

Shai Lavi

## *How dying became a 'life crisis'*

The controversy over euthanasia is one indication of America's fascination with biopolitical issues at the intersection of life and death.<sup>1</sup> Most states prohibit physicians from actively assisting patients to hasten death, but recognize a patient's right to withdraw unwanted life-support machinery ('passive euthanasia'). Currently, Oregon is the only state that deviates from this standard: under its 1995 Death with Dignity Act, physicians may prescribe lethal medication to patients for self-administration ('physician-assisted suicide'), but may not inject the lethal dose themselves ('active euthanasia').

Legal regulation notwithstanding, euthanasia continues to stir public debate. The recent case of Terry Schiavo reminded us that despite clear-cut legal resolutions, public opinion may still express unease with even the mild form of passive euthanasia. At the same time, the

not-too-distant publicity surrounding Dr. Kevorkian, the Michigan pathologist who offered death to his patients, revealed that even a convicted felon can attract public sympathy.

Like the controversy over abortion, the euthanasia debate is conceptualized as a conflict between the sanctity of life and freedom of choice. Proponents of euthanasia fight for the 'right to die' in the name of patient autonomy, while opponents of euthanasia claim that freedom has its limits, and that other values, primarily the 'sanctity of life,' must trump individual rights. This conflict commonly boils down to where precisely one draws the line on the euthanasia spectrum: between active euthanasia, on the one side, and the continuation of medical treatment in all but futile cases, on the other.

This framework reflects a relatively recent, post-World War II mindset and ignores the roots of the euthanasia debate that date back to the nineteenth century. Too much reflection has been devoted to justifying different positions within the debate, and too little to figuring out why euthanasia became such a hotly debated issue to begin with. The

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<sup>1</sup> To S. H. The author would like to thank Joshua Price for his insightful comments.

response – too readily available – that euthanasia is a logical, if highly controversial, solution to the contemporary problem of dying is hardly satisfying. It merely gives rise to another question: why and how did dying become such a problem for us?

We can trace the modern crisis of dying to a cultural transformation that predates both the medical and legal advancements of the twentieth century<sup>2</sup>: the medicalization of the deathbed. Associated with this phenomenon are the hastening of death and the prolongation of life. Both reflect a new way of experiencing dying and a new will to master death, shared by physician and patient. Thus, the question of freedom at the deathbed is not about how much or how little choice the terminal patient has, but rather how dying became a matter of choice in the first place.

Put differently, if euthanasia reflects a crisis in dying, it is because the framework in which euthanasia and other end-of-life choices are made has not enhanced the patient's freedom, but rather has undermined a more fundamental sense of freedom, which has little to do with the notion of having options. The following case offers a glimpse into the predicament facing the dying patient today.

While in her early fifties, Sandra, an art historian, began complaining of

headaches, sudden memory lapses, and visual impairment. A family physician referred her to a neurologist who suspected a brain tumor, which the CT and MRI scans confirmed. She had *glioblastoma multiforma* (GBM), a common and highly aggressive type of brain cancer that has no known cure. Her tumor – “the cypress growing in my head,” as she called it, alluding to one of Erich Kästner's children stories – was already five millimeters long and classified as grade 4, the most abnormal and hardest cancer to treat. All that the medical statistics could offer her was three months.

Within a week, Sandra was no longer able to walk on her own and became dependent on her only child, some friends, and paid help. Her doctors ruled out surgery since the tumor was located between the two hemispheres of her brain. They recommended a combination of radiation and chemotherapy instead. The physicians explained that the treatment would slow down the tumor's development and triple her life expectancy.

For a while she played with the idea of letting go, refusing any treatment that would prolong her dying without having any curative value. Underlying this wish was a detectable sense of cold rage against the medical establishment, which could not offer any real cure but still insisted on putting her through the medical ordeal.

