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# TERMINAL AMBIGUITY: LAW, ETHICS AND POLICY IN THE ASSISTED DYING DEBATE

RUTH C. STERN AND J. HERBIE DIFONZO\*

Don't let us get sick
Don't let us get old
Don't let us get stupid, all right?
Just make us be brave
And make us play nice
And let us be together tonight

Warren Zevon<sup>1</sup>

#### I. Introduction

Dostoyevsky's Kirilov inhabits a solitary night-time world and dreams of becoming a god.<sup>2</sup> He will accomplish this by killing himself, the supreme act of free will that will deliver him from pain and fear.<sup>3</sup> By conquering these demons, Kirilov will obliterate God, purveyor of the pain and fear of death.<sup>4</sup> And, with God removed, nothing will restrain the triumph of free will in a world where men are so liberated that they care not whether they live or die.<sup>5</sup> Spurning the after-life, Kirilov seeks only that present moment where time abruptly halts and becomes eternal.<sup>6</sup> On his suicide note he wants to draw a face with a tongue sticking out.<sup>7</sup>

It is easy to dismiss Kirilov as unhinged, a minor player in one of the blackest of comedies. However, if his logic is not entirely persuasive, it is, at least, seductive. Many of us, stricken with painful, lingering illness, might seek to challenge God's hold and end the suffering on our own. To determine the time,

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<sup>&</sup>lt;sup>1</sup> Warren Zevon, Don't Let Us Get Sick, on Life'll Kill Ya (Artemis Records 2000).

<sup>&</sup>lt;sup>2</sup> Fyodor Dostoyevsky, The Possessed (Constance Garnett trans., Random House 1936) (1872).

<sup>&</sup>lt;sup>3</sup> *Id.* at 114-15.

<sup>&</sup>lt;sup>4</sup> *Id*.

<sup>5</sup> Id.

<sup>&</sup>lt;sup>6</sup> *Id*.

<sup>&</sup>lt;sup>7</sup> Id. at 630.

place, and manner of our death—to substitute our judgment for that of God and nature—is the ultimate act of taking life and death into our own hands. Whether or not we aspire to some brief flicker of omnipotence, we have led ourselves to believe that autonomy is good for us, even if we have to kill ourselves to prove it.

Modern medicine, with all of its blessings and curses, has taken the self-determination debate to new extremes. In many ways it has sparked the fight of our lives. For the past several decades, patients have clamored for various rights: the right of informed consent, the right to refuse medical treatment, the right to die, the right to enlist the aid of others in helping us die. Though some of these issues cannot be easily resolved philosophically, let alone legally, courts and the legislatures have been appointed to define and delimit the rights of the ill and the dying. Now, having achieved some measure of empowerment, we must ask ourselves: how much is enough? How much empowerment is too much before it overwhelms the boundaries of our understanding, our ability to act intelligently in our own interest and that of others?

Suicide, traditionally an intensely private act, has become a matter of public discourse. We recognize that life, once woefully short, can, largely through medical intervention, become intolerably long and burdensome. To wrest control from God and the doctors, we turn to assisted suicide and euthanasia and ask that these measures be legitimated. Some would respond by freely and willingly handing over the instrumentalities of our death. Others would do so only under extraordinary circumstances. Many would agree to let us die, by removing respirators and artificial nutrition and hydration, but would not affirmatively help us die. Depending on where we stand on this continuum, there is either a little, or a lot, of Kirilov in all of us.

This essay examines, and rejects, several closely-held notions in the discourse on assisted suicide and euthanasia. The concept of a legal right to end one's life must yield to the pragmatic assessment of medical factors affecting the dying and the treatment options available to them. The legal entitlement framework has fostered a misperception that we must choose between assisted dying and a drawn-out, painful demise. Rather, this essay posits that end-of-life decisions—including, but not limited to, assisted suicide and euthanasia—properly belong within the matrix of competent, compassionate medical care. Patients, aided by physicians and loved ones, can be helped to make informed medical choices based on a range of treatment and life alternatives. In presenting these options, we outline the central legal and ethical arguments for and against assisted dying, elaborating on the merits and inconsistencies of each position.

At the start of the twenty-first century, our society has taken the measure of several judicial and legislative responses to end-of-life questions. The experi-

<sup>&</sup>lt;sup>8</sup> For purposes of verbal economy we will occasionally combine both practices under the term "assisted dying."

ence of officially-sanctioned aid in dying in Oregon and the Netherlands has furnished us with some understanding of how doctors and patients approach the desire for death under a facilitative legal regime. And, because these issues cannot breathe in a vacuum, we must consider them in light of current end-of-life medical practices. Insistence on the right to aid in dying creates a danger of prematurely ending the debate. In that sense, the Supreme Court, in denying us that right, may well have saved us from ourselves. Further, in authorizing assisted suicide, the Oregon legislature may have produced the most potent reasons to oppose it. Against the backdrop of gross deficiencies in medical end-of-life practice and education, the assisted dying debate is sorely in need of a re-framing of the issues and new principles to guide its resolution.

This essay is divided into four parts. Part II explores the extent to which disease, including mental illness, contributes to an individual's desire for death. Severe, debilitating infirmity strongly supposes a quest for relief, but does not inevitably lead to suicide as the means to achieve it. On the other hand, those who seek assistance in dying may be struggling to assert their true selves as their minds and bodies deteriorate beyond recognition. Part III examines ethical and legal perspectives on the death debate. Ethicists and judges have too narrowly constricted the dialogue, unduly limiting their own reasoning and the range of available options. This section further argues that the dominant paradigms must give way to an expanded consideration of complex social and medical realities in the life of each patient. Part IV analyzes the legislative response to the assisted dying debate. This section places in context some very disturbing aspects—from the individual patient's perspective—of the experiences of Oregon and the Netherlands with officially-sanctioned aid in dying. Overall, this section concludes that the legislative efforts to delineate the right to die have failed. Part V of this essay suggests that autonomy and compassion play a far more circumscribed role in end-of-life care than previously supposed. Moreover, reliance on questionable assumptions has produced untenable distinctions that further cloud the debate between assisted suicide and euthanasia. and between euthanasia and withdrawal of treatment. This essay concludes by calling for a reconceptualization of the dialogue, first by insisting on expanding the scope of medical school training to remedy deficiencies in end-of-life care and second, by proposing that assisted dying is only one of several solutions to end-of-life concerns. In this life-and-death debate, well trained doctors and their patients, not lawyers and judges, are the most appropriate arbiters.

#### II. DESIRING DEATH

Everyone struggles against despair, but it always wins in the end. It has to. It's the thing that lets us say goodbye.

JEFFREY EUGENIDES, MIDDLESEX9

<sup>&</sup>lt;sup>9</sup> Jeffrey Eugenides, Middlesex 524 (2002).

I never had that irresistible hunger for oblivion, not the way some people do. Mine was a surmountable despair. I just didn't. Surmount it.

DAVID LONG, THE INHABITED WORLD<sup>10</sup>

### A. Suicide: A Brief Overview

Nearly forty years ago, A. Alvarez noted an extraordinary increase in intentional death by drugs in Japan and parts of Europe.<sup>11</sup> Death by overdose had substantially displaced some of the more traditional and more violent means of suicide—shooting, knife wounds, hanging, jumping, and drowning.<sup>12</sup> People were choosing to forego the convulsive agonies brought on by ingestion of arsenic and strychnine and were swallowing sleeping pills instead.<sup>13</sup> One could slip away in peace and oblivion and achieve a death so painless it appeared "magical." Indeed, it is not uncommon for death by overdose to be mistaken for death by natural causes.<sup>15</sup>

Given the choice, when the time comes, we would all like to die in our sleep. This yearning for a gentle, permanent release from pain and suffering is a potent force behind support for assisted dying. After all, the right to orchestrate our own end would be of little comfort if we had to do serious violence to ourselves in order to exercise it. But this rosy ideal of a merciful end remains far removed from the shocking barbarity of so many self-inflicted deaths. Whatever the chosen method, suicide is, traditionally, the last refuge for people with decidedly unquiet minds.

The "logic of suicide," according to Alvarez, is "the unanswerable logic of a nightmare." His illumination of the suicidal mind is mesmerizing:

Once a man decides to take his own life he enters a shut-off, impregnable but wholly convincing world where every detail fits and each incident reinforces his decision. An argument with a stranger in a bar, an expected letter which doesn't arrive, the wrong voice on the telephone, the wrong knock at the door, even a change in the weather—all seem charged with special meaning; they all contribute. The world of suicide is superstitious, full of omens.<sup>17</sup>

For the suicidal, despair obscures the boundary between present and future,

<sup>&</sup>lt;sup>10</sup> David Long, The Inhabited World 268 (2006).

<sup>&</sup>lt;sup>11</sup> A. Alvarez, The Savage God: A Study of Suicide 158 (W.W. Norton & Co. 1990) (1970).

<sup>12</sup> Id. at 159.

<sup>13</sup> Id.

<sup>14</sup> Id

<sup>&</sup>lt;sup>15</sup> Kay Redfield Jamison, Night Falls Fast 30-31 (1999).

<sup>&</sup>lt;sup>16</sup> ALVAREZ, supra note 11, at 144.

<sup>17</sup> Id. at 121-22.

"and the present is painful beyond solace." The individual who views his life as a chain of failures may resort to an act that, by its very finality, is an ironic testament to success. Like Kirilov, one can rise above the wreckage, exert the power of will and be free to dictate how and when one will die. Yet even this moment of glory can be equivocal. Alvarez suggests that Kirilov is motivated less by his desire to become God than by the realization that he is so wretchedly un-godlike. 19

Whatever external meaning society struggles to attribute to it, suicide is rooted in a "terminal inner loneliness which no amount of social engineering will alleviate." At the time of death, ninety to ninety-five percent of those who commit suicide suffer from a diagnosable mental disorder. [D] epression and manic depression . . . schizophrenia, borderline and antisocial personality disorders, alcoholism and drug abuse" comprise the principal psychopathological causes. Suicide is the eighth leading cause of death for all men in the United States, and the eleventh leading cause overall. Although women attempt suicide during their lifetimes about three times more frequently than men, men are four times more likely to succeed in the effort. So

Suicide especially afflicts the young and the elderly. Of persons over sixty-five, one in seven suffers from depression but the great majority receives no treatment.<sup>26</sup> Elderly persons are apt to hide their symptoms out of shame or fear of seeming weak.<sup>27</sup> Doctors often fail to recognize the signs of depression in their older patients, or may believe that "nothing can be done for people with ample reason to be depressed."<sup>28</sup> Brain injury caused by stroke may promote depression, as can many medications commonly taken by the elderly: "steroids, anticancer drugs, . . . drugs for Parkinson's disease, high blood pressure, heart disease, rheumatoid arthritis and pain."<sup>29</sup> Medical advances that have prolonged the lives of the chronically ill elderly have also elevated the rate of

<sup>&</sup>lt;sup>18</sup> Jamison, supra note 15, at 93.

<sup>19</sup> ALVAREZ, supra note 11, at 146.

<sup>&</sup>lt;sup>20</sup> Id. at 121.

<sup>&</sup>lt;sup>21</sup> Jamison, supra note 15, at 100.

<sup>&</sup>lt;sup>22</sup> Id. at 100.

<sup>&</sup>lt;sup>23</sup> Id. at 100.

<sup>&</sup>lt;sup>24</sup> National Institute of Mental Health, Suicide in the U.S.: Statistics and Prevention, http://www.nimh.nih.gov/health/publications/suicide-in-the-us-statistics-and-prevention.shtml (last visited Oct. 12, 2007).

<sup>&</sup>lt;sup>25</sup> Centers for Disease Control and Prevention, Understanding Suicide Fact Sheet 2006, http://www.cdc.gov/ncipc/pub-res/Suicide%20Fact%20Sheet.pdf (last visited Oct. 12, 2007).

<sup>&</sup>lt;sup>26</sup> Jane E. Brody, *Age is No Barrier to Lifting Depression's Heavy Veil*, N.Y. TIMES, May 30, 2006, at F7, *available at* http://www.nytimes.com/2006/05/30/health/psychology/30brod. html?ex=1170997200&en=d5ed319e9ba99f01&ei=5070.

<sup>&</sup>lt;sup>27</sup> Id.

<sup>&</sup>lt;sup>28</sup> Id.

<sup>&</sup>lt;sup>29</sup> Id.

suicide among older persons.<sup>30</sup> And, while older women suffer serious depression at twice the rate of older men, elderly white males are eight times more likely to kill themselves than women of the same age.<sup>31</sup> In 2001, firearms were used in seventy-three percent of suicides by adults over the age of sixty-five.<sup>32</sup> So much for serene oblivion at the end of life.

#### B. Illness and Suicide

Several medical conditions, originating in or strongly impacting the brain and central nervous system, may contribute to a higher rate of suicide.<sup>33</sup> These disorders—Huntington's disease, multiple sclerosis, temporal lobe epilepsy, spinal cord injury, head and neck cancer, HIV/AIDS—can cause severe mood swings and sometimes dementia.<sup>34</sup> Overall, however, most people who kill themselves are in good physical health, including an estimated two-thirds of older people who die by suicide.<sup>35</sup> Terminally ill individuals comprise only a small proportion of suicides, perhaps as little as two to four percent.<sup>36</sup> The great majority of patients suffering from severe pain, disfigurement or disability do not desire death by suicide.<sup>37</sup> It is important not to minimize the increased risk of suicide among the chronically and terminally ill. But, more often than not, these individuals are "resilient, and fight for life throughout their illness."38 In one retrospective study, researchers found that a group of cancer patients who had committed suicide had "fewer psychosocial resources and showed a poorer adjustment to their illness than a control group of cancer patients who did not commit suicide."39 In another study, of those terminally ill patients who did express a wish to die, all displayed the symptoms of major depression.<sup>40</sup> Treatment for depression may dramatically reduce a patient's

<sup>&</sup>lt;sup>30</sup> Patrick J. Meehan et al., Suicides Among Older United States Residents: Epidemiologic Characteristics and Trends, 81 Am. J. Pub. Health 1198, 1199-1200 (1991).

