of physicians would not repeat the acts in similar cases in the future. One of the leading advocates of euthanasia and PAS in Australia said of his actions that he felt like an "executioner."²⁰ "Regret" by a minority of physicians who perform euthanasia or PAS does not constitute a fundamental change in the profession. But such findings do suggest problems and adverse effects that should not be ignored.

Harm 2: Psychological Anxiety

There are some data about whether euthanasia or PAS would disrupt the trust necessary for the physician-patient relationship and generate psychological distress, not reassurance. In the same survey where patients and the public indicated that discussions with physicians about end-of-life care that included discussion of euthanasia and PAS would increase

18. Ezekiel J. Emanuel, Elisabeth Daniels, Diane L. Fairclough, and Brian R. Claridge, "The Practice of Euthanasia and Physician-Assisted Suicide in the United States," *Journal of the American Medical Association* 280 (1998): 507-13.

19. Meier, Emmons, Wallenstein, Quill, Morrison, and Cassel, p. 1197.

20. Seth Mydans, "Legal Euthanasia: Australia Faces a Grim Reality," *New York Times* (February 2, 1997), p. A3.

their trust in their doctor, an almost equal proportion of cancer patients thought such discussion would decrease trust in their physician.²¹ More importantly, my colleagues and I found that 19.0 percent of cancer patients and 26.5 percent of the public would change from physicians who discussed euthanasia or PAS with them. Indeed, patients with significant pain were more likely to want to change physicians. While far from definitive, these data indicate that whatever psychological reassurance some patients might experience from legalizing euthanasia or PAS is likely to be offset by increases in psychological anxiety and distress induced in other patients, and the most adverse impact will be on the very patients most in need of help, those with significant pain.

Harm 3: Coercion to Use Euthanasia or PAS

Coercion of the patient is most likely to come from his or her family either because of financial or caregiving burdens. Unfortunately, there really are no substantive data that permit quantification of the number of dying patients that might be coerced to receive euthanasia or PAS. There are some anecdotes about such coercive pressures, such as the DeLury case in New York in which a husband was convicted of pressuring his wife, who suffered from severe multiple sclerosis, to intentionally end her life. According to his own diaries his motive was to eliminate the burdens he was experiencing in caring for her. Similarly, there are data that suggest financial pressures could lead to coercion. The SUPPORT study found that in 24 percent of cases, families of terminally ill patients lost most or all of their savings because of medical care costs.²² In addition, in as yet unpublished data, my colleagues and I found that 8.6 percent of caregivers of patients who had just died reported that the patients' medical care imposed a "great economic burden" on the family.²³ While there are no data on whether economic pressures from illness lead to coercion of patients to seek euthanasia or PAS, data do indicate that these pressures alone—independent of other factors of ill health such as severity of illness and poor physical functioning—incline family members not to want life-sustaining treatments for their dying relatives.²⁴ And while there are no data on how many requests for euthanasia and PAS are motivated by family pressures due to financial burdens, we have re-

21. Emanuel, Fairclough, Daniels, and Clarridge, "Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences."

22. Kenneth E. Covinsky, Lee Goldman, E. Francis Cook, et al., "The Impact of Serious Illness on Patients' Families," *Journal of the American Medical Association* 272 (1994): 1839–44.

23. E. J. Emanuel, D. Fairclough, J. Slutsman, E. Omandsun, and L. L. Emanuel, "Commonwealth-Cummings Project on Quality of Life at the End of Life" (unpublished manuscript).

24. Kenneth E. Covinsky, C. Seth Landefeld, Joan Teno, et al., "Is Economic Hardship on the Families of the Seriously Ill Associated with Patient and Surrogate Care Preferences?" *Archives of Internal Medicine* 156 (1996): 1737–41.

ported that in 7.9 percent of actual cases of euthanasia and PAS in the United States financial burden was a core motive.²⁵ More needs to be done to understand the impact of these financial pressures on desires for euthanasia or PAS and whether they lead to coercive family pressure to seek euthanasia or PAS. Existing data are suggestive that such pressures might exist and do influence preferences at the end of life.

Independent of financial burdens, terminally ill patients also impose significant caregiving responsibilities on families that could lead to coercive pressures to request euthanasia or PAS. For instance, the SUPPORT study reported that in 34 percent of families dying patients required a large amount of caregiving assistance.²⁶ We found that more than one-third of terminally ill patients reported significant or moderate caregiving needs for transportation, nursing care, homemaking, and personal care with 16.3 percent having significant caregiving needs. Such caregiving needs adversely affect the patients' families—family members of patients with significant needs are more likely to be depressed and to report that the patient is interfering with their lives. More importantly, we found that, second only to depression, having high caregiving needs was a significant predictor for terminally ill patients having seriously thought about euthanasia or PAS.²⁷ Whether this interest in euthanasia or PAS was the result of family coercion or pressure, as it was in the DeLury case, could not be determined from these data.

