

PHYSICIAN-ASSISTED DYING

There are Many Opinions, What are the Facts?

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INTRODUCTION AND DEFINITION OF TERMS

There has been a national discussion about Physician-Assisted Dying (PAD) for the terminally ill since at least the 1990s, when Dr. Jack Kevorkian helped end the lives of—by his count—more than 130 ailing people. His methods were flamboyant and unorthodox, but the Michigan pathologist, who died in 2011, brought into the open a necessary but long-suppressed debate about whether doctors should be allowed to help end the suffering of patients by lethal means. As an issue complicated by conflicting religious, moral, and practical considerations, PAD provides ample grounds for sincere disagreement among people of good will. In such a debate, it is essential to define terms carefully, and to avoid not only misinformation, but misinterpretation of objective facts.

A Gallup poll conducted in May 2014 found that nearly 70% of Americans believe physicians should be able to “legally end a patient’s life by some painless means.”¹ This figure has climbed steadily from 37% when Gallup first asked the question in 1947. Demonstrating the importance of terminology, support drops to 51% when the process is described as doctors helping patients “commit suicide,” though both phrases describe the same process. As a result, advocacy groups favor the term Physician-Assisted Dying rather than Physician-Assisted Suicide.

A different example of ambiguous terminology is Gallup’s titling of its report as being about “U.S. Support for Euthanasia.” The word “euthanasia” is legally ambiguous, because the law distinguishes between “active” and “passive” euthanasia.² With suitable consent, common means of allowing death by turning off respirators, stopping feeding, failing to resuscitate, and giving large doses of narcotics that control pain but also suppress respiration and could hasten death, are legally considered “passive euthanasia,” and are regarded as ethical in most jurisdictions and by most medical societies.

Passive euthanasia includes circumstances in which patients initiate their own deaths with means

provided by others. The State of Michigan repeatedly failed to convict Kevorkian as long as his patients initiated their own lethal infusions with an apparatus he provided. It was only when Kevorkian himself initiated the infusion (very publicly too—he showed his self-made videotape on 60 Minutes), that he was convicted of second-degree murder and imprisoned. This may seem a distinction without a difference, but not in our courts. Though there was no dispute that Kevorkian administered the drugs at the request of the patient, and that the patient was terminally ill (with ALS), in the eyes of the law Kevorkian had crossed over the line and had performed a forbidden act: “active euthanasia.”

This column will briefly review the history of legislation and the arguments surrounding PAD carried out strictly in the legal sense of “passive euthanasia.” It will not address the withdrawal of life support from individuals in a persistent vegetative state, such as Karen Quinlan in the 1970s, nor issues related to advance directives that were raised by the 2005 case of Terry Schiavo that were previously discussed in this *Journal*.³

LEGISLATIVE HISTORY

In Oregon, The Death with Dignity Act was approved on a ballot initiative in 1994, and—after it overcame various legal challenges—it was implemented in 1997. It allows mentally competent, terminally ill Oregon residents over 18 years of age to obtain a prescription for a lethal dosage of medication they can use to end their life if they decide their suffering has become unbearable.⁴

Patients must make one written and two oral requests over a period of 15 days; the prescribing physician and a consulting physician have to confirm the diagnosis and the prognosis; and if either doctor believes the patient’s mental competence is impaired, the patient must be referred for a psychiatric or psychological evaluation. The prescribing physician must inform the patient of potential alternatives

such as comfort care, hospice care, and pain control. Participation by physicians is voluntary.

Oregon's legislation was the first of its kind in the United States, but as reassuring experience accumulated there, similar legislation was passed in Washington in 2008 and Vermont in 2013. In more conservative New Mexico and Montana, the same result was achieved when courts declined to prosecute the responsible physicians because they could find no legal basis for opposing the right of an individual to assistance in dying. Similar discussions are underway in the legislatures and courts of New York and California. In Canada, enabling legislation was passed in British Columbia in 2012 and Quebec in 2014, and the Canadian Supreme Court legalized PAD nationwide in February 2015.⁵

The spreading legalization of PAD in North America lags by many years the experience in Europe. Assisted suicide has been permitted in Switzerland since 1942 because it is only a crime to assist someone to commit (or attempt to commit) suicide if it is done for selfish motives. Lethal drugs may be prescribed as long as the recipient takes an active role in administration of the drug; the recipient need not be a Swiss national.