<sup>&</sup>lt;sup>31</sup> Rummana Hussain, *Report: Elderly White Males Have Top Suicide Rate*, CHICAGO SUN-TIMES, Aug. 18, 2006, *available at* http://findarticles.com/p/articles/mi\_qn4155/is\_20060818/ai n16643166.

<sup>&</sup>lt;sup>32</sup> Centers for Disease Control and Prevention, National Center for Injury Prevention and Control Suicide: Fact Sheet, http://www.ct.gov/dmhas/lib/dmhas/prevention/cyspi/suicidefactsheet.pdf (last visited Oct. 12, 2007).

<sup>&</sup>lt;sup>33</sup> Jamison, supra note 15, at 103.

<sup>&</sup>lt;sup>34</sup> Brody, supra note 26, at F7.

<sup>&</sup>lt;sup>35</sup> N.Y. STATE TASK FORCE ON LIFE & THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT 12-13 (1994) (hereinafter referred to as "N.Y. TASK FORCE").

<sup>36</sup> Id. at 12.

<sup>37</sup> Id. at 13.

<sup>&</sup>lt;sup>38</sup> *Id*.

<sup>&</sup>lt;sup>39</sup> James Henderson Brown, et al., *Is it Normal for Terminally Ill Patients to Desire Death?*, 14 Am. J. of Psychiatry 208 (1986).

<sup>40</sup> Id. at 210.

wish to die, eliminating suicidal ideation in ninety percent of these cases.<sup>41</sup>

Patients with terminal illness face challenges in coping with conditions that are often progressive and debilitating.<sup>42</sup> Treatment for depression may help them to strengthen their ability to adjust to these circumstances.<sup>43</sup> While many individuals with chronic or terminal illness may experience thoughts about suicide, most of them never act on those thoughts by committing suicide.<sup>44</sup> It is, apparently, a fallacy that terminal illness necessarily and normally contains a component of severe depression.<sup>45</sup> In fact, patients who become seriously ill sometimes undergo a phenomenon whereby the process of overcoming their fear of death "dissolves many other anxieties or neuroses."<sup>46</sup> With these psychological distractions removed, patients are better able to appreciate the basic meaning of their lives.<sup>47</sup>

Pain in varying levels of severity is a common symptom in dying patients, affecting a majority of those with cancer, AIDS, and at least half of those hospitalized with other diagnoses. Pain can contribute to elevated levels of hormones that can induce stress to the heart and lungs. It can also lead to heart attacks and strokes by causing blood pressure to spike, and can "consume so much of the body's energy that the immune system degrades." When uncontrolled, pain can contribute to suicide and suicidal ideation. However, it is not generally an independent risk factor for suicide. Rather, the "significant variable in the relationship between pain and suicide is the interaction between pain and feelings of hopelessness and depression."

Pain takes many forms and, because the experience is so subjective, it is not well understood. It may compound a patient's problems by masking feelings of sadness and making depression harder to diagnose.<sup>54</sup> In addition, physical symptoms of chronic debilitating disease—appetite and weight loss, insomnia, fatigue and reduced concentration—often overlap with depressive symptoms, further complicating the diagnosis.<sup>55</sup> Patients with chronic, uncontrollable pain

<sup>&</sup>lt;sup>41</sup> N.Y. TASK FORCE, supra note 35, at 26.

<sup>42</sup> Id. at 16.

<sup>43</sup> Id. at 26.

<sup>44</sup> Id. at 11.

<sup>45</sup> Id. at 16.

<sup>&</sup>lt;sup>46</sup> Id. at 13.

<sup>47</sup> Id.

<sup>&</sup>lt;sup>48</sup> Kathleen Foley, *Patients Need Better End-of-Life Care Rather Than Assisted Suicide*, in Euthanasia 190-91 (Loreta Medina ed., 2005).

<sup>&</sup>lt;sup>49</sup> Tina Rosenberg, *Doctor or Drug Pusher?*, N.Y. Times Mag., June 17, 2007, at 50.

<sup>&</sup>lt;sup>50</sup> Id.

<sup>&</sup>lt;sup>51</sup> Id

<sup>52</sup> N.Y. TASK FORCE, supra note 35, at 17.

<sup>&</sup>lt;sup>53</sup> *Id.* at 17.

<sup>54</sup> Brown et al., supra note 39, at 209.

<sup>55</sup> Id. at 208-09.

may fall prey to feelings of anxiety, hopelessness and depression and see death as their only means of escape. <sup>56</sup> However, when used appropriately, "modern pain relief techniques can alleviate pain in all but extremely rare cases." <sup>57</sup> When all else fails, terminal sedation can prevent the patient from experiencing the pain and suffering by producing a sleeplike state. This option is considered less than ideal because it robs the patient of consciousness but may be considered for the terminally ill in their last weeks or days of life. <sup>58</sup>

Distinct from pain, suffering poisons a person's spiritual and psychological state, often promoting "a sense of anguish, dread, foreboding, futility, meaning-lessness" and loss of control. Suffering also includes physical symptoms associated with severe or terminal illness—such as difficulty breathing, nausea, diarrhea, constipation and fatigue. Not all pain produces suffering, nor does suffering necessarily involve pain. Neither is suffering confined to those with painful terminal illnesses. Patients with amyotrophic lateral sclerosis (ALS) and those who are quadriplegic due to spinal chord injury suffer intensely distressing disabilities and physical symptoms. In Brian Clark's Whose Life Is It Anyway? the character of Ken Harrison, paralyzed from the neck down, tries to explain why his life is no longer worth living:

It's a question of dignity. Look at me here. I can do nothing, not even the basic primitive functions. I cannot even urinate, I have a permanent catheter attached to me. Every few days my bowels are washed out. Every few hours two nurses have to turn me over or I would rot away from bedsores. Only my brain functions unimpaired but even that is futile, because I can't act on any conclusions it comes to.<sup>61</sup>

Proponents of physician-assisted suicide hasten to distinguish it from acts of self-killing and self-destruction. For the severely ill and disabled, the greatest suffering arises from the loss of control, first of the body, then of the self, "borne downward by the illness." Timothy Quill believes that those who seek a doctor's help in dying are waging a battle *against* self-destruction. Rather than the annihilation of the self, they seek death in order to salvage their personhood. Death is the means by which they will re-assert and re-establish the

<sup>&</sup>lt;sup>56</sup> N.Y. TASK FORCE, supra note 35, at 20-21.

<sup>&</sup>lt;sup>57</sup> *Id.* at 40.

<sup>&</sup>lt;sup>58</sup> *Id*.

<sup>&</sup>lt;sup>59</sup> Daniel Callahan, The Troubled Dream of Life 95 (1993).

<sup>&</sup>lt;sup>60</sup> Id. Callahan noted that the pain experienced by a victorious long-distance runner may lead to pleasure and that the knowledge that one has Alzheimer's disease produces a non-physical anguish.

<sup>61</sup> BRIAN CLARK, WHOSE LIFE IS IT ANYWAY? 141-42 (1978).

<sup>62</sup> CALLAHAN, supra note 59, at 133.

<sup>63</sup> Timothy E. Quill, Dying Patients Should Have Access to Both Hospice Care and Assisted Suicide, in Euthanasia: Opposing viewpoints 105, 110 (James D. Torr ed., 2000). 64 Id. at 110.

essence of their being.<sup>65</sup> There is nothing like illness, disability and death to remind us that we are no more and no less than "embodied selves."<sup>66</sup>

#### III. DEBATING DEATH

But surely a wish to die is not *necessarily* a symptom of insanity? A man might wish to die for perfectly sane reasons.

BRIAN CLARK, WHOSE LIFE IS IT ANYWAY?67

Life is the woman who loves you, the wind through your hair, the sun on your face, an evening stroll with a friend.

Life is also a woman who leaves you, a rainy day, a friend who deceives you. I am neither melancholic nor manic-depressive. I find the idea of dying horrible. But what is left to me is no longer life.

Piergiorgio Welby<sup>68</sup>

#### A. The Doctor-Patient Perspective

In 1988 the Journal of the American Medical Association published an anonymous article, "It's Over, Debbie." A resident in a large, private hospital receives a middle-of-the-night summons. He stumbles sleepily to the bedside of a young woman named Debbie who is dying of ovarian cancer. Except for some hurried details provided by a nurse and a quick look at her chart, the resident knows nothing about Debbie. The patient is emaciated, hollow-eyed, vomiting relentlessly, having difficulty breathing and has not responded to chemotherapy. Her only words to the resident are, "Let's get this over with." The resident withdraws to reflect briefly and concludes that, while he cannot cure her, he can "give her rest." He injects her with a lethal dose of morphine

<sup>65</sup> Id. at 110. See generally Lois Shepherd, Dignity And Autonomy after Washington v. Glucksberg: An Essay About Abortion, Death, And Crime, 7 CORNELL J.L. & Pub. Pol'y 431, passim (1998) for discussion of the role of dignity and autonomy in this issue.

<sup>66</sup> Callahan, supra note 59, at 146.

<sup>67</sup> CLARK, supra note 61, at 91.

<sup>&</sup>lt;sup>68</sup> Ian Fisher, A Poet Crusades for the Right to Die His Way, N.Y. Times, Dec. 20, 2006, available at http://www.nytimes.com/2006/12/20/world/europe/20welby.html (quoting Piergiorgio Welby). Welby battled muscular dystrophy for forty years and spent his last nine years attached to a respirator. A well-known advocate of euthanasia, he authored a book, "Let Me Die," and described his unwanted medical treatment as "unbearable torture." An Italian court denied him permission for sedation and for a physican to remove him from the respirator. Shortly thereafter and without legal approval, an anesthesiologist sedated Welby and his respirator was disconnected. Id. After Welby's death, his doctor was unanimously cleared by an Italian medical board. No Disciplinary Action for Doctor in Right-to-Die Case, N.Y. Times, Feb. 2, 2007, available at http://query.nytimes.com/gst/fullpage.html?res=9F07E0DE123FF931A35751C0A9619C8B63.

<sup>&</sup>lt;sup>69</sup> Anon., 259 J. Am. Med. Ass'n 272 (1988).

and she dies, peacefully, within minutes.70

The piece was greeted with storms of condemnation for the resident's having proceeded without consulting another physician and for committing what amounts to pre-meditated murder. Others questioned whether the article was a hoax, while fervent proponents of euthanasia like Derek Humphry approved of the result but not the young doctor's methods.<sup>71</sup> Still others expressed relief that the anonymous author had "forced the fact that doctors did perform active euthanasia out into the open." Said one physician, "It makes no sense to hide our heads in the sand."

Doctors are often placed in the agonizing position of having to observe terrible suffering while, at the same time, having to filter their responses through complex moral, ethical and legal considerations. Some see physician-assisted suicide as too easy, a "flight from compassion." Some support prohibition of aid in dying as a necessary safeguard against the arrogance of doctors—their willingness to apply entirely subjective criteria to the issue of "whether this life or that life is unworthy of continued existence."

The danger, however, comes not from the physician's belief that some lives are more worthy than others, but from the capacity to act on such judgments, especially "under the cloak of professional prestige and compassion." <sup>76</sup>

In an era of scarce health resources, terminally ill patients, fearful of burdening their families, might interpret the right to die as "the duty to die." Especially vulnerable are "the many individuals in our society whose autonomy and

<sup>&</sup>lt;sup>70</sup> Id.

<sup>&</sup>lt;sup>71</sup> See Ian Dowbiggin, A Merciful End 166 (2003). Derek Humphry is the author of Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying. First published in 1991, the book is now in a 3rd edition. Humphry founded the Hemlock Society, *Id.* at xvii, "committed to providing information regarding options for dignified death and legalized physician aid in dying." The Hemlock Society Home Page, http://www.compassionandchoices.org/hemlock (last visited Sept. 15, 2007). Humphry, believes that "[t]he right to choose to die when in advanced terminal or hopeless illness is the ultimate civil liberty." Who's Who and What's What: Derek Humphrey, http:// www.final exit.org/dhumphry (last visited Sept. 15, 2007). He is president of ERGO, Euthanasia Research and Guidance Organization, based in Oregon. About ERGO, http:// http://www.final exit.org/about.html (last visited Sept. 29, 2007).

<sup>72</sup> Dowbiggin, supra note 71, at 166.

<sup>&</sup>lt;sup>73</sup> Id. at 166.

<sup>&</sup>lt;sup>74</sup> Robert McCormick, *Physician-Assisted Suicide: Flight from Compassion, in Arguing Euthanasia* 135 (Jonathan Moreno ed., 1995).

<sup>&</sup>lt;sup>75</sup> Leon R. Kass & Nelson Lund, *Physicians Should Not Be Legally Permitted to Assist in Suicide, in Euthanasia*: Opposing Viewpoints, *supra* note 63 at 181, 187.

<sup>76</sup> Id.

<sup>&</sup>lt;sup>77</sup> See Alan Meisel & Kathy L. Cerminara, The Right to Die: The Law of End-of-Life Decisionmaking 1-4 to 1-5 (3d ed. 2004) (discussing the confusion of a right to die with a duty to do so among laypersons and health providers); Robert Misbin, *Physicians' Aid in Dying, in* Arguing Euthanasia, *supra* note 74, at 125.

well-being are already compromised by poverty, lack of access to good medical care, advanced age, or membership in a stigmatized social group."<sup>78</sup> Thoughts about cost-effectiveness, however unbidden, hover around a generation at risk of sacrificing its financial future to the expense of caring for elderly parents. <sup>79</sup> Old age has never "lasted so long or been so costly."<sup>80</sup> Medicare covers acute episodic illness, such as heart attack, cancer, or a broken hip and, therefore, provides little long-term help. Middle-aged children of the elderly exhaust their savings caring for parents and wonder whether they will ever be able to retire. <sup>81</sup> Viewed in the context of such systemic inequities, insisting on access to physician aid in dying seems an irrational and counterproductive strategy. Referring to the movement to legitimize assisted dying, Yale Kamisar has noted that, "at a time when millions of Americans lack adequate health care and Congress has refused to do anything about it," it seems ludicrous to argue that physician-assisted suicide is "the one health care right that deserves constitutional status." <sup>82</sup>

The most emphatic response to "It's Over, Debbie" arose from a group of physicians who proclaimed the "very soul of medicine" to be on trial. <sup>83</sup> Invoking the Oath of Hippocrates, they declared the resident's actions to be a clear violation of "one of the most hallowed canons of the medical ethic: doctors must not kill." On the one hand, it is difficult to quarrel with the unalloyed moral and ethical logic of such a statement. On the other hand, one wonders whether a strict construction of the Hippocratic Oath is, truly, the most valid or most helpful source of guidance on this issue. Doctors must not kill. Yet, in an untold number of instances, their ministrations are causing their patients to want to die. In a research project funded by the Robert Wood Johnson Foundation, 9,000 seriously ill patients in five major teaching hospitals were studied over the course of four years. <sup>85</sup> Viewed as "one of the most important studies on medical care for the dying," it concluded that doctors "routinely subject

<sup>&</sup>lt;sup>78</sup> N.Y. TASK FORCE, *supra* note 35, at 120.

