

INTRODUCTION

False Dichotomy versus Genuine Choice

The Argument over Physician-Assisted Dying

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Despite a growing consensus that palliative care should be a core part of the treatment offered to all severely ill patients who potentially face death,¹ challenging questions remain. How broad a choice should patients have in guiding the course of their own dying? What limitations should be placed on the physician's obligation to address patients' suffering? Physician-assisted death (also called physician-assisted suicide or physician aid in dying) has long been the focal point of ethical and political debate—a divisive, hot button issue in a domain in which there is otherwise considerable agreement.

At first glance, this focus on assisted death seems to miss the mark. If the question were posed, "What would you rather have, access to palliative care and hospice or access to physician-assisted death?" we would choose palliative care and hospice every time. To frame the question in this way, however, presents a false dichotomy. Palliative care should be part of the standard of care for all severely ill patients, even those who are continuing active, disease-directed treatment, and hospice should be the standard of care for all those who understand and accept that they are dying. We insist on a more inclusive question that fully addresses the needs, wishes, and realities of dying patients: "What would you prefer, access to excellent palliative care and hospice by themselves or access to excellent hospice and palliative care plus legal access to a physician-assisted death as a last resort if your suffering becomes intolerable and you wish an earlier, easier death?"

In this introduction and in the title of the book, we use the term *physician-assisted dying* because it is descriptively accurate and carries with it no misleading connotations. Other contributors to this volume prefer the synonymous

term *physician-assisted suicide* because it is technically accurate, and still others prefer *physician aid in dying* because it is relatively neutral. Although suicide can be considered heroic or rational depending on setting and philosophical orientation, in much American writing it is conflated with mental illness, and the term suggests the tragic self-destruction of a person who is not thinking clearly or acting rationally. Although distortion from depression and other forms of mental illness must always be considered when a patient requests a physician-assisted death, patients who choose this option are not necessarily depressed but rather may be acting out of a need for self-preservation, to avoid being destroyed physically and deprived of meaning existentially by their illness and impending death. While in general we use the more neutral term *physician-assisted death* for this reason, we have allowed our authors—and ourselves—to use any of the three terms interchangeably.

Both proponents and opponents of legalization of physician-assisted death can join together in support of improving access to and delivery of comprehensive palliative care for all severely ill patients who wish it and to support expansion of hospice benefits to those whose prognosis is too uncertain to fall within the usual six-month time frame. Both sides can also acknowledge and bemoan inadequacies in access to and delivery of health care services in general in the United States, as well as end-of-life care in particular.²

Where we proponents of legalization part company with opponents is in our belief that it is not fair or justified to postpone legal access to physician-assisted death while we await the solution of these most difficult social problems. Relief of suffering—and with it the freedom to face dying as one wishes—must be available to suffering patients now. It is also our belief that legalization is a small but important part of the larger process of improving end-of-life options and care for many dying patients.

Opposing Claims about Physician-Assisted Dying

This book brings together classic and new work by a group of distinguished authors to present the case for legalization of physician-assisted death for terminally ill patients who voluntarily request it. Some of the impetus for compiling this book comes from *The Case against Assisted Suicide: For the Right to End-of-Life Care*, edited by Kathleen Foley and Herbert Hendin and also published by the Johns Hopkins University Press.³ Indeed, the two might be considered complements. The contributors to the Foley and Hendin volume are articulate and thoughtful opponents of legalization of physician-assisted

death. We congratulate that book: it is helpful to have the best arguments opposing the practice collected in one place.

We think it is also important to put the best arguments for the practice into a single collection, both to counter the false dichotomy that the Foley and Hendin book seems to presuppose as well as other misconceptions and misunderstandings in the opposition literature and, more important, to explore genuine differences in values. We agree with much of those authors' critique of health care in general and end-of-life care in particular in the United States. However, we disagree with many of their value assumptions, with how they construct arguments opposing physician-assisted death, and especially with their reliance on "slippery slope" arguments that predict wholesale abuse if physician-assisted suicide were to be legalized throughout the United States—a prediction that this volume will show is not supported by the data from either Oregon or the Netherlands. Our book provides a very different analysis of existing data. Where there are disagreements, it will be up to the reader to determine which interpretation is more objective, though it is not always clear that data will settle a debate that is often more moral, philosophical, and religious than empirical.⁴ Nonetheless, for those who have an open mind on this question, these data are critical to understanding the practice and its implications for policy.