Her son searched the Web for second opinions and found a physician in Texas who was willing to perform the surgery despite the high risk. In the meantime, a close friend introduced her to a survivor who was still alive and active eight years after being diagnosed with a similar type of brain cancer. He introduced her to an unconventional treatment, preached the power of mind over body, and recommended a diet of weeds. She ended up accepting the radiology and chemother-

2 Several studies of the history of euthanasia have appeared recently: Ian Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America* (New York: Oxford University Press, 2003); N. D. A. Kemp, *Merciful Release: The History of the British Euthanasia Movement* (New York: Manchester University Press, 2002); Shai Lavi, *The Modern Art of Dying: A History of Euthanasia in the United States* (Princeton, N.J.: Princeton University Press, 2005).

apy not so much because she trusted the conventional doctors as much as she did not have the energy to fight them.

In the coming months, her life would be 'saved' once and again on a weekly basis. After radiology and chemotherapy had their turn, she underwent a newly licensed immunological treatment, accompanied by homeopathic treatment aimed at strengthening her immune system. Her physical condition fluctuated, at times allowing her to resume certain of her previous activities and even begin a new writing project. On other days, she suffered from terrible headaches, seizures, and some known medical complications such as thrombosis, which completely debilitated her.

Most of the time, she set her mind on coping with daily life: adhering to the strict schedule of radiology, chemotherapy, medication, and physiotherapy, while maintaining some kind of 'normal' life to distract herself from all of the above. But talk about a 'final exit' was there from the beginning and resurfaced every time it seemed like conventional medicine had nothing more to offer. With the help of a lawyer, she drafted a living will in which she requested to be disconnected from life-support machinery if she entered a persistent vegetative state. To her closest friends, she lamented not living in Oregon or, even better, in the Netherlands, where physician-assisted suicide is legal. Not that she would actually kill herself, but some comfort lay in knowing she had a last resort.

Sandra's story is not exceptional. It includes the basic components of the crisis facing mid-life terminal patients,<sup>3</sup> and

3 For other accounts of a medicalized death, see Sharon Kaufman, *And a Time to Die: How American Hospitals Shape the End of Life* (New

demonstrates how euthanasia may present itself as a way of dying. Her story allows us to examine critically the most common explanation of the modern crisis of dying and to achieve a new understanding of the emergence of euthanasia as its solution.

The most popular account of the modern crisis of dying places its origin in the latter half of the twentieth century, when the capacity of medicine to prolong life expanded dramatically. Chronic diseases (e.g., cancer, heart disease, and Alzheimer's) replaced the acute ailments of the nineteenth century (e.g., pneumonia, influenza, and other plagues) as the main causes of death. The growing use of antibiotics, surgery, and other technological advances, including life-sustaining machinery, had transformed mortality statistics. But extending life had the unintended but inevitable consequence of prolonging dying and suffering.

Meanwhile, according to the familiar story, the professional ambition of doctors to employ advanced medical treatment began to override the immediate interests of the dying patient. Many physicians considered the death of a patient to be a failure and launched battles on all medical fronts against an invincible enemy. A cultural and psychological denial of death augmented this phenomenon. A doctor would not even tell a patient that she was dying, a vow of secrecy shared by the patient's family and friends.

All of this allegedly changed in the 1960s, with the rise of patient rights, and in the 1970s, with the public discussion of the right to die. Euthanasia was understood to be a response to the growing intrusiveness of medical treatment

York: Scribner, 2005); Marilyn Webb, *The Good Death: The New American Search to Reshape the End of Life* (New York: Bantam Books, 1997).

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in the imperious setting of the modern hospital. The struggle for a right to die was seen as a challenge to the medical profession's monopoly over the treatment of the dying, and a transfer of power from physician and family to the dying patient herself. Euthanasia, in other words, empowered dying patients and offered them an alternative to the medical dictum to prolong life indefinitely. They could now decide to fight death or to embrace it.