<sup>&</sup>lt;sup>79</sup> Jane Gross, *Elder-Care Costs Deplete the Savings of a Generation*, N.Y. TIMES, Dec. 30, 2006, *available at* http://www.nytimes.com/2006/12/30/us/30support.html.

<sup>80</sup> Id.

<sup>81</sup> Id.

<sup>&</sup>lt;sup>82</sup> Yale Kamisar, *Voluntary Euthanasia Should Not Be Legalized*, *in* Euthanasia: Opposing Viewpoints, *supra* note 63, at 87.

<sup>&</sup>lt;sup>83</sup> Willard Gaylin et al., *Doctors Must Not Kill*, in Arguing Euthanasia, *supra* note 74, at 35.

<sup>&</sup>lt;sup>84</sup> *Id.* at 34.

<sup>&</sup>lt;sup>85</sup> See Joanne Lynn, Unexpected Returns: Insights from SUPPORT, in The Robert Wood Johnson Foundation Anthology, To Improve Health and Health Care, Vol. I (1997), http://www.rwjf.org/files/publications/books/1997/chapter\_08.html (describing selected findings and lessons from SUPPORT, a large, multi-year research-and-demonstration project that investigated the care provided to critically ill hospitalized patients at the end of life).

their patients to futile medical treatment, ignore their specific instructions for care, and allow them to die in needless pain."<sup>86</sup> This "plainly substandard"<sup>87</sup> care included the following: during the last three days of life, fifty-five percent of patients were conscious; of these, eighty percent endured pain, dyspnea, and fatigue. Forty percent of these patients suffered "severe pain"<sup>88</sup> "most of the time."<sup>89</sup>

Among the severely and terminally ill and those with prolonged unconsciousness or advanced dementia, infectious diseases such as pneumonia or urinary tract infection, if left untreated, might allow for a relatively peaceful death. Their "routine treatment," however, extends the degenerative process, resulting in "death by inches" and robbing the patient of any prospect of peace. Years ago, advanced cervical cancer caused death due to complications of kidney failure or urethral blockage, a comparatively merciful end. Now, patients can be kept alive by dialysis and other techniques until the tumor itself produces a "much more protracted and uncomfortable death." The medical arsenal—including, but not limited to, chemotherapy, radiation therapy, artificial hydration and nutrition, immunotherapy, and palliative surgery—often extends life expectancy from a few months to many years. When the technology falters, however, the patient's "prolonged remission" becomes "prolonged suffering."

Of course medicine's mission is to treat disease and illness and to prolong life. Patients fully, and rightfully, expect it to be so. At the same time, life-extending medications and techniques have transformed death into a "chronic, contrived, and manipulated phenomenon." Doctors find ample ethical justification to intervene at the treatment stage. Yet, when treatment finally fails and the patient is undergoing painful, protracted death, these very same ethics seem to justify abandonment. When the "ultimate price" for prolonging life "comes due," doctors fall back on the tenets of their profession, shun euthanasia, and the patient assumes the cost. 94

Doctors must not kill. But their efforts at recognizing and alleviating pain

<sup>&</sup>lt;sup>86</sup> Joe Loconte, *Hospice Care Can Make Assisted Suicide Unnecessary*, in Euthanasia: Opposing Viewpoints, *supra* note 63, at 98.

<sup>&</sup>lt;sup>87</sup> W. Clay Jackson, When All Else is Done: The Challenge of Improving Antemortem Care, 1 J. Clin. Psychiatry 146, 148 (1999), available at http://www.psychiatrist.com/pcc/pccpdf/v01n05/v01n0503.pdf.

<sup>&</sup>lt;sup>88</sup> *Id*.

<sup>&</sup>lt;sup>89</sup> Id.

<sup>90</sup> Callahan, supra, note 59, at 202.

<sup>&</sup>lt;sup>91</sup> Guy Benrubi, *Euthanasia—The Need for Procedural Safeguards*, in Arguing Euthanasia, *supra* note 74, at 115-16.

<sup>&</sup>lt;sup>92</sup> Id. at 115.

<sup>&</sup>lt;sup>93</sup> Kenneth Vaux, *Debbie's Dying: Mercy Killing and the Good Death*, 259 J. Am. Med. Ass'n 2140, 2141 (1988).

<sup>94</sup> Benrubi, supra note 91, at 116.

are "grossly inadequate." Medical education regarding palliative care is deficient, or doctors often fail to offer pain relief until the latest stage of illness, or what they offer is simply not enough.<sup>96</sup> Even hospice patients, who should expect the highest level of palliative care, report severe pain and shortness of breath in the last week of life.<sup>97</sup> "Medical school and residency training programs have often failed to adequately address pain management and end-of-life care."98 Although pain is "the most common symptom in the dying," insufficient palliative care especially afflicts women and minority AIDS and cancer patients, as well as thirty-six percent of nursing home residents with cancer and an appalling eighty-nine percent of children dying of cancer. Studies show that a majority of AIDS and cancer patients are provided with insufficient relief in the course of their terminal illness.<sup>99</sup> In a survey of 1,177 physicians who treated tens of thousands of cancer patients, "seventy-six percent reported that a lack of knowledge was a barrier to their ability to control pain."100 In another survey, only twelve percent of doctors viewed their medical school training in pain management as "excellent or good." 101

<sup>95</sup> N.Y. TASK FORCE, supra note 35, at 43; see also Melanie Thernstrom, Pain, The Disease, N.Y. TIMES, Dec. 16, 2001, available at http://query.nytimes.com/gst/fullpage.html? sec=health&res=9C02E4DD163FF935A25751C1A9679C8B63 ("Pain treatment belongs primarily in the hands of ordinary physicians, most of whom know little about it."); Robert D. Chen, M.D., Training the Pain Physicians of Tomorrow, AMER. Soc. of ANESTHESIOLOGISTS NEWSLETTER, Oct. 1999, http://www.asahq.org/Newsletters/1999/10\_99/train1099. html ("It is not unusual in an era of managed care medicine for primary care physicians to misdiagnose treatable acute pain conditions . . .").

<sup>&</sup>lt;sup>96</sup> Timothy E. Quill, When Palliative Care Fails, in Euthanasia 196, 200 (Loreta M. Medina ed., 2005); see also J. E. Mortimer and N.L. Bartlett, Assessment of Knowledge about Cancer Pain Management by Physicians in Training, 14 J. Pain Symptom Manage. 21, 21-28 (1997) (noting deficiencies in physician education on treating pain).

<sup>97</sup> Quill, *supra* note 96, at 201.

<sup>&</sup>lt;sup>98</sup> Helen Thomson, A New Law to Improve Pain Management and End-Of-Life Care, 174 West. J. Med. 161, 162 (2001).

<sup>&</sup>lt;sup>99</sup> Foley, Patients Need Better End-of-Life Care Rather Than Assisted Suicide, supra note 48, at 190-91.

<sup>&</sup>lt;sup>100</sup> Id. at 191. The study is reported at Jamie H. Von Roenn et al., *Physician Attitudes and Practice in Cancer Pain Management: A Survey From the Eastern Cooperative Oncology Group*, 119 Annals of Internal Med. 121 (1993).

<sup>101</sup> N.Y. Task Force, *supra* note 35, at 43. The medical profession does not, of course, shoulder all the blame for the want of adequate pain medication. Our society is of two minds on several issues relating to pain management. One prime example relates to medical marijuana. A plethora of scientific studies and clinical experience showing the efficacy of marijuana to treat AIDS wasting syndrome, muscle spasticity, chronic pain, and other serious medical conditions. *See, e.g.,* Oakley Ray & Charles Ksir, Drugs, Society, and Human Behavior (McGraw Hill 10th ed. 2004); D. I. Abrams, *et al.*, *Cannabis in Painful HIV-Associated Sensory Neuropathy: A Randomized Placebo-Controlled Trial,* 68 Neurology 515, 515-21 (2007) ("Smoked cannabis was well tolerated and effectively relieved

Severe, uncontrollable pain disrupts patients' sleep, and leads to further physical deterioration. <sup>102</sup> It reduces the will to engage in physical activity, and to complete even the simplest of daily tasks. <sup>103</sup> Along with other physical symptoms, pain can "directly diminish a patient's quality of life. <sup>104</sup> As limned by one observer, "[a] modern chronicler of hell might look to the lives of chronic-pain patients for inspiration." <sup>105</sup> Furthermore, the patient's family and professional caregivers become distressed at witnessing pain and suffering. The interrelated nature of the distress serves to amplify it, contributing to feelings of helplessness and hopelessness and, perhaps, the belief that euthanasia or assisted suicide are the only paths to relief. <sup>106</sup>

Doctors must not kill. But they do. In 1997, of a sample of physicians explicitly asked to assist in a patient's death, one quarter "provided patients with potentially lethal medication." In Britain, one in seven of 36,000 general practitioners "has admitted that he or she has broken the law by helping patients to die at their request." According to Kenneth Vaux, there are "numerous cases today in the medical and legal case files in which active euthanasia has been reluctantly allowed and the physicians involved have not been prosecuted." As to assisted suicide, the scarcity of criminal prosecutions stems from "the private, consensual nature" of the act as well as the difficulty of proving intent on the part of the doctor—many of the prescribed substances are routinely employed to treat pain. Prosecutors are often unwilling to bring euthanasia cases in light of the "public sympathy they often arouse" and problems with securing indictments and convictions.

chronic neuropathic pain from HIV-associated sensory neuropathy."); Stanley. J. Watson et al., *Marijuana and Medicine: Assessing the Science Base*, 57 ARCH. GEN. PSYCHIATRY 547, 547-52 (2000). Nevertheless, this issue has become a political and cultural battleground. At least a dozen states have authorized exceptions to their drug possession laws for medicinal uses of marijuana. Curt Woodward, *Wash. to Set Medical Marijuana Limits*, WASH. POST, July 7, 2007. But federal law continues to criminalize all possession of marijuana, and the federal government law has trumped state efforts to allow doctors to prescribe this type of pain relief. *See* Gonzales v. Raich, 545 U.S. 1 (2005) (holding that the federal Controlled Substances Act was not an unconstitutional exercise of the Commerce Clause as applied to seriously ill patients who have been prescribed marijuana).

<sup>102</sup> N.Y. TASK FORCE, supra, note 35 at 20.

<sup>&</sup>lt;sup>103</sup> *Id*.

<sup>104</sup> Id. at 21.

<sup>105</sup> Thernstrom, supra note 95, at 1.

<sup>&</sup>lt;sup>106</sup> Foley, Patients Need Better End-of-Life Care Than Assisted Suicide, supra note 48, at 189.

<sup>107</sup> Quill, When Palliative Care Fails, supra note 96, at 203.

David Pratt, Too Many Physicians: Physician-Assisted Suicide After Quill/Gluck-sberg, 9 Alb. L.J. Sci. & Tech. 161, 184 (1998-99).

<sup>&</sup>lt;sup>109</sup> Vaux, *supra* note 93, at 2141.

<sup>110</sup> N.Y. TASK FORCE, supra note 35, at 57.

<sup>&</sup>lt;sup>111</sup> *Id*.

prosecutor, "A jury will not find somebody guilty for something they believe in their hearts was a blessing, no matter what a legal statute says." 112

Several years after the appearance of "It's Over, Debbie," Timothy Quill, a physician, published his own account of an assisted suicide. He told of a patient, Diane, stricken with leukemia and nearly out of treatment options. He after extensive discussions with her, Dr. Quill acceded to her request and wrote her a prescription for barbiturates. Secure in knowing she could use them when and if the time came, Diane lived for several more months, said goodbye to friends and family, and took her life at home. Dr. Quill, who was not present at her death, later wondered "how many of the severely ill or dying patients secretly take their lives, dying alone in despair. He also wondered how many physicians "secretly help patients over the edge into death" when confronted with such profound suffering.

A grand jury refused to return an indictment after Dr. Quill admitted his role in Diane's death. The New York State Health Department's Board for Professional Medical Conduct also declined to pursue disciplinary proceedings. But Dr. Quill continued to be disturbed by the legal and medical subterfuge compelled by prohibitions against assisted dying. He noted how the law's restrictions "muddle clear thinking and discourage honesty," how he and his colleagues "have learned how to hedge our intentions and to act in purposefully ambiguous ways."

## B. The Legal Perspective

Dr. Quill's troubled conscience led him to the U.S. Supreme Court in 1997. Acting for themselves and on behalf of three mentally competent,

<sup>&</sup>lt;sup>112</sup> Esther B. Fein, *Decision Unlikely to Give Rise to More Prosecutions, Officials Say*, N.Y. Times, June 27, 1997, at A19 (quoting Frank Phillips, District Attorney for Orange County, N.Y.). For a discussion of euthanasia and assisted suicide prosecutions see Pratt, *supra* note 108, at 166-71.

<sup>&</sup>lt;sup>113</sup> Timothy Quill, Death and Dignity—A Case of Individualized Decision Making, in Arguing Euthanasia, supra note 74, at 55-62.

<sup>&</sup>lt;sup>114</sup> *Id*.

<sup>115</sup> Id. at 59.

<sup>116</sup> Id. at 60-62.

<sup>117</sup> *Id.* at 62.

<sup>&</sup>lt;sup>118</sup> *Id*.

