Law's Challenge to Medicine

In the same week that Dr Jack Kevorkian was acquitted for assisting in two suicides in Michigan,[1] the US Court of Appeals for the 9th Circuit made a more critical judgment. On March 6, 1996, that federal court found that Washington State's law prohibiting physician-assisted suicide was unconstitutional.[2] Overturing their colleagues who sat on a three-judge Court of Appeals panel,[3] the full Circuit decided 8-3 that there is a constitutional right to die. For the majority, Judge Stephen Reinhardt wrote that:

A competent, terminally ill adult, having lived nearly the full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced to a state of helplessness, diapered, sedated, incompetent.[4]

Although Kevorkian's personal acquittal gained more attention in the lay press, the decision by the full Court of Appeals has more far-reaching implications. This historic decision guarantees that an appeal eventually will reach the Supreme Court. In the immediate future, the decision could permit Oregon's Proposition 16,[5] which allows physician-assisted suicide, to go into effect.[6] Oregon's law, passed by public referendum in 1994, has been held up in lower courts under the 9th Circuit's jurisdiction.[7]

These legal developments will have important clinical repercussions for physicians who care for the terminally ill. If assisted suicide becomes legal, practitioners will need to incorporate this ill-defined constitutional right to a "dignified and humane death" into a workable clinical strategy. Abstract legal theory will need be put into practice when practitioners are faced with the ethical challenge of responding to a request for aid in dying. These determinations will require clinical sophistication that can be neither voted on nor legislated. Indeed, translating legal dictums into practice will require practitioners to move beyond the theoretical issue of whether patients have a legal right to physician-assisted suicide to the more pragmatic question of ensuring that patients are well cared for at the end of life. This challenge will become even more complex with recent legal developments.

Oregon's Proposition 16: Regulating Clinical Practice

We need only review Oregon's Proposition 16 to appreciate the discontinuity that can exist between a legal framework and the clinical reality of caring for dying patients. While the Proposition is based on a patient's theoretical right to die with dignity, in practice it does little more than articulate minimal standards of care. Under its provisions, a physician could write a prescription for a lethal dose of medication if a terminally-ill patient initiates a voluntary and repeated request for "assistance in dying." Patients must be residents of Oregon and have a life expectancy of less than six months. Assistance would be limited to writing a prescription for a lethal overdose. More direct physician-assisted suicide or voluntary active euthanasia would be prohibited. The Proposition prohibits direct physician administration of a lethal intravenous (IV) drip if a patient requests aid in dying. Similarly, it prohibits the insertion of an IV that the patient could then voluntarily activate. With any request, a 15-day waiting period would be required, as well as a concurring opinion from a second physician on the clinical diagnosis and the nature of the patient's request. Physicians would be required to request that patients "notify next of kin," although the patient would not be compelled to do so. A psychiatric evaluation would be mandated if the patient is either depressed or suffering from mental illness. No assistance could be provided while the patient is being evaluated for psychiatric illness.[5,8,9]

Although the physician would be mandated to speak with patients contemplating assisted suicide, the required content of that conversation is cryptic and telegraphic. The physician would be obliged to review the patient's diagnosis and prognosis and discuss the risks and results associated with the lethal medication. This discussion also must address "the feasible alternatives including, but not limited to, comfort care, hospice care, and pain control."

This ill-defined phrase describing palliative care options warrants closer examination because it captures the difference between a clinical and regulatory approach to the care of the dying. From a clinical perspective, the integrity of any decision about physician-assisted suicide would hinge on the thoroughness of this exploration of palliative care options.[10] The elusive requirements of this regulatory passage, however, turns this critical assessment into a contingent exercise based on feasibility. A definition of feasible, according to the Oxford English Dictionary,[11] suggests that if the assessment of a request for aid in dying is too closely linked to feasibility, this critical evaluation could devolve into an expedient assessment based on what can be "... dealt with successfully in any way." The dictionary defines "feasible" as:

1. Capable of being done, carried out, or dealt with successfully in any way; possible, practicable. 2. of a proposition, theory, story, etc.: likely, probable.

