

# Looking Back at Withdrawal of Life-Support Law and Policy to See What Lies Ahead for Medical Aid-in-Dying

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Current efforts to legalize medical aid-in-dying in this country follow a half century of remarkable legal developments regarding when, how, and on whose terms to intervene to prevent death and extend life in critically and terminally ill patients. The starting point—which I call the first stage along the path—was the creation in the two decades following World War II of powerful means of keeping very ill, and typically unconscious, patients alive. The second stage began in the late 1960s as physicians (and then others in society) began to grapple with the consequences of maintaining such patients on life-support indefinitely. Over five decades, judicial decisions, followed by implementing statutes and regulations, transformed legal rights and medical practices. Are the current developments—which center on legalizing medical aid-in-dying—a third stage along the same path, or do the striking differences between the issues raised about life-sustaining treatment and euthanasia suggest that they are separate? What lessons might those proceeding along the aid-in-dying path take from the development of the other path, and if the two paths are still distinct today, might they merge in the future?

## INTRODUCTION

Sixty years ago, Yale professor Ed Lindblom famously described the process by which public policies are created as “the science of ‘muddling through’” [1]. His thesis, which was meant as a corrective for theories positing that policies typically change either on the basis of rational cost-benefit planning or when a new group takes control of government and implements radical changes, fits the policies examined in this essay, namely,

those on medical decision-making about patients at the end of life. Over the past half-century, the changes in this arena have been dramatic, but they have arrived in an incremental fashion and with support coming from different constituencies for sometimes inconsistent reasons, just as Lindblom would expect.

In this article, I want to examine what the future may bring, looking especially at some inadequately addressed issues regarding the law on what is commonly termed “the right to die.” This body of law comprises

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†Abbreviations: CPR, cardiopulmonary resuscitation; DNR, Do Not Resuscitate order; EEC, Euthanasia Educational Council; ICU, intensive care unit; PVS, persistent vegetative state.

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not only statutes (both those adopted by legislators and those approved through ballot initiatives) but also court rulings and regulations (both formal rules promulgated by government agencies and private rules developed by professional bodies, to which agents of the state acquiesce). Will current legal developments regarding medical euthanasia and aid-in-dying adhere to the oft-quoted dictum of Oliver Wendell Holmes, Jr., that “The life of the law has not been logic—it has been experience” [2]? I believe that “logic”—in the form of arguments for consistency and fairness, voiced both in the public arena and in judicial and regulatory policymaking—may be important in shaping policies, but that the use of logic in the judicial process, and even more so its influence on legislators and the public, depends on the ways in which “experience” is brought into the reasoning process. Therefore, I will begin by summarizing the first two stages of medical and legal developments regarding life-sustaining treatment and extract from this overview some “experiences” with implications for the future.<sup>1</sup>

## PERSONAL CONTROL OVER TREATMENT OR OVER DEATH?

### *Stage One: Death and Dying in the Mid-1960s*

While most public policies lack a clear “starting line”—arising as they do in response to social and technological changes that themselves evolve slowly—it happens that a report issued five decades ago by a committee at one of the nation’s leading medical schools provides a clear picture of the issues facing physicians just as policies about discontinuing life-sustaining treatment were beginning to change. The Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, chaired by Henry Knowles Beecher, MD, a renowned professor of research anesthesiology, is often mentioned in discussions of organ donation, where “brain death” looms large. But the committee was actually formed to address another, more urgent problem created by modern medicine. Beginning in the early 1950s, physicians developed techniques for cardiopulmonary resuscitation (CPR) and then established intensive care units (ICUs) where patients in need of respiratory support and cardiac monitoring could be cared for. While such efforts allowed some patients to recover and leave the hospital, many others ended up on ventilators indefinitely, thereby creating complex problems for medical personnel and families alike. At the time, the prevailing view in medical ethics was that, having begun such care, physicians were obligated to continue it as long as respiration and circulation could be supported. Furthermore, since discontinuing treatment would cause death, physicians believed that “pulling the plug” exposed them to a charge

of criminal homicide.<sup>2</sup> Yet the consequences of lengthy treatment could be hard on caregivers as well as on patients’ family members, who were faced not only with a drawn-out dying process but also with potentially huge hospital bills. And, as Dr. Beecher made clear, dedicating scarce beds in ICUs to patients who had no prospect of regaining consciousness, much less of returning to their prior level of functioning, precluded having space to treat new patients, some of whom could recover. The publication of the Beecher committee’s report in 1968 [3] turned out to be perfectly timed to provide a legitimate basis for declaring some artificially maintained patients to be dead on neurological grounds (despite their beating hearts) and hence eligible to be organ donors, coming as it did just months after the first successful human-to-human heart transplant, which occurred in South Africa on December 3, 1967. But of greater interest for the present topic, being able to declare artificially maintained patients dead provided the ethical and legal grounds for removing these patients (most of whom were actually not potential organ donors) from ventilators and other supportive interventions.