In the Netherlands, acceptance of physician-assisted dying had been growing for decades, and was codified in 2002 with the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, which legalized euthanasia (both active and passive forms) under very specific circumstances. The patient's suffering must be unbearable with no prospect of improvement; the request for euthanasia must be voluntary and persist over time; the patient must be fully aware of his/her condition, prospects and options; at least one other independent doctor must confirm the conditions mentioned above; the death must be carried out in a medically appropriate fashion by the doctor or patient; the doctor must be present; and the patient must be at least 12 years old (patients between 12 and 16 years of age require the consent of their parents).⁶

According to the Netherlands Ministry of Foreign Affairs,⁷ the main aim of this policy was to bring into the open and gather data on practices that were already taking place, and thereby "to apply uniform criteria in assessing every case in which a doctor terminates life, and to ensure that maximum care is exercised in such exceptional cases." In essence the Criminal Code was amended to exempt doctors from criminal liability for

euthanasia if they report their actions and a review committee decides that the physician acted with due care. If, however, a review committee finds that a doctor has failed to satisfy the statutory criteria of due care, the doctor could be prosecuted.

Some American politicians, in an apparent attempt to delegitimize the PAD movement, have falsely accused the Netherlands of "killing senior citizens." In 2000, Republican Presidential candidate Steve Forbes stated that Dutch doctors "routinely kill patients without the patients' permission because they want a hospital bed." In 2012, Republican Presidential candidate Rick Santorum claimed that "forced euthanasia" accounted for 5% of all deaths in the Netherlands and that elderly Dutch people wear a bracelet reading "Do not euthanize me."⁸ This flagrant distortion from a Presidential candidate prompted the Dutch embassy to respond with relevant statistics disproving Santorum's claim.⁹

Other countries that have legalized assisted dying include Luxembourg (2009) and Belgium (2002).¹⁰

ARGUMENTS PRO AND CON

The debate about PAD involves several core concerns:

1. Religious objections: Many opponents of euthanasia, particularly the Roman Catholic Church, believe that assisting suicide is a sin, and is forbidden by Biblical teachings. Fabian Bruskewitz, the combative former Bishop of Lincoln, Nebraska, decreed in 1996 that members of Compassion and Choices in his diocese, an organization that advocates PAD, incur automatic excommunication.¹¹

On the other hand, multiple surveys have revealed the declining influence of the Catholic Church on personal aspects of family life such as contraception and divorce. According to the latest Pew survey of religious affiliations,¹² large numbers of Catholics (about 10 million between 2007 and 2014) have left the church, doubtless influenced in part by the child sex abuse scandals.

The same recent Pew survey found that the percentage of adult Americans who describe themselves as Christians has dropped from 78.4% in 2007 to 70.6% in 2014. Over the same period, the percentage of Americans who are religiously unaffiliated—describing themselves as atheist, agnostic or "nothing in particular"—has jumped more than six points, from 16.1% to 22.8%.

Gallup, commenting on its own 2014 poll mentioned earlier,¹ points out that support for PAD is

related to the individual's underlying religiosity. Americans who attend religious services less frequently are more likely to support PAD.

It seems reasonable to expect that if religious affiliation continues to wane, opposition to PAD for religious reasons will also decline.

2. Professional ethics and the physician's role as healer: There are several themes in this sector of the discussion.

a. The AMA's official position on PAD states that "allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer . . ." ¹³

Despite the apparent force of this uncompromising proclamation, the once all-powerful AMA now counts only about 15% of America's practicing physicians as members, and its influence on how physicians practice has fallen even lower. Most importantly, the AMA cannot jeopardize the certification or licensure of any physician who fails to adhere to its positions.

b. Some physicians consider PAD a violation of the Hippocratic Oath which—in its original form—contains the statement: "With regard to healing the sick . . . I will take care that they suffer no hurt or damage," but most physicians recognize that the Hippocratic Oath from the 5th century BCE is a poor basis for modern professional ethics. It was formulated at a time when no one could imagine the influence on medical practice of modern neuroscience, radiology, pharmacology, anesthesia, etc. It is doubtful that many practicing physicians have actually taken the Hippocratic Oath, since we no longer swear to Apollo, Asclepius, Hygeia, and Panacea, and most medical school graduations use a modern Oath.

c. Many feel that the first principle of medical practice is to do no harm. (Here it is worth an aside to note that the phrase "First, do no harm," is not part of the Hippocratic Oath. Whatever its ancient origins, this axiom most certainly was not expressed in English. Its familiar form, "primum non nocere," is Latin, a language Hippocrates did not know.)

