The issues presented by euthanasia and physician-assisted suicide (PAS) have become increasingly divisive in recent years, and for good reason. For one thing, only in modernity (at least since the Stoics) have we entertained the notion that an individual can be the master of his or her life, and perhaps only the past half century has brought us the notion that the individual can be the master of death as well. For another, human wisdom is usually the accretion of centuries of experience. No such development has been possible in this domain because infectious diseases relieved most generations of the dilemmas we now face posed by aging and the possibility of lingering death. While we have experienced the terrors of state-sponsored euthanasia in Nazi Germany, we have had little experience with euthanasia or PAS that is relatively “private” and occurs in an era in which most individuals will die in processes that are relatively long-term.

One can see this lack of experience in many of the arguments that have been raised for and against euthanasia or PAS. Proponents have often argued strongly from the position of absolute, inalienable rights, which are neither derived from nor dependent on experience, and are therefore neither undercut by the lack of prior experience nor defeated by the possibility of future (good or bad) experience. By contrast, opponents have often stood firm on the absolute absence of experience. They point out that we have never before experimented in this area, and argue that to do
so now will lead us down the slope to a parade of horribles, and therefore we had better remain absolute.

We are, however, perhaps entering a new era. At least in the United States, the arguments from absolutes have been legally foreclosed by the Supreme Court, which ruled that there is no absolute right, constitutionally enshrined, to control the time, place, and manner of one’s death, a ruling which also implicitly allows, if not invites, the creation of variegated experience in the laboratory of the states. Furthermore, we have begun to collect experience in the form of research that has told us much about the fears, hopes, and beliefs of real people, and in the form of very recent, actual experience with some types of PAS and euthanasia. It remains to be seen whether we will really walk through the land of trial and error, but it is clear that we have at least crossed the border. These developments have begun to alter the debate and the relevant issues, change that has spurred, and is reflected within, this review symposium on euthanasia and physician-assisted suicide.

I want to thank Mark Peterson and Byerly Woodward for supporting this endeavor and the authors for their contributions and remarkable degree of cooperation.


The useful core of *Asking to Die: Inside the Dutch Debate about Euthanasia* is the contribution of Gerrit van der Wal and P. J. van der Maas, “Empirical Research on Euthanasia and Other Medical End-of-Life Decisions and the Euthanasia Notification Procedure.” Their chapter reports the results of a study completed in 1996 that partly repeats the 1990–1991 Remmelink Committee study of the incidence of euthanasia and other medical end-of-life decisions in the Netherlands. Taken with the Remmelink report, *Asking to Die* enables one to compare earlier and later stages in the evolving Dutch practice of euthanasia since its partial legal normalization in 1984. This provides at least some test of often repeated claims that legalization of euthanasia would lead down a “slip-
pery slope,” at the bottom of which lay all sorts of abhorrent practices reflecting a lessened respect for human life. John Griffiths examines such claims in light of the new evidence in his provocative contribution, “The Slippery Slope: Are the Dutch Sliding down or Are They Clambering up?” Also useful are Johan Legemaate’s “Twenty-Five Years of Dutch Experience and Policy on Euthanasia and Assisted Suicide: An Overview,” and Gerrit K. Kimsma and Evert van Leeuwen’s “Euthanasia and Assisted Suicide in the Netherlands and the USA: Comparing Practices, Justifications, and Key Concepts in Bioethics and Law.” The former succinctly reviews developments in the Netherlands since 1973 that have led to the present situation, while the latter points out interesting differences between Dutch and American debates over the issue.

The book also contains a wealth of other material. There are discussions of subsidiary moral issues, like euthanasia in cases of purely psychological suffering. There are brief nuts-and-bolts treatments of topics like teaching programs on euthanasia, drugs used in euthanasia, and particular hospital protocols for euthanasia. There are summary “pro and con” statements on euthanasia from both religious and nonreligious viewpoints. Finally, and most extensively, there are personal accounts of particular cases of euthanasia from the points of view of physicians, patients, and family members.

None of the other material can rival the central importance of the empirical findings and interpretations. The personal accounts are nothing if not engrossing; such stories are, in the nature of things, dramatic and often moving, however matter-of-factly they are told. But how much can we really learn from them? The editors justify devoting more than two hundred pages to such accounts with these words:

There is an existential challenge to any person involved in euthanasia. Before any objective moral judgments can be made, in addition to gathering relevant facts and weighing ethical principles there is a crucial and often-ignored step: the imperative that decision makers reflect on all the relevant facts and allow the impact of those facts on the lives of those involved to sink into their consciousness. Thus, the following personal accounts presented here contribute to an analysis of euthanasia by bringing a missing ingredient; the euthanasia experience as it is lived. (262–263)

But, of course, no verbal account by a single individual can ever bring the reader face to face with “experience as it is lived;” or even “all the relevant facts.” All they can do is expose one to the perspective of the narrator
inevitably a partial and interested perspective. This holds even when a story seems to "ring true," for the requirements of good and convincing storytelling are quite different from those of accuracy and objectivity.

The partiality of these accounts is sometimes explicit, as in Arlene Judith Klotzko's interviews with Boudewijn Chabot and Henk Prins, two physicians involved in notorious cases—the first involving a psychiatric patient without a life threatening illness, the second involving a multiple handicapped infant unable to give consent. In both cases, one reads the story the physicians tell in their defense, but nothing from those who criticized their actions and who would, no doubt, tell the same stories quite differently. The same point applies to all these narratives. Vivid or not, they are perfect examples of purely anecdotal evidence and inevitably represent only one of many possible perspectives on the situations they relate.

Neither vivid nor particularly useful are the position statements on euthanasia, pro and con. At this point it may simply be too much to expect anyone to come up with anything new to say about the strictly philosophical issues involved, and nothing here suggests otherwise. In the course of delineating differences between the Dutch and American debates, Kimsma and Leeuwen offer capsule summaries of the going positions, neatly catalogued according to stance (pro or con), country (United States or Netherlands), and perspective (deontological, consequentialist, or "clinical pragmatic"). The effect is rather like that of a list of old recipes—and it cannot be said that the longer statements by Henk ten Have, Harry Kuitert, and Henk Jochemsem contain any more in the way of surprises that might dispel the prevailing sense of "been there, done that, had that argument."

Which brings us back to the empirical data and interpretations on which the main interest of the volume must depend. So how do these stack up? Unsurprisingly, I think the verdict so far must be that the evidence is inconclusive. After the Remmelink study, those who opposed voluntary euthanasia on the grounds that it would lead to involuntary killing expressed alarm at the so-called Remmelink thousand—the approximate number of cases of termination of life performed without a specific request reported in that study. But Griffiths points out that there is no evidence that the level of nonvoluntary termination of life in the Netherlands in 1990 was any higher than in countries like the United States, where euthanasia is illegal, or, for that matter, than in the Netherlands itself prior to 1984. Moreover, the number of involuntary cases actually seems to have declined slightly between 1990 and 1995.
But the rate of voluntary euthanasia has increased from 1.8 percent of all deaths in 1990 to 2.4 percent in 1995—more than a 30 percent increase in only five years. Whether this trend should be viewed with alarm is contentious. Euthanasia opponents will of course see any increase as a problem, but euthanasia advocates will not, since their whole point was to make euthanasia more comfortably available, at least in a limited number of cases. So does the increase merely reflect the greater ease with which those who face hopeless suffering are now free to escape it? Or are changing social expectations effectively pushing people into euthanasia who would otherwise have chosen life? This the statistics do not tell us. Has the increase leveled off, or is this the slow beginning to an uncontrolled landslide? Only time will tell—and there will be time to find out, given solid public support in the Netherlands and the current political situation there, which is more hospitable to euthanasia than in the past.

In the meantime, Griffiths suggests an alternative take on the real nature of what is happening in the Netherlands that gives one pause. Noting that euthanasia is routinely practiced everywhere despite laws against it, he concludes that:

The slippery-slope argument, applied to the Dutch experience . . . seems in a paradoxical way to get the direction of legal development backwards. It assumes a tendency toward relaxing legal control over medical behavior, whereas what is really going on is a quite massive increase of control . . . a whole new array of norms is coming into being to regulate behavior that hitherto was entirely unregulated. Medical practice in connection with death is being legally domesticated. (103)

Griffiths means this as a defense of legalization, but the point might actually cut both ways. If he is right, opponents of euthanasia might be better advised to pursue legal normalization, if they really want to control and minimize the practice. But, by the same token, might not defenders of euthanasia want to think twice before bringing the whole unwieldy apparatus of government and law to bear on a practice that now goes on quietly on the periphery of official control? The Dutch experience, so far, raises but does not answer these questions, among many others.

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“This book is about physician-assisted dying, which I think is both desirable and inevitable.” So begins *A Time to Die* by the Yale surgeon Charles F. McKhann. He then tells the story of his father’s death at the age of eighty-nine from “widespread intra-abdominal cancer” (1). His father underwent “palliative surgery, blood transfusions, and intravenous feedings” (2)—all of this despite the fact that it seemed “hopeless” and his father’s complaint “that too much was being done, that he just wanted to be left alone” (2). McKhann observes the irony of an intelligent, competent man, himself a physician who “had absolutely no control over stopping useless treatment which everyone knew could not give him more time” (2).

But there are other, deeper ironies—nay, confusions and fallacies—to this introduction that infect the book’s entire argument. Somehow a case in which the refusal of aggressive medical treatment would have been adequate becomes the opening both to symbolize and justify the need for euthanasia and physician-assisted suicide (PAS); somehow a case in which the patient and family were “too timid and conflicted” (2) to ask to stop treatments becomes the example for patients and families taking control through physician aid in dying; somehow McKhann thinks legalization of euthanasia and PAS suicide is the remedy necessary to the failures of care in his father’s case. Of course, McKhann is careful to note that for his father “it was never a question of assisted dying” (2), but then why begin a book that declares itself as an argument for the desirability of euthanasia and PAS with a story that is really about terminating life-sustaining treatments? Throughout this book, sentences are technically accurate but there is a pervasive, subtle conflation that confuses facts and arguments in an effort to strengthen the case for euthanasia and PAS. These conflations and confusions are not just McKhann’s, they are endemic to the debate about euthanasia and PAS.

The case of McKhann’s father illustrates a classic confusion, namely that euthanasia and PAS are the way to prevent the use of aggressive medical interventions that keep patients alive beyond the point of no hope. Frequently, people indicate that their support for euthanasia and PAS is based on the fact that they would not want to live “hooked up to machines” or “when it’s hopeless.” Advocates of euthanasia and PAS
encourage such thinking when they elide the moral and legal distinctions between intentionally ending a life through an intervention, such as an injection of muscle relaxants, and stopping medical treatments. Merging these positions allows the strong public support for the withdrawal and withholding of life-sustaining interventions to be appropriated for euthanasia and PAS. In June 1997 the U.S. Supreme Court made quite clear that these actions are legally distinct. There is a constitutional right to refuse medical treatments and even have a proxy exercise that refusal, while, by a vote of 9 to 0, the Court clearly stated that there is no constitutional right for either euthanasia or PAS. There is also a moral distinction. The safeguards we think appropriate and necessary for permitting euthanasia or PAS are not necessary for terminating medical care. For euthanasia or PAS a patient must be terminally ill; must be examined by a second physician, and when necessary by a psychiatrist; must be suffering despite optimal palliative care; only the request of a competent patient, not a proxy, can be honored; and, most important there must be a mandatory waiting period between the request and the actual ending of life. Conversely, a patient who wants a respirator turned off need not be suffering from another terminal illness, need not be examined by another physician, and need not wait days or weeks between the request and the turning off of the machine. Further, a proxy can request a respirator be stopped for an incompetent patient, even when the patient never expressed any view on the matter. Such differences in safeguards bespeak different moral evaluations about stopping medical interventions and actively injecting a patient with a life-ending drug.

Conflating the two actions confuses the debate about euthanasia and PAS. Despite his clarification, McKhann’s story of his father, his positioning it at the beginning of the book, his interweaving of other stories of terminating care—such as a story about turning off a respirator for a twenty-five-year-old who suffered severe brain damage from an automobile accident—into a book about euthanasia and PAS perpetuates and reinforces this confusion. The real solution to his father’s situation is not euthanasia but the willingness of physicians and the public to stop life-sustaining medical treatments, to say no to respirators and other interventions rather than to ask for an injection of drugs.