With this definition in mind, feasibility might range from the mere mention of available palliative care options to actual palliative care trials designed to respond to the patient's pain, anxiety, depression, or suffering.

If a comprehensive evaluation is integral to clinical integrity, then this regulatory requirement is too situational and open to erosion when the challenge of providing adequate palliative care is high. This is especially worrisome given the uncertainty voiced by Oregon physicians about their ability to diagnose terminal illness and identify depression in a patient who requests aid in dying.[9]

Instead of fostering an atmosphere in which a comprehensive evaluation is encouraged, the language of Proposition 16 suggests that feasibility will devolve into a
minimal standard of care and evaluation. This possibility is suggested when “comfort care, hospice care, and pain control” are described as alternatives to physician-assisted suicide and not as remedies that must be exhausted before aid in dying is contemplated.

This regulatory minimalism also is evident in Proposition 16’s treatment of informed consent. Instead of articulating a standard for decision-making that mandates informed consent from a competent patient, Proposition 16 requires that an “informed decision” be made by a patient who is either “qualified” or not “incapable.”

If consent is the paradigm within which doctors and patient communicate and collaborate, then the language of Proposition 16 represents a fundamental change in the doctor-patient relationship. Its provisions suggest a departure from the collaborative decision-making model advocated for informed consent[12] and discussions concerning advance directives.[13,14] The collaborative dialectic that matches the physician’s professional knowledge to the patient’s individual needs is destroyed by the regulatory framework offered by Proposition 16.

The therapeutic synthesis that can occur when patient and physician work together to aim the healer’s power in pursuit of shared goals[15] becomes difficult, if not impossible, to achieve. In the legal terrain, landscaped by Proposition 16, patients are on their own. They must initiate a request for aid in dying, endure a screening process by two physicians, and then independently obtain and fill a lethal prescription on their own. Finally, they must self-administer the drug. In this, the patient is fundamentally alone and isolated. In the name of self-determination, bordering on libertarianism, the patient is therapeutically divorced from his physician and family - if he or she so chooses.

If this social sequestration were not enough, the patient also becomes morally isolated. Under the provisions of Proposition 16, the patient is forced to accept lone moral responsibility for the suicide. This mandate is vividly illustrated by an excerpt from the “request for medication to end my life in a humane and dignified manner.”

This is the document that a patient must sign before a prescription for a lethal dose of medication can be written. The final line above the patient’s signature reads:

I make this request voluntarily and without reservation, and I accept full moral responsibility for my actions.

Although this request is most likely designed to protect the physician from liability,[16] this effort to create legal immunity has discounted physician participation in end-of-life care and has fostered the rise of the atomistic and libertarian patient who must travel life’s final journey alone. While this release is emblematic of changes in the nature of the doctor-patient relationship, it also is significant for its suggestion that an individual can assume full moral accountability for an act undertaken with the involvement of another. This is a libertarian fiction that misconstrues the nature of relationships and professional responsibility. This fiction is even more evident in Section 3.14 of the Act which maintains that, “Actions taken in accordance with this Act shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide under the law.” While the true nature of this Act can be obscured by the law, the law does not have the normative power to redefine morally significant actions.

Proposition 16’s transformation of the physician from a morally engaged partner to one who is absolved by the patient’s signed waiver is the most dramatic evidence that its legal framework does not capture the ethical complexity of a request for aid in dying. Its drafters were naive in asserting that a patient’s release could relieve practitioners of their felt ethical obligations simply because a patient agreed to “accept full moral responsibility.” The patient’s autonomy is insufficient to rid a sympathetic practitioner of moral complicity in an action that the patient could not do alone.[17] Even those physicians who might be willing to prescribe a lethal dose of medication cannot be released from their perceived fiduciary obligation to the patient simply because such aid is requested.

The narrowness of the legal framework supplied by Proposition 16 can be seen in its near total disregard of the role of pharmacists who would be requested to knowingly dispense lethal doses of medication. Unlike physicians who could conscientiously object to participating in an assisted suicide, no provisions were made for pharmacists who viewed such involvement as a breach of professional ethics.[8,18]

Regulation’s Limits: Transplantation and Assisted Suicide

If there is a lesson to be learned from Proposition 16, it is that we need to turn away from the public side of the physician-assisted suicide debate and better understand the more intimate dimensions of this contentious issue. We need to recall that every public referendum, legislative proposal, and high-profile court case has a private face. That side of the debate - perhaps because it is so intimate - is often unexamined and unexplained.