Countering these ethical concerns is the conviction of many physicians that alleviating physical or psychological pain is the true essence of our profession, that failing to do so is harmful to the patient, and it is both merciful and humane to facilitate a patient's escape from an illness that is unmanageable and insufferable.

3. Questions about the physician's prerogatives: Aside from considerations of professional ethics and the Hippocratic Oath, many physicians simply feel that physicians should not presume to act as secular gods, and even from a humanistic standpoint it is not our prerogative to interfere in the process of dying.

On the other hand, it can be argued that by the time patients reach the stage where PAD is considered, we have usually administered substantial medical care which has prolonged their life and their exposure to suffering beyond its natural extent. Simply by practicing modern medicine we have postponed death and brought our patients to their current state. Can we now abandon them to the consequences of what we ourselves have wrought? If, despite the best attempts at palliation, the patient's debilitation, pain, and misery exceed their tolerance, are we not obliged to use our wisdom, understanding, and courage to deal with it as they request?

Dr. Marcia Angell, former executive editor of *The New England Journal of Medicine*, asked: "Why should anyone—the state, the medical profession, or anyone else—presume to tell someone else how much suffering they must endure as their life is ending?" ¹⁴

4. The slippery slope: This is the concern expressed most consistently by opponents of PAD, who fear that it will be offered disproportionately to the poor, the elderly, the uninsured, or the disadvantaged; to the uneducated, the disabled, or the mentally incompetent. They postulate that some patients might even feel they owe it to their overburdened families to end their struggle.

Dr. Ezekiel Emanuel, Chair of the Department of Medical Ethics and Health Policy at the University of Pennsylvania, is a prolific, influential, and outspoken commentator on all manner of medical affairs, and an outspoken critic of PAD. ¹⁵ Speaking of terminally ill patients, he told the *NY Times* that "We should address what would give them purpose, not give them a handful of pills." ¹⁶ Proponents of PAD consider his statement startling in its insensitivity, and find it hard to imagine how to give "purpose" to patients whose little remaining time is being spent in misery, suffering, and despair.

The Oregon Health Authority's Division of Public Health keeps detailed records of how and why the law is used, which it releases every year. ¹⁷ After 17 years of experience, the consequences of legalized PAD are no longer hypothetical, and concerns about a slippery slope have proven groundless. There

has been no suggestion of coercion of the weak, disabled, or disadvantaged. Patients seeking PAD are disproportionately well educated and well off, and nearly all have had health insurance. They are the type of people who particularly value control and independence. Moreover, palliative care has not been weakened. Indeed, because all palliative options must be discussed with patients who request PAD, most experts believe that Oregon now has among the best palliative care in the country.

Critics of the Oregon law point to the increase in assisted deaths over the years—from 16 in 1998 to 105 in 2014—as evidence of a process run amok, but an increase was inevitable as people became more aware of the options offered by the law. During the past 17 years, 1,327 Oregonians received drugs, and 859 died from taking them; that’s less than 0.2% of the nearly 530,000 people who died in Oregon during that period. About one third of patients who obtained the drugs never used them, suggesting that they were satisfied to have gotten control over the manner and timing of their deaths. As Dr. Timothy E Quill recently put it: “Perhaps the knowledge that they could end their life if they so desired makes them feel less trapped—and therefore freer to keep going.”¹⁸

FINAL COMMENTS AND SOME PERSONAL REFLECTIONS

Death is the inevitable endpoint of life; how can it be outside the physician’s area of responsibility? Desperate patients, using various means such as auto-starvation or guns, are already choosing when they wish to stop living; can physicians not be involved to make their difficult passage easier? Regardless of what is reported publicly, can we ignore the reality of what we know is happening in private?

Much of the disagreement about PAD seems to revolve around semantics and labels. All 50 states permit competent patients to stop “life support,” or to say in advance that they do not want it started. No controversy accompanies a patient’s decision to forego or to stop chemotherapy in order to improve their quality of life at the cost of hastening death. Aren’t chemo or radiation therapies merely other forms of “life support,” or must that term be reserved for mechanical devices?