The voluminous literature opposing legalization makes a variety of points and argues in a number of characteristic ways. What follows is a quick summary of some of the most conspicuous of these points, since it is among the concerns of our book to show how these points can be addressed and refuted. In our estimation, thinkers who oppose legalization of physician-assisted death appear to rest their arguments on a number of problematic assumptions.

- *Physician-assisted suicide means that physicians will have control over who lives and who dies.* It isn't the physician who has control; it's the patient. Many contributors to our volume explore how patient autonomy is actualized in physician-assisted dying. For example, Herman van der Kloot Meijburg's account of his father's death, Pearlman and Starks' studies of patient motivation, and Back's examination of doctor-patient communication as patients seek an assisted death, all show how physicians participate reluctantly, out of a sense of commitment to their patients.

- *Already accepted methods of negotiating death, including withholding and withdrawal of treatment, treatment with high-dose opioids for severe terminal pain or shortness of breath, and the use of terminal sedation, are less morally problematic than actively assisting death, and so assisted death isn't warranted.* Although there is wide ethical and legal acceptance of such practices, even when they bring

about the death of the patient, this is not to say they are less morally problematic than actively assisting death. They still bring about death, and they frequently offer fewer protections for the patient.⁵ There are no systematic safeguards for patient voluntariness, transparency of action, or protection from pressures from family, clinicians, or health care institutions such as those in statutes or proposals for the legalization of physician-assisted death.

- *Because few patients would make use of physician-assisted death, it is not appropriate to make sweeping (and potentially dangerous) public policy for a small class of individuals, however compelling the stories of those individuals might be.* Three things are wrong with this claim: the assumption that if only a small proportion of dying people actually use it, the availability of physician assistance in dying isn't important to others who are facing death; the assumption that physician-assisted dying is dangerous; and the quite callous view that dismisses the rights and interests of those who would use it. The comfort provided by the possibility of an earlier, easier death, even if one never actually uses it, can be enormous. For those who do use it, the prospect of dying in a way of their own choosing rather than being gradually obliterated by disease can be of central importance in the meaning of their soon-to-be-completed lives.

- *Depression is endemic among those who are seriously ill, so such patients cannot make these decisions rationally.* The personal stories explored in this volume and, more important, the clinical data on patients in Oregon who actually received physician assistance at death, fail to show distorted thinking from depression.⁶ Depression assessment can be tricky in any end-of-life decision,⁷ a fact that argues for an open practice with careful clinical evaluation of all practices, legal or not, that might end in a patient's death. Society now allows patients to make other end-of-life decisions—for example, refusing further life-prolonging treatment such as dialysis⁸—that will also result in death, without assuming that the patient who makes such a choice is by definition depressed.

- *There is something wrong with patients who seek this kind of control.* All patients, like all people, eventually die. What patients sometimes seek is some control over the way in which their inevitable deaths come about. As a society, we admire those who use medicine to try to postpone their deaths, and we admire those who assume responsibility for the way they live their lives in other domains; there is no reason not to admire and assist them as they live the last portion of their lives.

- *Physician-assisted dying is an issue of life versus death.* This assumption, too, is in error. For a physician to assist in the death of a terminally ill patient does not make the difference between death and indefinitely continuing life;

rather, it makes the difference between an easier death now and a more difficult death a little later. The amount of life foreshortened is typically quite small. Data from the Netherlands, where these practices are legal, show that patients who choose physician-assisted dying forgo, on average, only a few weeks of life and that in the vast majority of cases, assisted death is provided in the last week or on the last day before death would otherwise have occurred.⁹

- *If physician-assisted suicide isn't legalized, it won't occur.* Nothing could be further from the truth; every study of physician practice in the United States, as well as studies in other countries, shows a measurable, fairly consistent incidence of physician-assisted suicide whether legal or not.¹⁰ Therefore, the more realistically posed question about legalization must focus on comparing an open, legally regulated practice with a secret practice.

- *Jack Kevorkian is an example of what legalizing physician-assisted death would bring.*¹¹ Neither Oregon's Death with Dignity Act nor any proposed statute for legalization in the United States would permit providing physician-assisted death for terminal patients without careful safeguards, including repeated oral and written requests, waiting periods, confirmation of the diagnosis of terminality, and provision for psychiatric evaluation if there is uncertainty about voluntariness. Many of Dr. Kevorkian's cases would not meet these safeguards, and he is probably more symptomatic of the dangers of a secretive, underground practice than representative of an open, publicly regulated practice of physician-assisted death.