Some have suggested the creation of peer review panels to bridge this gap between the law and clinical practice.[19,20] These boards would be empowered to review requests for physician-assisted suicide in light of professional guidelines.[21] One step closer to the clinical context than the law, they could help interpret legal guidelines within a medical framework knowledgeable about palliative care and the care of the terminally ill. If assisted suicide became legal, these panels could help to standardize care.

As valuable a role as these review boards might play, critics worry that this level of oversight still fails to capture the range of clinical and ethical concerns that need to be addressed when considering requests for physician-assisted suicide.[22] For example, the authors of New York State’s Task Force on Life and the Law,[23] a comprehensive report that opposed physician-assisted suicide, recently have voiced concern about our ability to regulate this delicate clinical encounter. They maintain that a “caring doctor-patient relationship” for a patient requesting assisted suicide cannot be prescribed through regulation.

Neither legislative fiat nor professional guidelines could establish this kind of relationship. Nor would the state have any effective mechanism to monitor the quality of the doctor

The limits of regulatory oversight may be more obvious if the process used to allocate organs for transplantation is considered. Most would acknowledge that organs are distributed fairly among patients who have been placed on their transplant region’s waiting list. These patients are selected by a regional review process that prioritizes transplants based on the patient’s severity of illness, the time awaiting transplant, and the availability of a histocompatible match. While this process is highly standardized for patients who have gained access to the transplant list, the same cannot be said of the manner in which physicians refer patients for consideration of transplantation. The initial decision to refer for transplant - or even suggest this possibility - often can be informed by the physician’s value judgment about how the patient came to need transplantation and the patient’s perceived “social worth.” This unilateral judgment - often made by physicians unfamiliar with transplantation eligibility criteria - can be determinative, thus depriving suitable candidates of more formal evaluation by a transplant center. Caplan[25] has written that:

“... Transplant centers, and the surgeons who administer particular organ transplant programs within them, need to deal only with those patients who have actually made it through their doors. But many potential recipients never appear on any center’s waiting list. The most important ethical decisions about allocation take place long before an organ actually arrives to be used at a particular transplant center... Those who get transplants almost always arrive in a transplant program as a result of a diagnosis by and a referral from a physician outside the program. Eligibility for transplantation is controlled and determined in large measure by doctors who normally have no direct contact with or special expertise in transplantation. If the disanalyses between the regulation of organ transplantation and the regulation of assisted suicide are considered, there is even more reason for concern. Unlike organ transplantation, which is generally accepted as a social good, the consensus about assisted suicide is no longer clear. Without prevailing societal norms, physicians can be judgmental whether they are for or against assisted suicide. In practical terms, a patient who requests aid in dying may be deprived of more formal review by a physician opposed to assisted suicide, while the physician who is sympathetic to a patient’s request could act without the concurrence of his colleagues.

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The lack of a clear societal consensus is especially worrisome because aiding a suicide does not require the assistance of another medical professional. The physician who wants to arrange a transplant cannot do so without formal review, collaboration with peers, and the procurement of an organ. In contrast, the physician who wants to assist in a suicide can do so unilaterally. Pellegrino[22] is correct in asserting the centrality of the physician in decisions regarding assisted suicide:

. . . the determination of the right circumstances is in the physician's hands. The physician controls the availability of and timing of the means whereby the patient kills himself . . .

Although the inability to regulate the intimate sphere between doctor and patient makes a compelling argument against legalizing assisted suicide, even its continued prohibition does not guarantee clinical prudence.

**Regulation From Within**

Despite the public nature of this debate, assisted suicide is a very private act. It is imperfectly regulated in the public sphere and often is too private an act to accommodate the presence of anyone but the physician, patient, and sometimes family. This suggests that physicians will need to be self-regulating when confronted by a request for assisted suicide. No one other than the physician will be able to assume this responsibility. In a true test of their professionalism, physicians will have to integrate the clinical facts and ethical dimensions of each case that presents this dilemma.