A second confusion McKhann perpetuates regards the role of pain in euthanasia and PAS. In chapter 1, McKhann explores “bad deaths,” or those that involve pain and suffering. He describes how situations “when no amount of medication gives adequate pain control” produce desires for an end. McKhann acknowledges that “one large study showed that of
people requesting assisted dying, fewer than 10 percent did so on the basis of pain alone” (30). The irony, however, is that when he describes the cases in which euthanasia or PAS would be acceptable—such as the case of “rational suicide” presented in chapter 2—they invariably entail “the dilemma of a person who is painfully and terminally ill” (22; my emphasis). Indeed, in the last chapter McKhann tells us that when he was recently forced to “find a primary care physician, the first such doctor to enter my adult life” (227), he posed the physician a question: “Suppose that ten years from now I developed cancer of the pancreas that could not be cured and was very painful. If I asked you for a prescription for Sec­

ional that I could have on hand to end my own life if the suffering became unbearable, would you give it to me?” (227; my emphasis).

Like most people in the United States, McKhann believes that pain is the essential reason people would seek euthanasia or PAS. He acknowledges the data that disputes this belief, but cannot accept it. In fact, McKhann’s explicit acknowledgment of these data is itself inaccurate. It is not just “one large study” (30) that has shown that pain is not the cause or reason why patients seek euthanasia or PAS. Every single study (and there are now at least ten of them)—whether in the United States, the Netherlands, or Australia; whether of patients with cancer, AIDS, or amyotrophic lateral sclerosis (Lou Gehrig’s disease); whether of patients who received euthanasia or PAS legally or illegally; whether of physicians who performed euthanasia or PAS—has found that pain is neither a primary nor an important factor in motivating patients’ interest in euthanasia or PAS. Among the most telling data are from Oregon where of the fifteen patients who legally received PAS, only one (7 percent) was experiencing significant pain. Indeed, terminally ill patients who did not request PAS were more likely to be experiencing significant pain than those who ended their lives by PAS. Presumably, what the terminally ill patients in pain want is relief from their pain and palliative care, not the ending of their lives.

Americans have a hard time believing these data. They contradict our beliefs and prejudices. People think, “If I were terminally ill and had excruciating pain, I would want to end my life.” The problem is we are healthy, have no serious illness, have not experienced the progressive decline of a serious illness. Our views are not those of terminally ill patients who are in pain. And our current views are unlikely to be the views we hold when we become terminally ill. But, being healthy, we have difficulty believing that the experience of serious illness changes
our views so radically, despite the enormous evidence that this occurs. Like McKhann, and reinforced by his book, we acknowledge and simultaneously ignore the data about pain and euthanasia, continuing the fairy tale discussion about what the doctor should do if I develop pancreatic cancer and severe pain. The real solution to untreated pain at death is better palliative care, not a prescription for Seconal.

A third confusion that permeates *A Time to Die* concerns the conditions under which euthanasia and PAS would be permitted. One of McKhann’s “bad deaths” is dementia: “Severe dementia is a horrible disability to contemplate” (22). After describing some of its horrors, he writes: “It is small wonder that Alzheimer’s disease is one of the great public fears and is already a controversial issue in many discussions of assisted dying. . . . Many people want to be able to die before reaching the end stages of dementia” (23). Surely McKhann is correct that many people do fear Alzheimer’s disease, but legalizing euthanasia and PAS would hardly help calm these fears. First, legalizing PAS, as in Oregon, does nothing for demented patients because they cannot take the drugs themselves. Having someone put the drugs into a gastric tube or down a patient’s throat is more akin to euthanasia than assisted suicide and remains illegal in Oregon. More important, every proposal to legalize active euthanasia requires the patient to be competent and personally initiate the request. Indeed, the philosopher Dan Brock is the only scholar I know who seriously advocates legalizing euthanasia for incompetent patients. Because politically this is a nonstarter, no one else publicly advocates this position, and it has not been proposed in any state legislature. Holding out the notion that legalizing euthanasia will help people who fear the ravages of dementia just fuels further fantasy and confuses the current debate.

In addition, McKhann suggests that over time we will move from accepting euthanasia for competent patients to accepting euthanasia for the incompetent. History is not on his side. While he analyzes the Dutch experience on many levels, McKhann again fails to connect various points of his argument. In the Netherlands, research has revealed that about one thousand patients per year—almost a third of all euthanasia and PAS cases—receive euthanasia when they are no longer competent. In only half of these cases was there any prior discussion about euthanasia or PAS. If McKhann’s prediction were correct, then over time there should be greater acceptance of these cases and even a formal change in the Dutch safeguards so that patients would no longer have to be competent to receive euthanasia. Neither is happening. Instead, euthanasia
accomplished without explicit, concurrent patient consent remains fiercely contentious and widely condemned. Indeed, the lengths to which advocates of the Dutch system go to diminish the importance of these cases only attests to how problematic they are and how little support they have. Further, there is no effort to “loosen” the Dutch safeguards to permit euthanasia of incompetent patients. In sum, McKhann has invoked the fear of dementia to motivate the need for legalizing euthanasia and PAS. The irony is that these interventions would never be used for demented patients. The solution lies somewhere else.

A fourth confusion relates to the support for euthanasia and PAS. Again, one of McKhann’s “bad deaths” is old age. “Old age itself often seems to be a reason to want to die. . . . Nursing homes are full of people ‘trapped in transit between retirement and death’ because our health care system will not allow them to die, regardless of their expressed wishes” (27).

Yet at another point in the book, McKhann acknowledges that support for euthanasia and PAS is strongest among the young, well-educated, well-off, and nonreligious. Actually, polling data consistently demonstrate that those over age sixty-five, African Americans, and Catholics strongly oppose euthanasia and PAS. But McKhann seems oblivious to the irony of his support for euthanasia of the elderly and the polling data. Indeed, it may be the eagerness of McKhann and others like him that make the elderly fearful, afraid they may be “encouraged” to die by younger people.

More generally, people concerned with social justice should seriously ponder the polling data. The well-off and well-educated—that is, those with good jobs and health insurance, with stronger social supports, used to getting their way, and able to navigate an increasingly complex health care system—support euthanasia and PAS; they are used to controlling their affairs. Euthanasia and PAS just extend this habit of control. Those opposed tend to be the vulnerable and not well insured, have trouble getting what they need from the health care system, and with social support structures that are tenuous at best. They oppose euthanasia and PAS because they are most likely to feel external pressure to hasten their death. Legalizing euthanasia and PAS may just perpetuate the social inequalities we already see in the health care system.

The epigram of the last chapter of A Time to Die is from Francis D. Moore, a renowned surgeon who between the 1950s and 1970s was the chief of the surgery department at Harvard’s Peter Bent Brigham Hospital. In his old age, Moore argues that “the doctor should be involved in making these terminations clean and safe” (224). A recent survey of
American oncologists revealed that support for euthanasia and PAS was significantly stronger among surgical oncologists than among the medical oncologists. This seemed ironic. Surgeons tend to be a pretty conservative lot. Moreover, surgeons tend not to manage dying patients; it is medical oncologists and other internists who are the ones called upon to care for the dying. I wondered if McKhann’s view, like that of his fellow surgeons, arises from the “surgical psychology,” the desire for quick fixes, for “doing something,” for “cutting it out.” As a class, surgeons are noted for doing, not talking; for cutting, rather than exploring patients’ feelings; for the interventional rather than the cognitive parts of medicine. Surgeons like things “sterile and safe” but death, even a good death, is anything but “sterile and safe.” There are the messy emotions of confronting mortality, resolving family relationships, and the dirty physical facts of fatigue and incontinence. Maybe the response to these messy and dirty aspects is to just get rid of them.

The issue of whether to legalize euthanasia and PAS is complex and depends upon some difficult determinations of whether on balance these interventions will improve the care of the 2.3 million Americans who die each year. In approaching these determinations, we need to be careful about the real impact of euthanasia and PAS. Unfortunately, A Time to Die confuses more than it clarifies. It makes the reader believe that euthanasia and PAS are like terminating life-sustaining treatments, desired by terminally ill patients in pain, and a solution for people’s fears of dementia and old age. None of this is true, but it would be hard to tell from this book.

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Participants in the physician-assisted suicide debate naturally look for guidance to the Dutch experience with euthanasia. In Euthanasia and Law in the Netherlands, readers will find an important discussion and analysis of how the Netherlands has come to permit euthanasia (and assisted suicide). In particular, Griffiths, Boed, and Weyers provide a
comprehensive review of the evolution of Dutch law from 1945 to 1997 (43–155) and very helpfully include the text from key provisions of the criminal code, major legislative proposals, and critical judicial opinions on euthanasia (308–351). Interestingly, the authors report, the Netherlands’ acceptance of euthanasia developed more from the insistence of physicians than the demands of patients (111).

The authors also provide an extensive discussion of what is actually known about euthanasia and other end-of-life decisions in the Netherlands (197–257), giving special attention to euthanasia without an explicit, contemporaneous request (226–228) and the rare cases of the euthanasia of severely disabled newborns (229–232) and the assisted suicide of patients with psychiatric disorders (233–235). Even those who disagree with the book’s arguments will find this to be a leading resource on the legal rules and medical practice of euthanasia in the Netherlands.

In their moral analysis (157–196), Griffiths, Bood, and Weyers reject the usual distinctions between euthanasia and the widely accepted practice of terminating life-sustaining treatment. In doing so, they respond to an important objection to the legalization of euthanasia in the United States. Ten years ago, Susan Wolf (1989) argued against such a legalization on the grounds that it would undermine progress in the legal rules for the termination of life-sustaining treatment. According to Wolf, the prohibition of euthanasia has permitted U.S. courts to leave treatment withdrawal decisions to doctors and patients without extensive judicial involvement. In addition, the courts have been willing to grant an expansive right of patients to refuse life-sustaining treatment, without limiting it on the basis of the patient’s condition or the type of treatment being refused. The patient need not be terminally ill to refuse life-sustaining treatment, and feeding tubes, as well as ventilators, can be withheld or withdrawn.

If euthanasia were legalized, however, wrote Wolf, courts would take a different view of their role and that of the law. In all likelihood, the courts would not be comfortable relying on the judgment of doctors and patients in employing euthanasia. Rather, courts would want prosecutors and police “roaming the halls” of hospitals to ensure that physicians did not cross the line between voluntary and involuntary euthanasia. Similarly (as is the case with assisted suicide in Oregon), a right to euthanasia would be limited in scope. Patients would need to be terminally ill, or suffering greatly and irreversibly, and they would need to be competent at the time of euthanasia.

Against this backdrop of euthanasia law, observed Wolf, courts would be much less likely to permit an expansive right to refuse life-sustaining
treatment. Rather, they would be more likely to bring treatment-withdrawal law in line with euthanasia law. There would be more judicial oversight of withdrawal decisions, and the right to refuse treatment would be limited to the more seriously ill patients and the more burdensome treatments. As Wolf noted, some judicial decisions, including O’Connor in New York and Cruzan in Missouri, had expressed skepticism of a broad right to refuse life-sustaining treatment. The existence of a right to euthanasia would have bolstered that skepticism.

In Euthanasia and Law in the Netherlands, the authors argue that in fact it would be a good idea if the law for treatment withdrawals became more like the law for euthanasia. Griffiths, Bood, and Weyers acknowledge that there are problems with the implementation of euthanasia in the Netherlands, but they remind us that comparable problems exist with decisions to withhold or withdraw life-sustaining treatment. For example, even when patients are competent, Dutch physicians often decide to withhold treatment without securing informed consent (218, 254). Data from the United States substantiate the authors’ concern about treatment withdrawals. Studies indicate that physicians are inclined to override living wills when they disagree with the patients’ wishes (Danis et al. 1991; Orentlicher 1994).

Griffiths, Bood, and Weyers observe that regulation of euthanasia needs to be improved in the Netherlands, but so does regulation of treatment withdrawals, aggressive pain relief, and other permitted practices that may lead to the patient’s death. Indeed, since deaths by withdrawal of treatment or aggressive pain relief are a much larger percentage of patients deaths than deaths by euthanasia, the magnitude of abuse is probably greater with those practices (296). In improving the regulation of these other end-of-life practices, say the authors, it is important that the state make regulation of the different end-of-life practices more similar (297). Otherwise, physicians are tempted to escape regulation by mischaracterizing what they are doing. For example, physicians can label the use of euthanasia as a case of treatment of pain justified by the doctrine of double effect and thus avoid the obligation to report the case to public authorities.