Still, the Beecher report did not provide a basis for discontinuing treatment for most “hopelessly unconscious” patients who were dependent on life-support but whose brain functions had not permanently ceased. Moreover, physicians in that era were not inclined to discontinue treatment. The roots of their reluctance lay both in attitudes inculcated during their training and in their pride in the seemingly miraculous powers at their disposal to keep alive patients who only a few years earlier would have been beyond rescue.<sup>3</sup> Beyond that, withdrawing care from dying patients—which at the time was still termed “passive euthanasia”—brought to mind the heinous behavior of their German counterparts during the Nazi era, who had participated in the “euthanasia” of millions of people, including mentally and physically disabled patients in hospitals, as well as Jews, “Gypsies,” and homosexuals in the concentration camps [4, at 797; 5].<sup>4</sup>

### *Stage Two: The Creation of Means to Effectuate Patients’ Wishes and Rights*

Yet, while physicians’ unwillingness to stop life-sustaining treatment may have aligned with the general “death-denying” ethos of the time [6], some members of the public (and a few physicians) had begun to express doubts about whether the flame was always worth the candle. For example, in 1967 Luis Kutner, a Chicago lawyer and human rights advocate (he had co-founded Amnesty International in 1961), created the “Living Will.” On its face, this document was not legally enforceable, since, at the time, the law did not allow a person

(called the “principal”) to issue instructions to another person (the “agent”) that would authorize the latter to act after the principal lost the ability to make decisions—including the ability to discharge the agent or to change the instructions. Instead of providing legally binding instructions, the Living Will was intended to reassure the family and physician that the signatory did not fear death and desired not to have the dying process prolonged by treatment. Living Wills were promoted by the Euthanasia Educational Council (EEC), which had been spun off in 1967 as a nonprofit organization by the Euthanasia Society of America, a body that had been formed to lobby for the adoption of laws to permit the ending of life “by painless means for the purpose of avoiding unnecessary suffering and under adequate safeguards,” as stated in its November 28, 1938, articles of incorporation. The Society previously had no success in changing laws in the US, possibly because its president favored legalizing non-voluntary euthanasia for persons “who are doomed to remain defective” [7]. Unfortunately for the EEC, the first attempt to make Living Wills legally enforceable came in the form of a Florida bill introduced in 1968 by Walter Sackett, MD, a state legislator. Rather than simply allowing individuals to exercise self-choice, the bill provided for removing care from “mentally retarded” patients in state hospitals, which Dr. Sackett estimated would save Florida \$5 billion over fifty years, just from letting “the state’s mongoloids . . . succumb to pneumonia” [8]. Once again, a utilitarian attitude and the echo of Nazi euthanasia doomed this “right to die” proposal.

Notwithstanding these complications, the question of whether or not life-support should be continued indefinitely when recovery is not expected gained added public prominence in the summer of 1975 when a dispute over the life-sustaining care of an unconscious 21-year-old woman, Karen Ann Quinlan, appeared on the front page of newspapers across the country. That April, she had attended a party where she consumed Valium along with alcohol; when her friends took her home, she lapsed into unconsciousness, and they rushed her to the hospital. There, she remained in a coma and was eventually diagnosed as being in a persistent vegetative state (PVS). About four months later, her family—after consulting with their parish priest—informed the physicians that they regarded her ventilator as an “extraordinary means” of keeping her alive and wanted it removed. The physicians were unwilling to take that step, not the least because they had been informed by the Morris County (NJ) prosecutors that if the patient died (as they expected she would) after the ventilator was removed, they would be prosecuted for criminal homicide. The Quinlans’ private sorrow became public when they petitioned a court to authorize the removal of their daughter’s life-support. The denouement came about a year later when, on March

31, 1976, the New Jersey Supreme Court granted their request, holding that the constitutionally protected “right to privacy,” which had been recognized in the context of contraception and abortion, was broad enough to encompass their request to remove Karen’s life support and allow her to die.<sup>5</sup> The New Jersey court did impose one important condition before the Quinlans’ instructions could be honored, namely, that the physicians’ diagnosis be confirmed by a hospital “ethics committee.” Hospitals across the country responded by appointing such bodies (typically consisting of physicians, nurses, a lawyer, a chaplain, and some lay persons drawn from the community), which were charged both with ensuring that decisions to forgo treatment are ethically grounded and follow proper procedures and with helping to resolve disagreements when they arise between (or within) the treatment team and the patient’s next of kin.

A second significant effect of the *Quinlan* case was to intensify legislative interest in living wills. Barry Keene, a young member of the California Assembly, had introduced a bill in 1974 to recognize people’s “right to die without prolongation of life by medical means.” As originally drafted, his “Natural Death Act” simply made living wills legally effective by removing the threat of civil or criminal liability for physicians who followed them. Yet during hearings on the bill concerns were raised by medical and religious groups about diagnostic errors and about patients “giving up” prematurely or making precipitous decisions upon learning of a dire condition. True to the “muddling through” model, the law that was adopted in 1976, shortly after the New Jersey court decision, seemed to reflect the “right to die” position, since it authorized physicians “to withhold or withdraw life-sustaining procedures in the event of a terminal condition,” while at the same time the statute’s definitions and procedures pointed to a narrower result [9]. First, a “life-sustaining procedure” was defined as any medical intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a *qualified patient*, would serve only to artificially prolong the moment of death and, where, in the judgment of the attending physician, death is *imminent whether or not such procedures are utilized* (emphasis added).