We cannot accurately estimate the numbers of dying patients who might be coerced to request euthanasia or PAS because of financial or caregiving burdens. However, these data indicate that this is likely to exist and to be a real factor, and they influence a large proportion of the 2.3 million Americans who die, more than just the 2–3 percent of dying patients who might desire euthanasia or PAS. Among the 1 million competent patients with a dying process who might be eligible to request euthanasia or PAS, these data suggest that 86,000 to 240,000 (8.6 percent to 24 percent of 1 million dying patients) impose significant financial burdens, while 160,000 to 340,000 (16 percent to 34 percent of 1 million dying patients) impose significant caregiving burdens on their families. If just a few percent of these patients are coerced to request euthanasia or PAS, then the number of patients who might be harmed by legalization of these interventions begins to equal and exceed the number of

25. Emanuel, Daniels, Fairclough, and Clarridge, "The Practice of Euthanasia and Physician-Assisted Suicide in the United States," p. 510.

26. E. J. Emanuel, D. Fairclough, J. Slutsman, E. Omandsun, and L. L. Emanuel, "Predictors and Outcomes of Significant Caregiving Needs and Economic Burdens Among Terminally Ill Oncology Patients: Results of the Commonwealth-Cummings Project," *Journal of Clinical Oncology* 17 (1998): 422a.

27. It is worth noting here that in this and two other groups of patients explicitly evaluated, pain was not an independent determinant of interest in or action regarding euthanasia and PAS. Depression and caregiving needs, but not pain, are the dominant predictors of patients' interest in euthanasia and PAS.

dying patients who might benefit from legalization. And such patients can be harmed even if the coercive pressures are resisted simply because they have had to confront these pressures at a time of vulnerability and because such pressure is likely to disrupt the already intricate task of negotiating a good death.

Harm 4: Premature Euthanasia or PAS

Properly utilized euthanasia and PAS are “last ditch” interventions, interventions that can be justified only after appropriate palliative options are attempted. In the Netherlands, physicians report that in 9 percent of euthanasia cases in nursing homes not all palliative measures were utilized prior to ending the patient’s life.²⁸ My colleagues and I recently reported that all patients whose lives were ended by euthanasia or PAS and who had pain were on opioid narcotics.²⁹ But some of these patients were not given all optimal care: 60 percent were not receiving hospice care; in addition, less than 10 percent received psychiatric evaluations for depression, and at least one depressed patient who was given euthanasia refused psychiatric care.³⁰ How many depressed patients were not diagnosed or not given proper treatment but were given euthanasia or PAS we could not determine. Others have reported that in 39 percent of cases patients who were given euthanasia were depressed, and in 19 percent of cases patients given PAS were depressed.³¹ These data suggest a lack of adequate palliative care for psychological symptoms prior to use of euthanasia and PAS.³² Another recent survey of all oncologists in the United States revealed the surprising finding that those oncologists who reported that administrative, financial, and other barriers prevented them from providing all the care they wanted for their terminally ill patients were much more likely to have performed euthanasia or PAS in the last year (1997–98).³³ All these data indicate that in both the Netherlands and the United States, many patients who received euthanasia and PAS received these interventions before all appropriate palliative interventions had been implemented. Again, it is impossible to estimate how many dying patients would have ended their lives to relieve pain and suffering before appropriate palliative measures were instituted if euthanasia and PAS were legalized. But these data suggest that such actions occur in the Netherlands despite safeguards; it is hard to imagine that with legalization the frequency of euthanasia or PAS without adequate

28. Muller, van der Wal, van Eijk, and Ribbe, p. 625.

29. Emanuel, Daniels, Fairclough, and Clarridge, “The Practice of Euthanasia and Physician-Assisted Suicide in the United States,” p. 510.

30. *Ibid.*

31. Meier, Emmons, Wallenstein, Quill, Morrison, and Cassel.

32. *Ibid.*

33. This was my data presented to the American Society of Clinical Oncology, May 18, 1998.

palliative care would decline in the United States. And the total numbers of patients would increase if the number of patients receiving euthanasia and PAS increased.

Harm 5: Euthanasia for Incompetent Patients

In the Netherlands, it has been documented that slightly more than 20 percent of patients who received euthanasia were not mentally competent to consent to euthanasia when their lives were ended. In only 53 percent of these cases did the patient ever express interest in receiving euthanasia.³⁴ Recent data from two studies in the United States suggest that a high proportion of euthanasia cases occur in mentally incompetent patients. A national survey of physicians revealed that in 5–7 percent of cases of euthanasia and PAS, patients were mentally confused more than 50 percent of the time when given these interventions.³⁵ In another 5.3 percent of cases patients were also unconscious when given euthanasia. More importantly, my colleagues and I found that in 15 percent of euthanasia cases, patients were not involved in the decision to end their lives, sometimes even when they were competent.³⁶ Thus, it appears that in 15–20 percent of the cases there will be provision of euthanasia without patient's consent. This occurs when the action is illegal and the penalties high and in the Netherlands with explicit and established safeguards barring such practices.

Harm 6: Family Suffering

As has been pointed out in this symposium, euthanasia and PAS are decisions that go beyond the individual patients and affect the family who live long after the event. There are no data on the positive or negative long-term effects on families of patients whose lives are ended by euthanasia and PAS.