While there is much to be said for the book’s call for better regulation of euthanasia, treatment withdrawal and aggressive pain relief, its main proposal for regulation will undoubtedly invite criticism. According to the authors, the Netherlands should rely primarily on professional self-regulation rather than the criminal law to prevent and respond to abuses by physicians (284–295). In their view, regulation will be better accepted
and more effective if it is noncriminal and if it is largely controlled from within the medical profession. Yet, as many readers will note, it is not clear that any profession can be relied upon to engage in effective self-regulation. There is an important role for professional self-regulation, but the primary source of control arguably must come from outside the profession.

While it is difficult to say where the truth lies on this question, we can at least refine the inquiry by considering the kinds of risks that attend internal and external regulation and ask which ones are more troubling. In the case of professional self-regulation, society has to worry whether physicians will adequately discipline their colleagues. The main risk is that doctors will be insufficiently deterred from wrongful conduct and that too many premature deaths will occur. Patients who are not ready to die will nevertheless receive a lethal injection or have their ventilators withdrawn.

In the instance of external regulation, however, society has to worry whether the outside regulating bodies will overly chill appropriate physician behavior. For example, if physicians are subject to tight scrutiny when they provide aggressive pain relief, the pain of dying patients may go untreated. This in fact seems to be a problem currently in the United States (Johnson 1996). Similarly, if governmental authorities are quick to question withdrawals of treatment, physicians may be too slow to stop unwanted life-sustaining treatment. Many people think that misguided regulation of long-term care facilities in the United States results in overuse of feeding tubes in those facilities (Kapp 1997).

In short, on the question of where regulatory authority for euthanasia should lie, we end up at much the same point as we do on the question of whether euthanasia should be permitted at all. If the regulation depends on the health professions, or if euthanasia is permitted, lives may be wrongly shortened. If the regulation depends on external control, or if euthanasia is not permitted, intolerable suffering may wrongly be imposed.

For some observers, the need to err on the side of preserving life will be decisive. To them, euthanasia should not be permitted, or, if it is permitted, there should be close scrutiny from outside the medical profession. For other observers, the balance will depend on the relative magnitudes of risks. It may be true that government agencies will engage in overregulation more than physicians will abuse their authority. If that is the case, the balance would tip in favor of professional self-regulation. On the other hand, it may be the case that physicians will more likely abuse their authority than government agencies will chill good care. In that case, the balance would tip in favor of external regulation. Another
relevant consideration would be to consider how much or what kind of life is at stake. Just as Oregon has limited its right to assisted suicide to patients who are terminally ill, and just as U.S. courts have given more leeway to withdraw feeding tubes from incompetent patients when the patients are either terminally ill or permanently unconscious (Curran et al. 1998), so might the locus of regulation depend on the severity of the patient’s condition.

In the end, the question of regulation, like the question of legalization, turns in large part on unanswered, and probably unanswerable, empirical considerations. Griffiths, Bood, and Weyers have done much to inform the debate with their book, but the range of debate is still considerable.

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References


Linda L. Emanuel’s collection of essays exploring physician-assisted suicide includes chapters written by prominent authors who have taken opposite sides in the public debate. For readers who have not explored
the issues in depth, the book provides an excellent opportunity to acquaint oneself with the major arguments in favor of and against legalization. The book is organized with three authors presenting “considerations in favor” (Angell, Batton, Loewy), three presenting “considerations against” (Pelligrino, Wolf, Childress), three “perspectives” (van der Maas, and L. Emanuel, E. Emanuel, Annas), and a “final synthesis” (L. Emanuel). In general, the presentation is balanced, though the perspectives and final synthesis are dominated by those who are opposed to legalization.

For readers who are familiar with the debate, much of the material has been published elsewhere, and each author’s perspective is well-known. Nonetheless, there is some exploration of relatively fresh ground that even those acquainted with the issues should consider reading:

1. Peg Batton explores the moral and clinical responsibility of those who choose to turn down requests for physician-assisted suicide. Virtually all proposed safeguards (Quill, Cassel, and Meier 1992), model statutes (Baron et al. 1996), and legislative initiatives have “opt out” clauses for physicians who for personal moral considerations cannot directly assist a patient to die even if they meet agreed-upon criteria. What are these physicians’ responsibilities to the patients they turn down, and what are the moral implications of exercising this option? Other than asserting that such physicians have the right to refuse to participate, this question has remained relatively unexplored by both proponents and opponents of legalization. Batton examines the impact of such a decision on the patient-physician relationship, and challenges such physicians to find common ground with their patients whenever possible rather than abrogating responsibility.

2. George Annas presents a novel and somewhat idiosyncratic belief that the provision of a potentially lethal dose of barbiturates (such as I reported in Quill 1991) does not legally constitute physician-assisted suicide. The primary intent must be to reassure the patient that there could be an escape rather than to end life. “Only physicians who believe they are intentionally killing their patients with overdoses of drugs, and who would feel the same if they shot their patients with a gun—or provided their patients with a loaded gun with the intent that they use the gun to kill themselves—should change their behavior to comply with the laws,” according to Annas. If others in law, ethics, and medicine concur with this belief, and would put such policy into writing so that this possibility could be predictably available, then we might not need to change the law. I
remain unconvinced that I understand the mental, ethical, and legal
gymnastics required to justify such a practice in this way, especially
in the current legal and political environment. Furthermore, the hon­
est and forthright discourse needed in such circumstances might be
undermined with such hedging of intent and responsibility.

3. Susan Wolf challenges us to consider the suffering of medically ill
children and adolescents, asking whether physician-assisted suicide
has any role in the treatment of such persons who do not have the
capacity to consent. Most proponents of legalization of physician-
assisted suicide require that two substantive anchors be present in
all cases: (1) voluntariness and (2) intolerable suffering. Certainly
most children are not capable of fully comprehending such a com­
plex decision, and therefore could not meet criteria for voluntari­
ness. But children are fully capable of suffering, and there is a long
history in medicine and society of underrecognizing and under­
treating pain and suffering in children. Therefore, simply because
we must say a firm “no” to physician-assisted suicide for children
does not mean that we should not challenge ourselves to address
their pain and suffering. Comprehensive palliative care such as hos­
pice programs clearly should be the standard of care for dying chil­
dren and adolescents, but we must also think about how we want
physicians to respond to a child’s suffering if it becomes severe and
unrelievable in spite of our best efforts. Would terminal sedation be
our last-resort response, and if so, what would be the criteria and
safeguards to protect against abuse? Responding to extremes of
suffering for those who are incapable of consent remains a daunt­
ing challenge that we cannot walk away from, but the answer is not
physician-assisted suicide.

4. Those who are frustrated by the glib and biased accounting of the
Dutch experience in the U.S. literature (Hendin 1998) will find the
perspectives chapter entitled “factual findings” refreshing. Because it
is cowritten by one of the authors of the Remmelink report (P. J. van
der Maas) and a staunch opponent of legalization of physician-
assisted suicide (Linda Emanuel), it may be a model for lessening bias
in the analysis of controversial data. Since seemingly “objective” data
can be subject to politicized analysis, it may be useful for both
researchers and analysts of these practices to include a balance of
open-minded persons from both sides of the debate. Such balance
might sharpen the questions asked as well as improve the depth of the
analysis.
Despite the diversity of opinions about the wisdom of legalizing or otherwise openly permitting physician-assisted suicide in the United States at this time, there is remarkable agreement among the authors about many issues:

1. Basic medical care in general and palliative care in specific are unavailable to many in need in this country. Physician-assisted death in any form (active or passive, intended or not) should never be an alternative to good medical care.

2. Palliative care, including excellent pain and symptom management and support for patients and their families ideally in their homes, is the standard of care for the dying against which all other interventions should be measured.

3. Pain can usually be controlled using modern analgesic methods. Unrelieved pain is infrequently the sole source of requests for physician-assisted death.

4. Patients have a right to refuse treatment, and a right to stop treatment once started if it stops meeting their goals, even if their desire is for a hastened death.

5. With access to state-of-the-art palliative care, there will be relatively few requests for physician-assisted suicide, and even fewer cases where alternatives cannot be found.

The fault lines appear when the authors consider the centrality of certain moral distinctions. Those opposed to physician-assisted suicide see bright lines between “active” and “passive” assistance in dying, and between “foreseeing” and “intending” death, and therefore see forgoing life supports as a clearly acceptable form of “letting die,” whereas physician-assisted suicide is labeled as a form of intentional “killing.” Proponents of physician-assisted suicide as a last resort see more gray in these distinctions, put more weight on the patient’s will and intention than those of the physician, and talk about the physician’s moral responsibility to respond to their patients’ unbearable suffering. If not physician-assisted suicide, then how should we respond to the tough cases? Simply saying “no” is inadequate without developing an alternative approach, since patients and their families still must face these seemingly intolerable situations whether or not physicians choose to help them.

Emanuel and others find great comfort in terminal sedation as a last-resort option. With terminal sedation, the patient is sedated to unconsciousness to escape otherwise unrelievable suffering, and then food and fluids are withheld. Ethically, it can be viewed as a combination of the
double effect (sedation is given to relieve suffering, not to cause death; and death is foreseen but not intended) and the withholding of life-sustaining therapy (patients have the right to avoid unwanted bodily invasion) (Quill, Lo, and Brock 1997). Many who are adamantly opposed to physician-assisted suicide support this last-resort practice relatively uncritically (Lynn et al. 1997; Byock 1993). To them, the differences between this terminal sedation on the one hand and physician-assisted suicide and euthanasia on the other are crystal clear. To others, however, terminal sedation is tantamount to “slow euthanasia,” especially when the patient is requesting to escape suffering through death (Billings and Block 1996; Orentlicher 1997). Certainly death is inevitable with terminal sedation, and, unlike other forms of cessation of life supports, it does not require any illness, much less a terminal one, to ensure that death occurs.

When comparing terminal sedation to euthanasia (Quill, Lo, and Brock 1997), terminal sedation is more “passive” and “indirect” in causing death (the sedative infusion has the primary purpose of helping the patient to escape suffering, and there is no injection of curare to paralyze respirations once heavy sedation is achieved). Yet the withholding of life support would not be possible without the physician’s “active” initial intervention of inducing an iatrogenic coma. The patient’s or the physician’s intention in carrying out this aggregate act is more open to interpretation, and may vary according to the specific clinical situations as well as the values and beliefs of the particular patient and doctor. As a result, conscientious people are likely to reach different conclusions regarding intention and responsibility.

Comparing terminal sedation and physician-assisted suicide along the same parameters may be even more open to interpretation. Physician-assisted suicide is “active” in that the physician provides the means, but “passive” or “indirect” in that the patient must be the final actor. As Annas points out, the means provided may have other potential purposes (sedation for anxiety, hypnotic for sleep, reassurance about a potential escape that the patient may never take), and therefore might be considered to be within the purview of the double effect, where death is foreseen as a possibility but not intended by the physician (Quill, Dresser, and Brock 1997). While I am generally skeptical of such ethical and mental gymnastics, they illustrate how subjective and ultimately indeterminant analyses of intention can be, and how sometimes “activity” and “passivity” differ in the eyes of the beholder (physicians tend to experience the removal of a respirator as “active,” despite it being categorized as “passive” by ethicists.)
Furthermore, "unbundling" terminal sedation into its two main elements in order to justify it according to the double effect and withholding of therapy might be viewed with skepticism by some. If we do believe that the active/passive distinction and the double effect are critical for all patients and all physicians (not just those who come from certain religious traditions), then the relative positions of terminal sedation and physician-assisted suicide according to these constructs remain debatable. Each intervention may have a small place as we search with patients for the least harmful alternative to intolerable terminal suffering, given the patient's clinical dilemma and the personal values of both patient and doctor, but personally I don't see one practice as inherently safer or morally superior to the other.

I found two arguments in the book worrisome in that they undermine a forthright examination of the genuine predicament in which some patients and their families find themselves. The first was put by Emanuel as the claim that "there has never been an era with less physical suffering than ours, or more potential to relieve it" (256), and the "weakness of the mercy arguments for these practices in today's United States" (258). It is not clear to me if the suggestion is that terminal suffering in the United States is not severe enough to warrant considering allowing patients this kind of escape, or if it is that physician-assisted suicide should not be allowed because many aspects of our society are unmerciful. In either event, I respectfully disagree.