A “qualified patient” is one who has waited for 14 days after two physicians diagnose a “terminal condition” (one that is “incurable” and will produce death, and which life-sustaining procedures can merely postpone) before executing a “directive” to his or her physician. Taken literally, for a person to take advantage of the statute would require a miracle: a person who is imminently about to die despite medical interventions would have to still be alive and—despite the burdens of the illness and the means used to combat it—fully competent two weeks later, at which point he or she could execute a directive to

remove the interventions.<sup>6</sup>

More fundamentally, people are generally less concerned about withdrawing medical interventions when death will occur very soon despite treatment than they are about medical interventions being continued indefinitely without prospect of recovery. Finally, though the plight of Karen Quinlan stimulated the California law's adoption, Karen and comparable patients receiving life-sustaining treatment for a condition that arose suddenly would, ironically, not have been able to execute a binding directive to terminate that treatment. Despite its problems, the California act inspired other states to adopt similar statutes and, perhaps more important, reassured families and physicians that it was not just medically, morally, and legally acceptable to cease life-prolonging interventions but, in the absence of special, confounding factors, that one is obligated to follow the patient's wishes that this be done.

It soon became apparent, however, that most patients on life-support had not provided written instructions, leaving the next of kin having either to determine what the patient would have decided or, when information is insufficient for such a "substituted judgment," then deciding what course of action would be in the patient's "best interest." Several years later, a presidential bioethics commission recommended that states adopt "durable power of attorney for health care" statutes [10]. Durability in this context means that the powers given to the agent continue, or perhaps spring into being, when the principal becomes incapacitated, for example, as a result of a progressive illness or a sudden injury. The existence of a legally recognized document—in which a person can not only appoint an agent to make healthcare decisions but also provide instructions or general guidance about what the person would want done under various circumstances—removes some of the burden of decision from the shoulders of the attending physician and family member. It also allows people to specify whom among their relatives and friends they want to empower to make decisions on their behalf, rather than having this responsibility placed, by operation of the law, in the hands of their next of kin (which might be a group of people, all equally related to the patient but not always of the same mind about the right course of action).

The adoption of such statutes accelerated in the wake of the next high-profile "right to die" court decision, which involved the request of the parents of Nancy Cruzan, who had been unconscious in a hospital for five years following an automobile accident, to withdraw the feeding tube that was keeping her alive. In 1990, the US Supreme Court upheld Missouri's power (as articulated by the state's supreme court) to require that a surrogate decision maker's request to withdraw life-support be supported by "clear and convincing evidence" that such a step was what the patient would have chosen if competent

[11]. (On remand of the case to the state court, the Cruzans provided additional evidence to establish Nancy's wish not to be maintained under such circumstances, and the probate judge ruled that the feeding tube could be removed.) Although Missouri is one of the few states to require this higher level of proof of a patient's wishes (most follow the normal standard for civil cases, "preponderance of the evidence"), the drawn-out process, in the hospital and then in the courts, experienced by the Cruzans led to an upsurge in interest in filling out advance directives.<sup>7</sup> Also in 1990, Congress adopted the Patient Self-Determination Act, sponsored by Senator John Danforth of Missouri, which requires most hospitals, nursing homes, home health agencies, and health plans to provide patients an explanation of their rights under state law to make decisions about their health care, including the forgoing of life-sustaining treatment, to ask whether the patient has, or wishes to fill out, an advance directive, and if so to document that in the medical record.

### *What Can We Learn from Stage Two?*

Over the past fifty years, the developing law regarding life-sustaining treatment produced several major results and a host of smaller social as well as legal changes. In the initial struggle between professional authority (to insist on continuing treatment) and respect for persons, the law favored the latter. The ascendancy of this principle in the end-of-life context may not seem surprising, since during the early years of this period judges, legislators, and regulators were refining and enlarging the contours of the new concept of "informed consent" in medical care and research.<sup>8</sup> Yet cases like *Quinlan* and *Cruzan* made three distinctive contributions.

First, the cases made clear that informed consent encompasses the right to withhold as well as to give consent and that this extends to declining interventions that are capable of extending life. Second, the judicial rulings—as well as the statutes enacted to facilitate people's ability to achieve the autonomy over their own bodies that the judges had articulated—recognized that the right to control one's treatment remains even when a patient lacks the current ability to make such a choice. Indeed, even in *Cruzan*, which is often remembered for the evidentiary barrier it erected to exercising the right, the justices accepted as a starting point that competent patients have a constitutional as well as common law right to refuse life-sustaining treatment and that this right may be exercised on their behalf by surrogates. The third, related point that emerged from the cases is that "substituted judgment" (making the choice that the patient would have made) takes priority over decisions grounded in the "best interests" of the patient. This preference for letting a person determine what treatment they will or will not accept at a future time when they lack the ability to make



that decision seemed unexceptionable to the courts as it has to most advocates for patient rights as well, but it has drawn criticism from some academics, such as John Robertson and Rebecca Dresser, who have argued that a currently incapacitated patient differs in important ways from his or her former self, and that bodily continuity does not justify letting that former self override the best interests of the present patient when severe dementia has caused a break in personal identity [12,13].

The cases also established several less sweeping points that have shaped medical and legal thinking about allowing patients to die. The first concerns the relationship between withholding and withdrawing life-sustaining treatment. In the early years of the period some physicians accepted that patients could decline treatment (after all, the physicians were not prepared to go out and drag patients into the hospital) but they still insisted that once treatment had been commenced it could not be stopped if doing so would result in a patient's death. One of the early contributions of medical ethicists to the topic was to insist on the equivalence of the two acts; they pointed out that the contrary position could discourage physicians from embarking on a trial of therapy (which could save some lives) out of concern that they would be locked into continuing the treatment even if it did not achieve the aim that justified trying it in the first place [10].