Overall, the benefit of legalizing euthanasia or PAS is improvement in the dying experience for a maximum of 25,000 terminally ill patients with unremitting pain. The benefit from psychological reassurance for patients is likely to be offset by increases in anxiety and psychological distress of other patients. The existing data do not permit us to estimate how many terminally ill patients might experience coercion to request euthanasia or PAS and to receive euthanasia or PAS without having received optimal palliative care or without having given their informed consent. However, each year hundreds of thousands of terminally ill patients would be at risk for these harms. Even if a small percentage of terminally ill patients suffer these harms, the benefits from legalizing

34. Van der Maas, van der Wal, Haverkate, et al., p. 1704.

35. Meier, Emmons, Wallenstein, Quill, Morrison, and Cassel, p. 1197.

36. Emanuel, Daniels, Fairclough, and Clarridge, "The Practice of Euthanasia and Physician-Assisted Suicide in the United States," pp. 509–10.

euthanasia or PAS would be overwhelmed. Under such circumstances are the benefits of legalization of euthanasia and PAS worth the risk of harms? The case for rushing forward does not seem very strong.

THE INEQUITABLE DISTRIBUTION OF THE BENEFITS AND HARMS OF LEGALIZATION

Finally, there is a point of equity that hardly gets mentioned in the debate about the legalization of euthanasia and PAS. Part of the reason there is such a rush to legalize euthanasia and PAS is that the benefits and the harms are not likely to be fairly distributed; the advocates are likely to reap the benefits while avoiding most of the harms.

The pressure to legalize euthanasia and PAS comes from relatively educated, well-off, politically vocal people. Polls consistently demonstrate that supporters of legalization of euthanasia and PAS tend to be financially well-off, well-educated, white, nonreligious, and under sixty-five years of age.³⁷ (How ironic that this sociodemographic description fits most federal judges, as well as philosophers and other academics.) These are people who have positions of authority in society, who control their work and home environments, and who are used to realizing their life plans. If euthanasia or PAS were legalized they would receive the benefits, especially the reassurance of knowing these options are available. Furthermore, they are likely to be protected from the harms of legalization. They tend to have good health insurance, intact, supportive families, and the social skills and know-how to get what they want from an increasingly bureaucratized health care system.

Conversely, the harms of legalization are likely to fall on vulnerable members of our population. Coercion to opt for euthanasia or PAS and inadequate uses of palliative care are likely to fall on financially less well-off and comparatively powerless patients who may not be insured or may be underinsured, who cannot get all the medical services they need, for whom the costs of care are likely to constitute a large financial burden, and who may not have the social skills to navigate the health care system. Again, the polling data suggest that the poor, African-Americans, and older people tend to oppose legalization of euthanasia and PAS.³⁸ They know their interests and know that they are most vulnerable to abuse.

37. Emanuel, Fairclough, Daniels, and Clarridge, "Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences"; and Robert J. Blendon, Ulrike S. Szalay, and Richard A. Knox, "Should Physicians Aid Their Patients in Dying?" *Journal of the American Medical Association* 267 (1992): 2658–62.

38. R. L. Lichenstein, R. H. Alcsér, A. D. Corning, J. G. Bachman, and D. J. Doukas, "Black/White Differences in Attitudes toward Physician-Assisted Suicide," *Journal of the National Medical Association* 89 (1997): 125–33, p. 128; Emanuel, Fairclough, Daniels, and Clarridge, "Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences"; and Blendon, Szalay, and Knox.

Further, the data on actual practices both from the Netherlands and the United States, including all of Dr. Kevorkian's cases, suggest that women are much more likely to be the recipients of euthanasia or PAS than are men.³⁹ Our data from oncologists showed that in 60 percent of euthanasia and PAS cases females were the patients.⁴⁰

The benefits and harms of legalizing euthanasia and PAS are likely to reinforce inequities in the delivery of health care services and the disparities of wealth and power in our society. And there is very little that the proposed safeguards will do to prevent this, since these sociodemographic disparities are common in the health care system and have been quite resistant to strenuous efforts to eliminate them.

CONCLUSION

Will legalization of euthanasia and PAS significantly improve the care of the 2.3 million patients in the United States who die each year? There is no compelling evidence that the answer is in the affirmative. And the focusing of so much attention and energy on debating, campaigning, litigating, and studying euthanasia and PAS is beginning to detract from the primary goal of improving end-of-life care. There are important challenges to providing better end-of-life care. These include providing better and more mental health care, home care, and spiritual care. The health care system has scarce resources, especially scarce time, money, attention span, managerial talent, and so forth. The euthanasia and PAS debate has been useful in focusing some of these scarce resources on the dying and in galvanizing improvements in care of the dying. Much of the nation, including the medical establishment, national foundations, and the National Institutes of Health, is focused on improving end-of-life care. Continued attention and resources focused on euthanasia and PAS are likely to impair, not improve, the care of the 2.3 million decedents by diverting valuable resources.

39. Van der Maas, van der Wal, Haverkate, et al.

40. Emanuel, Daniels, Fairclough, and Clarridge, "The Practice of Euthanasia and Physician-Assisted Suicide in the United States," p. 509.



Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls

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ABSTRACT

Euthanasia or assisted suicide—and sometimes both—have been legalized in a small number of countries and states. In all jurisdictions, laws and safeguards were put in place to prevent abuse and misuse of these practices. Prevention measures have included, among others, explicit consent by the person requesting euthanasia, mandatory reporting of all cases, administration only by physicians (with the exception of Switzerland), and consultation by a second physician.