The book suggests a relatively romantic notion of what "natural" dying is like under the auspices of excellent medical care and minimizes the daunting dilemmas that patients and families are facing today in part as a result of our medical successes. People in the United States are definitely living longer, but much of the later phases of life can be filled with increasing morbidity and dependence, and a series of agonizing choices about when and whether to stop treatments, and then how to proceed once treatments are stopped (Olshansky et al. 1991; AMA 1990). Most pain can be controlled, but sometimes at a cost of diminishing consciousness, so that many will choose to tolerate pain. In looking at patients' self-reports of symptoms one week prior to death on hospice programs (our best-case scenario), approximately 2 to 35 percent report their pain as "severe" or "intolerable," and 25 percent report their shortness of breath as "unbearable" (Kasting 1993). Other symptoms are also daunting (nausea, vomiting, bleeding, open wounds, weakness, etc.) and frequently even harder to relieve than pain. Furthermore, the suffering of the terminally ill often is a combination of physical symptoms and psychosocial,
spiritual, and existential suffering, sometimes stated as tiredness of prolonged dying, dependence and debility, made intolerable in part because they can go on so long. While few of these patients would explicitly request a physician-assisted death, it hardly sounds as if their deaths were easy, natural, or not in need of our best attempts at mercy. In fact, many such patients eventually make decisions toward the end of the process that hasten death, usually indirectly, but often the result of explicit conversation and decision making.

Sometimes patients and families reach a point where there seems initially to them to be no dignity in the dying process, but with expert help and support, personal growth and meaning can frequently be found (Byork 1977). Yet, it is also possible to overly romanticize the process to the point that we stop seeing what our patients and families are experiencing and trying to tell us (Quill 1996). Partnership and nonabandonment by health care providers involve being a guide, listener, and fellow traveler who keeps an open mind at all times to the patient’s experience (Quill and Cassel 1995). Because some elements of our health care system are inadequate is no excuse to abandon those who are suffering severely in the face of excellent care and asking for our help.

The second worrisome aspect of the overall presentation is the ease with which requests for forgoing life supports and even terminal sedation are accepted based on the right to refuse treatment, yet requests for physician-assisted suicide are categorically deemed impossible to adequately evaluate. This judgment seems unfair and arbitrary: if you want physician-assisted suicide, we cannot establish that you are acting of your own free will, and are not being coerced by adverse social forces, whereas if you want an intervention that we approve of that ends in your death, we will take your request seriously, perhaps even at face value. Both of these approaches are dangerous to patients.

The right to stop life supports is subject to similar risks as physician-assisted suicide. About 10 to 15 percent of dialysis patients die because of a conscious decision to stop their treatment (Cummings and Eggers 1993). These patients don’t necessarily want to die, but rather reach a point where they don’t want to keep living under the circumstances in which they find themselves. Dialysis treatment is very expensive to the health care system and to individual patients and families, yet we have responsibly evaluated patients making this request and sorted out potentially coercive external factors. In my opinion, this is a model for how other potentially life-ending treatments should be conducted—an open, fully documented system with ethical, psychiatric, and specialty consul-
tation as needed. The risks of the slippery slope cited in this book for physician-assisted suicide have been present in allowing patients to stop life supports, yet they have not come to pass.

The argument could be made that stopping life supports is subject to an inherent safeguard because the world of patients who are dependent on life supports provides an appropriate benchmark. However, no such argument can be made for terminal sedation because it is inherently lethal with or without a terminal illness. As such, it too should be subject to similar safeguards, second opinions, and careful documentation. Should patients be allowed to request terminal sedation or would their explicit request be a sign of coercion and potential lack of free will? Should we only allow terminal sedation as long as the patient does not request it, leaving it exclusively in the hands of the medical profession? Should we warn patients to be careful how they formulate their requests for a hastened death, so they are considered to be within their rights and not mentally ill or suicidal? Should not all of these requests—whether stopping a life support, terminal sedation, or physician-assisted suicide—be subject to a similar critical yet open-minded inquiry, including input from our most experienced colleagues? Physicians are clearly obligated to help patients search for alternatives to any intervention that will likely result in their death, but physicians also have an obligation to listen and learn from their patients’ experience, and to be as responsive as possible.

For those who oppose physician-assisted suicide based on absolute religious, moral, or professional prohibitions, no amount of data or analysis will change their minds. Yet, as Batton reminds us, such physicians still have an obligation to decide how they will address their patients with severe, unrelievable terminal suffering. Terminal sedation may be morally acceptable to such physicians, and it is far better than walking away from the problem, or pathologizing the patient. The idea is to find the least harmful last-resort responses when needed that are acceptable to the patient, family, and physician, and responsive to the patient’s particular clinical problem. Safeguards need to be created for all such practices that balance timely responsiveness to actual patient dilemmas yet protect patients against potential coercion and abuse.

For those who do not hold an absolute moral objection to physician-assisted suicide, slippery-slope concerns repeatedly surface from both proponents and opponents of legalization. Would legalization undermine efforts to improve palliative care? Would there be a huge number of cases? Would patients choose an easy exit and bypass palliative care?
Would people choose this option because of financial pressures? Would it be disproportionately used by the poor, or by ethnic minorities? Would people choose this because of untreated pain? Van der Maas and Emanuel reviewed some data from the Netherlands and the United States, but virtually all authors hungered for more data. Since this book has been released, the first year’s data from Oregon have been published (Chin et al. 1999). These data, though only reflecting one year’s experience, seem to explode several myths:

Myth 1: Allowing a Physician-Assisted Death Will Undermine Good End-of-Life Care. Last year in Oregon, hospice referrals were up 20 percent, morphine prescriptions per capita increased, and the public’s and the medical profession’s awareness of hospice’s effectiveness increased. In addition, the Oregon Health Sciences University Hospital found funding for a palliative care consultant, and in-hospital deaths were the lowest in the nation when compared with at-home deaths (Toll et al. 1999).

Myth 2: There Will Be Many Cases, Especially from Society’s Most Vulnerable Groups. Out of an estimated 28,900 deaths in Oregon, only fifteen legally sanctioned physician-assisted deaths were reported. All were white, none lacked insurance, and none cited financial concerns as a motivating factor. All met the legally specified criteria. There were many more inquiries than acts, and many with legally-sanctioned access to potentially lethal medication died of “natural” causes, one died with terminal sedation, and four died by voluntarily stopping eating and drinking (Coombs-Lee in press).

Myth 3: Patients Would Not Choose This Option If They Had Access to Good End-of-Life Care. Twelve of the fifteen patients who chose an assisted death were enrolled in hospice programs, and the other three had been repeatedly referred and refused. Most had already waged long medical battles against their diseases.

Myth 4: Most Requests for Physician-Assisted Death Stem from Inadequate Pain Control. Only one of the fifteen cases (7 percent) cited inadequate pain control as a factor in their decision, whereas 30 percent of a matched control group cited inadequate pain control prior to death. More often the symptoms were a complex mix of physical symptoms, fatigue, debility, and dependence. (These data are very similar to the Netherlands [van der Maas, van Delden, and Pijnenborg 1992; van der Maas et al. 1996].)
Myth 5: Patients Who Want This Option Have a Pathological Need to Control Their Future. Patients who chose this option had increased concern about personal autonomy and increased fear of loss of bodily control (incontinence or vomiting). Twenty-one percent of the cases had severe loss of function prior to death, as compared with 84 percent of a matched control group who died in other ways. The notion that these needs are pathological, or that these patients had not suffered enough, is patronizing, paternalistic, and inaccurate.

Emanuel rightly recognizes that fear of a bad death underlies much of the support for legalization of physician-assisted suicide, and that much of that fear can be addressed by improving access to, delivery of, and education about palliative care. Patients who have seen a loved one die in extreme pain that could have been relieved had the attending physician been more knowledgeable about modern pain management should be reassured by the promise of excellent palliative care. Patients and families who fear being abandoned by the caregiver if they give up on aggressive disease-oriented treatment should be reassured by the potential support and expertise of hospice and palliative care programs. I agree that if dying patients receive adequate palliative care, most will not need or want a physician-assisted death. But what of the few whose suffering and dying becomes intolerable in spite of our best efforts? Do we not have an obligation to address their needs? If we are afraid, then how reassuring will we be to someone who has seen or can imagine a worst case scenario? Doctor, will you help me under those circumstances?

Here we come to a second level of fear that Emanuel does not address as well. Will I be listened to if I reach a point where I am ready to die, or will my motivation and sanity be questioned? Will my suffering and requests for help in dying be taken as seriously if I am not on a life support as if I am on one? Will my personal values and beliefs be taken seriously even if they are different from those of my doctor, the health care system, or of currently dominant modes of medical ethics? Can my doctor make an open-ended commitment that if my suffering gets to be horrible, he or she will help me find an escape that works? In my opinion, concern about being judged, not listened to, and not helped if one is suffering severely and is ready to die is also a central part of the public’s fear, and one not so easily addressed by most hospice and palliative care programs. Dying should be a time of honesty and openness about one’s wishes, fears, and requests. People want us to improve palliative care, but many also want to know that there could be an escape they can count on should their suffering become unbearable. Those who have this assur-
ance, and have a committed medical partner to work with, can live their final time without fear of their worst case scenario. Fortunately, as demonstrated in Oregon, few will actually need such help if they receive excellent palliative care and are allowed an open discussion.

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References


The character of the debate over physician-assisted suicide (PAS), like a chameleon, changes to fit the cultural background—and it is changing its character again in the current era. What once was epitomized by an angry proposition in California and a near-mythic public figure known as Kevorkian is becoming a discussion of economics, discrimination, and definition. The divisions are not sharp and the language itself is changing. Given this context, any book detailing the PAS debate may at once be far-reaching and reach closure prematurely. *Physician-Assisted Suicide: Expanding the Debate* characterizes the issues and offers some unusually insightful perspectives; yet it also skirts a few essential elements of the growing and changing discussion about assisted suicide.
As end-of-life researchers, we have long been voices against the legalization of PAS, largely for practical reasons. Our work is focused on improving the health care system for seriously ill Americans and their families. Until we can be confident that the care we need is readily available at the end of life, a debate on physician assistance in causing death is at the least a distraction from more critical issues and at the worst hazardous. This society needs changes in provider education, Medicare reform, and innovative and systemwide quality improvement in order to make excellence at the end-of-life routine. Several essays in this book both reinforce and challenge our position, and it is on these essays we focus.

This book also touches upon many other areas significant to the debate—though we could not discuss all of them in this essay. Of note are the commentaries on religious perspectives (Catholic, Anglican, Protestant, and Jewish), which provide thoughtful and detailed religious analyses. Religious positions are frequently taken for granted or oversimplified; providing greater explication is an important service. Certainly, in a society as diverse as the United States, alternative religious perspectives would be valuable. Also of note is the editors’ willingness to wade into greater controversy. One essay pushes the boundaries of the debate by raising the issue of terminal sedation, a topic which has become both legally and medically sensitive (see David Orentlicher’s “Supreme Court and Terminal Sedation: An Ethically Inferior Alternative to Physician-Assisted Suicide”). Another essay suggests an analogy to contraception from which to build feminist arguments for rational suicide (Dena Davis’s “Why Suicide Is Like Contraception: A Women-Centered View”). Such a comparison, while philosophically useful, may be dangerous as a basis for public policy in a society that is not entirely comfortable with anything having to do with sexuality or death.

As our position against legalization indicates, we see a number of problems inherent in the social policy questions in the debate over PAS. These include the inexact nature of the language used in the debate, the concern for vulnerable populations, and the ever-present economic concerns. However, several essays still present forceful arguments in favor of legalizing assisted suicide, and we note here where we believe these arguments to be new and thought-provoking. We begin, though, by addressing some commonplace misinterpretations of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) project, since those misunderstandings undergird many of the essays.
Interpretations of Support

A number of the essays in this volume build upon widely-held misunderstandings of the SUPPORT project. Most prominently, the essays often claim that SUPPORT showed that “half of the patients had severe pain in their last days.” However, the data actually indicate that about half of the patients in SUPPORT were unconscious near death. Among the other half, about half of their surviving family members reported that the patient had “moderate” or “severe” pain, “more than half” of the time, in their last three days.