The growing recognition of a right to die also attested to the decline in the taboo surrounding death. Today, the dying patient must be informed of his medical condition, and he must express prior consent to treatment. For proponents of euthanasia, the second half of the twentieth century stands for the triumph of human choice over the domination of medical technology and conservative values. For its opponents, the rise of euthanasia marks the degradation of traditional values and the dangers of freedom run amok. Both sides agree that the hastening of death and the right to die stand in opposition to prolonging life and valuing its sacredness.

Sandra's story, however, reveals that the desire for euthanasia does not necessarily emerge as a reaction to the medical prolongation of life. Euthanasia, for her, is not a solution to an overly medicalized death, but another medicalized way to face death. Along with the decisions to undergo intrusive medical care or to withhold medical treatment, and to follow the advice of mainstream doctors or that of alternative medicine, she juggles in her mind the possibilities of fighting death or shortening life. These should be seen as different tactics in one overall scheme, best described as the wish of the modern patient, with the aid of the medical profession, to master the time and manner of death.

The underlying crisis that Sandra is facing has little to do with lack of choice. Her predicament stems from the unresolved tension between the medical efforts directed at achieving greater control over dying, whether through treatment or euthanasia, and the inherent futility of this effort. The history of euthanasia may help further illuminate how the modern wish to master death stems from, and in the final analysis leads to, a fundamental attunement of helpless rage.

Common perceptions notwithstanding, euthanasia is not a late-twentieth-century response to the intrusiveness of earlier medical interventions. The first euthanasia debate in the United States took place in the 1870s and preceded both the technological and legal developments so commonly associated with it. In 1870, Samuel D. Williams, a British businessman, made this proposition:

In all cases of hopeless and painful illness it should be the recognized duty of the medical attendant, whenever so desired by the patient, to administer chloroform – or such other anaesthetic as may be and by supersede chloroform – so as to destroy consciousness at once, and put the sufferer to a quick and painless death; all needful precautions being adopted to prevent any possible abuse of such duty; and means being taken to establish beyond the possibility of doubt or question that the remedy was applied at the express wish of the patient.<sup>4</sup>

Following his proposal, Iowa and Ohio made the first attempts to legalize euthanasia in 1906.<sup>5</sup> This was a time when

4 Quoted in Charles B. Williams, "Euthanasia," *Medical Record* 70 (1894).

5 Lavi, *The Modern Art of Dying*, 93–95. For a somewhat different approach, see Jacob M.

most Americans still died a death unmediated by medical technology at home and were little concerned with the issue of patient rights. Still, these early proposals share with many contemporary proposals, if not the letter of the law, then its spirit.

To understand why the euthanasia debate emerged as early as the 1870s, we must first recognize the medicalization of dying as a cultural rather than technological transformation. This process evolved during the mid-nineteenth century. The most apparent manifestation of the medicalization of death took place when the doctor replaced the priest as master of ceremonies. Prior to the medicalization of death, it was common for doctors to withdraw their care from an incurable patient, leaving the dying in the trustworthy hands of the attending family, friends, and clergy. Many physicians held to the simple belief that if they could do nothing to cure the patient, they had no reason to stay at the bedside. Thus, they would willingly step aside to allow the performance of deathbed rites.<sup>6</sup>

By the mid-nineteenth century, this widespread practice of abandoning the deathbed of an incurable patient had become unacceptable. One might hypothesize that the growing presence of the physician at the deathbed was a consequence of developments in medical technology and in the capability of physicians to cure acute illnesses. This hypothesis loses its explanatory force once

we recall that nineteenth-century medicine had made no real progress in its capacity to treat the dying patient. With the exception of the replacement of opium with its alkaloid, morphine, in the second half of the nineteenth century, the ability of the medical profession to treat terminal patients was no different during most of the nineteenth century than it had been during the previous century. Not until far into the twentieth century did radical changes take place in medicine's power to relieve pain and prolong life.<sup>7</sup>

