

From the Editors

Last Rights: Hippocratic Hypocrisy Meets Reality—a Personal Reflection

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California has just become the largest U.S. state to legalize “physician-assisted dying.” And therein lies a story—or at least my version of it.

San Francisco in the late 1980s was in some ways a sort of human slaughterhouse. As an epicenter of the HIV epidemic, before the virus was even identified and long before any real treatment became available, death was common, and among young people as well. As, not so long before, a renowned expert had reportedly said, “It is time to close the book on infectious diseases, and declare the war against pestilence won”—later discredited as a misquote but a belief widely shared nonetheless—this surge in morbidity and mortality caught everybody by surprise. Landing in the city by chance, to continue my education and training, I became a trained hospice caregiver and volunteered as a caregiver at and board member of AIDS organizations, attending international AIDS conferences and writing widely on related topics, while drafting local, state, and national HIV policy as well. It was a heady time, a baptism by fire for many young health professionals. But what I most recall are all the people who died premature and often very difficult deaths, and some of those who took care of them breaking down and weeping even at medical meetings due to the overwhelming suffering all around us. There were mass “die-ins” in the streets to protest official inaction. Only later did it become clear the extent to which PTSD lingered in the people who had lived through those years.

The history of the AIDS epidemic has been widely covered, and despite the undeniable progress in treatment, prevention, and understanding, there will alas be much more to endure and write about. Even without the possible resurgence of this or other infectious diseases, heart disease and cancer remain our two leading causes of death, but the real underlying diagnosis is birth itself, for nobody gets out of here alive. Becoming all too aware of this central fact of life at a relatively early age, I immersed myself in healthcare ethics in general and physician-assisted dying (PAD) in specific. In those days AIDS patients were passing around the formulas needed to end their own lives and were asking for explicit dosages of opiates and other medications in hospital beds. Over the next couple of decades I served on multiple hospital and other ethics committees and taught at many venues, from elementary to medical schools—and, it must be noted here, a quarter century ago we founded *CQ*, a most rewarding venture in publishing works by some of the brightest figures in the field on the whole spectrum of ethical issues abounding in healthcare. But for me, and I suspect many others, the ethics of the “right to die” remained a central ethical concern.

With respect to PAD, some signature memories followed:

- In 1988, *JAMA* published an anonymous story by a physician of euthanasia titled "It's Over, Debbie," and discussion of it was widespread in both medical and general circles. I was astounded to see a situation I knew was occurring widely printed frankly in such an august publication, especially as the American Medical Association (AMA) itself had always been so vehemently opposed to PAD.
- In 1989, I conducted and published a survey of almost 700 San Francisco physicians—members of the mainstream medical association, affiliated with the AMA—on PAD, showing that a majority supported a legal PAD option. This was the first modern survey of this kind, and many more followed over the years, with generally consistent results. Respondents scribbled comments on their survey forms, and the one that has stuck with me read simply: "It is time we are as humane with our patients as we are with our pets."
- In 1990, Dr. Jack Kevorkian assisted the death of a woman with an early Alzheimer's diagnosis, further igniting the public debate. Like many, I found Kevorkian ghoulish; also like many, I thought him courageous in his advocacy and his successful effort to put this issue on the front page. I reviewed his autobiography for the local paper and called it "creepy" and him "the wrong spokesman for the right issue." I met him on a conference panel and confirmed that impression.
- In 1991, Timothy Quill, M.D., published his story of actively hastening a patient's death in the *New England Journal of Medicine*; his reasoned, compassionate story and persona again sparked much debate. Meeting him later, I was impressed that he appeared as thoughtful and trustworthy as any physician could hope to be.
- In 1992, California voters rejected a ballot proposition that would have legalized PAD, 54%–46%. I wrote an op-ed for the California Medical Association (CMA) journal gently suggesting that their longtime just-say-no position was no longer representative of clinical reality. Response was large and positive—privately.
- In 1997, I served as moderator for a California state assembly hearing on PAD; when the CMA's representative said that in 30 years of oncology practice he had never had a patient ask him about PAD, the chair retorted, "Perhaps they are afraid to ask you." I had nothing to add to that.
- In 1999, I convened meetings of many ethics committee chairs and members to develop and review clinical guidelines for PAD. Published in the *Western Journal of Medicine*, they were the subject of a cover story in the *New York Times* titled "Guidelines for the Unthinkable." But subsequent legal guidelines for the practice have been notably consistent with what our consensus guidelines recommended.
- In 2006 and 2008, other California bills to legalize PAD failed, but by then legalization had taken place in other states and in Europe. In California the CMA remained a primary opponent, citing the Hippocratic oath and other concerns, and its influence aborted these and previous attempts.
- In 2013, the latest attempt (after three previous failures) of the San Francisco Medical Society (SFMS) to convince the CMA to change its PAD policy from "oppose" to "neutral" via policy I had drafted was rejected without debate.