With regard to the experience of pain near death, care must be taken in generalizing from SUPPORT data for a number of reasons. First, it was based on a population fifteen years younger than the average age at death, mostly those dying in teaching hospitals. Second, most were deaths due to overwhelming physiological instability—multiple organ system failure being treated in intensive care. In these situations, families reasonably hope for cure, or at least prolonged survival, until the last day of life. The patient is technology-bound, with ventilators, arterial lines, special beds, and other equipment. Family members may have felt that one could not have such an experience and not be “in pain,” and they also may have felt that pain was quite acceptable if treatment enhanced the prospects of survival. Third, family members may have been interpreting spontaneous motions, inability to speak, and restlessness as “pain,” especially when the patient soon died. The situation might have been seen differently if the patient had survived, and especially if the patient, as is usual, did not really remember what took place during the critical illness. At the most, about one-quarter of a distinctly biased (young) population were reported by family to have had substantial pain near death.

On a second issue of misinterpretation, the SUPPORT data did not uncover any cases of accelerating death through aggressive sedation or otherwise. That we have observed more than four thousand deaths without seeing demands for physician assistance in suicide, aggressive sedation to bring about death, or other behaviors that many of these authors presume to be widespread, should raise some red flags about the assumption by many contributors in this volume that physician assistance in dying is commonplace. Of course, it is possible that the fact that we were

1. Findings from SUPPORT can be found in various journals, but a summary bibliography is in the Journal of the American Geriatrics Society (Freeborn in press).
observing itself causes changed behavior, but especially in the nearly seven thousand patients who were merely observed (without intervention, except for interviews), it is difficult to believe that such widespread practice would have gone so completely undetected. SUPPORT enrolled every patient at five hospitals who had one of nine serious illnesses—no doctor’s patient was exempt, and no patient’s chart was exempt from review. It seems unlikely that the 61 percent of those who die in hospitals are commonly recipients of physician actions intended to cause death. PAS appears an unlikely practice in hospitals or nursing homes (which are even more scrutinized and regulated than hospitals).

The essay by Merrill Matthews Jr. (“Would Physician-Assisted Suicide Save the Healthcare System Money?”) reflects the myth that has pervaded this debate: the perception that assistance in suicide is happening covertly in substantial numbers (“Many U.S. physicians are already granting patients’ requests for assistance in dying” [320]). This assumption has been refuted by a methodologically rigorous national study (Meier et al. 1998) that found that though a substantial proportion of physicians in the United States report that they receive requests for PAS and euthanasia, only about 6 percent have complied with such requests at least once. The claim that physician-assisted suicide is already widespread and therefore may as well be regulated is not supported by current evidence.

Finally, the authors do not really take into account the very important findings of SUPPORT with regard to the relative importance of decision making and of system arrangements. SUPPORT’s intervention consisted of the same rational decision-making model that underlies the claims of autonomy and choice held dear by advocates of physician-assisted suicide. The fact that our intervention failed utterly to make a difference in the course of care should give some pause to those who assume that decision making is central to how care unfolds. Perhaps our language misleads us—what we call “decisions” may be largely socially dictated, as various authors in this volume contend. Most deaths appear just to follow the conventional course (Lynn et al. in press). This possibility is underscored by SUPPORT’s finding that striking regional disparities in the likelihood of dying in hospitals had a very strong correlation with hospital bed supply—and not with patient preferences, family support, wealth, and other intimate characteristics of patients and families (Pritchard et al. 1998). How we build the care system is the strongest correlate of what happens. Indeed, 88 percent of the variance in where Medicare patients died was explained by hospital bed supply and hospice investment (ibid.). Before
advocating for patient choice, further examination of whether and how patients make decisions is necessary.

In summary, SUPPORT’s evidence for serious pain near death is troubling but not definitive. Our study indicates that PAS must be rare, and our evidence on decision making raises questions as to whether individual choice in fact is central to the course of care. The debates on PAS should take these data-driven observations into account.

The Language of the Debate

The language used can largely shape the context of the debate—one word may frame the question in a wholly new perspective. For example, many advocates of legalized assistance prefer the term physician-assisted death and consider the more commonly utilized term physician-assisted suicide to be misleading because of the obvious negative societal connotations of suicide. However, from an etymological perspective, the word suicide means self-killing and implies a sense of individual control, which is important to those concerned about the possible slide down the “slippery slope” to legalized euthanasia. Though this specific point is never raised in the book, several authors provide commentary on the importance generally of word choice and definition. Concepts such as “autonomy,” “agency,” and “intent” have significant implications for the debate and can color the discussion in important ways, subject to interpretation of the writer and reader, speaker and listener.

As this debate has progressed, no longer do we solely speak in simplistic terms of autonomy (in the usual sense) versus a state interest in protecting human life. In fact, in the very first essay in this collection, Patricia Mann (“Meanings of Death”) argues that to frame the prolegalization position as one of positing a right to self-determination and autonomy is short-sighted. She points out that rarely is anyone in this society acting solely as a self-agent; instead, each of us utilizes a broader notion of agency that includes acting on behalf of or to achieve an end for a provider, a family member, or society in general. Medical care is not about an exclusive relationship between patient and doctor; it is almost impossible to make care decisions that are not in some way responsive to or in consideration of other actors. Mann’s insight and recognition of this impossibility frame a more realistic discussion about how real people will grapple with the policy implications of assisted suicide.

Though this point is an important and well-made one, Mann herself oversimplifies the discussion of agency and generalizes in a hypotheti-
cal scenario involving a physician caring for a very ill patient: “Suppose we become very ill, perhaps unto death, and we are in the care of a highly respected doctor at a major medical institution. The agency of this doctor is quite clear. Everything in her medical training and practice promote in her a strong desire, compounded by a sense of medical duty via the Hippocratic oath, to find a method of returning us to health” (20).

With this example, Mann seems to sidestep the very heart of the issue—all of the actors, including physicians, in any end-of-life scenario are ordinarily acting with multiple agencies and outcomes in mind. Many physicians no longer fit her caricature but instead explicitly recognize that the best care can mean not extending a life a little longer. Sometimes the best care for a seriously ill patient is accepting the inevitability of death and making the remaining time comfortable and meaningful. Indeed, in the only population-based study of the issue, 98 percent of dying persons in LaCrosse, Wisconsin, had a treatment deliberately withheld at the time of death (Hammes and Rooney 1998).

The concept of “intent” also has received much scrutiny, particularly on Capitol Hill. During the 1998 congressional session, legislators considered “The Lethal Drug Abuse Prevention Act of 1998,” which was ostensibly written to put an end to the practice of legalized PAS (i.e., Oregon’s Measure 16 and any other state legislature considering legalization) on the basis that a state cannot act outside the public health and safety boundaries imposed by the Controlled Substances Act. Yet, even for opponents of legalized assisted suicide, this bill was relatively easy to oppose. The bill would have invited Drug Enforcement Administration officials to step in and to determine whether physicians were prescribing opioids or barbiturates with the intent of relieving pain and other symptoms or, alternatively, with the intent of causing death. During Senate hearings, one Senator suggested that the prescription of some specific amount of pain medications would provide clear and convincing evidence of the intent to hasten death. This is not true; any dose size can be justified for treatment of pain with regard to an individual patient’s needs. Determining “intent” would require knowing something about the physician’s thoughts and values. The terms of the debate are readily misconstrued by a clinically ignorant public or policy maker. The assisted suicide debate on Capitol Hill—not yet over—raises the question of whether federal legislation can ever be drafted to punish those who intend to cause death illegally, while exonerating, or better yet encouraging, professionals to work to ensure comfortable and meaningful deaths.
Slippery Slopes

The term *slippery slope* refers to the idea that if PAS were legalized for a narrow group in specific instances, society will be unable to protect others or prevent unauthorized movement toward euthanasia. Several essays in this book push the boundaries of this oft-cited concept and encourage the reader to consider the ramifications of slides down the slippery slope to the inappropriate or indiscriminate application of PAS to the disabled, racial minorities, and those adjudicated incompetent to make decisions for themselves. Society clearly has some risk of sliding down these slopes toward more permissive policies, extending access to PAS to those beyond the narrowly defined categories now proposed and perhaps even toward sanctioning euthanasia. The inability clearly to define eligibility criteria (i.e., competence and terminal illness) and the controversy over society’s need to protect certain categories of people (i.e., the disabled and racial minorities) contribute to the potential for moving down the slope.

Determining Competence

Don Marquis, in “The Weakness of the Case for Legalizing PAS,” elaborates on the slippery-slope argument. He notes that although Oregon and other statutory models have included competence as a necessary safeguard, this protective boundary may be quite frail. Marquis argues that a right to assistance in suicide based on self-determination—analogous to the legal option to forgo life-sustaining treatment—would eventually be broadened to allow for the use of advance directives and surrogates to choose assisted suicide. Marquis suggests that such a right might eventually be extended to competent individuals who otherwise might live a long time. After all, if the basis for the right is self-determination, why should it be limited to a narrow class of persons?

Felicia Ackerman picks up this thread in her essay, “Assisted Suicide, Terminal Illness, Severe Disability, and the Double Standard.” Ackerman identifies three positions in the assisted-suicide debate: (1) PAS should be legally available to all competent adults; (2) PAS should be legally available only to the terminally ill, or possibly to the terminally ill and the severely and permanently disabled; and (3) PAS should be legally available to no one. The current debate is between positions 2 and 3, but Ackerman argues that the more reasonable debate would be between positions 1 and 3, as position 2 involves numerous double standards. Ackerman focuses on the fact that terminally ill persons who are suffering intractable
pain are deemed eligible for PAS under proposed statutes (as well as Oregon’s Measure 16). Ackerman notes that there are others who suffer but have not been labeled “terminally ill.” She goes on to argue that the legalization of PAS is often advocated on behalf of those who are considered less “valuable” by society, and she muses that it seems presumptuous and paternalistic to decide for others what would constitute such a standard. Thus, Ackerman highlights the potential for sliding down the slope due to the subjective judgment necessarily involved when labeling someone “terminally ill” and therefore eligible for assistance in death.

**Defining Terminal Illness**

Though Ackerman targets the arbitrariness of using “terminal illness” as a standard, Bernard Baumrin (“Physician—Stay Thy Hand!”) is the only contributing author to explicitly note the difficulty of relying on such an ill-defined category:

> The case of the terminally ill is not straightforward because the range of complications and the elasticity of the relevant time frame make determining who is to count as terminally ill either too easy or too difficult—too easy because anyone who has an illness or condition which will result in death if not cured is terminally ill, and nevertheless there may be much time left, and life well worth living for anyone who is terminally ill. “Terminally ill” is only superficially a medical term; at base it is a catchall for such states as declining rapidly, irreversibly ill (i.e., incurable with a prognosis of imminent death—but then imminent has a wide range itself), prone to sudden heart attack, stroke, seizure, etc. (180)

Baumrin touches on an often neglected issue, and one that seems necessary in any complete discussion of legalizing PAS—*prognosis*. Oregon’s Measure 16, as well as other model legislation drafted by state legislators or academics, generally contain a provision that the person accessing the right to assistance in suicide be deemed “terminally ill” by one or more physicians. However, no useful definition of “terminal illness” exists. No data-driven standards are yet available to allow such determinations to be uncontroversial, as evidenced by efforts of the Office of the Inspector General of the Health Care Financing Administration to target hospice providers for what they consider fraudulent overbilling of Medicare.

The definition used in the Medicare Hospice Benefit is “a prognosis of six months or less if the illness runs its normal course.” Thus far, no reg-
ulation, statute, or court decision has specified what that might mean. Data from SUPPORT reveal that prognostication is terribly unreliable (Lynn 1997); thus we have no consistent and accurate way of determining how to decide who counts as terminally ill. SUPPORT demonstrated that prognostic models will contrast sharply based on disease; that is, it is much easier to determine likely survival span for a person with metastatic lung cancer than it is for a person with congestive heart failure. Even in lung cancer, the median likelihood of survival is still a 20 percent chance to live two months on the day before actual death, and a 50 percent chance just one week ahead of death. Further, the appropriate statistical interpretation of a prognosis of six months is unclear. Does this mean a better than 50 percent chance of dying within six months or a 90 percent chance? The definition chosen has immense policy implications, particularly with regard to eligibility for PAS. Efforts to identify eligibility for special services (i.e., hospice) have been wrought with problems and, presumably, eligibility for PAS will be no easier to determine.