<sup>&</sup>lt;sup>119</sup> Lisa W. Foderaro, New York Will Not Discipline Doctor for His Role in Suicide, N.Y. Times, Aug. 17, 1991, at 125.

<sup>&</sup>lt;sup>120</sup> *Id.* The Board reasoned that Dr. Quill himself "did not directly participate in any taking of life," distinguishing him from Dr. Jack Kevorkian and his "suicide machine." *See infra* text at note 206 for more on Dr. Kevorkian.

<sup>121</sup> Quill, When Palliative Care Fails, supra note 96, at 203.

<sup>122</sup> Id. at 203.

<sup>123</sup> Vacco v. Quill, 521 U.S. 793 (1997).

terminally ill patients, he and two other physicians challenged New York's prohibition against assisted suicide. 124 On the same day that the Supreme Court decided *Vacco v. Quill*, 125 it handed down its decision in *Washington v. Glucksberg*. 126 *Glucksberg*, also brought by physicians on behalf of themselves and competent, terminally ill patients, considered a constitutional challenge against Washington State's ban on assisted suicide. 127 That the petitioners in these cases viewed the judiciary as a "sympathetic partner" stemmed from prior court endorsement of the right to refuse medical treatment. 128 For a while, it did seem as though the courts were inclined to regard the issues as matters of self-determination. As Susan Channick has observed, "[i]n death and dying jurisprudence, the centerpiece of rights talk is personal autonomy." 129 In *Glucksberg* and *Quill*, however, the Supreme Court chose not to go down this path. 130 In fact, it virtually ignored autonomy as the critical element in the decision to end one's life. 131 Ultimately, the concept of personal choice became lost in the depths of judicial reasoning and, to date, has not resurfaced.

In 1976, Joseph Quinlan, acting as guardian for his daughter, Karen Ann, sought court authorization to remove her from her respirator. The young woman had lapsed from a coma into a persistent vegetative state after prolonged oxygen deprivation. Even before it reached the courts the Quinlan drama held the public riveted. 1970s culture had rediscovered mortality and found it fascinating. Elisabeth Kubler-Ross published her groundbreaking work, *On Death and Dying*, in 1969. Ernest Becker's *The Denial of Death* won the Pulitzer Prize in 1974. Furthermore, in Karen Ann Quinlan's plight, the public became aware of the very mixed blessings of emerging medical technologies. Karen's high school year-book picture became familiar world-wide, appearing on television screens and in newspapers and

<sup>&</sup>lt;sup>124</sup> *Id*.

<sup>&</sup>lt;sup>125</sup> *Id*.

<sup>&</sup>lt;sup>126</sup> Washington v. Glucksberg, 521 U.S. 702 (1997).

<sup>127</sup> Id.

<sup>&</sup>lt;sup>128</sup> Susan Channick, *The Myth of Autonomy at the End-of-Life: Questioning the Paradigm of Rights*, 44 VILL. L. REV. 577, 593-94 (1999).

<sup>&</sup>lt;sup>129</sup> Id. at 581.

<sup>130</sup> Glucksberg, 521 U.S. at 702; Quill, 521 U.S. at 793.

<sup>131</sup> Id.

<sup>&</sup>lt;sup>132</sup> In re Quinlan, 355 A.2d 647, 651 (N.J. 1976).

<sup>133</sup> Id. at 653-55.

<sup>&</sup>lt;sup>134</sup> See Kingwood College Library, American Cultural History, 1970–1979, http://kclibrary.nhmccd.edu/decade70.html (last visited Oct. 5, 2007) ("Many of the books published in the 70's revolved around a general theme of man's alienation from his spiritual roots.").

<sup>135</sup> ELISABETH KUBLER-ROSS, ON DEATH AND DYING (Macmillan 1970) (1969).

<sup>136</sup> ERNEST BECKER, THE DENIAL OF DEATH (Free Press Paperbacks 1997) (1973).

<sup>&</sup>lt;sup>137</sup> See The Pulitzer Prize Winners, http://www.pulitzer.org/ (last visited Oct. 5, 2007).

magazines.<sup>138</sup> When *In re Quinlan*<sup>139</sup> was decided by the New Jersey Supreme Court it was hailed as "the Brown v. Board of Education of the right-to-die movement."<sup>140</sup>

In granting Joseph Quinlan's request, the court accorded Karen a right to privacy, guaranteed by the Bill of Rights and previously recognized in *Griswold v. Connecticut* and *Roe v. Wade*.<sup>141</sup> Balancing this right against asserted State interests, the court concluded that the latter weakens "and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims." Given Karen's condition, and her inability to consciously exercise that right, the court allowed her father to act on her behalf. 143

Quinlan, consistent with his Catholic beliefs, sought detachment of the respirator (an extraordinary life-prolonging measure) but not the cessation of artificial nutrition and hydration (ordinary measures). Years later, Karen's mother, Julia, recalled how she and Joseph had hoped that, with the respirator removed, Karen would be "placed back in her natural state, and she would die on God's time." It is apparent also, from the tone and language of its opinion, that the court expected Karen would die soon after the respirator's removal. She lived for nine more years.

In 1990 the U.S. Supreme Court in *Cruzan v. Director, Mo. Dept. of Health*<sup>147</sup> declined to replicate *Quinlan*'s "right to privacy" reasoning as the basis for permitting refusal or withdrawal of medical treatment. The Court

<sup>&</sup>lt;sup>138</sup> Indeed, more than two decades after her death, the photograph is still readily viewable in her Wikipedia entry. *See* Wikipedia, http://en.wikipedia.org/wiki/Karen\_Ann\_Quinlan (last visited Oct. 19, 2007).

<sup>&</sup>lt;sup>139</sup> In re Quinlan, 355 A.2d 647 (N.J. 1976).

<sup>&</sup>lt;sup>140</sup> Dowbiggin, *supra* note 71, at 147 (quoting Peter G. Filene, In the Arms of Others: A Cultural History of the Right-to-Die in America 73 (1998)).

<sup>&</sup>lt;sup>141</sup> Quinlan, 355 A.2d at 663; see Roe v. Wade, 410 U.S. 113 (1973); Griswold v. Connecticut, 381 U.S. 479 (1965).

<sup>&</sup>lt;sup>142</sup> Quinlan, 355 A.2d at 664.

<sup>&</sup>lt;sup>143</sup> *Id*.

<sup>144</sup> Ordinary means are defined as those that offer a reasonable hope of benefit and do not unduly burden the patient or family. Food and water and common medical treatments have traditionally been considered ordinary means. In contrast, extraordinary means are defined as those which offer no hope of reasonable benefit and which are unduly burdensome to the patient and family. The distinction between these two types of care is not always clear and often depends on the particular circumstance of the patient as well as the relevant medical technologies. *See* William Saunders, *What is the Church's Teaching on Euthanasia?*, ARLINGTON CATHOLIC HERALD, Dec. 15, 1994, http://www.catholicculture.org/library/view.cfm?id=307.

<sup>&</sup>lt;sup>145</sup> CNN Transcript, http://transcripts.cnn.com/TRANSCRIPTS/0503/23/i\_ins.01.html (last visited Oct. 5, 2007).

<sup>&</sup>lt;sup>146</sup> *Id*.

<sup>&</sup>lt;sup>147</sup> Cruzan v. Dir. Mo. Dept. of Health, 497 U.S. 261 (1990).

<sup>148</sup> Id

appeared to prefer grounding such right of refusal in common law rights to bodily integrity through informed consent. In the course of its analysis, however, the Court did find that a competent person's right to refuse life-sustaining treatment arose from a constitutionally-protected liberty interest. But it was never clear, as some euthanasia activists claimed, that the Court intended to recognize a broad "right to die." Is a property of the refusal in common law rights to die.

Nancy Beth Cruzan, like Karen Ann Quinlan, was the object of intense media attention. 152 She was in her 20's when paramedics found her, unconscious and not breathing, following an automobile accident.<sup>153</sup> Severely oxygen-deprived, her breathing was restored but she required a permanent hydration and feeding tube. 154 By the time her case reached the Supreme Court, she had been hospitalized for seven years in a persistent vegetative state. 155 Regarding her wishes as to lifesaving medical procedures, she left no record except for a conversation with a roommate. 156 During this discussion, Nancy indicated that, if sick or injured, she would not want to go on living unless she could do so "halfway normally." 157 According to Missouri state law, clear and convincing evidence of an incompetent's wishes are required before medical treatment can be terminated. 158 Nancy's parents, acting as her surrogates, sought to discontinue artificial nutrition and hydration. 159 They had lost their battle in the state's highest court, unable to satisfy the law's requirement as to proof of Nancy's preferences. 160 They were left with no choice but to challenge the constitutionality of the statute.<sup>161</sup>

The Supreme Court, for purposes of weighing the constitutional merits of the law, assumed the existence of a "constitutionally protected right to refuse lifesaving hydration and nutrition." However, when balanced against the protections offered by the Missouri statute, the right was deemed not strong enough to invalidate the law. Weary yet persistent, the Cruzans returned to

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<sup>149</sup> Id. at 271.
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<sup>150</sup> Id. at 279.

<sup>&</sup>lt;sup>151</sup> See Dowbiggin, supra note 71, at 165.

<sup>&</sup>lt;sup>152</sup> See William H. Colby, Long Goodbye: The Deaths of Nancy Cruzan 118, 181-86, 221, 241, 243, 258-61, 267, 282, 342-43, 367 (2002).

<sup>&</sup>lt;sup>153</sup> *Id.* at 3-9.

<sup>&</sup>lt;sup>154</sup> *Id*.

<sup>155</sup> Id.

<sup>156</sup> Cruzan v. Dir. Mo. Dept. of Health, 497 U.S. 268 (1990).

<sup>157</sup> Id.

<sup>158</sup> Id. at 280.

<sup>159</sup> Id. at 265.

<sup>160</sup> Id.

<sup>&</sup>lt;sup>161</sup> Id. at 279-280.

<sup>&</sup>lt;sup>162</sup> Id. at 279.

<sup>&</sup>lt;sup>163</sup> See Louis M. Seidman, Confusion at the Border: Cruzan, "The Right to Die," and the Public/Private Distinction, 1991 Sup. Ct. Rev. 47, 48 (1991) ("Cruzan presented the Court

state court.<sup>164</sup> There, they filed a motion of intent to offer evidence from three of Nancy's former co-workers as to her views on life-sustaining treatment.<sup>165</sup> The Attorney General's office withdrew from the case and Nancy's feeding tube was finally disconnected.<sup>166</sup> She died twelve days later.<sup>167</sup>

The right to refuse life-sustaining treatment was crucial to the plaintiffs' arguments in *Vacco v. Quill.* At issue was a New York statute making it a crime to aid another in committing or attempting to commit suicide. The plaintiffs contended that, while New York permitted competent, terminally ill persons to hasten their deaths by refusing life-support measures, these same persons were prohibited from hastening death by ingesting drugs prescribed by a physician. The distinction, they claimed, was arbitrary and irrational, a clear violation of the 14th amendment's Equal Protection clause. The Furthermore, they argued, such unequal treatment bore no rational relation to legitimate state interests.

The Court of Appeals for the Second Circuit agreed, finding it impermissible for New York law to differentiate between two classes of persons in the final stages of terminal illness.<sup>173</sup> Those who are on life support are permitted to hasten death by directing the removal of life-prolonging treatment.<sup>174</sup> Those who are similarly situated but not on life support are barred from hastening death "by self-administering prescribed drugs."<sup>175</sup> In the Second Circuit's view, the withdrawal of life support, often accompanied by palliative drugs that may themselves contribute to death, requires an affirmative act by the physi-

with an excruciatingly difficult problem in drawing an appropriate boundary between realms of private and public decision making—between the private domain of individual rights and the public domain of community preferences.").

<sup>&</sup>lt;sup>164</sup> Lisa Belkin, Missouri Seeks to Quit Case of Comatose Patient, N.Y. Times, Oct. 12, 1990 at A15.

<sup>165</sup> Id.

<sup>&</sup>lt;sup>166</sup> Andrew H. Malcolm, Judge Allows Feeding-Tube Removal, N.Y. TIMES, Dec. 15, 1990 at 110.

<sup>167</sup> Andrew H. Malcolm, *Nancy Cruzan: End to Long Goodbye*, N.Y. TIMES, Dec. 29, 1990 at 18. The year after Nancy's death, her father said, "I've wondered sometimes if we have finally accomplished for God what he set out to do. People say that's blasphemy, but I don't mean it that way. I mean it as, 'Where does God fit into the equation?'" The family's ordeal did not end with Nancy's death. Mr. Cruzan hanged himself in 1996. Eric Pace, *Lester Cruzan is Dead at 62; Fought to Let His Daughter Die*, N.Y. TIMES, Aug. 19, 1996, at B12.

<sup>&</sup>lt;sup>168</sup> Vacco v. Quill, 521 U.S. 793, 797-98 (1997).

<sup>169</sup> Id. at 796.

<sup>&</sup>lt;sup>170</sup> *Id*.

<sup>&</sup>lt;sup>171</sup> Id. at 807.

<sup>172</sup> Id. at 793.

<sup>173</sup> Quill v. Vacco, 80 F. 3d 716, 729 (2d Cir. 1996).

<sup>&</sup>lt;sup>174</sup> *Id*.