A second thing that these cases generated in the medical and legal literature was the idea that the justification for refusing treatment might turn on its being "extraordinary." Physicians as well as laypeople had for some time described high-tech medicine in such terms, but the core concept is more ancient than that and quite unrelated to the level of technology employed. It came into the law in this field through *Quinlan* because it is a concept in Catholic doctrine, on which the Quinlans had been instructed by their parish priest. The church holds that a person's moral obligation to preserve his or her own life extends to the use of ordinary means while the use of extraordinary means is supererogatory. In this context "extraordinary" refers to acts that would impose a burden on the individual or on others that is excessive in light of the benefit that will be produced. Thus, if I suffer a simple broken leg which gets infected with a bacterium that could kill me before my leg mends, treatment with an antibiotic that will cure the infection is not extraordinary, even if the antibiotic is somewhat costly or has some unpleasant side-effects. But if I develop pneumonia when I am near death from painful, untreatable cancer, I may refuse even an inexpensive antibiotic that would cure my pneumonia because in this circumstance prolonging my life would impose a burden on me that is disproportionate to the benefit. No list exists of interventions that are always ordinary or always extraordinary. That judgment is contextual and ultimately subjective: Joseph Quinlan regarded

his daughter's feeding tube as ordinary care and insisted that it remain, while Joe Cruzan decided his daughter's should be disconnected because it did not provide a result that was beneficial to her.

A third factor involves a difference between the court cases, which were almost always brought by surrogates on behalf of incapacitated patients, and the statutes that authorized one form or another of advance directive. The cases typically arose when—often after months or even years of treatment—the family of a permanently unconscious patient had finally given up hope and asked the physicians to remove life-support. For them, the problem was not that the patient was near death but rather that the patient, as a person, had "died" long before, and they no longer believed that the patient's wishes or interests were being respected by the continuation of treatment. The "muddling" here involves how judges incrementally came to see a wider range of interventions as non-obligatory in such patients. In contrast, the muddling in statutes arose from legislative struggles between those who favored wide patient choice and those who believed that advance directives should apply only when patients are near death, such that further treatment can provide no actual benefit but will only prolong the dying process—or, as the California statute put it, prevent a "natural death." The subtext here—which I believe is important to note—is that courts are more likely to follow a principle (such as respect for persons) to its natural conclusion than are legislatures, where the tug and pull of opposing viewpoints may lead to the imposition of restrictions that are loosened or abandoned with time and experience.

The final effect worth noting reflects broader changes in relations between patients and physicians that is still occurring on account of the increased commercialism of medicine (patients as "consumers" making choices among healthcare "providers" who advertise, like any other merchant) and the decreased likelihood that people will be treated by the same physician over a long period. For example, the term "advance directive" is now commonplace but to an earlier generation, the notion of patients "directing" their physicians would have been as foreign as physicians giving patients "orders" was familiar [14]. Likewise, the change in attitudes toward the value of life-sustaining treatment has also affected physicians. The 1960s physician felt obligated by his commitment to preserving life to continue to treat as long as biological life could be sustained. Fifty years later, most physicians readily accept that there are many cases (such as patients in PVS or those suffering from incurable conditions) when the proper response is not to offer, and certainly not to insist on, ventilators, feeding tubes, or other interventions. Now, the positions have frequently flipped: a physician who is reluctant to continue life-support in a patient who is very unlikely to recover may find that the

patient's next of kin interpret "informed consent" to mean that they are entitled, on the patient's behalf, to "direct" the medical team to continue to provide such treatment. The judgment whether care in such circumstances is "futile" or "non-beneficial" is ultimately a subjective matter. Although one would expect that the patient (or family's) views should control this subjectivity, the situation has become so challenging for medical personnel that many states have laws that allow physicians to end the relationship and transfer the patient's care if another provider is willing to take the patient on, and if not, to withdraw the life-support. (Of course, a family may change its mind when it becomes apparent that no other physicians are willing to provide the requested interventions or when the medical team makes clear that it is not proposing to abandon the patient and will take all needed steps to keep the patient as comfortable as possible throughout the dying process.)

In sum, when it comes to care at the end of life, the world of 2020 looks markedly different than it did fifty years ago. Not only has the overhanging threat of criminal prosecution for treatment-cessation disappeared, but so has physicians' professional and psychological resistance to withdrawing life-support, which now takes place routinely and without controversy in hospitals across the country. Ethics committees (and now, ethics consultants) still provide advice, though in my experience they are seldom called because of an ethical dilemma presented by the act of forgoing life-support but are instead more likely to be involved in cases where miscommunication has occurred.<sup>9</sup>

### *Applying the Lessons from Stage Two to Medical Aid-in-Dying (and Euthanasia)*

Throughout much of the 20<sup>th</sup> century, advocates repeatedly tried to legalize medical euthanasia but failed to gain sufficient popular support to persuade lawmakers. Recently, however, the movement to allow physicians to utilize medical means to end patients' lives intentionally has succeeded in changing long-standing prohibitions, first in northern Europe and now elsewhere around the world, including in nine American jurisdictions.<sup>10</sup> The questions that interest me are, first, whether this set of developments should be viewed as the third stage in the process I've just described and, second, whether the effects and lessons we drew from those earlier developments have implications for the way the legalization of what US proponents term "medical aid-in-dying" will develop.