The inability to predict an approximate time of death for most people and most diseases is a major liability in considering the legalization of PAS. Margaret Battin (“Physician-Assisted Suicide: Safe, Legal, Rare?”) states that there has been a recent shift “away from a culture which sees dying primarily as something that happens to you, to a culture which sees it as something you do—a deliberate, planned activity” (66). Her point has merit but must be tempered by the reality of our limited ability to predict the time remaining for any individual. Control over the last phase of life requires either knowing how much one may be giving up or not caring whether one might be forgoing substantial time to live. In short, prognostication is much more problematic for those who would restrict PAS to the terminally ill than is generally acknowledged.

Disability

Three authors, one of whom (Ackerman) was discussed above, tackle the question of disabled individuals and the implications of extending the right to assisted suicide to this population, thereby adding another facet to the list of slippery-slope arguments.

Jerome Bickenbach (“Disability and Life-Ending Decisions”) firmly argues for a ban against legalized PAS, adding some novel arguments for doing so. Bickenbach claims that the belief that disabled persons have a lower quality of life seeps into institutions, fueling a self-fulfilling prophecy: this belief results in decisions and practices that actually do
create a lower quality of life, a life unnecessarily limited in many ways. The disabled “choose” PAS because others have chosen for them a lesser quality of life. This is the “inequality of autonomy,” according to Bickenbach, that justifies the ban.

This argument was also advanced by disability-rights advocates when the U.S. Supreme Court was considering PAS, but Bickenbach draws out the implications. If autonomy is to serve as the basis for the legalization of assisted suicide, why should it matter what that person’s physical abilities are? Not Dead Yet (a disability rights organization) and others have argued that should PAS be legalized, it should be legal for all people regardless of health status. Bickenbach notes that neither of the two lower federal courts (2d and 9th Circuits) nor the country’s highest court ever explicitly evaluated the value of a disabled person’s life. The courts also have never suggested that the right to PAS should extend to people who do not have a severe disability. Implicit in the absence of these words, says Bickenbach, is “precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide” (130).

Anita Silvers (“Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups”) takes a slightly different tack and delves into why the disabled are considered a population vulnerable in the face of legalization of PAS. Silvers understands the protectionism arguments for the disabled but counters by cautioning against the potential effects of paternalism. The state’s determination that the disabled are in special need of protection actually results in diminution of the disabled population’s power for self-determination. A state that protects the disabled by banning PAS simultaneously removes the disabled person’s power to choose how he or she will die. Similarly, Silvers is critical of denying PAS to disabled persons in the name of some common good: “To refuse suffering people the social change that would bring them optimal relief, but also to bar other avenues of relief on the grounds that such relief is less than optimal for the community at large, burdens those already suffering by imposing more real suffering on them in the name of an abstract and idealized community which still sets them apart” (148).

Race

Patricia King and Leslie Wolf (“Lessons for PAS from the African-American Experience”) detail this notion of “choice” from the perspective of a different minority group—African Americans. The authors
make the case that PAS should not be legalized until the causes of African-American vulnerability that pervade the health care system (as a microcosm of American society generally) are acknowledged and treated. The Tuskegee syphilis study is perhaps the most well-known example of abuse of such vulnerability—there are many others which add up to create a sense of mistrust on the part of African Americans toward health care institutions. The authors explain how African Americans might be coerced into “choosing” PAS because of prevailing racism:

Physicians may be too quick to interpret ambivalent statements made by patients as pleas to die, because at an unconscious level they perceive the patient as not deserving of money, resources, or other efforts that might be needed for care. Alternatively, patients may have absorbed the negative messages that society has heaped upon them and perceive themselves to be unworthy of the efforts that might be needed to prolong their treatment or provide them with palliative treatment. These patients might be easily coerced into believing that it would be easier for them and others if their lives ended sooner. (105)

As several of the authors in this volume observe, a number of communities may be vulnerable to discrimination or unequal access, indicating additional layers in debate over the legalization of assisted suicide. The elderly, for example, were addressed in only one essay—Leslie Pickering Francis’s “Assisted Suicide: Are the Elderly a Special Case?”—but are a population of special significance. As most of us are likely to die well beyond the age of sixty-five, the elderly will be greatly affected by any PAS policy. For society at large there exist many unknowns that make informed decisions difficult. Can we make a voluntary, informed decision about how and when we want to end our lives when there is no way to predict how much time we may have left to live? How do we create social policy and ensure that we do not slide down one of the slippery slopes described in this section? Without the availability and expectation of good end-of-life care for all persons, assisted suicide cannot be a true “choice,” regardless of an individual’s societal label.

**Economics**

A fair assessment of PAS is not possible without recognizing the practicalities of our care system, a system in which it is easier to get open-heart surgery than Meals on Wheels. Even if individual patient-centered choices
are possible and plausible, one would have to confront the serious problem of there being so few real choices. The current care system seriously constrains choice; for example, ready access to home care, companionship, or even adequate pain management are often not available. If it is not available, it cannot be “chosen.”

A few of the authors, most notably Mann, do tackle the question from a financial and quantitative perspective. As Mann questions, we are accustomed to considering the costs associated with other momentous decisions, so why not this one? She claims that the influx of managed care organizations and their profit-driven structures will undoubtedly encourage the practice of assisted suicide. She might have taken this argument a step further, however, by considering how upcoming risk adjustment might complicate such simplistic thinking (Iezzoni et al. 1998). Though the existing financial schema do not encourage quality care for vulnerable and expensive populations, systemwide incentives can bring about change.

**Conclusion**

The U.S. Supreme Court’s decisions on PAS can be interpreted very narrowly. In essence, the court stated that assisted suicide is not a right granted to the American people under the Constitution. The court explicitly left the practical and moral implications of legalization to state legislatures and public debate. Starting with those decisions, the contributing authors in this book stretch the reader’s understanding of an array of nuanced deliberations. Arguments in the assisted suicide debate continue to be refined, extended, discarded, and recovered—in concert with changing public policy. With the passage of time and changes in public policy come new ethical concerns and new answers. Since the Supreme Court issued its decisions, Oregon has passed and implemented Measure 16, legalizing PAS in that state.

With legalization comes new questions: Should a right to assisted suicide be granted to all residents of the state, regardless of health insurance status? Does an ethical conflict arise from allowing Medicaid coverage of PAS when so many in this country do not have access to even basic health care services? What are the public policy implications of paying physicians to bring about death? Though this collection of essays could not possibly have anticipated all the directions of this debate, the essays offer a wide variety of issues from which to continue discussion. Notably,
the book brings to light the fact that we all have our own interpretations for what our “choices” are, a fact that can be heavily dependent on societal status and access to care. Further, the book challenges the reader to consider all the possible slippery slopes society could potentially slide down should legalized assisted suicide become the norm.

Finally, underlying all of the topics raised in this book is a more fundamental question: should the debate about the legalization of PAS be a priority at this time? Since good choices are routinely not available to most of us—and especially to the poor, the frail, minorities, and the very sick—it may be inappropriate or premature to place PAS in the spotlight. Certainly, the issue will not go away. However, reexamination of this controversial issue should await a time when we can count on quality care at the end of life. Many other problems in end-of-life care need resolution first.

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Review Essay

On the Structure of the Euthanasia Debate: Observations Provoked by a Near-Perfect For-and-Against Book


Something is amiss with the euthanasia debate, and I want to use a smart new book to try to show what it is. The book is *Euthanasia and Physician-Assisted Suicide: For and Against*, an eagerly awaited volume by three well-known philosophers, Gerald Dworkin, R. G. Frey, and Sissela Bok. Dworkin and Frey are on the “for” side of the euthanasia and physician-assisted suicide debate; Bok is on the “against” side. This little book provides an ideal occasion to comment on the structure of the debate over euthanasia and physician-assisted suicide, a debate that has been developing over the past ten years or so in medical, academic, and public circles; indeed, this little book is a virtually perfect specimen for showing what is going on in these debates. More important, however, it is also a near-perfect specimen for showing what, unfortunately, isn’t going on.

Of course, the Dworkin, Frey, and Bok book is just one of many, many current volumes in the controversies over euthanasia and physician-assisted suicide, and it is a better book than many—among other things, in the distinction of its authors, in the clarity and rigor with which most of it is argued, and in its sensitivity to many of the deepest issues. It has everything: discussions of the difference between killing and letting die, the distinction between foreseeing and intending; the tenuous relation-
Table 1  The Debate over Physician-Assisted Suicide

<table>
<thead>
<tr>
<th>Principal Arguments for Physician-Assisted Suicide</th>
<th>Principal Arguments against Physician-Assisted Suicide</th>
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<tr>
<td>The argument from autonomy.</td>
<td>The argument from the wrongness of killing.</td>
</tr>
<tr>
<td>The argument from the relief of pain and suffering.</td>
<td>The argument concerning the integrity of the physician.</td>
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<td></td>
<td>The slippery-slope argument.</td>
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The structure between allowing and causing. It discusses the principle of double effect, the risks of the slippery slope, the delicate matter of the integrity of the medical profession. But while this little book serves as a model of the entire debate, it also serves to show what is wrong with this debate.

The Structure of the Assisted-Dying Debate

From its beginning, the structure of the debate over physician-aided dying has pitted arguments about self-determination or autonomy and about relief of suffering on the “for” side of the case, against arguments about the intrinsic wrongness of killing, the integrity of the medical profession, and damaging social effects—the slippery-slope argument—on the “against” side. The debate can be mapped as detailed in Table 1.

This structure then invites an extended back-and-forth pattern of objection and counterobjection, which I’ve described in previous works\(^1\) as looking something like Table 2 on the following pages.

Of course, this is only a truncated skeleton of the back-and-forth, adversarial character of the for-and-against debate; it could be extended in great detail. Just the same, most of the points made by most of the major partisans in this debate can be plotted fairly specifically somewhere on this scheme. For example, Dan Brock’s analyses of autonomy would fit under I; Bernie Gert’s defense of terminal sedation under II.A.1.a. Timothy Quill’s defense of physician assistance in suicide as a “last resort” would fit under II.A.2; Ezekiel Emanuel’s concerns about the physician’s role would fit under IV.A.1. In the Dworkin, Frey, and Bok volume, Frey’s spirited attack on the attempt of opponents of legalization to defend such practices as overuse of opiates and terminal sedation, while at the same time rejecting euthanasia and physician-assisted sui-

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\(^1\) This analysis of the debate over physician-assisted suicide is taken from Battin 1982 and 1996 and modified for presentation here.
I. The Argument from Autonomy

Just as a person has the right to determine as much as possible the course of his or her own life, a person also has the right to determine as much as possible the course of his or her own dying. If a terminally ill person seeks assistance in suicide from a physician, the physician ought to be permitted to provide it, provided the request is made freely and rationally.

A. Objection

True autonomy is rarely possible, especially for someone who is dying, since not only are most choices socially formed, but in terminal illness depression and other psychiatric disturbances are likely to be a factor.

1. Counterobjection

Even if many choices are socially shaped, they must be respected as autonomous.

2. Counterobjection

Rational suicide is possible, and it is possible for patients to make choices about dying without distortion by depression.

B. Objection

One cannot obligate another to do what is morally wrong, even if one's choice is made freely and rationally. Since suicide is wrong, the physician can have no obligation to assist in it.

1. Counterobjection

No adequate moral argument shows that suicide in circumstances of terminal illness is morally wrong.

2. Counterobjection

The physician is not obligated to provide assistance in dying, but should be free to do so if he or she wishes.

II. The Argument from Relief of Pain and Suffering

No person should have to endure pointless terminal suffering. If the physician is unable to relieve the patient's suffering in other ways acceptable to the patient and the only way to avoid such suffering is by death, then death may be brought about.

A. Objection

Thanks to techniques of pain management developed by hospices and others, it is possible to treat virtually all pain and to relieve virtually all suffering. Thus the dying process can be valuable as a positive, transformative experience of new intimacy and spiritual growth.