Practitioners will need a better account of the philosophical arguments that frame this contentious debate[26] as well as the clinical dynamics that accompany a request for aid in dying. They need more than the public account of assisted suicide in order to reflect on the intimate interaction of patient and doctor at a bedside or in a dying patient's home when a request for aid in dying is made. It will be in the relative isolation of these settings that a patient who is confronted by uncontrollable pain or a dreaded diagnosis that portends suffering and uncertainty will ask for help to end his or her life. The script of each of these tragedies will not be legislated or dictated by case law. Instead, each case will be written by patient and doctor scripted by the confluence of their life narratives. In a private conversation, each will draw on their personal values to explore this delicate question together.

A request for aid in dying is complicated by the fact that most clinicians will have a strongly held - if not fully examined - point of view about the ethics of assisted suicide. Although there are conflicting data in recent surveys that examine physician attitudes towards assisted suicide, the literature suggests that a physician's receptivity to assisted suicide will be dictated primarily by religious beliefs and, in some studies, specialty, age, practice setting, and other demographic characteristics.[9,27,28] Although a comprehensive review of this literature is beyond the scope of this essay, it is important to stress that these studies indicate that physicians and their patients view the question of physician-assisted suicide with reliably held beliefs. These preexisting beliefs have the potential to distort the dynamic between patient and physician when a request for assisted suicide is made. Accordingly, physicians should discuss their personal beliefs on this divisive issue with patients in order to engage in a frank discussion of the clinical and normative dimensions of a request for aid in dying.

Disclosure of physician attitude is only the first step in true moral engagement with the patient considering assisted suicide. A discontinuity often exists between what patients think they believe and what they might be willing to do. For example, physicians who theoretically endorse assisted suicide may be more cautious when asked whether they would participate in the act. In Oregon, for example, although 73% of physician respondents agreed that "competent, terminally ill patients have the right to commit suicide,"[29] 53% of practitioners would not be willing to write a prescription for a lethal dose of medication if physician-assisted suicide were legal.[9] This discrepancy between public words and private deeds is another facet of the complex clinical dynamic associated with assisted suicide.

The failure to address the tension between what is professed by practitioners and what actually occurs in clinical practice can distort doctor-patient encounters. The presence of these preexisting views - which may be the more intimate views that are privately held and not as fully examined than those that are publicly expressed - can present a formidable barrier to doctor-patient dialogue when this difficult question is broached. A clinician who approaches these discussions convinced that assisted suicide is morally proscribed may exacerbate patient distress with guilt. This will make an already problematic situation more difficult for patients who are likely to initiate such requests with great trepidation. A patient who feels so burdened as to be moved to ask for aid in dying does not need to be judged but rather needs an opportunity to be heard in a forum that will promote healing and palliation. A failure to sympathetically engage a patient who makes this request will undermine doctor-patient communication before it even begins and when nuanced dialogue is needed most. This failure to communicate will compromise the physician's appreciation of the patient's motivations and will limit the practitioner's ability to respond constructively to depression, pain, or suffering.

Alternately, a practitioner who is philosophically sympathetic to the position that patients should have the right to aid in dying might be too permissive in acquiescing to a request. A close reading of Quill's description[29] of his now famous encounter with his patient Diane suggests that Quill was overidentified with her. In speaking of Diane's suicide, Quill writes:

. . . she called up her closest friends and asked them to come over to say good-bye, telling them that she would be leaving soon. As we had agreed, she let me know as well. When we met, it was clear that she knew what she was doing, that she was sad and frightened to be leaving. But when we met, it was clear that she knew what she was doing, that she was sad and frightened to be leaving, but that she would be even more terrified to stay and suffer.

In response to a request for assisted suicide, a rush to an abstract moral judgment about the propriety of a request occurs at the expense of true moral engagement with the patient. At its worst, it becomes coercive - dictating a patient's choice and abridging voluntary choices. More often, it is less authoritarian and is procedurally limiting; that is, it abridges the practitioner's ability to appreciate the singular narratives that will inform every request for aid in dying. This forecloses an opportunity for a healing encounter regardless of the decision about assisted suicide.