- In 2015, a new legislative attempt to legalize PAD in California began, garnering much attention due to some high-profile cases. Sensing that perhaps the time had come but that such a law would still never pass over the continued knee-jerk opposition of the CMA, I drafted a letter to the CMA leadership, from the San Francisco Medical Society, which read, in part:

RE: PHYSICIAN AID-IN-DYING (PAD)

As you may recall, the SFMS delegation to the CMA has brought resolutions to the HOD urging a “neutral” position on this topic, for two primary reasons:

- (1) Physician Opinion: Extensive survey data now shows that physician opinion on this topic is strongly divided, with even a majority in support of a legal option. Our SFMS position evolved following a survey of 676 of our members which indicated a majority support some legal option for PAD. A dozen other surveys indicate this is true. The most recent such survey, by MedScape in 2014 of over 21,000 physicians of many specialties, had a 54% “yes” response on the basic question “Should physician-assisted suicide be allowed?”:
- (2) State experience: The “laboratories” of states that have legalized PAD is showing that the feared consequences have not materialized (in Oregon and Washington; with Montana, Vermont, and New Mexico’s experiences too new to draw upon). In fact, contrary to fears about negative impacts on end-of-life care, as noted in a review in the *New England Journal of Medicine*, “The legalization of assisted death has been associated with substantial improvements in palliative care in Oregon, in areas including the appropriate training of physicians, the communication of a patient’s wishes regarding life-sustaining treatment, pain management, rates of referral to hospice programs, and the percentage of deaths occurring at home.

We of course understand that this is a very complex and emotional topic, and we certainly support continual improvements in end-of-life care. We would advocate for nothing that we felt would harm patients or medical practice, or that would require violations of medical ethics. However, we feel strongly that the evidence with respect to medical opinion and experience on this topic logically leads to a CMA position of “studied neutrality.”

The CMA, to its credit, this time decided to respond by actually asking for reevaluation of the long-standing anti-PAD policy (in contrast, a state oncology society conducted a member survey that yielded support of legal PAD and then ignored that). The CMA posted the PAD question online for member input and garnered almost 100 comments, with those favoring neutrality outnumbering those favoring the current CMA policy by at least 2–1, if not more. Then the CMA Council on Legislation, which advises on policy matters, convened a morning-long meeting on the legislation. Testimony, including from the legislator authors of the PAD bill, was eloquent, informed, and heated. When the committee chair asked for a straw vote, the result also strongly supported neutrality—at least 3–1

in this case, if not more. I'll never forget that moment—some of those voting seemed shocked, looking around at the others with their hands up, seemingly silently asking, "Oh, you too?" It was as if a sea change of opinion had quietly occurred, such as with marriage equality or the legalization of cannabis—both changes the CMA had favored in recent years. Thus, the CMA removed its long-time opposition to PAD.

With CMA opposition removed at last, the PAD bill moved forward and, via arcane procedural maneuvering, reached the California governor's desk. Our governor is known to be unpredictable, but in any event we knew his fellow Catholics would be weighing in, expressing strong opposition to this bill. For the first time, I called on anybody I knew who knew him—his schoolmates, physicians, and political allies—and asked them to contact him if they felt strongly regarding PAD in any way. My hope and prediction was that he would not sign the bill but simply allow it to become law. But soon his message came, and it was clear he had thought deeply about it, that some of the people I had called had in turn spoken with him. He concluded, "I do not know what I would do if I were dying in prolonged and excruciating pain. But I am certain that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."

The response was immediate, garnering front-page stories around the nation. Physicians and others who had worked with me on this issue years before got in touch, elated. Many said they never believed it would happen in their lifetime (conversely, some medical students remarked, "You mean that was illegal?"). Some old allies confessed they cried. And I was not immune to that. Driving over a mountain road on the day after the governor signed the bill, spotting a road-killed animal, I was caught by surprise by the emotion welling up in me and had to pull over and let it come out in tears and sobs, my first in years. Images of many patients; of animals; and of endless, seemingly fruitless debates came to me. I realized I too had not truly expected us to prevail on this issue. More than two decades of work had finally paid off; California had legalized PAD, and as a common prediction goes, as California goes, so goes the nation. Or, perhaps. We shall see.

But what of "ethics"?

When I taught medical and other students on the topic of PAD, in addition to the conceptual teachings on autonomy, beneficence, and much more, I often used this vignette: A physician has two patients, both near death and asking her to help them die. In one room she enters and turns up the morphine drip, saying, "I can't speed your death, but this will treat your suffering"—and the patient dies, sooner than otherwise would have occurred. In the second room, she turns up the morphine, saying, "Here, this will end your life." She took the exact same action in each room. In the first room her actions have been endorsed by the AMA, United States Supreme Court, and widespread practice. In the second she can be called an unethical killer, eligible for charges of murder.