- *In Oregon and in the Netherlands, legalization has been accompanied by real abuse, and patients are sometimes railroaded into choosing assisted death.* Thanks to a series of three comprehensive studies of end-of-life decisions in the Netherlands over a period of sixteen years (discussed in part 3 of this book), Dutch practice is well understood. Data for the entire period of legalization in Oregon are also available. There is no evidence of abuse in Oregon, and on close inspection the notorious "1,000 cases"¹² of life-terminating acts without explicit request, said to represent serious abuse in the Netherlands, prove not to do so. The Dutch do not defend everything that has happened in their country regarding physician-assisted suicide, but they do not experience the serious, wholesale abuse of which opponents often accuse them. The Netherlands has the lowest, not the highest, rate of ending life without the patient's explicit request compared to voluntary euthanasia with request of all six European countries recently studied.¹³ Furthermore, in both Oregon and the Netherlands legalization has been associated with marked improvements in palliative and end-of-life care.

• *Good palliative care, including that provided by hospice, is incompatible with physician-assisted death.* Of all the misconceptions and errors perpetrated by opponents of legalization, this is perhaps the most damaging in its departure from the truth. As Constance Putnam has argued, the choice between “hospice or hemlock” is not the issue.¹⁴ Much of this volume explores the deep compatibility of excellent palliative care and physician-assisted death as a last resort. The majority of patients in Oregon who chose assisted death under the Death with Dignity Act were enrolled in hospice programs, and the majority of Oregon hospices have chosen to continue to care for those who are considering this choice. In addition, the Netherlands now has approximately one hundred inpatient hospices, and twenty-four-hour pain-control hotlines provide immediate advice for physicians. As several of the accounts of the practice in the Netherlands in part 3 of this volume show, better palliative care has been very much a goal of medical policy.

Our intent is not simply to rebut the claims of those who oppose physician-assisted death. This volume’s principal objective is to make the positive case for the availability of physician-assisted death as a last resort, and to do so by presenting some of the strongest arguments put forward by respected philosophers, ethicists, lawyers, religious leaders, and clinicians. Some of our contributors make the case for the moral acceptability of physician-assisted dying; others primarily address the case for legalization; many are concerned with both. This volume thus makes the positive argument that the practice should have a small but critical role among the range of end-of-life possibilities available to patients.

Here, it is important to understand the shape of the argument over physician-assisted death.

*Principal Arguments for
Physician-Assisted Death*

- Patient autonomy
- Mercy—the relief of pain and suffering
- Nonabandonment—commitment to patient and family

*Principal Arguments against
Physician-Assisted Death*

- The wrongness of killing
- The integrity of the physician
- The risk of abuse (the slippery-slope argument)

Although many of these arguments are used by both sides, two philosophical concerns are central to the case for physician-assisted death: liberty, variously

called freedom, self-determination, or (as philosophers put it) autonomy; and mercy, which asserts an individual's right to seek to be free from pain and suffering. These two basic principles, liberty and mercy (the right to live one's life as one sees fit, subject to the constraint that one not harm others, and the right to be free from pain and suffering, the obverse, one might say, of the right to the pursuit of happiness), are fundamental principles of the society in which we live. No one may be deprived of liberty, or be forced to suffer, without adequate cause. What is crucial to understand is that the burden of proof lies with those who object to these two cardinal points: they must show either that some still more basic principle trumps these claims or that honoring them would have seriously negative consequences. The third principle, nonabandonment, more precisely a norm of practice for physicians and other health care professionals, follows from the first two. There is an ethical requirement for physicians to try to respond to autonomous requests from their patients, especially when the requests revolve around extremes of suffering in those who are already dying.

Philosophers, ethicists, lawyers, religious leaders, and clinicians who oppose physician-assisted suicide appeal to principles as well. Quite plausibly, they assert that killing is intrinsically wrong—which, in the sense they have in mind, it is. Since physician-assisted dying does involve directly ending life, the accusation that it is killing and that killing is wrong might seem to have some purchase. However, physician aid in dying is certainly not “killing” in the pejorative sense of robbing someone of a life he or she values and that could otherwise continue; in physician-assisted death, the direct ending of life is an act of aid and reflects a deep concern for a person's well-being in the face of a death coming in any case—and thus the exact opposite of killing in the pejorative sense they have in mind. In a culture that accepts killing in self-defense, in war, and (more controversially) in capital punishment, it is hard to see why we should prohibit assisting a person who earnestly wants help in ending his or her own life, when that person's illness is terminal, the person is suffering, and life is ending anyway.