The present paper provides evidence that these laws and safeguards are regularly ignored and transgressed in all the jurisdictions and that transgressions are not prosecuted. For example, about 900 people annually are administered lethal substances without having given explicit consent, and in one jurisdiction, almost 50% of cases of euthanasia are not reported. Increased tolerance of transgressions in societies with such laws represents a social “slippery slope,” as do changes to the laws and criteria that followed legalization. Although the initial intent was to limit euthanasia and assisted suicide to a last-resort option for a very small number of terminally ill people, some jurisdictions now extend the practice to newborns, children, and people with dementia. A terminal illness is no longer a prerequisite. In the Netherlands, euthanasia for anyone over the age of 70 who is “tired of living” is now being considered. Legalizing euthanasia and assisted suicide therefore places many people at risk, affects the values of society over time, and does not provide controls and safeguards.

KEY WORDS

Euthanasia, physician-assisted suicide

1. INTRODUCTION

Euthanasia is generally defined as the act, undertaken only by a physician, that intentionally ends the life of a person at his or her request^{1,2}. The physician

therefore administers the lethal substance. In physician-assisted suicide (PAS) on the other hand, a person self-administers a lethal substance prescribed by a physician.

To date, the Netherlands, Belgium, and Luxembourg have legalized euthanasia^{1,2}. The laws in the Netherlands and Luxembourg also allow PAS. In the United States, the states of Oregon and Washington legalized PAS in 1997 and 1999 respectively, but euthanasia remains illegal³. The situation in the state of Montana is currently unclear; a bill legalizing PAS was passed by the state legislature in 2010, but was recently defeated by the state’s Senate Judiciary Committee.

In the Netherlands, euthanasia and PAS were formally legalized in 2001 after about 30 years of public debate¹. Since the 1980s, guidelines and procedures for performing and controlling euthanasia have been developed and adapted several times by the Royal Dutch Medical Association in collaboration with that country’s judicial system. Despite opposition, including that from the Belgian Medical Association, Belgium legalized euthanasia in 2002 after about 3 years of public discourse that included government commissions. The law was guided by the Netherlands and Oregon experiences, and the public was assured that any defects in the Dutch law would be addressed in the Belgian law. Luxembourg legalized euthanasia and PAS in 2009. Switzerland is an exception, in that assisted suicide, although not formally legalized, is tolerated as a result of a loophole in a law dating back to the early 1900s that decriminalizes suicide. Euthanasia, however, is illegal⁴. A person committing suicide may do so with assistance as long as the assistant has no selfish motives and does not stand to gain personally from the death. Unlike other jurisdictions that require euthanasia or assisted suicide to be performed only by physicians, Switzerland allows non-physicians to assist suicide.

In all these jurisdictions, safeguards, criteria, and procedures were put in place to control the practices, to ensure societal oversight, and to prevent euthanasia and PAS from being abused or misused⁵. Some criteria

and procedures are common across the jurisdictions; others vary from country to country^{5,6}. The extent to which these controls and safeguards have been able to control the practices and to avoid abuse merits closer inspection, particularly by jurisdictions contemplating the legalization of euthanasia and PAS. The present paper explores the effectiveness of the safeguards and the “slippery slope” phenomenon.

2. SAFEGUARDS AND THEIR EFFECTIVENESS

2.1 Voluntary, Written Consent

In all jurisdictions, the request for euthanasia or PAS has to be voluntary, well-considered, informed, and persistent over time. The requesting person must provide explicit written consent and must be competent at the time the request is made. Despite those safeguards, more than 500 people in the Netherlands are euthanized involuntarily every year. In 2005, a total of 2410 deaths by euthanasia or PAS were reported, representing 1.7% of all deaths in the Netherlands. More than 560 people (0.4% of all deaths) were administered lethal substances without having given explicit consent⁷. For every 5 people euthanized, 1 is euthanized without having given explicit consent. Attempts at bringing those cases to trial have failed, providing evidence that the judicial system has become more tolerant over time of such transgressions⁵.

In Belgium, the rate of involuntary and non-voluntary euthanasia deaths (that is, without explicit consent) is 3 times higher than it is in the Netherlands^{8,9}. (“Involuntary euthanasia” refers to a situation in which a person possesses the capacity but has not provided consent, and “non-voluntary euthanasia,” to a situation in which a person is unable to provide consent for reasons such as severe dementia or coma). A recent study found that in the Flemish part of Belgium, 66 of 208 cases of “euthanasia” (32%) occurred in the absence of request or consent¹⁰. The reasons for not discussing the decision to end the person’s life and not obtaining consent were that patients were comatose (70% of cases) or had dementia (21% of cases). In 17% of cases, the physicians proceeded without consent because they felt that euthanasia was “clearly in the patient’s best interest” and, in 8% of cases, that discussing it with the patient would have been harmful to that patient. Those findings accord with the results of a previous study in which 25 of 1644 non-sudden deaths had been the result of euthanasia without explicit consent⁸.