<sup>175</sup> Id.

cian.<sup>176</sup> Rather than resulting from the natural progression of the disease, the ensuing death is caused by dehydration or respiratory failure.<sup>177</sup> Thus, terminating life by withdrawing treatment is "nothing more nor less than assisted suicide."<sup>178</sup> Further, in light of statutory and common law rights to refuse unwanted medical procedures, the preservation of the treatment withdrawal/assisted suicide distinction serves no state interest: "Physicians do not fulfill the role of 'killer' by prescribing drugs to hasten death any more than they do by disconnecting life support systems."<sup>179</sup>

The Supreme Court reversed, finding the distinction between treatment withdrawal and assisted suicide to be well grounded in medical and legal traditions: "When a patient refuses life-sustaining medical treatment, he dies from the underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication." The concept of intent was also important to the Court's determination. 181 A physician who complies with a request to terminate treatment intends only to honor his patient's wishes and to discontinue futile or degrading measures. 182 A physician who provides aggressive palliative care, drugs which may hasten a patient's death, is acting to relieve the patient's pain. 183 But "a patient who commits suicide with a doctor's aid necessarily has the specific intent to end his or her own life, while a patient who refuses or discontinues treatment might not."184 Moreover, the Court of Appeals had incorrectly assumed that the right to refuse treatment arose from "a general and abstract 'right to hasten death' "185 rather than the "rights to bodily integrity and freedom from unwanted touching." 186 Unlike the Second Circuit, the Supreme Court found the distinction between terminating treatment and aiding a suicide to be rationally related to valid public interests. 187 Among them was preserving life as well as the integrity of the medical profession, protecting the vulnerable from pressure to end their lives, and avoiding a "possible slide toward euthanasia." That the differentiation may be proper under an Equal Protection analysis, however, does not resolve the medical issues. Physicians and patients who perceive no meaningful differ-

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176 Id.
177 Id.
178 Id.
179 Id. at 730.
180 Vacco v. Quill, 521 U.S. 793, 801 (1997).
181 Id. at 801-02.
182 Id. at 801.
183 Id. at 802.
184 Id.
185 Id. at 807.
186 Id. (citing Cruzan v. Dir. Mo. Dept. of Health, 497 U.S. 268, 278-79 (1990)).
187 Vacco v. Quill, 521 U.S. at 800-01.
188 Id. at 808-09.
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ence between withdrawal of treatment and assisted suicide will, most likely, fail to be persuaded or comforted by legal arguments to the contrary.

The plaintiffs in *Glucksberg* also had their moment of victory in the court below. Sitting *en banc*, the U. S. Court of Appeals for the Ninth Circuit concluded that "the Constitution encompasses a due process liberty interest in controlling the time and manner of one's death—that there is, in short, a constitutionally-recognized 'right to die.'" As in *Vacco v. Quill*, the Supreme Court upon review was forced to reiterate and clarify its holding in *Cruzan* as to the rationale for the right to refuse medical treatment. Further, in reversing the Ninth Circuit, the Court alluded to "our Nation's history, legal traditions, and practices" embodied in the longstanding "commitment to the protection and preservation of all human life." Despite its very clear language in *Planned Parenthood of Southeastern Pa. v. Casey* on liberty as "the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life," Court in *Glucksberg* refused to extend due process protection to the right "to assistance in committing suicide."

The lack of unanimity in the Court's reasoning in *Glucksberg* and *Vacco v. Quill* is reflected in the six published opinions (one majority opinion in each case for the five-Justice majority, and four separate concurring opinions). <sup>195</sup> The complex nature of the problem engendered various legal rationales and no real consensus. None of the Justices considered autonomy a salient factor in his or her reasoning. Justice Souter preferred to rely on the analytical framework suggested in Justice Harlan's dissent in *Poe v. Ullman.* <sup>196</sup> Specifically, Justice Souter viewed the issue as "whether the statute in question falls inside or outside the zone of what is reasonable in the way it resolves the conflict between the interests of state and individual." <sup>197</sup> Justice O'Connor confined her discussion of rights to the observation that a terminally ill individual in great pain is not legally barred from obtaining medication to alleviate that pain, even "to the point of causing unconsciousness and hastening death." <sup>198</sup>

In the Glucksberg majority opinion, Chief Justice Rehnquist acknowledged

<sup>&</sup>lt;sup>189</sup> Washington v. Glucksberg, 521 U.S. 702 (1997).

<sup>&</sup>lt;sup>190</sup> Compassion in Dying v. Washington, 79 F. 3d 790, 816 (9th Cir.1996), rev'd sub nom. Washington v. Glucksberg, 521 U.S. 702 (1997).

<sup>&</sup>lt;sup>191</sup> Vacco v. Quill, 521 U.S. at 807.

<sup>192</sup> Glucksberg, 521 U.S. at 710.

<sup>&</sup>lt;sup>193</sup> Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 851 (1992).

<sup>&</sup>lt;sup>194</sup> Glucksberg, 521 U.S. at 728.

<sup>&</sup>lt;sup>195</sup> See id.; 521 U.S. at 736 (O'Connor, J., concurring); 521 U.S. at 752 (Souter, J., concurring in the judgment); 521 U.S. at 789 (Ginsburg, J., concurring in the judgments); 521 U.S. at 789 (Breyer, J., concurring in the judgments).

<sup>&</sup>lt;sup>196</sup> *Id.* at 752, 756 (Souter, J., concurring in the judgment) (citing Poe v. Ullman, 367 U.S. 497, 543 (1961) (Harlan, J., dissenting)).

<sup>&</sup>lt;sup>197</sup> Glucksberg, 521 U.S. at 768 (Souter, J., concurring in the judgment).

<sup>198</sup> Id. at 733-37 (O'Connor, J., concurring).

that, although Due Process protections of rights and liberties "sound in personal autonomy," that alone did not "warrant the sweeping conclusion that any and all important, intimate, and personal decisions are so protected." That the patients in *Quill* and *Glucksberg*, all competent, had carefully and thoughtfully considered their decisions to hasten their deaths was simply not dispositive. Yet the real value of these Supreme Court decisions may well reside in their restraint. Chief Justice Rehnquist, writing for the Court in *Glucksberg*, concludes his opinion with the hope and expectation that end-of-life issues will continue to be discussed in other, perhaps more appropriate, forums: "Throughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society."

In declining to usurp the role of the legislature, the Court "changed the focus of the discussion from rights talk to informing public policy." As the effects of decriminalizing assisted suicide were largely unknown, the question of rights may have been posed to the Court prematurely. Further, the Court was uncomfortable with "bootstrapping" the morality and desirability of assisted suicide onto *Cruzan*'s right to refuse life-sustaining treatment. Proponents of assisted suicide would have to find their own moral justification for hastening death.

#### IV. LEGISLATING DEATH

This is probably the first time that this august body has been addressed by someone under indictment on two counts of first-degree murder.<sup>205</sup>

Jack Kevorkian, acceptance speech for the 1994 Humanist Hero Award from the American Humanist Association. 206

<sup>199</sup> Id. at 727 (majority opinion).

<sup>&</sup>lt;sup>200</sup> Channick, supra note 128, at 605.

<sup>&</sup>lt;sup>201</sup> Glucksberg, 521 U.S. at 735.

<sup>&</sup>lt;sup>202</sup> Channick, supra note 128, at 607.

<sup>&</sup>lt;sup>203</sup> Id. at 600.

<sup>&</sup>lt;sup>204</sup> Id. at 607.

<sup>&</sup>lt;sup>205</sup> Jack Kevorkian, Acceptance Speech for the 1994 Humanist Hero Award, *in* Jack Kevorkian, *A Modern Inquisition*, The Humanist, Nov.-Dec. 1994, at 7, *available at* http://findarticles.com/p/articles/mi m1374/is n6 v54/ai 15922710.

<sup>&</sup>lt;sup>206</sup> A strident advocate of physician-assisted suicide, Dr. Kevorkian claimed to have helped more than 130 terminally ill people in their deaths. In the 1990s, he successfully evaded four prosecutorial attempts at a murder conviction. Pam Belluck, *Assisted-Suicide Advocates See Gains in Kevorkian Case*, N.Y. Times, Mar. 30, 1999, at A14. In 1999, however, Kevorkian was convicted of second-degree murder in Michigan and sentenced to ten to twenty-five years in prison. Monica Davey, *Kevorkian Freed After Years in Prison for Aiding Suicide*, N.Y. Times, June 2, 2007, at A8. He was released in 2007, having agreed as a condition of parole not to participate in future suicides. *Id*.

I bargained for salvation an' they gave me a lethal dose.<sup>207</sup> Bob Dylan, *Shelter from the Storm* 

#### A. Obstacles to Statutory Development

In his reticence about according constitutional remedies to the plaintiffs in *Glucksberg*, Chief Justice Rehnquist was acknowledging the need for objectivity and ongoing analysis in end-of-life matters.<sup>208</sup> He was fully aware of the "subjective elements that are necessarily present in due-process judicial review."<sup>209</sup> In deferring to the functions of public debate and legislative action, Rehnquist ensured that judicial treatment of due process protections would not "be subtly transformed into the policy preferences of the Members of this Court."<sup>210</sup> Perhaps the Justices had taken a lesson from *Roe v. Wade*,<sup>211</sup> that imposing a constitutional right on a bitterly contested issue does not conclusively resolve it. The tension between public and private spheres may not be so easily resolved.<sup>212</sup>

The outraged response of physicians to "It's Over, Debbie" was not necessarily echoed in the public's reaction. In an editorial in *The Journal of the American Medical Association*, George Lundberg, MD observed that "many of our patients would want active euthanasia if needed, and they would want it performed by doctors." As he saw it, the medical profession could "ignore the pressure," refuse to participate, even actively attempt to "repress the movement," or it could begin to explore the development of medically ethical guidelines. That such guidelines have not emerged may be due to the medical profession's continued resistance and the public's lack of consensus. 216

In 1985, New York's Governor Mario Cuomo convened the Task Force on Life and the Law, a panel of doctors, nurses, lawyers, clergy, and medical ethicists.<sup>217</sup> The panel was given "a broad mandate to recommend public poli-

<sup>&</sup>lt;sup>207</sup> Bob Dylan, Shelter from the Storm, on Blood on the Tracks (Sony 1975).

<sup>&</sup>lt;sup>208</sup> Washington v. Glucksberg, 521 U.S. 702, 722, 735 (1997).

<sup>&</sup>lt;sup>209</sup> Id. at 722.

<sup>&</sup>lt;sup>210</sup> *Id.* at 720 (citing Moore v. City of E. Cleveland, Ohio, 431 U.S. 494, 502 (1977)).

<sup>&</sup>lt;sup>211</sup> Roe v. Wade, 410 U.S. 113 (1973).

<sup>&</sup>lt;sup>212</sup> See Seidman, supra note 163, at 59 ("Most of constitutional law consists of an effort to delineate a boundary between [the public and private] spheres, and much of the modern critique of constitutional law consists of an attack on the coherence of this boundary.").

<sup>&</sup>lt;sup>213</sup> Anon., supra note 69.

<sup>&</sup>lt;sup>214</sup> George D. Lundberg, 'It's Over, Debbie' and the Euthanasia Debate, 259 J. Am. Med. Ass'n 2142, 2143 (1988).

<sup>&</sup>lt;sup>215</sup> Id.

<sup>&</sup>lt;sup>216</sup> See infra Section IV.B for a discussion of euthanasia in the Netherlands and physician-assisted suicide in Oregon.

<sup>217</sup> N.Y. TASK FORCE, supra note 35, at vii.

cy on issues raised by medical advances."<sup>218</sup> In 1994, the Task Force produced an exhaustive report on matters pertaining to suicide, terminal illness, and end-of-life care, unanimously recommending that New York's law not be changed to accommodate euthanasia or assisted suicide.<sup>219</sup> Donald McKinney, a Task Force member, proposed that, while the law should not sanction a deliberate act to aid someone in taking his or her own life, "it should be left a private act, with society able to be called in to judgment when and if the motive should be impugned."<sup>220</sup> While not an ideal system of justice, it was one that afforded "the least possibility of abuse."<sup>221</sup>

McKinney's comments suggest that euthanasia was as ill-suited to a legislative solution as it was to a judicial one. In 1990, Washington State filed Ballot Initiative 119, the first state voter referendum on euthanasia and physician-assisted suicide. Most of the state's physicians opposed it, and the American Medical Association mailed out thousands of anti-119 brochures. Lavish amounts of money spent by pro-life organizations as well as rhetoric supplied by public figures like C. Everett Koop and Archbishop John Cardinal O'Connor helped sway voters and defeat the initiative. In California, the campaign for a ballot initiative on "aid-in-dying" began in 1988 and culminated in defeat by voters four years later. Subsequent attempts to legislate assisted suicide in California failed in 1995, 1999, 2005, 2006 and 2007. In 2000, voters in Maine defeated a ballot initiative by the extremely narrow margin of fifty-one percent to forty-nine percent. In Michigan, Dr. Kevorkian's home state, voters rejected an assisted suicide initiative in 1998.

<sup>&</sup>lt;sup>218</sup> *Id*.

<sup>&</sup>lt;sup>219</sup> *Id.* at 120. In 1997, while the U.S. Supreme Court decisions in *Quill* and *Glucksberg* were pending, the Task Force issued a supplemental report confirming its earlier recommendations. The panel also re-emphasized the distinction between physician-assisted suicide and treatment withdrawal and its opposition to the legalization of assisted dying. N.Y. Task Force on Life and the Law, When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context, Supplement to Report (April 1997), *available at* http://www.health.state.ny.us/nysdoh/taskfce/sought.pdf.

<sup>&</sup>lt;sup>220</sup> N.Y. TASK FORCE, *supra* note 35, at 102 (internal citation omitted).

<sup>&</sup>lt;sup>221</sup> Id. at 103 (internal citation omitted).

<sup>&</sup>lt;sup>222</sup> Kathi Hamlon, International Task Force on Euthanasia and Assisted Suicide, Failed Attempts to Legalize Euthanasia/Assisted-Suicide in the United States, www.international taskforce.org/usa.htm (last visited Oct. 7, 2007).

<sup>&</sup>lt;sup>223</sup> Dowbiggin, supra note 71, at 170.

<sup>&</sup>lt;sup>224</sup> Id.

<sup>&</sup>lt;sup>225</sup> Id. at 171.

<sup>&</sup>lt;sup>226</sup> See Hamlon, supra note 222. On the failure to advance the California bill in 2007, see International Task Force on Euthanasia and Assisted Suicide, Assisted-Suicide Advocates Fail to Advance Bill in California, Update 2007, http://www.internationaltaskforce.org/iua41.htm#1.

<sup>&</sup>lt;sup>227</sup> Hamlon, supra note 222.