Opponents of physician-assisted dying claim that the consequences of legalizing physician-assisted suicide would be bad in two further respects: legalization would corrupt physicians and thus undermine the integrity of the medical profession, and it would fuel a slide down the slippery slope from a few sympathetic cases to widespread abuse. Yet there is no evidence for these claims, and there is substantial evidence to the contrary. The opposition must show that the principles of liberty and freedom from suffering, basic to an open, liberal, democratic society, should be overridden. This we believe they cannot do.

Since people of good will and considerable clinical, policy, and legal experience differ significantly on many of the issues underlying physician-assisted dying, those wanting to deeply explore both sides of this complex issue will want to read both the Foley and Hendin volume and this book. However, the present volume stands on its own in presenting the strongest arguments supporting ethical acceptance and legalization of the practice of physician-assisted dying. Here the practice is seen not as an alternative to excellent palliative care but as a last resort for those relatively infrequent cases in which palliative care becomes ineffective or unacceptable to dying patients whose conception of dying well includes some measure of control over the circumstances of death.

Brief Introduction to the Chapters

The contributors to part 1 examine the critical values of autonomy and mercy, the anchor points of the case for assisted dying, both of which are essential foundations for physician involvement in these activities. Autonomy in this context focuses on the values and wishes of the particular patient who finds himself or herself in an untenable situation. Patient autonomy is clearly a central point in considerations of assisted death, since it is the patient's life and death that are at stake in these decisions. However, assistance in dying, if it is also to involve physicians, cannot be solely a matter of patient choice; it must also be a response to medical distress, to actual or imminent suffering. The nature of the patient's suffering and why it is intolerable to the patient must be understood by the physician, who must then try to respond as a matter of mercy and in fulfillment of his commitment not to abandon the patient. Thus autonomy, mercy, and nonabandonment go hand in hand: for the physician to participate in assistance in dying, it must both be the patient's choice and help the patient avoid suffering that is intolerable or about to become so.

Marcia Angell, a distinguished physician and editor-in-chief emerita of the *New England Journal of Medicine*, explores the concept of mercy, drawing from her personal experience as the daughter of a man who took his life violently to avoid further indignity from his terminal illness. Timothy Quill and Christine Cassel, also physicians, use their experience in geriatrics, primary care, and palliative care to explore the central value of nonabandonment: the obligation of the physician who assumes care of a patient not to desert the patient at the end of his or her life; given the not infrequent tendency of physicians to distance themselves from their patients when nothing more can be done, this obligation is of particular weight. Tom Preston, Martin Gunderson, and David Mayo—

a physician, a lawyer, and a philosopher—provide a sustained examination of the concept of autonomy and its centrality in physician-assisted death. Drew Batavia, a law professor who lived with a severe disability until his death in 2003, looks at the issue from the viewpoint of a disabled person and offers a broader analysis of this community's views about choice and about the possibility of an assisted death than is ordinarily presented. In the final chapter of part 1, physician Eric Cassell draws on his considerable clinical experience and philosophical background to understand human suffering and the real threat that terminal illness poses to the integration of the person, exploring in particular the interface of illness, suffering, and control.

The chapters in part 2 explore some of the clinical, philosophical, and religious issues that underlie end-of-life practices. Robert Pearlman and Helene Starks, a physician and a researcher, using an extended series of in-depth interviews with patients and their families, explore the question why a dying patient seeks physician-assisted death. The answer is not simply avoidance of pain and suffering but also the wish to retain some measure of control over the circumstances of one's dying. The physician Tony Back extends this clinical picture by examining the complex, delicate interaction among doctor, patient, and family as they communicate concerning the decision to seek assisted death. Tom Beauchamp, a philosopher, critically explores the often-used distinction between killing and letting die, and Dan Brock, also a philosopher, examines conceptual and practical distinctions among two already accepted methods of hastening death—voluntary cessation of eating and drinking and terminal sedation—and the more controversial physician-assisted suicide. Finally, Bishop John Shelby Spong explores some of the religious implications of physician-assisted death, showing how it is compatible—even when it is called “suicide”—with a deep understanding of Christianity.