Some proponents of euthanasia contend that the foregoing figures are misrepresentative, because many people may have at some time in their lives expressed a wish for or support of euthanasia, albeit not formally. The counterargument is that the legal requirement of explicit written consent is important if abuse and misuse are to be avoided. After all, written consent has become essential in medical

research when participants are to be subjected to an intervention, many of which pose far lesser mortality risks. Recent history is replete with examples of abuse of medical research in the absence of explicit informed consent.

2.2 Mandatory Reporting

Reporting is mandatory in all the jurisdictions, but this requirement is often ignored^{11,12}. In Belgium, nearly half of all cases of euthanasia are not reported to the Federal Control and Evaluation Committee¹³. Legal requirements were more frequently not met in unreported cases than in reported cases: a written request for euthanasia was more often absent (88% vs. 18%), physicians specialized in palliative care were consulted less often (55% vs. 98%), and the drugs were more often administered by a nurse (41% vs. 0%). Most of the unreported cases (92%) involved acts of euthanasia, but were not perceived to be “euthanasia” by the physician. In the Netherlands, at least 20% of cases of euthanasia go unreported⁷. That number is probably conservative because it represents only cases that can be traced; the actual number may be as high as 40%¹⁴. Although reporting rates have increased from pre-legalization in 2001, 20% represents several hundred people annually.

2.3 Only by Physicians

The involvement of nurses gives cause for concern because all the jurisdictions, with the exception of Switzerland, require that the acts be performed only by physicians. In a recent study in Flanders, 120 nurses reported having cared for a patient who received life-ending drugs without explicit request¹⁵. Nurses performed the euthanasia in 12% of the cases and in 45% of the cases without explicit consent. In many instances, the physicians were absent. Factors significantly associated with a nurse administering the life-ending drugs included the nurse being a male working in a hospital and the patient being over 80 years of age.

2.4 Second Opinion and Consultation

All jurisdictions except for Switzerland require a consultation by a second physician to ensure that all criteria have been met before proceeding with euthanasia or PAS. In Belgium, a third physician has to review the case if the person’s condition is deemed to be non-terminal. The consultant must be independent (not connected with the care of the patient or with the care provider) and must provide an objective assessment. However, there is evidence from Belgium, the Netherlands, and Oregon that this process is not universally applied^{10,13}. In the Netherlands, for example, a consultation was not sought in 35% of cases of involuntary euthanasia⁷. In 1998 in the

Netherlands, 25% of patients requesting euthanasia received psychiatric consultation; in 2010 none did¹⁶. Moreover, non-reporting seems to be associated with a lack of consultation by a second doctor¹⁴.

In Oregon, a physician member of a pro-assisted-suicide lobby group provided the consultation in 58 of 61 consecutive cases of patients receiving PAS in Oregon¹⁷. This raises concerns about the objectivity of the process and the safety of the patients, and raises questions about the influence of bias on the part of these physicians on the process.

Networks of physicians trained to provide the consultation role when euthanasia is sought have been established in the Netherlands (Support and Consultation on Euthanasia in the Netherlands) and Belgium [Life End Information Forum (LEIF)]¹⁸. Their role includes ensuring that the person is informed of all options, including palliative care. However, most LEIF physicians have simply followed a 24-hour theoretical course, of which only 3 hours are related to palliative care, hardly sufficient to enable a LEIF member to provide adequate advice on complex palliative care needs¹⁹. The development of expertise in palliative care, as in any other specialty, requires a considerable amount of time. In the United Kingdom, it involves a 4-year residency program, and in Australia and the United States, 3 years.

Oregon requires that a patient be referred to a psychiatrist or psychologist for treatment if the prescribing or consulting physician is concerned that the patient's judgment is impaired by a mental disorder such as depression. In 2007, none of the people who died by lethal ingestion in Oregon had been evaluated by a psychiatrist or a psychologist²⁰, despite considerable evidence that, compared with non-depressed patients, patients who are depressed are more likely to request euthanasia and that treatment for depression will often result in the patient rescinding the request²¹⁻²³. In a study of 200 terminally ill cancer patients, for example, the prevalence of depressive syndromes was 59% among patients with a pervasive desire to die, but only 8% among patients without such a desire²¹. Despite that finding, many health professionals and family members of patients in Oregon who pursue PAS generally do not believe that depression influences the choice for hastened death²⁴.

A recent Oregon-based study demonstrated that some depressed patients are slipping through the cracks²⁵. Among terminally ill patients who received a prescription for a lethal drug, 1 in 6 had clinical depression. Of the 18 patients in the study who received a prescription for the lethal drug, 3 had major depression, and all of them went on to die by lethal ingestion, but had been assessed by a mental health specialist.

There is evidence, therefore, that safeguards are ineffective and that many people who should not be euthanized or receive PAS are dying by those means.

Of concern, too, is the fact that transgressions of the laws are not prosecuted and that the tolerance level for transgressions of the laws has increased. Moreover, as the next section will explore, the boundaries of what constitutes "good" practices with respect to euthanasia and PAS continue to change, and some of the current practices would just a few decades ago have been considered unacceptable in those jurisdictions that have legalized the practices.