<sup>&</sup>lt;sup>228</sup> Id.

a contentious one in state legislatures: In 2007, bills legalizing euthanasia or assisted suicide were introduced, but not passed, in Arizona, California, Hawaii, Rhode Island, Vermont, and Wisconsin.<sup>229</sup>

Jack Kevorkian and his "mercitron" may have done much to raise the public's consciousness as to euthanasia. He claimed to have helped more than 130 people die, not all of them terminally ill. With his sinister and rather unsavory aspect and his overzealousness, Kevorkian alienated many who might otherwise have been sympathetic to his cause. Kevorkian was most effective in portraying end-of-life illness as agonizing and untreatable. Having thus frightened the public, he then offered up his expedient brand of mercy. In 1991, Dr. Timothy Quill referred to Kevorkian and his antics as "a kind of sideshow." Neither Kevorkian's crusade nor the "news coming out of the Netherlands" could manage to dispel the cloud of uncertainty lingering over the euthanasia question. 236

B. Assisted Suicide Abroad and at Home: The Netherlands and Oregon<sup>237</sup>

The Dutch have tolerated assisted dying for at least several dec-

<sup>&</sup>lt;sup>229</sup> International Task Force on Euthanasia and Assisted Suicide, Euthanasia & Assisted-Suicide Measures Proposed (2007), http://www.internationaltaskforce.org/us\_bills.htm (last visited Oct. 9, 2007).

<sup>&</sup>lt;sup>230</sup> See International Task Force on Euthanasia and Assisted Suicide, *The Real Jack Kevorkian*, http://www.internationaltaskforce.org/fctkev.htm (last visited Oct. 9, 2007); see also Davey supra note 206, at A8.

<sup>&</sup>lt;sup>231</sup> Belluck, supra note 206, at A14.

<sup>&</sup>lt;sup>232</sup> Id.

<sup>&</sup>lt;sup>233</sup> See Foley, supra note 48, at 187.

<sup>&</sup>lt;sup>234</sup> Id.

<sup>&</sup>lt;sup>235</sup> Belluck, supra note 206, at A14.

<sup>&</sup>lt;sup>236</sup> Dowbiggin, supra note 71, at 169.

<sup>&</sup>lt;sup>237</sup> Belgium and Switzerland also have legalized euthanasia and/or assisted suicide. However, because the Dutch law came first and Dutch practice has been more extensively studied, this essay limits mention of the Belgian and Swiss laws and practice to the following summary: In 2002, Belgium passed a law allowing euthanasia and assisted suicide for patients who request it while suffering unbearably and for whom clinical treatment is considered hopeless. See Herman Nys, Physician Assisted Suicide in Belgian Law, 12 Eur. J. HEALTH L. 39 (2005). In the first two years under the new legislation, approximately 400 deaths by euthanasia were recorded. Expatica.com, 400 Belgian Euthanasia Cases in Two Years, July 9, 2004, http://www.expatica.com/actual/article.asp?channel\_id=3&story\_ id=9350. In 2005, the euthanasia rate doubled, as Belgian doctors reported 400 cases in that year. Expatica.com, Euthanasia Cases Double Since Legalisation, Feb. 7, 2006, http:// www.expatica.com/actual/article.asp?channel\_id=3&story\_id=27432. The head of the Federal Control and Evaluation Commission for Euthanasia suspected, however, that the actual number of euthanasia deaths may be up to five times the official number. Id.; Expatica.com, Belgian Euthanasia Cases 'Exceed Official Reports,' Sept. 5, 2005, http://www.expatica. com/actual/article.asp?channel\_id=3&story\_id=23437. Observing that euthanasia only ac-

ades. 238 Beginning in the 1970s, a series of court cases effectively decriminalized euthanasia and conferred immunity from prosecution on euthanizing doctors.<sup>239</sup> In 1990, the Dutch government appointed a commission to study how euthanasia was actually being practiced in the Netherlands.<sup>240</sup> The resulting Remmelink report, issued the following year, revealed that in over 1000 of Holland's 130,000 annual deaths, "physicians admitted they actively caused or hastened death without any request from the patient."241 In 25,000 cases, physicians made end-of-life decisions likely to result in death without consulting their patients. 242 Despite regulatory guidelines, physicians in 1990 reported patient euthanasia deaths to the authorities in only eighteen percent of the cases.<sup>243</sup> By 1995, simplified notification procedures had improved the reporting rate to forty-one percent.<sup>244</sup> A euthanasia study conducted in 1995 and 1996 reported that an average of ten percent of eligible physicians had declined to take part in the study.<sup>245</sup> Observing that the incidence of underreporting and physician non-participation could compromise the study's accuracy, Dr. Sherwin Nuland posited the likelihood "that the physicians whose patients experienced the worst complications would be most reluctant to answer questions

counts for between three and four deaths out of every 1000, the Commission viewed the increased rate of euthanasia "as the result of progressive diffusion of information on euthanasia rather then [sic] a change in attitude." Expatica.com, *Belgium Keeps Tight Reins on Euthanasia Legislation*, Nov. 9, 2006, http://www.expatica.com/actual/article.asp?channel\_id=3&story\_id=34248.

In Switzerland, by contrast, assisted suicide has been effectively privatized; it is a crime only if those helping can be shown to have acted in self-interest. See Olivier Guillod & Aline Schmidt, Assisted Suicide under Swiss Law, 12 Eur. J. Health L. 25 (2005); BBC News, Family's Plea on Assisted Death, June 2, 2006, http://news.bbc.co.uk/2/hi/uk\_news/wales/5041306.stm; BBC News, Dignitas: Swiss Suicide Helpers, Jan. 20, 2003, http://news.bbc.co.uk/2/hi/europe/2676837.stm.

<sup>238</sup> Herbert Hendin, Legalized Euthanasia in the Netherlands Has Resulted in Many Deaths Without Consent, in Euthanasia supra note 48, at 149 [hereinafter Hendin, Legalized Euthanasia].

<sup>&</sup>lt;sup>239</sup> Id. at 149-50.

<sup>&</sup>lt;sup>240</sup> Id. at 151.

<sup>&</sup>lt;sup>241</sup> Herbert Hendin, Safeguards Cannot Prevent Abuse of Legalized Euthanasia, in EUTHANASIA: OPPOSING VIEWPOINTS, supra note 63, at 145 (emphasis added) [hereinafter Hendin, Safeguards Cannot Prevent Abuse]; see also Norman L. Cantor & George C. Thomas III, The Legal Bounds of Physician Conduct Hastening Death, 48 BUFF. L. Rev. 83, 169 (2000) ("All empirical studies of the Dutch experience show that some percentage of euthanasia acts are performed on incompetent patients despite the ostensible impermissibility of such acts under Dutch law.").

<sup>&</sup>lt;sup>242</sup> Hendin, Safeguards Cannot Prevent Abuse, supra note 241, at 145.

<sup>&</sup>lt;sup>243</sup> Id. at 154.

<sup>&</sup>lt;sup>244</sup> Id. at 154.

<sup>&</sup>lt;sup>245</sup> Johanna H. Groenewoud et al., Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands, 342 New Eng. J. Med. 551, 552 (2000).

about untoward events."246

The Dutch, apparently undeterred by these findings, officially legalized assisted suicide and voluntary active euthanasia in 2001.<sup>247</sup> Eligible candidates now include those suffering from psychological distress as well as chronic and terminal illness, children, and individuals with mental retardation or brain damage.<sup>248</sup> At least one critic of euthanasia in the Netherlands has claimed that, because it is easier, euthanasia has replaced the use of palliative and hospice care for the chronically sick and dying.<sup>249</sup>

Opponents of the "Dutch cure" were especially repelled by the specter of involuntary euthanasia. 250

The failed initiatives in California and Washington in the early 1990s would have allowed euthanasia by lethal injection as well as assisted suicide. <sup>251</sup> In contrast, physician-assisted suicide, limited to competent, terminally ill adults, seemed a more respectable, moderate alternative. <sup>252</sup> The state of Oregon, with its political culture of "libertarianism, progressive populism, and the lowest rate of churchgoing" in the nation, proved highly hospitable to assisted suicide. <sup>253</sup> In 1994, the state's voters approved the Oregon Death with Dignity Act (ODWDA). <sup>254</sup> However, implementation was delayed by a federal court ruling that the statute violated the Fourteenth Amendment. <sup>255</sup> After this decision was vacated on procedural grounds, <sup>256</sup> the Act was held in further abeyance pending the Supreme Court's decisions in *Glucksberg* and *Quill*. <sup>257</sup> In 1997, Oregon voters defeated a measure to repeal the Act by an even greater margin than the majority originally supporting it in 1994. <sup>258</sup>

<sup>&</sup>lt;sup>246</sup> Sherwin B. Nuland, *Physician-Assisted Suicide and Euthanasia in Practice*, 342 New Eng. J. Med. 583, 583 (2000).

<sup>&</sup>lt;sup>247</sup> Dowbiggin, supra note 71, at 169.

<sup>&</sup>lt;sup>248</sup> Hendin, Safeguards Cannot Prevent Abuse, supra note 241, at 144; see also Rita L. Marker, International Task Force on Euthanasia and Assisted Suicide, Euthanasia, Assisted Suicide & Health Care Decisions: Protecting Yourself & Your Family, 2006, http://www.internationaltaskforce.org/rpt2006\_1.htm#108.

<sup>&</sup>lt;sup>249</sup> Hendin, Legalized Euthanasia, supra note 238, at 159.

<sup>&</sup>lt;sup>250</sup> Hendin, Safeguards Cannot Prevent Abuse, supra note 241, at 145.

<sup>&</sup>lt;sup>251</sup> Marker, supra note 248.

<sup>&</sup>lt;sup>252</sup> Id.

<sup>&</sup>lt;sup>253</sup> Dowbiggin, supra note 71, at 171.

<sup>&</sup>lt;sup>254</sup> OR. REV. STAT. § 127.800 (2000).

<sup>&</sup>lt;sup>255</sup> Lee v. Oregon, 891 F. Supp. 1429, 1438 (D. Or. 1995) (holding that the Act violated the Fourteenth Amendment's Equal Protection Clause because it "singles out terminally ill persons who want to commit suicide and excludes them from protection of Oregon laws that apply to others."), vacated and remanded, 107 F.3d 1382 (9th Cir. 1997).

Lee v. Oregon, 107 F.3d 1382 (9th Cir. 1997) (holding that the plaintiffs, doctors, patients, and residential care facilities challenging the facial validity of the Act failed to establish actual injury, as required for standing).

<sup>&</sup>lt;sup>257</sup> Pratt, *supra* note 108, at 187.

<sup>&</sup>lt;sup>258</sup> Id.

The federal government responded by seizing on the Controlled Substances Act ("CSA")<sup>259</sup> as a means to obstruct operation of the Oregon statute. In November 2001, United States Attorney General John Ashcroft issued an interpretive rule declaring that physicians who prescribe lethal substances to assist in suicide are in violation of the CSA.<sup>260</sup> An Oregon federal district judge issued a permanent injunction against enforcement of Ashcroft's rule and was upheld by the U.S. Court of Appeals for the Ninth Circuit.<sup>261</sup> The Supreme Court agreed, concluding that the CSA did not authorize the Attorney General to prohibit doctors from prescribing regulated drugs in accordance with the ODWDA.<sup>262</sup> As of this writing, the Act remains in effect.

Somewhat strangely, the facilitation of suicide contemplated by the ODWDA is legislatively determined not to constitute "assisted suicide, mercy killing or homicide, under the law."263 The statute further forbids the use of "lethal injection, mercy killing or active euthanasia" to end a patient's life. 264 To qualify for death with dignity under the law, one must be an adult Oregon resident, mentally competent, terminally ill and, within reasonable medical judgment, likely to die within six months. 265 The patient's request for life-ending medication must be voluntary and in writing.<sup>266</sup> Upon receipt of such request, the attending physician must determine whether the patient is terminally ill, refer the patient to a consulting physician for confirmation of the diagnosis, and ensure that the patient is making an informed decision.<sup>267</sup> If, in the attending physician's opinion, the patient's judgment is impaired by a psychiatric or psychological illness or depression, the physician shall refrain from prescribing the medication and refer the patient for counseling.<sup>268</sup> If the counselor determines the patient's judgment is not impaired, the physician may prescribe the medication.<sup>269</sup> Once a physician deems it appropriate to prescribe the medication, there is no further obligation to follow up with the patient or to be present when the drugs are ingested.<sup>270</sup>

Oregon's Department of Human Services ("DHS") issues yearly reports on physician compliance and the characteristics of those who have died pursuant

<sup>&</sup>lt;sup>259</sup> 21 U.S.C. §§ 801-802, 811-814, 821-830, 841-844a, 846-848, 850-856, 858-864, 871-890, 901-904 (2000).

<sup>&</sup>lt;sup>260</sup> Oregon v. Ashcroft, 192 F. Supp. 2d 1077, 1078-79 (D. Or. 2002), aff'd, 368 F.3d 1118 (9th Cir. 2004), aff'd sub nom. Gonzales v. Oregon, 546 U.S. 243 (2006).

<sup>&</sup>lt;sup>261</sup> *Id*.

<sup>&</sup>lt;sup>262</sup> Gonzales, 546 U.S. at 274-75.

<sup>&</sup>lt;sup>263</sup> Or. Rev. Stat. § 127.880 (2000).

<sup>&</sup>lt;sup>264</sup> Id.

<sup>&</sup>lt;sup>265</sup> Id.

<sup>&</sup>lt;sup>266</sup> *Id*.

<sup>&</sup>lt;sup>267</sup> Id. at § 127.815.

<sup>&</sup>lt;sup>268</sup> *Id.* at §§ 127.815, 127.825.

<sup>&</sup>lt;sup>269</sup> *Id.* at § 127.825.