Contributors to part 3 turn their attention to the empirical data about patterns of practice in those places where physician-assisted death has been legalized, especially Oregon and the Netherlands. Linda Ganzini, a physician researcher at Oregon Health and Science University, reviews cumulative data from the Oregon Health Division reports on the practice of physician-assisted suicide under Oregon law and additional research conducted since legalization. Peter Goodwin, an Oregon physician who has been active in the referendum movement as well as both the *Glucksberg* and *Quill* Supreme Court cases, corrects common misrepresentations of two controversial cases in Oregon, drawing on his experience as a clinician at the bedside and in the care of these patients. Barbara Coombs Lee, a nurse and lawyer and the executive director of

the Compassion in Dying Federation, an organization dedicated to improving end-of-life care and expanding choice at the end of life, presents her experience in assessing and working with patients who desire a hastened death.

From the Netherlands, a number of well-respected authorities provide a comprehensive picture of legalized voluntary active euthanasia and physician-assisted suicide there. Hans van Delden, Jaap Visser, and Els Borst-Eilers (who was Minister of Health in the Netherlands for many of the years under study) review thirty years' experience in the Netherlands, including three major nationwide studies and an account of the distortion of this data by Herbert Hendin and other American authors. Herman van der Kloot Meijburg, the former director of bioethics for the Dutch Hospital Association, provides a vivid personal account of his father's death in a country in which active voluntary euthanasia and physician assistance in suicide are legal. Gerrit Kimsma, a physician, and Evert van Leeuwen, a philosopher, both on the faculty of the Free University in Amsterdam, offer a perspective from the bedside. The comprehensive picture these three chapters paint is illustrated in an anonymous offhand remark one of us heard in the Netherlands some years ago: "We Dutch have to fear dying less than you Americans do."

In part 4, some of the legal and political turmoil that has surrounded questions of physician-assisted death is examined. Eli Stutsman, an Oregon attorney who has been active in defending the state's Death with Dignity Act and in working to pass similar legislation in other states, discusses some of the politics of legal change in Oregon and other parts of the country. Kathryn Tucker, well known for her role as the lead lawyer along with Lawrence Tribe in the two cases contesting this issue before the United States Supreme Court, *Glucksberg v. Washington* and *Vacco v. Quill* (decided jointly in 1997), and as an important litigator on behalf of Compassion in Dying in improving accountability for inadequate pain treatment, provides an overview of these two cases and developments in their wake.

Alan Meisel, a professor of law, provides an analysis of the legal implications of the distinction between actively and passively hastening death that have been central to the thinking of many ethicists. Of particular importance in this analysis is the distinction between negative and positive rights, a distinction missed by opponents who believe that a "right" to physician-assisted death would obligate physicians to perform it. Sylvia Law, also a law professor, explores the political and constitutional issues raised by the movement for legalization of physician-assisted death and puts it into context with other liberation movements over the past forty years. Finally, law professor Charles Baron traces

the legal risks of maintaining the current policy of passive legal prohibition outside of Oregon.

The brief concluding essay presents our answer to the dilemmas presented in this book and in the counterpart volume edited by Foley and Hendin. We firmly believe that physician-assisted death should be one—not the only one, but one—of the last-resort options available to a patient facing a hard death. We agree that these options should include high-dose pain medication if needed, cessation of life-sustaining therapy, voluntary cessation of eating and drinking, and terminal sedation. We also believe, however, that physician-assisted dying, whether it is called physician-assisted death or physician aid in dying or physician-assisted suicide, should be among the options available to patients at the end of life. Clinical assessments required before accessing any of these last-resort options are more similar than they are different. We believe that physician-assisted dying, as one among them, should be safe and legal—and relatively rare.¹⁵ Most important, like all the other options, it should be a matter of open choice for patients, since different people who are dying have different ideas and values about what would be, for them, the “least worst” death.¹⁶ An open practice that includes frank conversation, a broad search for alternatives, second opinions by those with expertise in palliative care, and clear documentation is better for patients, families, and society than the current secret practice, which discourages open discussion, often has patients and families acting on their own, is not documented, and encourages altering the truth about actions and motivations. We invite readers to look at the arguments and data and make up their own minds, for the deeper the understanding we all have of the underlying issues, the better able we will be to develop sensible policies that are both responsive to and protective of patients and their families.

Notes

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