The recent changes take two forms. The first is physician-performed, voluntary, active euthanasia. Over a ten-year period beginning in 1973, courts in the Netherlands recognized a set of criteria, developed by a doctors' association, which, when followed, allowed physicians who administered lethal medications at the request of

patients with painful terminal conditions to avoid conviction for euthanasia. Upholding this practice in 1984, the supreme court left the criminal law on the books, meaning that each instance should (at least in theory) prompt an official investigation, but a physician who had complied with the criteria would not be prosecuted. In 2001, the Dutch parliament adopted a statute that formalized that practice [15]. A physician who properly reports a case of voluntary, active euthanasia carried out in compliance with a set of substantive and procedural criteria (*e.g.*, that a fully informed patient, with an incurable condition and unbearable suffering, has requested the physician's assistance in dying, that the physician consulted on the case with another physician, and that reasonable alternatives were absent) is not subject to prosecution.<sup>11</sup>

The second type of law grew out of the process by which existing prohibitions were overcome by right-to-die proponents in the United States. Following the 1984 Dutch court decision, supporters of legal change attempted to qualify a euthanasia initiative for the 1988 California ballot but failed to collect signatures from a sufficient number of voters. In 1991, an initiative to allow physicians to provide lethal injection to patients was placed on the ballot in Washington State, but was defeated by a margin of 54 to 46 percent. The following year, a similar proposal lost by the same margin in California. The proponents concluded that some voters had rejected these proposals because they feared that physicians might end patients' lives before the latter were truly ready for that to occur. Therefore, the Death with Dignity Act, which qualified for the November 1994 ballot in Oregon, was crafted more narrowly: under it physicians, rather than being authorized to give lethal injections, could only write prescriptions for lethal drugs, which patients would then self-administer [16]. The measure was approved 51 to 49 percent, but did not go into effect for several years.<sup>12</sup> This approach insulates a physician against a charge of "assisting suicide" for writing the prescription that enabled a patient to kill him or herself, provided the physician acted in accord with a set of criteria (*e.g.*, repeated voluntary requests for such aid-in-dying from a competent patient with a terminal condition, as confirmed by another physician), but unlike the law in the Netherlands and a number of other countries, a physician who directly administered the lethal medication could be convicted of homicide.

Viewed from a social perspective, the legalization of medical euthanasia and aid-in-dying seems like the latest step along the path that was sketched above. But from a legal and ethical perspective, the changes occurring now seem so different from the existing path as to be discontinuous. A review of five of the major characteristics of the End of Life Option Act (AB 15) that was approved by California voters in November 2015 (which is modeled on the Oregon law), shows how aid-in-dying is funda-

mentally dissimilar to earlier legal developments.

First, earlier court decisions and statutes were in the mainstream of the general law applicable to medical practice. They reflect the law's increasing recognition over the past fifty years of patients' right to be informed decision-makers about whether to accept or decline medical interventions. In contrast, AB 15 is embedded in the criminal law. It not only provides specific exceptions to the criminal prohibition on assisting suicide but actually creates a raft of new crimes to deter physicians and families from overreaching.

Second, such laws burden the physician-patient relationship with a great deal of paperwork and reporting requirements that go hand-in-hand with the criminal law framework. These requirements have no counterpart in the treatment-termination context. The requirements may well be necessary, but the notable difference from ordinary medical practice may contribute to some physicians' discomfort with becoming involved.

Third, AB 15 is built on making a distinction between action and inaction resulting in death, while the judicial decisions on treatment termination replaced that distinction with an ethical (and legal) analysis based on physicians' duty to act or to forgo acting. To illustrate this point, consider three patients: the first dies when he receives a powerful anti-cancer drug that his oncologist erroneously prescribed at ten times the proper dosage; the second suffers an unexpected but reversible cardiac arrest during surgery and dies when the surgeon fails to attempt CPR; and the third, who has agreed to a Do Not Resuscitate (DNR) order because he is already very sick, dies from a reversible cardiac arrest when CPR is not attempted. In all three cases, current ethical and legal analysis holds that the deaths are causally related to the something that the physician did or failed to do. Since the cardiac arrests were reversible, it would be stipulated that multiple causes—some "natural" and some under human control—contributed to the patients' death. Nor would the analysis turn on action versus inaction. In the first two cases, the physicians are culpable for the deaths, one for a wrongful act and the other for a wrongful omission. No wrong occurred in the third case even though that death resulted from the same inaction as in the second case (the withholding of a medical intervention of known value), since that physician was under no duty to act to reverse the cardiac arrest.<sup>13</sup>

In contrast, AB 15 is premised on a purported difference between giving a patient a lethal injection (which is prohibited) and giving a patient a prescription for lethal medication but not administering it (which is permitted). The distinction can be described in terms of action: in the first situation, an action by the physician—administering the lethal medication—directly results in the patient's death, while in the second, inaction by the physician—

refraining from administering the lethal medication—is followed by the patient's death. Or the difference can be described in causal terms: in the first case, the injection directly causes death, while in the second prescribing the drug is not the immediate cause of the death. Yet clearly, in the second as well as the first situation, the patient died because of what the physician did.

The fourth difference between aid-in-dying and the earlier legal developments is even more striking: AB 15 requires the patient to have decision-making capacity when the request for the physician's aid is made. Yet the central feature of the second stage in the development of the law on death was giving power to surrogates to act on behalf of persons who had lost mental capacity. First, cases such as *Quinlan* and *Cruzan* recognized each person's right to have treatment ended even though the person is no longer able to voice that command. Second, advance directive statutes provide a means to exercise that authority by designating the future circumstances when a person would not want life to be prolonged by medical interventions. The limitation in AB 15 to persons who are currently competent is curious when one considers that in public discussions of the need for aid-in-dying legislation, some of the most heartfelt pleas for their adoption come from people who have, or who worry about developing, degenerative neurological conditions, such as Alzheimer's Disease.<sup>14</sup> Yet, by the time such patients' condition becomes "terminal" they would almost certainly not meet AB 15's competence requirement.