While no physician should ever be obliged to assist a patient with a suicide, all physicians have an affirmative obligation to explore a patient's request fully and comprehensively. While this will be difficult when the belief systems of the patient do not cohere with those of the physician, all practitioners should be expected to give patients a fair hearing when a request is made. A marker of whether we have listened to and heard our patients is that we must reexamine our own generalizable beliefs when confronted with the details of a particular case history. While we may ultimately remain convinced by our preexisting beliefs about physician-assisted suicide, there is a heuristic value to being challenged by the patient's heartfelt views.

It is important to recognize that there is no generic request for physician-assisted suicide. Each case has nuances that are biographical and contextual that need to be cultivated in order to reach a reasoned decision, and practitioners will need to discriminate among different types of requests. For example, is the request an acute grief reaction in response to a new diagnosis or the product of a long and debilitating illness? These diagnostic differences will suggest different therapeutic responses. A failure to see each request as unique will deprive patients of the attention and care they deserve when they contemplate difficult choices at the end of life.

**Conclusions**
As a failure to attend to the clinical and narrative details of a case can result in suboptimal practice, the consequences of having transformed the debate over physician-assisted suicide into a legal one has resulted in the irony that it has had little impact on the care of dying patients. In the years since Dr. Kevorkian assisted in his first suicide, the SUPPORT study designed to describe and influence patterns of end-of-life care was conducted. Phase 1 findings from SUPPORT demonstrated that only 47% of physicians knew when patients wanted to forgo cardiopulmonary resuscitation and that 46% of “Do not resuscitate” orders were written two days before death. Even more alarming was the finding that 50% of conscious patients suffered moderate severe pain at least half the time, according to family reports. These deficiencies were not corrected with the study’s experimental interventions.[30]

While the deficiencies in the care of dying patients demonstrated in the SUPPORT study cannot be attributed to our collective attention over the ethical and legal propriety of physician-assisted suicide, they do force us to consider the paradox of how such suboptimal end-of-life care could have continued in light of our near national obsession with physician-assisted suicide during the study’s period of investigation. Given these findings, advocates and opponents of physician-assisted suicide must ask whether terminally ill patients have been helped by the tenor and nature of this contentious debate.

While this public discourse has increased patient curiosity about physician-assisted suicide, little attention has been paid to the more private sphere in which patients and physicians might consider requests for aid in dying. Instead of considering this complex and nuanced clinical reality, we have collectively focused on the rights of the terminally ill to control their deaths. This often occurs at the expense of considering the medical profession’s more general affirmative obligations to the terminally ill.

Operating in this legal realm clouds many of the pressing needs of the terminally ill patient. Articulating the right to suicide before ensuring the right to universal healthcare care or even to palliative care seems premature and misplaced. It would be akin to asserting that all individuals have the right to a phone call after being arrested without recognizing that too many arrests were unfounded by the evidence. Although the right to place a call is an important one, it is a right most would prefer not to have to exercise. If given the choice, most of us would prefer to not be falsely arrested than to remediate this abuse of one’s liberty with a few moments on a telephone. Therein lies the correlation with the debate about physician-assisted suicide: although this right remains contestable, it is at best only remediation for our collective indifference to the care of the dying so poignantly illustrated in the SUPPORT study.

It is the ultimate irony that the effort to foster patient self-determination and autonomy through physician-assisted suicide may have exacerbated matters by fostering the beliefs that the experiences of the terminally ill patient are accessible only to the patient, that communication is impossible, and that any type of engagement with the patient is an unwanted obstruction to their autonomy. Motivated by an ethic of self-determination and patient autonomy, the current debate over physician-assisted suicide may have precluded authentic self-determination and the possibility for sharing experiences with another. The solution to this quandary will not be found in rights language but in an ethic of caring that seeks to keep the terminally ill part of our broader community, that struggles to find meaning in our shared fragility, and that acknowledges the vulnerability that accompanies any encounter with death.

References

4. 1996 WL 94848 9th Cir (Wash).