Another example of our semantic schizophrenia is the way we usually overlook dialysis patients when we discuss end-of-life care and “life support.” They often choose to end their lives by stopping dialysis,¹⁹ and it has been estimated that 22–28% of all U.S. hemodialysis

patients who die each year, and 38% of those over age 75, cease therapy prior to death. Treatment discontinuation is the leading cause of death among patients over 70 (and second leading cause for patients overall).^{20,21} This phenomenon is hardly a secret; the Renal Resource Center for Australia has a particularly frank and thorough discussion of dialysis end-of-life issues on its website.²²

The mechanism of death for a patient who chooses to die by not eating or drinking is similar to that of any patient who discontinues dialysis. The patient who stops oral intake develops dehydration that causes renal failure, hyperkalemia, and painless cardiac arrest, usually in less than 10 days. Notably, when patients make this choice, we do not force feed them or start IV’s.

Finally, guns are ubiquitous in our violence-riddled society, so it is a rare person who doesn’t have, or can’t get, access to a firearm with which to end their lives.

Clearly then, patients have many options for hastening death, so a physician’s prescription doesn’t change the outcome, just the neatness, ease, and tranquility of the ending. Through the years, without public discussion or consequences, countless physicians have aided countless patients to determine the time and circumstances of their deaths by quietly providing a prescription for a powerful sleeping pill such as secobarbital, with a “warning” to the patient that it could be fatal if they take too many. The standard 30 day supply dispensed by most pharmacies is sufficiently lethal, and the powder can be emptied from capsules and combined in a palatable vehicle like applesauce.

Laws like those in Oregon and the Netherlands are thus less revolutionary than they seem; they simply bring this practice into the open so data can be gathered and the process can be standardized. Mishaps become less likely and the potential for abuse is minimized. It is hardly unimportant that physicians who can discuss these matters openly with patients gain the opportunity to dissuade them from proceeding if the physician deems their decision to be inappropriate. Finally, physicians who have no strong ethical or other objections to PAD, but always felt uncomfortable circumventing the law, may be prompted by legalization to grant patients’ requests.

Organizations for the rights of the disabled (such as the Patient’s Rights Council and Not Dead Yet²³) insist that PAD could be used to encourage the disabled to get out of the way and stop consuming resources. Despite all evidence to the contrary, they assert that

there are “major flaws” in Oregon’s law “and the state’s reporting system,” and there is no way to know how many or under what circumstances patients have died from physician-assisted suicide. This seems a strange complaint, since unreported PAD undoubtedly took place in Oregon before the law went into effect and we knew less about those cases than we know now. Their arguments have not deterred the courts or legislatures that have legalized PAD.

Countering these anti-PAD organizations is Compassion and Choices,²⁴ successor to The Hemlock Society. It works “to improve patient rights and choice at the end of life, including access to aid in dying.” It provides end-of-life consultation for dying patients and their families at no cost, including assistance with advance directives, and litigates patient cases related to end-of-life care and choice.

FINAL THOUGHTS

At its core, this issue is a conflict between the patient’s autonomy and society’s interest in protecting life, which entails protecting the individual from external harm. With increasing frequency, courts and legislatures are deciding that autonomy is dominant; that patients own their bodies and have

the indisputable right to make decisions about it. Depriving patients of autonomy deprives them of their liberty and causes psychological harm and distress. The Canadian Supreme Court’s recent decision went further in one important regard. Dispensing with the artificial distinction between active and passive euthanasia, they concluded that as long as the patient gives informed consent their dignity and autonomy are preserved, and it doesn’t matter whether the physician assists actively or passively.⁵

America’s democracy is based on the principle that the individual’s liberty is paramount. As long as its exercise harms no others, it is protected from the power of the state or even that of the majority. We thus have a cultural resistance to exercises of the power of the state over the individual. When that fundamentally conservative legal principle combines with the growing cultural trend toward social progressivism,²⁵ acceptance of PAD is likely to spread rapidly.

Meanwhile, thoughtful regulation and monitoring, comprehensive reporting, and an ongoing critical debate are required. We must also ensure that physician-assisted-dying remains a choice grounded in caring relationships among the patient, the family, and health care professionals.

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