The requirement that to qualify for aid-in-dying a patient must have a terminal condition is the fifth significant distinction from existing law on dying involving patients who refuse to allow life-support to be begun or continued. Understandably, physicians often initially resist a patient's wish to forgo treatment if the patient could survive for a considerable time with manageable burdens or disabilities (which could be mitigated with palliative care); further, they typically bring in a consultant to verify mental capacity and to rule out depression. But in the end most physicians today accept that decisions about using medical means to prolong life belong to the patient. Similarly, although the first legislation on living wills, such as California's 1976 act, was framed around "imminent death," modern advance directive laws are not. For example, California's current durable power of attorney law, adopted in 1999, allows a person to specify that the agent should not prolong life not only in the case of "an incurable and irreversible condition that will result in . . . death within a relatively short time" but also when it is reasonably certain that the person "will not regain consciousness" or when "the likely risks and burdens of treatment would outweigh the expected benefits" (with no requirement that death would otherwise occur within a specified time) [17]. In contrast, AB 15 requires that

patients provided aid-in-dying must have a prognosis of death within six months, confirmed by a second physician. In countries that allow euthanasia, physicians are also required to determine that no reasonable alternative treatment is available and that the patient experiences unbearable suffering, though analysis of Dutch records reveals that even in cases where alternative treatments have not been tried (about 35 percent of cases), physicians do not count them as “reasonable” if they are rejected by the patient, and suffering is not limited to physical pain but is taken to include the psychological distress patients feel about their quality of life [18].

## THE OUTLOOK FOR LAW ON MEDICAL AID-IN-DYING

The future shape of medical aid-in-dying and euthanasia may turn on one more difference that I chose not to include in the preceding catalogue of differences, even though it is arguably the most significant, because the very claim that such a difference exists depends upon how one understands what the second stage was all about. We can see, over those fifty years, the meaning of “patient self-determination” being worked out in the context of life-sustaining treatment. But should the result be described as respecting competent persons’ decisions about what medical care they will accept even when doing so will cause their death? Or should it be described as allowing patients to decide whether life is worth preserving and to determine the time and circumstances of their death?

Proponents of aid-in-dying favor the latter view, which would place this new area of law into continuity with the previous two stages. The difficulty with this interpretation is that logically it seems like a basic right of all persons, not to be limited to patients with terminal illness. Indeed, in the Netherlands one sees that logic playing out, as some non-terminal patients have received euthanasia by convincing a physician that a non-medical problem has made their lives not worth living; likewise, the statute adopted in 2002 in Belgium includes special consultation for patients who are not terminally ill [19].

Over time, the same may occur in the US because if the underlying principle is the primacy of personal choice, then it may be hard for courts to uphold the rather arbitrary distinction between persons with a six-month prognosis of death and those with marginally, or even substantially, longer life-expectancy. In states where aid-in-dying has been legal for a while, the persons who use it are generally not motivated by a desire to escape irremediable pain, even though that is often thought to be the major reason to legalize aid-in-dying, as reflected in Governor Brown’s signing message for AB 15 [20]. Rather, the few patients who avail themselves of the option mostly wish to avoid the indignities experienced in

the dying process or, more broadly, to extend the control they have had over their lives into the choice of how they will die. Judges in such a state might well conclude that limiting this benefit only to patients with a limited life expectancy discriminates unfairly against others who lack a terminal diagnosis but have equally strong reasons to exercise control over the time and manner of their death.

Of course, courts are usually deferential to the distinctions that legislatures draw. Back in 1997, when aid-in-dying was still a hypothetical in this country, having not yet been implemented in any US jurisdiction, the Supreme Court rejected an attempt to establish it on constitutional grounds. The plaintiffs had contended that since New York allows physicians to cause death by removing patients’ life-support, the state was violating the equal protection clause by depriving patients who are not dependent on life-support of the right to die by having physicians provide them with a prescription for a lethal medication [21].

Would a similar decision be rendered today if the plaintiffs were people without a terminal illness who argued that they should have an equal right to the law’s protection of medical aid-in-dying? Were the state to defend its law on the ground that terminal patients are distinct group, a court could well ask, how are they different? Is it that their terminal condition has made their impending death the central fact of their lives, which we acknowledge by providing them some measure of control over that reality? Or is it that lives that are so near death are not valued in the same way as others, so the law can be more relaxed in how it protects them? In honesty, we must acknowledge that both phenomena exist. On the one hand, Brittany Maynard, a 29-year-old California woman with an incurable brain tumor gained wide public support in her campaign to legalize medical aid-in-dying in California, as well as sympathy when she availed herself of the law in Oregon, where she ended her life on Nov. 1, 2014. On the other hand, when patients are near death, legal requirements meant to protect them are frequently disregarded. For example, data from Oregon reveal that the challenges that physicians face in diagnosing depression in terminally ill patients result in patients with depression requesting, receiving, and using lethal medications, despite the supposed prohibition on individuals with depression availing themselves of medical aid-in-dying [22]. Further, this problem is not limited to patients near death, as many people with mental and physical disabilities lack adequate access to needed health services and have higher rates of premature death [23].