1. Counterobjection

“Virtually all” is not “all”; if some pain or suffering cannot be treated, there will still sometimes be a need to avoid them by directly caused death.

a. Counter-counterobjection

Complete sedation can be used where pain cannot be controlled.
Table 2  Continued

i. Counter-counter-counterobjection
Complete sedation means complete obtundation, and because the patient can no longer communicate or perceive, is equivalent to causing death. If these are permitted, why not more direct methods of bringing about death?

2. Counterobjection
There can be no guarantee of a positive, transformative experience.

III. The Argument from the Intrinsic Wrongness of Killing
The taking of a human life is simply wrong; this is evident in the commandment “Thou shalt not kill.”

A. Objection
But killing is socially and legally accepted in self-defense, war, capital punishment, and other situations, and so it should be socially and legally accepted when it is the voluntary, informed choice of the person who would be killed.

2. Counterobjection
In self-defense, war, and capital punishment, the person killed is guilty; in assisted suicide the person killed is innocent.

IV. The Argument from the Integrity of the Profession
Doctors should not kill; this is prohibited by the Hippocratic Oath. The physician is bound to save life, not take it.

A. Objection
In its original version the Hippocratic Oath also prohibits doctors from performing surgery, providing abortifacients, and taking fees for teaching medicine. If the Oath can be modified to permit these practices, why not assistance in suicide, where the patient is dying anyway and seeks the physician’s help?

1. Counterobjection
To permit physicians to kill patients would undermine the patient’s trust in the physician.

   a. Counter-counterobjection
   Patients trust their physicians more when they know that their physicians will help them, not desert them as they die.

V. The Slippery-Slope Argument
Permitting physicians to assist in suicide, even in sympathetic cases, may lead to situations in which patients are killed against their will.

A. Objection
A basis for these predictions must be demonstrated before they can be used to suppress personal choices and individual rights.

1. Counterobjection
The basis for these predictions is increasing cost pressures, as well
Table 2  Continued

as greed, laziness, insensitivity, prejudice, and other factors
affecting physicians and their institutions.
   a. Counter-counterobjection
       It is possible, with careful design, to erect effective protections
       against abuse by doctors or institutions.

2. Counterobjection
   Vulnerable patients will be socially programmed to think of them­selves as unworthy to remain alive, and the elderly, the chronically
ill, the disabled, and others will be maneuvered into choosing to end
their lives.
   a. Counter-counterobjection
      Only patients with documented terminal illnesses would be
      allowed this option.
         i. Counter-counter-counterobjection
             Restrictions of this sort cannot be enforced; pressures to
die would spread beyond the terminally ill.

cide, would fall under II.A.2.a.i; Sissela Bok’s sensitive analysis of the
slippery-slope argument would fall under V, V.A.1, and V.A.2. Historical
figures fit here too; for example, Thomas Aquinas argues III; David
Hume I.A.2. Indeed, virtually all of the past and current discussion can
be plotted somewhere on this scheme, or at least on the more complete
expansion of it. And, of course, many authors fit in more than one place,
making more than one point. All of these points are important, and
they’re all well worth making. But they must all be seen as part of a
larger, overall argument, and it is this overall structure that we must also
examine. This will turn out to involve a structural problem about how the
debates are conducted and what turf, so to speak, they occupy.

Starting Points

Within the overall structure of the debate, it is important to notice what
starting points various authors take. On the first page of the first chapter in
Euthanasia and Physician-Assisted Suicide: For and Against, Dworkin—
arguing on the “for” side of the issue—attacks the opposition, repre­
sented in this case by Leon Kass’s ringing view that “doctors should not
kill.” Only a few pages later, at the beginning of the second short chapter,
Frey—likewise arguing the “for” side of the debate—also begins by
attacking the opposition: he shows how the opposition’s position concern­
ing pain control and terminal sedation fails to be coherent, and why the
normative asymmetry often alleged between them does not hold. However, Bok, defending the “against” view in the second part of the book, does something different: while she reviews some of the sorts of arguments Dworkin and Frey make, she largely addresses concerns about the social effects of acceptance or legalization of physician-aided dying.

All three authors are making moves entirely characteristic of the debate. What both Dworkin and Frey do, on the “for” side, is to move straight to the attack. Indeed, they acknowledge that their basic strategy of argument is, in their words, “ad hominem”; they claim that “those who oppose medically assisted dying themselves favor policies that cannot be morally distinguished from the policies we favor and they oppose” (3). Dworkin and Frey’s move here is a sophisticated, clever one: it exposes the confusion of the opposition in trying to draw a line between allowing to die (which the opposition accepts) and causing to die (which it says it rejects). They do a terrific job of pressing this attack. Strictly speaking, their argument is not a formal ad hominem, since it does not address irrelevant personal characteristics of the opponent but rather addresses highly relevant features of the opponent’s position; it is, rather, an adroit reductio in which contradictions in the opponent’s position are exposed—they say they do not accept physician-assisted suicide or euthanasia, but they accept practices which are functionally equivalent to these. But in running this clever, sophisticated argument, Dworkin and Frey, on the “for” side, make a problematic move of their own. What they do is assume the principles on which their side of the argument is based, principles of autonomy and freedom from suffering, without explicitly or directly defending these principles.

We might assume that this defense would be easy to mount. The principle of autonomy, or self-determination, or liberty, is a familiar, fundamental principle in ethical theory, and might seem to need little direct defense. So too, it might be argued, is the principle of the right to (try to) avoid pain and suffering: the principle that one is entitled to try to avoid pain and suffering, and that pain and suffering ought to be relieved where possible. But neither Dworkin or Frey, both philosophers of considerable distinction and skill, defends these issues directly, although here is where the really interesting philosophical work might occur.

Meanwhile, Bok, defending the “against euthanasia” position, exploits its strongest point: the slippery-slope argument that the legalization or acceptance of euthanasia or physician-assisted suicide would lead to
pressures on vulnerable patients, that people would be edged or forced into dying when that was not their choice. While Bok considers other arguments, this is her central claim. Bok's concerns are important, crucial ones. But they are the only ones she considers decisive: thus one can't join the discussion with her about anything else except this issue. Thus, both in their ad hominem against the opposition's position and in their direct discussion of the points Bok will raise, Dworkin and Frey are, as it were, lured into fighting the rest of the battle on what is essentially Bok's turf, the slippery-slope set of concerns about social effects. They score points against elements of her position; but she gains the home-court advantage. Thus, although defeated in the initial maneuver and outclassed in the technical argumentation over the issues of causation and intention, Bok in a sense wins the day, even though the arguments she uses about the slippery slope are not fully persuasive. Her achievement lies in the fact that she is able to cast the slippery-slope issue as the central one, the one on which, it is assumed, views about legalization will stand or fall.

There are two distinct problems with this relocation of the debate over physician-assisted suicide and euthanasia on slippery-slope turf. For one thing, the slippery-slope argument involves predictive empirical issues about possible future abuse of patients. If you let practice A happen now, it argues, consequences B will occur, and they will be very, very bad. To be sound, there must be evidence to support such an argument. But there isn't any good evidence to support it, and the little evidence that there is—especially that from the Netherlands—seems to cut the other way.2 Slope arguments are complex, both in their causal and precedential forms, and their conclusions cannot be confirmed in advance of the future they predict. But neither can they be disconfirmed, at least in the broad social contexts in which they are usually used, and they have tremendous, though often unwarranted, persuasive power. Furthermore, slope arguments tend to be one-sided: used in the contexts of social debate, these arguments are often employed to present evidence favoring one side of a picture but not the evidence favoring the other. By their very nature, slope arguments tend to be unreliable—though, of course, this does not entail that the bad consequences predicted could not materialize.

2. In the second report of the Remmelink Commission, the authors of these exhaustive studies of euthanasia in the Netherlands conclude that “in our view, these data do not support the idea that physicians in the Netherlands are moving down a slippery slope” (Van der Maas et al. 1996:1705).
The difficulties of the slippery-slope argument are well-known to social commentators. But there is a more important point about them that is often overlooked in the context of social debate. It concerns the appropriate weight to be given to slope arguments versus other considerations. Suppose slippery-slope evidence did suggest that some patients would be abused—how should this weigh against the freedoms of other patients to make specific end-of-life choices? Slippery-slope arguments hold that practice A should be prevented in order to prevent undesirable outcome B, but in their usual forms do not assess arguments about the moral consequences of suppressing A. If slippery-slope arguments are the central concern, they tend to block out other major concerns that should be regarded as central too, or perhaps more central. Thus, on two counts, the structure and location of the debate skews the answer.

**For-and-Against Structure in Philosophical Argumentation**

*For and Against* is not merely a partial title of this little volume; it is a description of its structure, a structure that mirrors the entire debate. Of course, the book’s title is in part dictated by the series: Cambridge’s For and Against series (edited by Frey) seeks to offer “a new and exciting approach to the investigation of complex philosophical ideas and their impact on the way we think about a host of contemporary moral, social, and political issues” (frontispiece), for instance about such topics as social welfare and individual responsibility. This structure of adversarial debate is used effectively in many areas of human discourse, including philosophy and in particular bioethics.

But here the trouble becomes evident. A for-and-against argumentative format isn’t just a universally good idea; rather, a for-and-against format may or may not be appropriate to a particular topic, depending on, among other things, the degree of infancy or maturity of the debate. A new social and ethical issue, just breaking open into explicit debate when it may have been festering unrecognized beneath the surface of public consciousness for years, needs the kind of philosophical exploration that for-and-against analysis yields: the elements of the debate need to be isolated, identified, catalogued, and critiqued. But after a debate begins to mature, it becomes time to pursue attempts at resolution: here, the search should be for common elements, points of agreement, ways of reaching both practical and theoretical consensus about the issue at hand. There
have been many, many for-and-against works on the issue of physician-aided dying, including treatises, popular articles, edited collections, and assemblages of amici briefs to the U.S. Supreme Court. The Dworkin, Frey and Bok volume, like much of my own work, properly counts among these, but there are comparatively few works that attempt to seek consensus. I believe, however, that the debate has now matured enough to demand them. New, evolved structures of reflective consideration, not just debate, will suit the issue better; it is time for all of us to move on.

**Refocusing the Debate**

Two things must happen in the debate over physician-aided dying if it is to avoid calcification and extended political friction, as has resulted in the abortion debate. First, the debate needs to enlarge the range within which it is conducted. This involves expanding the scope of the issue or issues which are seen as central: specifically, the orbit of the core of the debate needs to extend beyond slippery-slope issues to focus far more directly on the positive case that is offered for accepting and legalizing euthanasia and physician-assisted suicide. There are basic philosophical issues here about autonomy and self-determination, freedom, and control, about the moral issues in suicide: these need direct scrutiny.

One might think these would be easy to defend. After all, the central notions of liberty—of self-determination and autonomy, about freedom to choose how to live one’s life—are said to be central to the liberal traditions of western culture. Here, popular discussion in the physician-assisted suicide debate may have an edge over academic dispute: chatlines, letters to the editor, popular books, and other vehicles of public discussion are full of ringing appeals to freedom, self-determination, and get-government-off-my-back conceptions of individual liberty in matters of dying. But the philosophers are strangely reluctant to take these issues on, knowing, of course, how complex they can be. What is the appropriate scope of individual autonomy? If there are certain kinds of actions, like enslavement or murder, that one ought not undertake, is bringing about one’s own death one of them? How is such action to be described, in any case? As “suicide,” or “self-deliverance,” or “aid-in-dying,” or “has-tened death,” or in any of the various euphemisms and derogatory labels employed in the public debates? Does an individual have a basic right to (try to) avoid pain and suffering, and if so, is this perhaps the obverse of the right to pursue happiness, or is it rooted in some deeper, more basic
interest? It is not that these issues are unknown in the academic debates over physician-aided dying, but that they have not been cast as central; it is the slippery-slope argument that has been largely cast as central, when it may well be secondary to these more fundamental conceptual issues. This is not to say that the slippery slope argument is not important; it is, enormously so. But it is not the only important thing about this issue. Of course, to restructure the debate so that these more fundamental issues become central does not entail that the debate will be resolved in favor of the “pro” side, but only means that the debate must focus more directly on the deeper issues at hand.

It is instructive to notice the rhetorical structure of the Dworkin, Frey, and Bok book. Both sides end up allowing the slippery-slope issues of abuse to take the main court, and, implicitly, to be the issue on which practical policy measures like legalization turn. Dworkin and Frey argue that the slippery-slope argument does not succeed; Bok argues that it does. But all seem to agree that if it did succeed, it would prove decisive in issues of policy.