3. THE "SLIPPERY SLOPE" ARGUMENT

The "slippery slope" argument, a complex legal and philosophical concept, generally asserts that one exception to a law is followed by more exceptions until a point is reached that would initially have been unacceptable. The "slippery slope" argument has, however, several interpretations²⁶, some of which are not germane to the euthanasia discussion. The interpretations proposed by Keown in 2002²⁷ appear very relevant, however. He refers to these collectively as a "practical slippery slope," although the term "social slippery slope" may be more applicable. The first interpretation postulates that acceptance of one sort of euthanasia will lead to other, even less acceptable, forms of euthanasia. The second contends that euthanasia and PAS, which originally would be regulated as a last-resort option in only very select situations, could, over time, become less of a last resort and be sought more quickly, even becoming a first choice in some cases.

The circumvention of safeguards and laws, with little if any prosecution, provides some evidence of the social slippery slope phenomenon described by Keown^{5,28}. Till now, no cases of euthanasia have been sent to the judicial authorities for further investigation in Belgium. In the Netherlands, 16 cases (0.21% of all notified cases) were sent to the judicial authorities in the first 4 years after the euthanasia law came into effect; few were investigated, and none were prosecuted⁵. In one case, a counsellor who provided advice to a non-terminally ill person on how to commit suicide was acquitted²⁹. There has therefore been an increasing tolerance toward transgressions of the law, indicating a change in societal values after legalization of euthanasia and assisted suicide.

In the 1987 preamble to its guidelines for euthanasia, the Royal Dutch Medical Association had written "If there is no request from the patient, then proceeding with the termination of his life is [juristically] a matter of murder or killing, and not of euthanasia." By 2001, the association was supportive of the new law in which a written wish in an advance directive for euthanasia would be acceptable, and it is tolerant of non-voluntary and involuntary euthanasia^{7,30,31}. However, basing a request on an advance directive or living will may be ethically problematic because the request is not contemporaneous with the act and

may not be evidence of the will of the patient at the time euthanasia is carried out.

Initially, in the 1970s and 1980s, euthanasia and PAS advocates in the Netherlands made the case that these acts would be limited to a small number of terminally ill patients experiencing intolerable suffering and that the practices would be considered last-resort options only. By 2002, euthanasia laws in neither Belgium nor the Netherlands limited euthanasia to persons with a terminal disease (recognizing that the concept of “terminal” is in itself open to interpretation and errors). The Dutch law requires only that a person be “suffering hopelessly and unbearably.” “Suffering” is defined as both physical and psychological, which includes people with depression. In Belgium, the law ambiguously states that the person “must be in a hopeless medical situation and be constantly suffering physically or psychologically.” By 2006, the Royal Dutch Medical Association had declared that “being over the age of 70 and tired of living” should be an acceptable reason for requesting euthanasia³². That change is most concerning in light of evidence of elder abuse in many societies, including Canada³³, and evidence that a large number of frail elderly people and terminally ill patients already feel a sense of being burden on their families and society, and a sense of isolation. The concern that these people may feel obliged to access euthanasia or PAS if it were to become available is therefore not unreasonable, although evidence to verify that concern is not currently available.

In Oregon, although a terminal illness with a prognosis of less than 6 months to live has to be present, intolerable suffering that cannot be relieved is not a basic requirement (again recognizing that the concept of “intolerable suffering” is in itself ambiguous). This definition enables physicians to assist in suicide without inquiring into the source of the medical, psychological, social, and existential concerns that usually underlie requests for assisted suicide. Physicians are required to indicate that palliative care is a feasible alternative, but are not required to be knowledgeable about how to relieve physical or emotional suffering.

Until 2001, the Netherlands allowed only adults access to euthanasia or PAS. However, the 2001 law allowed for children aged 12–16 years to be euthanized if consent is provided by their parents, even though this age group is generally not considered capable of making such decisions⁵. The law even allows physicians to proceed with euthanasia if there is disagreement between the parents. By 2005, the Groningen Protocol, which allows euthanasia of newborns and younger children who are expected to have “no hope of a good quality of life,” was implemented^{34,35}. In 2006, legislators in Belgium announced their intention to change the euthanasia law to include infants, teenagers, and people with dementia or Alzheimer disease³⁶.

In Belgium, some critical care specialists have opted to ignore the requirement that, in the case of non-terminally-ill patients, an interval of 1 month is required from the time of a first request until the time that euthanasia is performed. One specialist reported that, in his unit, the average time from admission until euthanasia was performed for patients that seemed to be in a “hopeless” situation was about 3.5 days³⁷. Beneficence, this specialist argued, was the overriding principle.

Initially, euthanasia in the Netherlands was to be a last-resort option in the absence of other treatment options. Surprisingly, however, palliative care consultations are not mandatory in the jurisdictions that allow euthanasia or assisted suicide, even though uncontrolled pain and symptoms remain among the reasons for requesting euthanasia or PAS³⁸. Requests by the Belgian palliative care community to include an obligatory palliative care consultation (“palliative filter”) were denied¹⁹. From 2002 to 2007 in Belgium, a palliative care physician was consulted (second opinion) in only 12% of all cases of euthanasia³¹. Palliative care physicians and teams were not involved in the care of more than 65% of cases receiving euthanasia. Moreover, the rates of palliative care involvement have been decreasing. In 2002, palliative care teams were consulted in 19% of euthanasia cases, but by 2007 such involvement had declined to 9% of cases. That finding contradicts claims that in Belgium, legalization has been accompanied by significant improvements in palliative care in the country³⁹. Other studies have reported even lower palliative care involvement^{8,13}. It must be noted that legalization of euthanasia or PAS has not been required in other countries such as the United Kingdom, Australia, Ireland, France, and Spain, in which palliative care has developed more than it has in Belgium and the Netherlands.