Another major Equal Protection challenge may be raised to the distinctive feature of the US aid-in-dying statutes: the requirement that the final act of taking the lethal medicine be undertaken by the patient alone. Why are people who are mentally capable of requesting a pre-



scription but physically incapable of taking the prescribed medication deprived of the control over their dying process that the statute gives to otherwise similar people who have the ability to lift a glass of water and put pills in their mouth? This “muddled” rule reflects its history: the drafters followed a strategy of placating “right-to-die” proponents while reassuring skeptics who feared the law could devolve into involuntary euthanasia. Yet separating prescription from administration leaves a physician able to ensure that a patient’s request is competent, knowing, and voluntary at the moment when the patient makes it and the physician writes the prescription. But physicians typically are not present when the medication is actually taken, nor does some other third party monitor the patient’s capacity or voluntariness at that point. Thus, might a court ruling on a request from patients with physical limitations to be allowed to rely on another person to place the pills in their mouth or assist them in getting water to wash them down conclude that the risk of abuse or error in this situation is no greater than what can occur in the regime that the legislature found satisfactory, in which patients may not be acting competently or voluntarily at the moment when the lethal medication is taken?

### CONCLUSION: SEPARATE PATHS, CAPABLE OF MERGING

The first fifty years of developing law on life-sustaining treatment suggests that Holmes’ dichotomy between “logic” and “experience” is misleading. Holmes’ point was that the common law was built out of what had occurred in the disputes judges were called upon to resolve. When we claim that the law embodies certain principles we are actually describing rules that judges have created using the litigants’ experiences, not the sorts of “first principles” from which rules are derived in a logical process. In this way, judges—like legislators and regulators—are “muddling through,” seeking to use past experiences to resolve present disputes by adjusting the law incrementally and in response to competing constituencies. Yet, more than other actors in the policymaking process, judges are expected to provide logical explanations for their rulings. And they do, but again, this involves not logic *rather than* experience but logic *and* experience because they are selecting among all the possible experiences of individuals and groups, as well as all the disparate ideas circulating in relevant fields (*e.g.*, the equivalency of withholding and withdrawing a medical intervention; the meaning of “extraordinary means”; etc.), when they populate their syllogisms and analogies with the ideas they find most salient and congenial.

As we look ahead to the probable legal developments regarding medical aid-in-dying and euthanasia, there are two more lessons to learn from the way the law on

end-of-life care transitioned from stage one (the status quo that remained in place through the 1960s) through the fifty years of stage two. The first is that judges led the way in developing law on the treatment of patients on life-support, and legislation followed, implementing and regularizing the rights and duties identified in the landmark judicial decisions. Judges took in ideas from ethicists and theologians and experiences from doctors, nurses, and patients, and their holdings evolved (*e.g.*, to allow a wider range of medical interventions to be treated as non-obligatory). The current process of developing law on medical aid-in-dying and euthanasia also began in the courts, in the Netherlands, in the US, and elsewhere, but the judicial task was a very different one: not to resolve a dispute between private parties but to define the proper scope of state power to control (through the criminal law) the actions of private parties. So, the experiences that the litigants brought to each case were influential in shaping the law, but the constitutional framework of government supplied “principles” of a sort that are absent in common law cases, although the actual content of those principles—equal protection, due process, the protection of life—are also built from the facts of the cases in which they have been previously applied.

In my view, the development of law on medical aid-in-dying is now proceeding along a different path than the one that ran from the first to the second stage of law on forgoing life-support, separated by the stark differences described above. Their future direction cannot be precisely predicted because they are the sorts of paths that people create over time as they walk through an open field, not the sort that have been laid out in paving stones in a city park. Moreover, the people walking along these two paths can take note of what those on the other are doing and may alter their course—to be nearer to or further away—based on what they see. From the newer path, one can notice that actions along the other that once were regarded as aberrant—such as stopping treatment of a patient before trying every experimental therapy—are now treated as a choice that the patient can make without setting off alarms. They might also notice that doctors and nurses are capable of treating similar patients very differently—vigorously pursuing every possible chance for a cure or forgoing basic tube-feeding—without being morally paralyzed by this contradiction. Conversely, on the older path doubts might arise about surrogate decision-making in treatment termination cases when, in a jurisdiction that allows medical euthanasia, physicians may invoke an advance directive to take the life of incompetent patients who have not reaffirmed the wish to die and who must be physically restrained in order to administer the lethal medication [24]. And, as they proceed—either along their two paths or on some combined path—the physicians, nurses, hospital administrators, legislators,

judges, and lawyers on both paths may wonder whether they are muddling through or are merely in a muddle.

## ENDNOTES

1 Although I find merit in some of the objections usually raised about euthanasia and aid-in-dying—namely, that these practices may decrease the use of palliative care, push vulnerable patients to early deaths, and diminish the sanctity of life, with deleterious effects on the physician-patient relationship [25, 26, 27, 28]—those are not the focus of this paper.

2 Dr. Beecher himself held that view and had, at a symposium in November 1967, quoted Berkeley law professor David Louisell to the effect that a physician could be charged with homicide if an action he takes “causes death” in a patient who still has a heartbeat [29, quoting 30, at 91-92]. Beecher also worried that if the relatives of patients whose death followed removal from the respirator were ever successful in a civil case against the medical team, “[d]octors will fear to use their best judgment” and the “numbers of irretrievably injured and unconscious” patients will increase, thus preventing the admission to the hospital of patients in need of care for other conditions [29, at 1429].

3 The prevailing view in the medical profession was that, “Failure to provide some minimal level of care, even to a permanently unconscious patient, might undermine [the public’s] trust and with it the health care professions’ general capacity to provide effective care. Furthermore, the self-identity of physicians, nurses, and other personnel is bound in significant ways to the life-saving efforts they make; to fail to do so is felt by some to violate their professional creed” [10, at 183].