So in the conflicting eyes of the law and of much ethical perspective as well, it is really all about intention (which seemed ironic and/or logical in the Buddhist hospice where I worked for a time). In hospitals and hospices, many people know just what is going on: PAD, via terminal sedation or other routes—but call it something else. Even Catholic or other anti-PAD physicians I've known have admitted to this, saying, "Sure, it happens all the time but we must not let that be known

and legitimized, nor call it what it is (PAD).” And thus Hippocratic hypocrisy has long been more the norm than not.

Is this “bad”? Not wholly. If everybody knows that palliative, even terminal, sedation can be an appropriate option in end-of-life care and if this sedation is made available, legalizing it, with whatever putative downsides, might indeed be redundant. And some also argue that somebody other than physicians should be enlisted to do it (a proposal that always sounds, to me, like patient abandonment at a crucial time; plus, what sort of people—see Kevorkian—might choose “euthanist” as a profession?). But the reality is that many do not have access to such care and reassurances, and keeping the practice so hidden leads to suboptimal practices and outcomes. And then there is the requirement that otherwise ethical professionals must play sleight-of-hand to please old legal and ethical codes to which a majority of people—physicians and others—no longer subscribe (remember, the Hippocratic oath, for all its wisdom, is rarely taken in full these days and proscribes both abortion and surgery).

But here is an ironic note and one of the main reasons I came to support legalized PAD so strongly: in my own experience, and in talking with so many physicians and patients through the decades, I came to believe that the most common effect of granting PAD to a terminally ill patient can be the extension of life. Kevorkian’s first case was an extreme example of a woman, terrified of dementia, choosing to end her life long before necessary—taking a preemptive strike. Tragically, that is not rare. Assuring patients they will have this choice often allows them not to use it. Paradoxical? Yes, but this trend is confirmed by many clinicians with vast experience in helping terminally ill patients. This dynamic could not be ethically researched, but I and many others are convinced it is true. Thus, ironically, PAD can extend life—probably more often than it shortens it.

The relative number of patients who actually carry through with their request for PAD has been shown to be small and likely will remain so. But if you or your loved one is part of that small cohort, that’s the case that matters. It is no doubt true that most—but not all—wishes for PAD can be reduced by better care and communication. Legalizing PAD and arguing about it are valuable tools, like acupuncture points, to goad improvement of overall end-of-life care. We know that such improvement can be a side effect of the PAD debate. The palliative care movement and all its adjuncts are invaluable and in no way conflict with PAD, despite what some may fear. The intent of all of these efforts is better deaths—meaning better final times of a life.

The ethical concepts and literature regarding PAD are vast, fascinating, and often contradictory. I’ve contributed to that myself, for better or worse. I think that most clinicians can find the ethical issues and input interesting—but not so helpful at the bedside. We know now that many if not most physicians desire less intensive and invasive life-extending treatment for themselves than they tend to provide for their patients, and that many patients suffer for that duality, no matter how well intended. I am very aware that many people still need better access to healthcare, and that this need is more widespread than the right to refuse it or even to ask for PAD. I don’t believe the World War II Nazi experience is very instructive—they started at the bottom of a slippery slope—nor do I think that the most vocal disability advocates who oppose PAD, however well intended, truly speak for disabled people as a whole. The fundamental value here, as in so much of the modern healthcare ethics movement, remains one of informed patient

preference, of control of one's own body and life and the end thereof. Or, as is often asked, Whose life is it, anyway?

In some long-forgotten medical journal of the 1800s, an author likened the practice of PAD to "Obstetrics of the Soul." That striking term and concept seem to date from ancient times and have been used in other contexts since but consistently refer, as at the start of a life, to a sort of deliverance. Californians will now be granted a basic human right to deliverance none of us hopes to ever have to use. So now I feel a great sense of responsibility, for helping to enable this new law in our vast state, although it is now out of my hands. We must and I believe will implement it well, with all—but not too many—of the so-called safeguards against abuse contained in our guidelines and in the law. It's a tricky and complex balance, but I believe that, collectively, Californians will be up to the job.

There are so many people now gone who died desiring to be granted this right, and so many who have worked to make it a legal option. And although I have refrained from reciting a litany of far too many deserving names here, I trust those still with us know who they are, and I thank them, sincerely and deeply. In the time since California's new law was signed by our wise governor, I have been flooded with gratitude to so many people, living or gone. If the fundamental, shared goal of lessening suffering in this world, wherever and however we might, is what has guided our efforts, the countless hours spent on this issue might at last turn out to look like time very well spent.

Addendum: One name must be mentioned here: that of CQ founding coeditor Dr. Thomasine Kushner, mentor, colleague, and true friend, who 25 years ago casually asked, "Would you like to join David Thomasma and I in starting a new ethics journal with Cambridge University Press?" I am indebted to her—and to her late, great husband, Malcolm—more than I can ever truly express. But Tomi, this essay is for you.