What then was the source of this new professional calling that hailed the doctor to the deathbed? What could the physician possibly offer to a patient whose condition was by definition helpless? It is this paradox – the duty to provide care in the absence of any possible cure – that gradually began to dominate the medical treatment of the dying patient in the nineteenth century and continues to do so today. Physicians at the time began to believe that irrespective of their power to cure or to alleviate suffering, they had a responsibility to hold out some, even if very limited, course of action to the dying patient, to help her overcome a sense of helplessness. At times, this responsibility was more important than any particular medicine that the physician could supply the patient. This was especially true at the deathbed, when no real cure could be offered, only a promise of hope stemming from a modern rage against the perceived impotency of dying.

Early attempts to codify professional medical ethics heralded this new duty of the medical profession. Thomas Percival, one of the first medical ethicists in the early nineteenth century, declared

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Appel, "A Duty to Kill? A Duty to Die? Rethinking the Euthanasia Controversy of 1906," *Bulletin of the History of Medicine* 78 (2004): 610–634.

6 Shai Lavi, "Euthanasia and the Changing Laws of the Deathbed: A Study in Historical Jurisprudence," *Theoretical Inquiries in Law* 4 (2) (2003): 729–761.

7 See, for example, Sherwin B. Nuland, *How We Die: Reflections on Life's Final Chapter* (New York: A. A. Knopf, 1996).

it the responsibility of the physician to “minister hope and comfort” to the dying. Another such etiquette read: “Let me here exhort you against the custom of some physicians, who leave their patients when their life is despaired of, and when it is no longer decent to put them to further expense . . . . Even in cases where his skill as a physician can be of no further avail, his presence and assistance as a friend may be agreeable and useful both to the patient and to his nearest relations.”<sup>8</sup>

The new disposition of hope was more than a mere psychological state or attitude of physician and patient; it colored the entire regime of caring for the dying. This modern sensibility replaced the older ‘hope’ that characterized the traditional deathbed: the Christian belief in redemption, which had prevailed in earlier American *ars moriendi*.<sup>9</sup> In fact, under the new regime, the old ministers of hope, as harbingers of death, were kept away from the deathbed. But as modern medicine clearly could not offer the promise of an otherworldly salvation, physicians opted for a more tangible and limited hope: not the promise of a world to come, but a this-worldly guarantee that as long as life persisted, something could always be done for the dying patient.<sup>10</sup>

The turn to worldly hope did not resolve the paradox facing the medical doctor, but rather encapsulated it. Modern medicine found itself in the impos-

sible position of simultaneously offering the verdict of hopelessness and the promise of hope. Both the modern physician and patient were caught between the fatality of the prognosis, knowing that nothing could prevent the approaching death, and the wish never to stop pursuing some course of action. The option ‘simply’ to await death gradually became unthinkable.

The history of the nineteenth-century medicalization of the deathbed can be told by pointing to different variations on this desire for hope in the face of hopelessness. This disposition gave rise to a variety of medical protocols for treating the dying, and it is in this context that euthanasia, too, emerged.

‘Heroic medicine’ offered one kind of hope.<sup>11</sup> This school of medical practice was founded in the late eighteenth century, and was associated in America with the work of Benjamin Rush. Rush believed in the power of medicine to cure patients even in the most critical conditions. Rush and his followers held out the hope of full recovery, and its efficacy depended on the use of extreme and dangerous means. Heroic medicine, a highly respectable practice at the time, included bloodletting, purging, vomiting, and blistering. In the course of the nineteenth century most of these methods became obsolete and the school lost much of its reputation, but one may recognize its imprint even today in high-risk surgeries and experimental medical treatments.

A second variation on the theme of hope was the nonorthodox medical practitioners, or ‘quacks,’ as their rivals

8 John Gregory, *Lectures on the Duties and Qualifications of a Physician* (London: Alex. Smellie, 1805), 37.

9 On the *ars moriendi* tradition, see David William Atkinson, *Renaissance and Baroque Studies and Texts*, vol. 5, *The English Ars Moriendi* (New York: P. Lang, 1992).