<sup>&</sup>lt;sup>270</sup> Id. at § 127.815.

to the Act. According to the DHS, from the passage of the ODWDA in 1997 to 2006, 292 people died from ingesting lethal medication.<sup>271</sup> Most of them were white, between the ages of sixty-five and eighty-four, and suffering from cancer, ALS, or HIV/AIDS.<sup>272</sup> Only nine percent of participants had less than a high school education, while forty-one percent had a college degree or higher.<sup>273</sup> Almost without exception, they were medically insured, either privately or through Medicare or Medicaid.<sup>274</sup> The vast majority died at home (ninety-three percent), with seventy-six percent enrolled in hospice care.<sup>275</sup>

The principal end of life concerns motivating these patients were "loss of autonomy," "loss of dignity," and the feeling of being less able to engage in activities that make life enjoyable.<sup>276</sup> More than half were distressed at losing control of bodily functions, while more than a third feared they had become a burden on family, friends or caregivers.<sup>277</sup> Less prominent among the participants' concerns was the financial implications of treatment (seven percent).<sup>278</sup> During 2006, a far greater number of participants was concerned about inadequate pain control than in previous years, an increase from twenty-two percent to forty-eight percent.<sup>279</sup> During 2006, a far greater number of "participants were concerned about inadequate pain control . . . than in previous years . . .," an increase of twenty-two percent to forty-eight percent.<sup>280</sup>

These statistics seem to undermine the assertion that poor, uninsured and uneducated persons who are ill are especially at risk of pressure to commit suicide. Furthermore, the factors of intolerable pain or fear of inadequate pain control, while certainly significant, appear not as paramount as one might expect.<sup>281</sup> This does not mean, however, that, in general, relief of pain for many patients is adequate or even acceptable.<sup>282</sup> Nor does it mean that the 292 Oregon patients who opted for death might not have benefited, whatever their ultimate choice, from decent palliative care.<sup>283</sup>

The ODWDA requires physicians to document compliance with the statute

OR. DEP'T OF HUMAN SERVS., SUMMARY OF OREGON'S DEATH WITH DIGNITY ACT—2006 1 (2006), available at http://oregon.gov/DHS/ph/pas/docs/year9.pdf.

<sup>&</sup>lt;sup>272</sup> OR. DEP'T OF HUMAN SERVS., EIGHTH ANNUAL REPORT ON OREGON'S DEATH WITH DIGNITY ACT 12, Table 1 (March 9, 2006) [hereinafter cited as "DHS Report"].

<sup>&</sup>lt;sup>273</sup> *Id.* at Table 1.

<sup>&</sup>lt;sup>274</sup> *Id.* at Table 4.

<sup>&</sup>lt;sup>275</sup> Or. Dep't of Human Servs., *supra* note 271.

<sup>276</sup> Id

<sup>&</sup>lt;sup>277</sup> DHS Report, supra note 272, at 23.

<sup>&</sup>lt;sup>278</sup> Id.

<sup>&</sup>lt;sup>279</sup> *Id.* at 2.

<sup>&</sup>lt;sup>280</sup> Id. at 2.

<sup>&</sup>lt;sup>281</sup> *Id.* at 2.

<sup>&</sup>lt;sup>282</sup> See Marker, supra note 248.

<sup>&</sup>lt;sup>283</sup> Summary of Oregon's Death with Dignity Act—2006, supra note 271, at 1.

in the patient's medical record.<sup>284</sup> These records are then submitted to the DHS for preparation of its annual review.<sup>285</sup> As physicians are essentially self-reporting, there is no way to know how many prescriptions went unreported or to confirm the accuracy of the physician's documentation. Upon completion of each year's report, the DHS destroys all pertinent patient records, thus preventing any examination of each doctor's compliance from year to year.<sup>286</sup> In fact, the DHS has neither the regulatory authority nor the resources to ensure that physicians are acting in accordance with the law.<sup>287</sup>

Almost entirely absent from these annual reviews is data concerning the doctor-patient relationship. According to one report, two-thirds of patients seeking assistance under OWDWA could not get a prescription from the first physician they contacted.<sup>288</sup> Nearly half asked two or three other physicians.<sup>289</sup> DHS reported that, in 2005, the median length of the doctor-patient relationship was eight weeks.<sup>290</sup> This statistic does not indicate how often the patient was seen or the nature and extent of the doctor-patient discussions. Although the great majority of patients were enrolled in hospice care, there is no information as to whether hospice personnel were consulted or any way involved in the patient's decision to end his or her life.

That Oregon physicians so frequently and unilaterally deemed their patients mentally competent is also troubling, given the well-established link between mental illness and suicide.<sup>291</sup> Since 1998, only fourteen percent of patients have been referred for psychiatric evaluation, a mere five percent in 2005.<sup>292</sup> The ODWDA does not require an initial psychiatric evaluation, nor is the physician required to treat depression or any other mental illness if one is found.<sup>293</sup> Most doctors are inadequately trained in diagnosing depression, particularly in complex cases where the patient is terminally ill.<sup>294</sup> Medical illness "may obscure indicia of depression, rendering the diagnosis difficult."<sup>295</sup> According to one large-scale study, terminally ill patients requesting suicide "all suffered

<sup>&</sup>lt;sup>284</sup> Id. at 9.

<sup>&</sup>lt;sup>285</sup> Or. Rev. Stat. 127.855 § 3.09 (1999) & 127.865 § 3.11 (1999).

<sup>&</sup>lt;sup>286</sup> Marker, supra note 248.

<sup>&</sup>lt;sup>287</sup> See Linda Prager, Details Emerge on Oregon's First Assisted Suicides, Am. Med. News, Sept. 1998, at 10.

<sup>&</sup>lt;sup>288</sup> Amy D. Sullivan et al., Legalized Physician-Assisted Suicide in Oregon—The Second Year, 342 New Eng. J. Med. 598, 601 (2000).

<sup>&</sup>lt;sup>289</sup> Id. at 603.

<sup>&</sup>lt;sup>290</sup> DHS Report, supra note 272 at 24, Table 4.

<sup>&</sup>lt;sup>291</sup> See supra text accompanying notes 20-31.

<sup>&</sup>lt;sup>292</sup> DHS Report, supra note 272, at 23.

<sup>&</sup>lt;sup>293</sup> See N. Gregory Hamilton & Catherine Hamilton, Competing Paradigms of Response to Assisted Suicide Requests in Oregon, 162:6 Am. J. PSYCHIATRY 1060, 1061 (2005).

<sup>&</sup>lt;sup>294</sup> N.Y. TASK FORCE, supra note 35, at 127.

<sup>&</sup>lt;sup>295</sup> Id.

from symptoms of depression or irrational hopelessness."<sup>296</sup> Under the traditional clinical model these patients would be treated for their symptoms.<sup>297</sup> Under the OWDWA, they may well be given prescriptions for lethal drugs.<sup>298</sup> Moreover, even if a patient is initially deemed mentally competent, there is no further physician follow-up to ensure that the patient remained competent to the time when he or she actually took the fatal overdose.<sup>299</sup>

Proponents of assisted dying often claim that merely possessing the means and the knowledge of how to end their lives brings solace to the terminally ill. Thus, "[o]ne woman had purchased poison more than a decade before she died, when her cancer was first diagnosed, so that she would never be without the means of controlling the end of her life, should it become unbearable." Some doctors even believe that this sense of control may prolong a patient's life. This view, while well-intentioned, conflicts with the well-established psychiatric practice of removing lethal instrumentalities from the proximity of suicidal individuals. As depression so often accompanies suicide, it is difficult to be certain that the decision to use lethal drugs is based on a rational determination to end one's life, free of the distorting overlay of mental illness.

Another suspect entry in the DHS Report for 2006 is its finding that patients who ingested the medication suffered complications only five percent of the time. The five percent of their patients ingested the lethal medication. The other sixty-five percent were, evidently, not present to witness their patient's deaths and may be providing information based on "secondhand accounts" or "guesswork." The authors of the DHS report acknowledge that accounts by "family members, friends or other health professionals" attending the patient's death are often the source of the physician's narrative. The source of the physician's narrative.

The most common complications associated with assisted suicide are vomiting, spasm and difficulties with completion ("longer-than-expected interval be-

<sup>&</sup>lt;sup>296</sup> Hamilton & Hamilton, supra note 293, at 1060.

<sup>&</sup>lt;sup>297</sup> Id.

<sup>&</sup>lt;sup>298</sup> Id.

<sup>&</sup>lt;sup>299</sup> Marker, supra note 248.

<sup>&</sup>lt;sup>300</sup> See Derek Humphry, Voluntary Euthanasia is Ethical, in Euthanasia: Opposing Viewpoints, supra note 63, at 22.

<sup>&</sup>lt;sup>301</sup> Sullivan et al., supra note 288, at 603.

<sup>302</sup> Hamilton & Hamilton, supra note 293, at 1063.

<sup>&</sup>lt;sup>303</sup> Id

<sup>304</sup> DHS Report, supra note 272 at 24, Table 4.

<sup>&</sup>lt;sup>305</sup> DHS Report, *supra* note 272, at 23-24, Table 4. According to the DHS Report, "other" health care providers were present in 54 percent of the cases. DHS Report, *supra* note 272, at 23.

<sup>306</sup> Marker, supra note 248.

<sup>307</sup> DHS Report, supra note 272, at 9.

tween administration of medications and death.").<sup>308</sup> In the Netherlands, the Royal Dutch Medical Association advises doctors to be present when their patients undergo assisted suicide or euthanasia.<sup>309</sup> A physician who elects not to be present, perhaps at the patient's request, must arrange to be available if the complications develop.<sup>310</sup> One Dutch study examined problems arising in 114 assisted suicide cases (roughly half the number of all 246 patients dying pursuant to ODWDA since 1998), and found complications in seven percent of these cases.<sup>311</sup> In some instances, physicians had to step in and administer a lethal injection.<sup>312</sup> In Oregon, since nearly two-thirds of physicians are not present when their patients ingest the lethal medication, they are not there to witness any complications which might occur. Those in attendance are constrained by statute from ending a patient's life by lethal injection, mercy killing or active euthanasia.<sup>313</sup> Thus, they are barred from interventions which, in the event of complications, might end the patient's nightmare.

If the "Dutch cure" arouses some medical and ethical alarms, the "Oregon cure" should too. Questions regarding physician reporting, follow-up and lack of presence at the patient's death, along with cursory attention to mental health concerns, all seem to mock the statute's stated intent to deliver death with dignity. At the beginning of the 21st century, no other state has followed Oregon's example in enacting legislation to permit assisted suicide. But the story is far from over.

#### V. Lessons on Dying

The elders of the tribe meet and decide to propitiate Nature by sacrificing a young girl. A maiden is selected. . . . She is ordered by the elders to dance herself to death. She pleads pathetically, telling them that she is not that good a dancer.

Woody Allen, A Guide to Some of the Lesser Ballets<sup>314</sup>

I am no coward, but I am so strong, [it is] so hard to die.

Meriwether Lewis<sup>315</sup>

<sup>&</sup>lt;sup>308</sup> Groenewoud et al., supra note 245, at 554.

<sup>&</sup>lt;sup>309</sup> *Id.* at 556.

<sup>310</sup> Id.

<sup>311</sup> Id. at 555.

<sup>312</sup> Id. at 554.

<sup>&</sup>lt;sup>313</sup> Or. Rev. Stat. 127.880 § 3.14 (1999).

<sup>&</sup>lt;sup>314</sup> WOODY ALLEN, A Guide to Some of the Lesser Ballets, in Without Feathers 17 (Random House 1972) (1975).

<sup>&</sup>lt;sup>315</sup> STEPHEN AMBROSE, UNDAUNTED COURAGE 456 (1996). Ambrose provides a poignant account of Lewis's suicide. *Id.* at 465.

#### A. The Limited Uses of Autonomy

Two words crop up often in the dialogue on assisted dying: autonomy and compassion. Depending on where one stands on the euthanasia and assisted suicide question, these terms have different operative meanings. During the latter part of the 20th century, patients fought vigorously for the right of informed consent and self-determination in their medical care decisions. They achieved the right to refuse treatment, even if to do so would result in their deaths. Aiming even higher on the autonomy scale, they petitioned for the right to determine the time and manner of their deaths. When the Supreme Court denied them, ti put an end, at least temporarily, to "rights talk." It also neutralized autonomy as the "guiding principle" behind the debate. Now that assisted dying has entered the realms of ethics, medical practice and public policy, the role of autonomy is only one of the many factors for consideration. As for compassion, when it comes to the dying, we preach a great deal and practice very little. If nothing else, the euthanasia debate has highlighted serious deficiencies in end- of- life care.

Legalizing assisted dying would probably do little or nothing to improve the lot of "the 2.3 million Americans who die each year." But just thinking about it might help us to re-focus our priorities. The remainder of this essay explores some of these priorities.

One of the legacies of the *Cruzan* decision was a concerted effort, at both the state and federal levels, to expand the use of advance care directives and health care proxies.<sup>322</sup> Despite such efforts, only twenty-nine percent of Americans

<sup>&</sup>lt;sup>316</sup> In re Ouinlan, 355 A.2d 647, 663 (N.J. 1976).

<sup>&</sup>lt;sup>317</sup> Compassion in Dying v. Washington, 79 F.3d 790, 816 (9th Cir. 1996), *rev'd sub nom* Washington v. Glucksberg, 521 U.S. 702 (1997).

<sup>318</sup> Glucksberg, 521 U.S. at 734.

<sup>&</sup>lt;sup>319</sup> See Ezekiel Emanuel, The Future of Euthanasia and Physician-Assisted Suicide: Beyond Rights Talk to Informed Public Policy, 82 MINN. L. Rev. 983, 983 (1998) ("the majority holdings [in Washington v. Glucksberg and Vacco v. Quill] permanently shifted the forum, the arguments, the perspective, and the justifications in the debate over PAS and euthanasia. The forum is no longer the courts, but the legislatures and public squares. The arguments are no longer about constitutional rights, but ethics and prudent policies."); see also Meisel & Cerminara, supra note 77, at 1-4 ("The language of 'rights' denotes to many an adversarial relationship between patients and health care professionals and perhaps, consciously or unconsciously, conjures up images of the two most dreaded of all legal phenomena: the criminal prosecution and the malpractice lawsuit.") Of course, in the American legal polity "rights talk" never ends for long. See, e.g., John B. Mitchell, My Father, John Locke, and Assisted Suicide: The Real Constitutional Right, 3 Ind. Health L. Rev. 43 (2006).

<sup>320</sup> Channick, supra note 128, at 609, 617.

<sup>321</sup> Emanuel, supra note 319, at 985.