The usefulness of a single palliative care assessment has been challenged—even when it is an obligatory requirement, as is the case at the University Hospital of the Canton of Vaud, Lausanne, Switzerland (the first hospital to allow, in 2005, assisted suicide in Switzerland⁴⁰)⁴¹. Among U.K. palliative care physicians, 63% feel that a single assessment is insufficient to fully evaluate and address the needs of a person requesting euthanasia or PAS⁴². A similar number of U.K. psychiatrists have expressed similar concerns^{43,44}, and only 6% of Oregon psychiatrists are comfortable providing consultations for patients requesting PAS⁴⁵.

Originally, it was the view of the Supreme Court of the Netherlands, the Royal Dutch Medical Association, and the ministers of Justice and Health that euthanasia would not be an option in situations in which alternative treatments were available but the patient had refused them. When this view conflicted with the accepted ethical principle that patients are allowed to refuse a treatment option, the law was

altered to allow access to euthanasia even if the person refused another available option such as palliative or psychiatric care. One consequence of the change is that, the appropriateness of suicide prevention programs may begin to be questioned, because people wanting to commit suicide should, on the basis of autonomy and choice, have the same rights as those requesting euthanasia.

There are other examples that a “social slippery slope” phenomenon does indeed exist. In Switzerland in 2006, the university hospital in Geneva reduced its already limited palliative care staff (to 1.5 from 2 full-time physicians) after a hospital decision to allow assisted suicide; the community-based palliative care service was also closed (JP. Unpublished data). Of physicians in the Netherlands, 15% have expressed concern that economic pressures may prompt them to consider euthanasia for some of their patients; a case has already been cited of a dying patient who was euthanized to free a hospital bed⁴⁶. There is evidence that attracting doctors to train in and provide palliative care was made more difficult because of access to euthanasia and PAS, perceived by some to present easier solutions, because providing palliative care requires competencies and emotional and time commitments on the part of the clinician^{47,48}. At the United Kingdom’s parliamentary hearings on euthanasia a few years ago, one Dutch physician asserted that “We don’t need palliative medicine, we practice euthanasia”⁴⁹. Compared with euthanasia cases, cases without an explicit request were more likely to have a shorter length of treatment of the terminal illness¹⁰.

Advocates of euthanasia have largely ignored these concerns about the “social slippery slope” and have opted to refute the “slippery slope” argument on the basis that legalizing euthanasia and PAS has not led to exponential increases in cases of euthanasia or PAS or in a disproportionate number of vulnerable persons being euthanized^{7,26,30}. However, there is evidence that challenges those assertion.

The number of deaths by euthanasia in Flanders has doubled since 1998³⁰. Of the total deaths in this Flemish-speaking part of Belgium (population 6 million), 1.1%, 0.3%, and 1.9% occurred by euthanasia in 1998, 2001, and 2007 respectively³⁰ (about 620, 500, and 1040 people respectively in those years). The requirement of the law to report euthanasia cases (aided by laxity in prosecuting cases that fall outside the requirement) may explain some, but not all, of the increase³¹. Chambaere *et al.*¹⁰ reported in the *Canadian Medical Association Journal* that in Belgium, euthanasia without consent had decreased from 3.2% in 1998 to 1.8% in 2007. But a closer review of the original study shows that the rate had declined to 1.5% in 2001 and then increased again to 1.8% in 2007³⁰.

In Holland, the overall rate of euthanasia was 1.7% of all deaths in 2005, down from 2.4% and

2.6% in 2001 and 1995 respectively, but no different from 1990 when the rate was 1.7%⁷. However, the Dutch government’s official statistics indicate a rise of 13% in 2009 compared with 2008; euthanasia now accounts for 2% of all deaths. Given the increasing numbers, interest in developing facilities that provide euthanasia (similar to those of the Swiss pro-assisted suicide group Dignitas) has recently been increasing. In Oregon, although the number of cases of PAS remain very small relative to the population, the rate has been increasing: 24 prescriptions were written in 1998 (16 of which led to deaths by PAS), 67 prescriptions in 2003 (43 of which led to deaths by PAS), and 89 in 2007⁵⁰.

In Belgium, the rates of involuntary and non-voluntary euthanasia have decreased; together they accounted for 3.2%, 1.5%, and 1.8% of all deaths in 1998, 2001, and 2007 respectively (1800, 840, and, 990 people respectively in those years)³⁰. In the Netherlands, the rate decreased from 0.7% in 2001 to 0.4% in 2005⁷. The actual rate is probably higher, given the large number of unreported cases. Notwithstanding the decrease, the rates are perturbing.