10 Lavi, *The Modern Art of Dying*, 44–61.

11 On ‘heroic medicine’ and other schools of medical practice in nineteenth-century America, see James H. Cassedy, *Medicine in America: A Short History, The American Moment* (Baltimore: Johns Hopkins University Press, 1991).

labeled them. One of the deceitful strategies of the quack doctor was to give a discouraging diagnosis of the patient's condition, and then match it with an excessive confidence in the powers of the drugs that he could provide. Either the patient would recover, in which case his medication would prove effective, or the patient would expire, in which case his predictions would prove accurate. The medical establishment strongly opposed such charlatanism and drew clear boundaries between true physicians and imposters. These efforts led to the creation of the American Medical Association in 1847 and to the official certification of doctors. The battle, however, was never completely settled, and the demand for hope beyond the limits of the medical establishment is prevalent.

The hope offered by mainstream physicians of the mid-nineteenth century, one which continues to dominate today's hospitals, was distinguishable from both heroic medicine and nonorthodox treatment. This third variation of worldly hope was promoted in the second half of the nineteenth century by 'conservative medicine.'<sup>12</sup> Founding figures of this school include Oliver Wendell Holmes, Sr., and Worthington Hooker. The group sought to lay new foundations to medical practice based on the limited and verifiable power of medicine. These physicians strongly objected to empty promises and unproven remedies. Their position was not based on the moral objection that the end (a hopeful patient) could not justify the means (deceit). In their mind, the *kind* of hope that the physician was expected to minister to the dying patient was differ-

ent from the kind provided by his rivals. The task of the physician was not merely to create a feeling of hope but to secure one based on the real healing powers of medicine. Hooker describes this hope:

The hope of the physician should be an intelligent hope. It should be based upon just and definite conclusions. It should be discriminating, and should be varied in its degree according to the character of each individual case.... Hope may thus be indulged in relation to the different stages of a case, without regard to the final event of it, which may be so distant and so clouded in doubt that no calculations can be made in regard to it.... This in many cases is much better than to come to him every day with the simple expression of the hope that he will at length recover. In the tedium of his confinement if it be a long one, he soon tires of looking far ahead to the bright field of convalescence, but finds relief in the time and spots lighted up of hope by the way – the oasis thus made in the desert of sickness.<sup>13</sup>

Hooker's notion of "intelligent hope" expressed the modest megalomania that distinguished the medical practices of the latter half of the nineteenth century from heroic medicine in the first half. It acknowledged the limitations of the medical profession but turned them into a virtue. It is the only hope that the medical profession can guarantee with confidence, and it is the only hope that really matters for the dying patient.

To this growing list of hopes at the disposal of the dying patient, we must add now the hope in the form of the medical hastening of death. It may be somewhat surprising to add euthanasia to this list.

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12 Martin S. Pernick, *A Calculus of Suffering: Pain, Professionalism, and Anesthesia in Nineteenth-Century America* (New York: Columbia University Press, 1985), 22.

13 Worthington Hooker, *Physician and Patient* (New York: Baker and Scribner, 1849), 345 – 346.

After all, what hope could there be in death? But once we see that the other medical treatments offered to the dying patient suffered from the same internal tension between limited hope and desperate hopelessness, the connection becomes clear. The medical hastening of death became a last resort to the problem of dying, a limited hope of mastery in the face of a hopeless condition.

Holmes recognized how thin the line separating the medical prolongation of life and the medical hastening of death. “No human being,” he wrote, “can rest for any time in a state of equilibrium where the desire to live and that to depart just balance each other.” As long as the patient is in good mind and hopeful, he will not be bothered by inconveniences. But when hope of cure or improvement are gone, “every incommodity stares out at him, each one of them packing up his little bundle of circumstances and calling him to move to his new home, even before the apartment is ready to receive the new bodily tenant.”<sup>14</sup>

Though Holmes was by no means advocating euthanasia, his telling metaphor demonstrates how the modern impatience toward awaiting death gave rise to the medical hastening of death. Proponents of euthanasia believed that death should follow as soon as hope was gone. If medicine cannot create hope, it should hasten death. The modern deathbed thus became, simultaneously, the place where all hope is lost and the place where a final effort to overcome helplessness includes the hastening of death.

