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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 Levens einde—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. Alcser, 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.