Battin *et al.*⁵¹ examined data from Oregon and the Netherlands and concluded, as have others³⁰, that there was no evidence that vulnerable people, except for people with AIDS, are euthanized disproportionately more. “Vulnerable” was defined in that study as individuals who are elderly, female, uninsured, of low educational status, poor, physically disabled or chronically ill, younger than the age of majority, affected with psychiatric illnesses including depression, or of a racial or ethnic minority. Finlay and George challenged the study on the basis that vulnerability to PAS or euthanasia cannot be categorized simply by reference to race, sex, or other socioeconomic status. Other characteristics, such as emotional state, reaction to loss, personality type, and the sense of being a burden are also important⁵². Patients are also vulnerable to the level of training and experience that their physicians have in palliative care and to the personal views of their physicians about the topic. For example, one study showed that the more physicians know about palliative care, the less they favour euthanasia and PAS⁵³.

Two recent studies further contradict the findings by Battin and colleagues. Chambaere *et al.* found that voluntary and involuntary euthanasia occurred predominantly among patients 80 years of age or older who were in a coma or who had dementia¹⁰. According to them, these patients “fit the description of vulnerable patient groups at risk of life-ending without request.” They concluded that “attention should therefore be paid to protecting these patient groups from such practices.” In another study, two of the factors significantly associated with a nurse administering life-ending drugs were the absence of an explicit request from the patient and the patient being 80 years of age or older¹⁵.

4. THE RESPONSE

What can be done, then, when the best of palliative care is unable to address suffering?

Zylicz, a palliative care specialist who has worked extensively in the Netherlands with people requesting euthanasia and PAS, provides a taxonomy to understand the reasons underlying the requests and provides stepping stones for addressing the requests. The requests can be classified into five categories (summarized by the abbreviation ABCDE)⁵⁴:

- Being afraid of what the future may hold
- Experiencing burnout from unrelenting disease
- Having the wish and need for control
- Experiencing depression
- Experiencing extremes of suffering, including refractory pain and other symptoms

Strategies are available to begin to address severe refractory symptoms, to treat depression, and to deal with the fear that some people have of what the future with a terminal disease may hold. Approximately 10%–15% of pain and other physical symptoms (such as dyspnea and agitated delirium) cannot be controlled with first- and second-line approaches and become refractory. For these symptoms, there is the option of palliative sedation. Palliative sedation is defined as “the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers in patients that are imminently dying”⁵⁵. Its intent is not to hasten death, which differentiates it from euthanasia. The goal is to achieve comfort at the lowest dose of sedative possible (usually with midazolam infusion, not with opioids) and at the lightest level of sedation. Some patients therefore achieve comfort at light levels of sedation, allowing them to continue interacting with family; in others, comfort is achieved only at deep levels of sedation.

Studies have shown that losing a sense of dignity and hope and taking on a sense of burden prompt some people to seek euthanasia and PAS^{21–23,56}. Strategies to improve the sense of dignity, based on empirical studies that have explored the concept of dignity within palliative care, have been shown to work⁵⁷. Similar strategies need to be developed in the areas of hope and burden.

Given effective palliation, including palliative sedation for patients with refractory symptoms, the only remaining issue is that of legalizing “on-demand” euthanasia and PAS when there is no terminal disease or when the person is tired of living or has a mental illness. Legalizing euthanasia and assisted suicide in these circumstances is most concerning and would have major implications over time, including changing a society’s values and making suicide prevention

programs redundant because people wishing to commit suicide would then be entitled to do so.

5. SUMMARY

In 30 years, the Netherlands has moved from euthanasia of people who are terminally ill, to euthanasia of those who are chronically ill; from euthanasia for physical illness, to euthanasia for mental illness; from euthanasia for mental illness, to euthanasia for psychological distress or mental suffering—and now to euthanasia simply if a person is over the age of 70 and “tired of living.” Dutch euthanasia protocols have also moved from conscious patients providing explicit consent, to unconscious patients unable to provide consent. Denying euthanasia or PAS in the Netherlands is now considered a form of discrimination against people with chronic illness, whether the illness be physical or psychological, because those people will be forced to “suffer” longer than those who are terminally ill. Non-voluntary euthanasia is now being justified by appealing to the social duty of citizens and the ethical pillar of beneficence. In the Netherlands, euthanasia has moved from being a measure of last resort to being one of early intervention. Belgium has followed suit³⁷, and troubling evidence is emerging from Oregon specifically with respect to the protection of people with depression and the objectivity of the process.

The United Nations has found that the euthanasia law in the Netherlands is in violation of its *Universal Declaration of Human Rights* because of the risk it poses to the rights of safety and integrity for every person’s life. The UN has also expressed concern that the system may fail to detect and to prevent situations in which people could be subjected to undue pressure to access or to provide euthanasia and could circumvent the safeguards that are in place.

Autonomy and choice are important values in any society, but they are not without limits. Our democratic societies have many laws that limit individual autonomy and choice so as to protect the larger community. These include, among many others, limits on excessive driving speeds and the obligation to contribute by way of personal and corporate income taxes. Why then should different standards on autonomy and choice apply in the case of euthanasia and PAS?

Legislators in several countries and jurisdictions have, in just the last year, voted against legalizing euthanasia and PAS in part because of the concerns and evidence described in this paper. Those jurisdictions include France, Scotland, England, South Australia, and New Hampshire. They have opted to improve palliative care services and to educate health professionals and the public.

6. CONFLICT OF INTEREST DISCLOSURES

The author has no financial conflict of interest to declare.

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