The Debate Matures: The Possibility of Consensus

I’ve just said that I think the debate over physician aid in dying must be encouraged to mature, to move beyond the polarizing for-and-against, adversarial structure that appropriately characterizes issues in their infancy. A centrist, consensus position may already seem to be emerging, particularly in practical medical contexts. The palliative care movement in particular, as is widely known in medical ethics contexts, offers a solution to the end-of-life dilemmas over pain and suffering that seem to have given rise to the issues of euthanasia and physician-assisted suicide in the first place. Palliative care focuses first on the recognition, treatment, and prevention of pain. Its practitioners advocate better attention to pain management in terminally ill patients, more reliable assessment of pain, the use of escalating, ladder-type schedules of pain management, antecedent interception of pain before it begins (a technique pioneered by hospice care), and more thorough training of physicians and restructuring of provider incentives to provide better pain management. Palliative care also involves attention to the question of what to do in those cases in which pain cannot be adequately managed: here, it advocates the use of pain control even in contexts in which it is foreseen, though not intended, that a shorter life may result; and in very extreme cases, it accepts the use
of terminal sedation: sedating the terminally ill patient into unconsciousness, and then withholding or withdrawing artificial nutrition and hydration that would be required to keep an unconscious patient alive.

But while there is some progress here—indeed, real growth—toward a more mature phase of the debate, I do not think its direction will be straight ahead. In almost every way the new attention being given to palliative care is an excellent development, but the construction of the position dedicated to palliative care as a centrist position is not, I think, fully warranted. Palliative care does not provide a compromise between the “pro” and “con” positions, at least not an adequate compromise, and it is not really centrist. While it permits more extensive pain control, and while it permits actions that are functionally equivalent to physician-assisted suicide and euthanasia (as Dworkin and Frey have so effectively shown), it still does not permit active euthanasia or physician-assisted suicide in the senses which many advocates have in mind. Palliative care does answer one of the underlying concerns of the “pro” side—relief from pain and suffering—but it does not address very well the other basic principle, autonomy or self-determination. After all, many proponents of the legalization of physician-assisted suicide and/or voluntary active euthanasia do so because they support the desire that some terminally ill patients express for control over the timing, character, and circumstances of their deaths—not so much because they fear pain, but because they want to be the architects of the ends of their lives. The palliative care movement certainly represents progress, but it does not yet represent, I think, full resolution of the issues between the “for” and “against” sides of the debate.

A more mature phase of the intellectual discussion may also seem to be beginning. Some works advance the discussion toward resolution by reserving judgment on the theoretical and policy issues while exploring the realities of concrete application, whether the practices in question, physician-assisted suicide and euthanasia, are legalized or remain underground. For example, the report of the American Psychological Association’s task force on physician-assisted suicide, now in preparation, is expected to include an extended discussion of the practical considerations practicing psychologists face. The U.S. Supreme Court’s 1997 decisions in *Washington v. Glucksberg* and *Vacco v. Quill* may also seem to be a comparatively mature, consensus-seeking decision, since it actually did not side with either the “pro” or the “con” factions in the debate (although because the decision held that there is no constitutional right to physician-assisted suicide, it is sometimes seen as defeat for the “pro”
side); rather, it sidestepped the moral issue by turning the matter over to the individual states. However, many discussions that claim to or are perceived to seek consensus are not fully successful; they still want resolution on one side or the other of the same continuing battle. For example, Linda Emanuel’s piece, “Facing Requests for Physician-Assisted Suicide,” advises physicians how to deal with patients who seek assistance in suicide, and thus to some extent allows recognition of the issue, but after a lengthy series of steps designed to deflect the patient into other forms of care, tells them to reject the request if it persists at the end. This is not compromise or resolution; this is to side with the “against” faction, even after a more sensitive-seeming discussion. The Supreme Court’s decision can be read not as resolution, but as evasion of the issue. Conversely, some writers on the “pro” side continue to call for legalization without much attention to slippery-slope issues at all. And it is difficult to find a writer with a foot firmly planted on each side of the fence, or better still, for whom there is no longer any fence at all. I do not yet see the kind of genial, comprehensive summation of the issue that is sensitive to the concerns of both sides, that manages synthesis without ignoring or trivializing the principal concerns on both sides, that can be called a real resolution of the issues, one that could elicit consensus and agreement at both policy and practical levels.

On the contrary, many authors seem to assume the problem will just go away, if pain control can be sufficiently improved and medicine’s enthusiasm for prolonging life beyond a reasonable point restrained.3 Perhaps real resolution is not possible and consensus a silly dream. But perhaps resolution and consensus are possible, and in any case I think it is the obligation of those engaged in the current discussion to begin to try to seek them: after all, the circumstances in which these issues arise—where death at the conclusion of long, terminal illness awaits an ever-larger proportion of the population—are what the future increasingly brings.

This is what makes a volume like that of Dworkin, Frey, and Bok so frustrating in the end, and yet such a perfect exemplar of the debate as it is actually conducted. The two sides each have their say: sometimes brilliant, sometimes sensitive, always lively and accessible. But there is no real rebuttal between them, except as one side anticipates what it takes the other’s critique to be. Nor is there anything beyond rebuttal, some-

3. I’ve discussed this point at greater length in Battin, Rhodes, and Silvers 1998.
thing deeper and more profoundly reconciling. In other real-life situations, referees or commentators sometimes serve to point out where one side fails to acknowledge the concerns of the other, where the sides do not quite join the issue, where one or both sides aren’t really listening. Sometimes, too, the partisans themselves in a debate genuinely seek real understanding of the other side’s concerns, and hope to reach real resolution. I don’t see much effort to seek a resolution in common here, either in demand for an end to polarization or in an effort on the part of the partisans involved to understand and absorb the concerns of the other side(s) in the debate, not just dismantle their arguments. I think it is a real disappointment, reflecting the condition of the debate itself, that a volume as smart and clever as the Dworkin, Frey, and Bok for-and-against volume, a volume with such distinguished authors, appearing at this advanced point in the long discussion of these issues, does not seem to have tried to reach resolution either. Of course, in the classroom situations for which this volume is intended, the lack of resolution may be a virtue because resolution can be left as an exercise for the student. But it is not a virtue in the context of the larger discussion; resolution is what the debate, after many long years, now needs.

Is Real Resolution Possible?

It may seem that a book like Dworkin, Frey, and Bok’s does not reach resolution because, in the end, real resolution is not possible, and its authors are too smart to take on a losing game. But I think this is wrong; I think it is possible to reach resolution in this debate in a way that will satisfy most of the concerns of most parties to the debate. Consider the principal tension: autonomy on the one hand, versus the risks of the slippery slope on the other. Relief of pain, I think, along with concerns about the integrity of the medical profession and the moral status of killing, are secondary matters that can be dealt with more or less satisfactorily in most cases. Pain control is not an issue, but a matter of practical inadequacy; virtually all parties agree that it ought to be given priority. At root, rather, is a tension between what the patient really wants, in his or her heart of hearts, and what may be done to him or her to serve the agendas of other parties. The core issue, I think, is who decides? Will it be the patient, the physicians, the family, or some impersonal set of institutional procedures developed to govern cases of this sort? Each has its advantages and its disadvantages.
These are real tensions, not to be minimized. They explain why the slippery-slope issues have such prominence; here, issues about who decides are most nearly approached. But the tension can I think be reduced by reinspecting the temporal location of decision making about dying. Typically, medicine has been structured so that decisions about aspects of terminal care are delayed as long as possible, often until a crisis occurs and a decision must be made immediately. By this time, the patient is in distress, the family is in distress, and many peripheral aspects of the decision are swept aside. Things need to be done right away: doctors are busy; schedules are tight; the readings on the monitors are already slipping. Decision making in crisis is different in character from reflective decision making, and part of what gives rise to the current tension over end-of-life is the fact that institutional structures and conventional medical practice favor one sort of decision making rather than another. Advance directives play some role, but they have many deficiencies: they may have been executed in casual, inadequately informed circumstances, they are variously too specific, too general, or not fully clear, and in any case they are often ignored.

But the decisions at hand are decisions about basic policy-level approaches to end-of-life issues—about whether it may be acceptable to forgo or discontinue treatment in order to let death occur; about whether one should always try to completely obliterate pain, even at the cost of obliterating consciousness, or whether some pain might be acceptable; about whether forgoing nutrition and hydration is viewed as a welcome strategy or as a repugnant charade; and about whether active aid-in-dying is viewed as morally permissible or morally wrong. Patients—that is, people—often form their ideas about these things long in advance, indeed long before the start of an illness that might lead to practical questions about dying, and what they develop is a kind of personal philosophy about these issues—a more general, reflective view, often idiosyncratically their own, that would govern specific practical questions.

If decision making takes place earlier, in the more leisured space of life when real reflection is possible, it is far less likely to be warped by intense institutional or familial pressures. Of course, a patient cannot decide the precise details of his care far in advance, since it is not clear what illness and what circumstances will arise, but he can certainly indicate the kinds of things he would seek and he would avoid—his personal philosophy concerning end-of-life issues. To convey this personal philosophy is, we might say, to articulate a “personal policy.” It is to express what sorts of things one would favor and what one would not. This is not quite the same
thing as executing an advance directive, that is, executing a restrictive, stipulative document with legal force; it is more a matter of making one's basic values and preferences a matter of record in one's medical history and in one's family's ongoing lore, as the basis for all further discussion. Advance reflective decision making—or better, *advance personal policy making*, as it might be called, both satisfies the principle of autonomy but protects against the slippery slope, the two deepest core concerns in the debate. Some people will want the kind of terminal care that emphasizes palliation and uses only a limited range of means; others will want direct, open address to the possibility of assisted or self-termination of their own lives; still others will want many options in between. Advance directives in the conventional sense capture only a part of this, and they are characteristically executed much further along in a terminal process; they govern specific medical procedures once a terminal course has begun. *Advance personal policy making* is grander, if you will; it involves the antecedent, lifelong, philosophically reflective exploration of one's deeper commitments about living and dying. Advance directives, limited and specific as they characteristically are, might be seen as the tip of the iceberg, so to speak—telltale symptoms of an underlying personal philosophy that could be expressed as a personal policy, but hardly the whole thing.

I hardly have space here to explore this conjecture in full detail, but it is the kind of direction in which I think the discussion of physician-assisted suicide and euthanasia should now go, both in the public and academic areas. The benefits of polarized, for-and-against discussion have now been realized—the Dworkin, Frey, and Bok volume can be viewed as a convenient model and summation—and it is time to turn to exploring the possibilities for resolution. Advance personal policy making may be only one of these, and there may be other fruitful avenues for exploration, but it is high time to turn to these possibilities. After all, the majority of people in developed countries will die the kinds of deaths of diseases with long terminal courses in which these issues arise, and it is crucial to find ways of resolving the debates that, if they continue to incite public polarization and political controversy, could make these deaths worse.

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Books Received

Aging


AIDS


Comparative Studies of Health Care Delivery, Politics, and Policy


Economics and Finance


Health Care Delivery

*Extending the Boundaries of Care: Medical Ethics and Caring Practices.* Tamara Kohn and Rosemary McKechnie, eds. New York: Berg, 1999. 256 pp. $65.00 cloth; $19.50 paper.


History and Humanities


Law and Ethics


Healthcare Law and Ethics: Issues for the Age of Managed Care. Dean M. Harris. Chicago: Health Administration, 1999. 330 pp. $52.00 cloth.

The Law and the Public’s Health. 5th ed. Kenneth R. Wing. Chicago: Health Administration, 1999. 358 pp. $56.00 cloth.

Medical Sociology


Politics and Policy


*Crossing the Border: Encounters between Homeless People and Outreach Workers.* Michael Rowe. Berkeley: University of California Press, 1999. 206 pp. $45.00 cloth; $17.95 paper.


*Policy and Health: Implications for Development in Asia.* John W. Peabody et al. New York: Cambridge University Press, 1999. 461 pp. $44.95 cloth.

Public and Environmental Health


Miscellaneous


*Food Security and Nutrition: The Global Challenge.* Uwe Kracht and Manfred Schulz, eds. New York: St. Martin’s, 1999. 692 pp. $75.00 cloth.