Dying has become a crisis in contemporary America not because of the grow-

ing number of terminally ill patients, nor because dying is now a more painful and prolonged process. The problem of dying dates back to the late nineteenth century – to the medicalization of death, and more specifically to the emergence of a wish for an intelligible hope in the face of a hopeless existence.

The solutions available to the dying patient today are, in principle, the same as the ones Americans had in the late nineteenth century: heroic, alternative, and conservative prolongation of life, and active hastening of death. In the end, none of these solutions have the power to overcome the crisis of dying. In fact, Sandra’s case and its historical precedents demonstrate how these ‘solutions’ form the setting in which the contemporary crisis of dying takes place. The absence of freedom has little to do with limitations on the freedom of choice, and much to do with the futile attempt to subject dying to choice. The ethical significance of euthanasia is revealed in the hubris of modern man’s desire to master death, the crushing of this will, and its enragement once it faces the limited solace offered by medicalized mastery.

An imagined interlocutor may challenge this bleak depiction of the modern condition. Is there no alternative to the paradox facing the dying patient? Is there no Alexandrian sword that can cut this Gordian knot? If the crisis of dying is a result of the endless attempts to master death, can the dying patient not adopt an alternative mindset of accepting death rather than attempting to control it? Can contemporary patients not await death as was the old religious custom of the *ars moriendi* tradition, which offered guidance to the dying patient and her surroundings in the last article of life? Or, to raise a more contemporary solution, is the hospice not pre-

<sup>14</sup> Oliver W. Holmes, cited by E. P. Buffet, “Pleasures of Dying,” *New Englander and Yale Review* 55 (1891): 240–241.



cisely this kind of alternative of accepting death in an attempt to counter the process of medicalization?

The existence of alternative ways of dying need not be foreclosed. In the private realm, in *pianissimo*, good deaths are still possible.<sup>15</sup> But for the majority of the population, medicalized death – whether in the hospital, nursing home, hospice, or even private home – remains the rule. The challenge of the medicalization of death borders the insurmountable. A simple refusal to accept medical treatment is hardly a solution. Remember Sandra. Such refusal is immediately interpreted by the medical profession as well as by surrounding family and friends as a loss of hope, as a passive withdrawal from the world, as resentful rather than powerful. The challenge before the dying patient remains how to await death not out of despair nor out of vanity. In the words of Nietzsche on death, “One must turn the stupid physiological fact into a moral necessity. *So to live, that one has also at the right time one’s will to death!*”<sup>16</sup>

It may seem that the right to die and the legalization of euthanasia fulfill Nietzsche’s advice, but as we have seen, euthanasia today stands for hope in facing dying rather than an acceptance of death. A more appropriate account of the modern condition can be found in Kafka’s reflections on the will to die. Referring to himself and thinking no doubt of modern man, he wrote: “You, who can’t do anything, think you can

bring off something like that? How can you even dare to think about it? If you were capable of it, you certainly wouldn’t be in need of it.”<sup>17</sup>

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15 Max Weber, *From Max Weber: Essays in Sociology*, ed. H. H. Gerth and C. Wright Mills (New York: Oxford University Press, 1946), 155.

16 Compare Friedrich Nietzsche, *Will to Power*, trans. Walter Kaufmann (New York: Vintage Books, 1968), sec. 916. I owe this revised translation to Philippe Nonet.

17 Franz Kafka, as cited in D. J. Enright, ed., *The Oxford Book of Death* (New York: Oxford, 1983), 96.