4 During the 1976 Hastings Center symposium on the shadow that Nazi doctors’ actions cast over subsequent medical practice and research, Laurence McCullough observed: One of the reasons that the Nazi experience haunts our contemporary decisions is the feeling that German society somehow got on a slippery slope, and that recalling that experience may help us avoid such a problem in our own case. When we were talking about euthanasia and the arguments of some people that the Nazi experience indicates where euthanasia leads, Mrs. Dawidowicz rightly pointed out that the Nazis’ euthanasia was not euthanasia as we might use the term. . . . Our slippery slope might yet be analogous to Nazi Germany’s in a more abstract way. If we consider the rationale which gives social utility or economic returns precedence over individual freedom, then we might see how our society could approach the kind of thinking that underlay the Nazi experience [5, at 15].

5 Some of the neurologists who examined Karen Ann Quinlan, including Dr. Fred Plum, who was central in defining the new condition that came to be known as PVS, were not convinced that she would be unable to breathe on her own after the ventilator was turned off. And indeed she did continue and lived another decade. Yet some years later when her father, Joseph Quinlan was asked whether he planned to have the feeding tube removed, since he was prepared to let her die by having the ventilator withdraw, he replied, “Oh, no, that’s her nourishment.”

6 One would think that, at the very least, the survival of such a patient for 14 days would cast serious doubt on the original prognosis that death was “imminent” (a term the Natural Death Act did not define, but which usually means “about to happen” or “happening before anything else”).

7 For example, the Society for the Right to Die (the then-current name of the Euthanasia Society of America) received 300,000 requests for advance directive forms in the month following the *Cruzan* decision [31].

8 The term “informed consent” first appeared in *Salgo v. Leland Stanford Jr. Univ. Bd. Trustees* [32], though the prohibition on operating without a patient’s permission was well established in earlier

decisions, *see, e.g.*, *Schloendorff v. Society of New York Hospital* [33]. 9 It is not unusual for families to misunderstand one or another of the medical specialists called in to consult on a hospitalized patient. For example, the family at the bedside of an unconscious patient with incurable brain cancer asks the nephrologist when she comes to check on the patient, “How is he doing?” The nephrologist, pleased to see that the patient’s kidneys are still functioning, replies, “Everything’s fine.” The nephrologist may be thinking, “I don’t have to worry about this patient because he’ll have normal kidney function when he dies in a day or two,” but the family hears, “the patient is doing well.” Not surprisingly, if the attending physician suggests that it is time to withdraw life support, the family is shocked and resists, which leads the attending to think the family is in denial about the cancer or does not have the patient’s interest foremost in their thinking. The resulting stand-off is really a problem of communication, not ethics, but it often falls to the ethics committee to sort it out.

10 As of August 2019, physician aid-in-dying has been legalized by statute in California, Colorado, the District of Columbia, Maine, New Jersey, Oregon, Vermont, and Washington, and by judicial decision in Montana.

11 As John Keown notes [34], commentators generally agree that despite government claims that the guidelines developed by the medical association and applied by the courts prior to 2001 were strictly enforced, in fact every guideline was routinely violated and physicians were not punished even in cases where none of the guidelines had been followed (pp.144-56). Interestingly, the Dutch government describes the 2001 statute as using “open concepts” to allow the regional committees charged with reviewing physicians’ reports of euthanasia cases to have scope for the “developing views within society” (p. 161). The intentional imprecision of such concepts as “unbearable suffering” and “no reasonable alternative” allow the muddling through towards a socially acceptable position to be done in the relatively low-profile setting of the committees, whose 2015 “Code of Practice” continues to emphasize subjective judgment and to withhold measurable requirements (pp. 157-71).

12 The statute was first challenged by a national right-to-life group on equal protection grounds, but in 1997 the state prevailed in the Ninth Circuit court of appeals. A measure on the November 1997 ballot to repeal the act was then rejected (60 to 40 percent) by the voters. In November 2001, U.S. Attorney General John Ashcroft asserted his authority under the Controlled Substances Act to punish Oregon physicians who prescribed medications for aid-in-dying; his order was enjoined by lower federal courts, and in January 2006, the Supreme Court held that federal law did not give the attorney general the authority he had claimed.

13 Early in the second stage, when some physicians were still clinging to the felt difference between withholding and withdrawing life-sustaining treatment, the possibility was raised that ICUs could have timers that would turn each patient’s mechanical support off at a set time each day; if it had been decided that further treatment was inappropriate, the physicians could simply not turn the equipment back on and the cause of death would not be any human “action.” But it was obvious that the purported distinction in this hypothetical remained totally artificial, and further the failure to turn on the ventilator for a patient who was expected to recover would not be excused even though it too resulted from an inaction.

14 After being diagnosed with early Alzheimer’s dementia in 1989, Janet Adkins, then a 53-year-old resident of Portland, Oregon, became an outspoken advocate for physician aid-in-dying. Concerned about losing her capacity to act, she went to Michigan a year later where she became the first person to die by use of the “suicide machine” created by Dr. Jack Kevorkian. As he later recounted, he explained to her how the process would—and did—work: after she laid down on a cot in a VW van in which he had installed his device, he would insert a line into a vein in her arm, so that when she pushed a button, drugs would enter that line, rendering her unconscious and then stopping her heart, and she would die [35].

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