<sup>&</sup>lt;sup>322</sup> Channick, *supra* note 128, at 591-92. On advance directives and related documents generally, see Meisel & Cerminara, *supra* note 77, chap. 7, *Advance Directives*.

have executed living wills and, among them, relatively few young people.<sup>323</sup> Worse, patients who do express their preferences in writing have no blanket assurance that their wishes will be honored. In one study of living wills, "physicians overrode a patient's treatment preference twenty-five percent of the time and, in three-quarters of those overrides, the physician withheld treatment desired by the patient."<sup>324</sup> The drive to promote autonomy through the creation and implementation of advance directives has "essentially failed."<sup>325</sup>

The assumption that autonomy is paramount among patient concerns is mistaken. In a study conducted by SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), a group of patients were given intensive medical staff intervention and information designed to promote informed decision-making. Surprisingly, these autonomy-enhancing measures had no significant impact on patient treatment choices, nor did they increase patient satisfaction. 327

When thrust upon the unwilling and confused, autonomy can be frightening

Residents attending the course demonstrated statistically significant increases in their overall skill ratings in the delivery of bad news, with improvement in the specific areas of information giving and responding to emotional cues. Although cumulative scores for discussions about patient preferences for treatment did not increase residents demonstrated enhanced specific skills including discussing probability, presenting clinical scenarios, and asking about prior experience with end-of-life decision making.

Stewart C. Alexander, et al., A Controlled Trial of a Short Course to Improve Residents' Communication with Patients at the End of Life, 81 ACADEMIC MEDICINE 1008, 1008 (2006).

<sup>&</sup>lt;sup>323</sup> National Hospice and Palliative Care Association, *Advance Care Planning is Critical*, (March 13th, 2006) *available at* http://www.nhpco.org/i4a/pages/Index.cfm?pageID=4818; Channick, *supra* note 128, at 628.

David Orentlicher, The Alleged Distinction Between Euthanasia and Withdrawal of Life-Sustaining Treatment: Conceptually Incoherent and Impossible to Maintain, 1998 U. ILL. L. Rev. 837, 844-45 (1998) (Part of the dissonance between the intent manifest in advance directives and the results so at odds with that intent may be due to the resistance in some quarters to the "precommitment" concept in end-of-life medical care). See, e.g., Rebecca Dresser, Precommitment: A Misguided Strategy for Securing Death with Dignity, 81 Tex. L. Rev. 1823, 1823 (2003) (arguing that reliance on advanced treatment directives is "misguided and morally troubling."); Joanne Lynn, Why I Don't Have a Living Will, 19 MEDICINE & HEALTH CARE 101, 103 (1991) (arguing in favor of "family choice over the opportunity to make our own choices in advance") (emphasis in original).

<sup>&</sup>lt;sup>325</sup> Robert Burt, *The End of Autonomy*, in IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT?, HASTINGS CENTER REPORT SPECIAL REPORT 35, no.6, S9-S13, at S9 (2005); *see* Jackson, *supra* note 87 at 149 (reporting that "the completion of a living will alone has been repeatedly demonstrated to fail to improve compliance with the wishes of patients and their families").

<sup>326</sup> Burt, *supra* note 325, at S9.

<sup>&</sup>lt;sup>327</sup> Channick, *supra* note 128, at 592-93. A more recent study of a short course designed to improve physician's communication skills with patients on end-of-life issues reported mixed results:

and burdensome. Modern patients, already overwhelmed by coordinating doctors and medical procedures and negotiating with insurance companies, must also choose among various treatment alternatives.<sup>328</sup> When faced with multiple treatment options, especially experimental procedures, patients are told by doctors to perform their own research and decide according to their values.<sup>329</sup> One exasperated patient remarked, "At 57, it's a little late to be starting medical school."<sup>330</sup> Patients do benefit from being better-informed about their health. but, left to filter all the data on their own, they often feel abandoned. Physicians who provide continuous support and guidance throughout the treatment process help to improve patient survival rates and lower medical costs: "It is impossible to overestimate the bracing impact of that old-fashioned guide, the doctor who can be a patient's constant, her Pole Star."331 In the words of one discouraged patient, "filt's patchwork, and frustrating, that there is not one person taking care of me who I can look to as my champion."332 Yet, in 2003, less than a fifth of first-year medical students intended to pursue careers in primary care medicine. 333 The "discrete and episodic" nature of the new doctor-patient relationship de-emphasizes autonomy and is plainly antithetical to notions of informed consent.334

The SUPPORT data further reveal that most patients and families don't want to be responsible for end-of-life care decisions. Patients are often too ill and frail to meaningfully assess their treatment options. Further, according to Robert Burt, cognitive difficulties limit the ability of all patients to comprehend the reality of death, especially their own. One argument against assisted suicide is the fear that patients will be taxed with the responsibility for ending their own pain and suffering. Whatever they choose to do, the "blame will attach only to the dying person, and will be attached by the dying person to himself." One can imagine that, to avoid these dilemmas, patients might willing-

<sup>&</sup>lt;sup>328</sup> Jan Hoffman, *Awash in Information, Patients Face a Lonely, Uncertain Road*, N.Y. Times, Aug. 14, 2005, available at http://www.nytimes.com/2005/08/14/health/14patient.html.

<sup>&</sup>lt;sup>329</sup> *Id*.

<sup>&</sup>lt;sup>330</sup> *Id*.

<sup>&</sup>lt;sup>331</sup> Id.; see also National Quality Forum, A National Framework and Preferred Practices for Palliative and Hospice Care Quality, Table 1 at vii-viii (2006) (detailing 38 "preferred practices" of palliative care), available at http://www.rwjf.org/files/research/txPHreportPUBLIC01-29-07.pdf.

<sup>&</sup>lt;sup>332</sup> Denise Grady, Cancer Patients, Lost in a Maze of Uneven Care, N.Y. TIMES, July 29, 2007, at A1 (quoting Karen Pasqualetto).

<sup>333</sup> See Hoffman, supra note 328.

<sup>334</sup> Channick, supra note 128, at 625.

<sup>&</sup>lt;sup>335</sup> Burt, *supra* note 325, at S9.

<sup>336</sup> Id. at S10.

<sup>&</sup>lt;sup>337</sup> Ezekiel Emanuel, Whose Right to Die?, ATLANTIC MONTHLY, Mar. 1997.

<sup>338</sup> Burt, *supra* note 325, at S11.

ly sacrifice autonomy for humane medical care. The question is whether, in assessing the best end of life options, they should have to.

#### B. The Myths of Compassion

Whatever our position on assisted dying, our calls for compassion must acknowledge that we treat the dying rather badly. We marginalize them and, whether through inadequate pain control or overly aggressive treatment, we cause them "needless suffering." As of 2002, only five of 126 American medical schools required a separate course in end-of-life care.<sup>340</sup> Despite the training opportunities available in hospice programs, only seventeen percent of residency programs offered a hospice rotation.<sup>341</sup> Yet, when surveyed, medical school students, residents and faculty expressed near-universal endorsement of the importance of end-of-life care. 342 Approximately one-third of those students and one-fifth of those residents have not been taught basic pain management.<sup>343</sup> In clinical programs, "students are systematically protected from, or deprived of, opportunities to learn" about care of the dying. 344 Even when they do participate in clinical programs, students lack role models with sufficient expertise and experience to provide leadership.<sup>345</sup> Less than twenty percent of students surveyed had taken a course in end-of-life care.<sup>346</sup> Further educational deficiencies were noted in "treatment of depression, bereavement care, and attention to the fears and concerns of dying patients."347 Opponents of euthanasia refuse to countenance a response to suffering that involves "kill[ing] the sufferer."348 But while good palliative care is an undeniably worthy goal, pain control is not always the principal issue in end-of-life dilemmas. Patients facing imminent death often require a range of services to guide and assist them as well as their families.

Hospice care would seem to offer some promise of relief, with its medical care, social work services and supportive counseling for the terminally ill and their families.<sup>349</sup> Over the past decade, however, the median length of hospice has been a mere twenty-two days, with one-third of patients dying within seven

<sup>&</sup>lt;sup>339</sup> Foley, *supra* note 48, at 194.

<sup>340</sup> Id. at 192.

<sup>341</sup> Id. at 192-93.

<sup>&</sup>lt;sup>342</sup> Amy Sullivan et al., *The Status of Medical Education in End-of-life Care*, 18 J. Gen. Intern Med. 685, 688 (2003).

<sup>&</sup>lt;sup>343</sup> *Id.* at 691.

<sup>&</sup>lt;sup>344</sup> *Id*.

<sup>&</sup>lt;sup>345</sup> *Id*.

<sup>346</sup> Id. at 688.

<sup>347</sup> Id. at 691.

<sup>&</sup>lt;sup>348</sup> See generally Foley, supra note 48, at 187.

<sup>&</sup>lt;sup>349</sup> Kathleen M. Foley, *The Past and Future of Palliative Care*, 35 Hastings Center Report (Special Report: Improving End of Life Care: Why Has It Been So Difficult?) S42, S43 n.6 Supplement (2005).

days of admission.<sup>350</sup> Such "brink of death" care deprives patients of the opportunity, over the course of several months, to prepare for death.<sup>351</sup>

To be eligible for hospice care, terminally ill patients traditionally had to abandon advanced or more aggressive medical treatment.<sup>352</sup> Recently, some private insurers and hospice programs have begun to offer more creative options.<sup>353</sup> Patients may avail themselves of hospice's supportive services while, at the same time receiving "sophisticated medical treatments that may slow or even halt their disease."<sup>354</sup> This new approach, called "open access" hospice, attracts patients who elect to continue curative or life-prolonging care.<sup>355</sup> Some even improve enough to leave the program.<sup>356</sup> Rather than spend their last weeks in a "last rites" atmosphere, patients can receive assistance through their final six, or even twelve, months of life.<sup>357</sup>

This approach, while encouraging, is not universally available and does not appeal to all terminally ill patients.<sup>358</sup> There will still be those who express a desire for death. When they do, it is essential that physicians recognize that "medically ill suicidal individuals are no different from other suicidal individuals."<sup>359</sup> As A. Alvarez has chillingly described, the world of the suicidal is infested with omens.<sup>360</sup> A depressed patient may interpret a physician's willingness to assist in suicide as validating the decision to die, confirming that the choice is correct.<sup>361</sup> In reality, the patient may be pleading for a very different kind of reassurance.<sup>362</sup>

There is a type of discomfort known as "existential" suffering that afflicts the severely ill<sup>363</sup> It encompasses the more spiritual and cultural aspects of suffering, such as fear of dependence and fear of becoming a burden to one's family

<sup>350</sup> Id. at S45.

<sup>&</sup>lt;sup>351</sup> *Id*.

<sup>&</sup>lt;sup>352</sup> Reed Abelson, A Chance to Pick Hospice, and Still Hope to Live, N.Y. TIMES, Feb. 10, 2007, at A1.

<sup>&</sup>lt;sup>353</sup> Id.

<sup>354</sup> Id.

<sup>&</sup>lt;sup>355</sup> *Id.* at C4; *see*, *e.g.*, Continuum Hospice Care, Open Access, http://www.hospicenyc.org/access.html (last visited Sept. 27, 2007) ("In Open Access hospice, eligibility for hospice services is determined solely by the regulatory requirements: appropriate prognosis certified by a licensed physician and election of the benefit by patient or proxy. The patient's Plan of Care may include any potential treatment, including life-prolonging treatments, and as long as the patient remains eligible, he or she will receive hospice care.").

<sup>&</sup>lt;sup>356</sup> *Id*.

<sup>&</sup>lt;sup>357</sup> Id.

<sup>358</sup> Foley, supra note 48, at 191-92.

<sup>359</sup> Hamilton & Hamilton, supra note 293, at 1060.

<sup>360</sup> ALVAREZ, supra note 11, at 144.

<sup>361</sup> N.Y. TASK FORCE, supra note 35, at 95.

<sup>&</sup>lt;sup>362</sup> Id.

<sup>&</sup>lt;sup>363</sup> Foley, *supra* note 48, at 191-92.

as well as to oneself.<sup>364</sup> It accompanies the disintegration of one's personality and the loss of a role in society.<sup>365</sup> In its 2006 Summary of Oregon's Death with Dignity Act, the Oregon DHS reported that ninety-six percent of the state's death-with-dignity participants cited loss of autonomy as a principal concern.<sup>366</sup> Given the questionable power of autonomy to ease the souls of the sick and dying, one can only speculate as to what the participants truly meant. Perhaps they were referring to these existential factors, or perhaps they simply wanted to die. Whatever their motivation, one wonders at the degree of compassion expended by a doctor who writes a prescription for lethal drugs and then bows out of the patient's life.

Oregon's incremental "arm's length" solution seeks to legitimate physicianassisted suicide by distinguishing it from active euthanasia. 367 The distinction, says Ezekiel Emanuel, is a "charade" and "impossible to operationalize." 369 Doctors, in a self-protective stratagem, "frequently label actions as PAS [physician-assisted suicidel when in fact the actions are euthanasia."370 Thus, a doctor may provide assistance with ingesting drugs to a patient who has difficulty swallowing. The physician tries to mitigate his own discomfort by classifying the action as one thing but certainly not another. Some competent patients are unable to end their lives on their own, whether because of weakness, neurologic disease or difficulty using their hands.<sup>371</sup> One Netherlands study found that, because of physical limitations affecting numerous patients seeking death, "general practitioners and nursing home physicians preferred euthanasia to assisted suicide."<sup>372</sup> Emanuel estimates that as many as twenty percent of physician-assisted suicide attempts result in failure to end the patient's life.<sup>373</sup> He doubts that the state would prosecute physicians who, in these instances, step in to provide humane medical assistance.<sup>374</sup> As a matter of social policy, "[t]he real choice is to legalize both PAS and euthanasia, or to legalize neither."375

In the realm of assisted dying, this is not the only distinction that "obfuscates

<sup>&</sup>lt;sup>364</sup> *Id*.

<sup>&</sup>lt;sup>365</sup> *Id.* at 192.

<sup>&</sup>lt;sup>366</sup> OR. DEP'T OF HUMAN SERVS., supra note 271 at 2.

<sup>&</sup>lt;sup>367</sup> Emanuel, *supra* note 319, at 1001 n.63.

<sup>&</sup>lt;sup>368</sup> Id. at 1003.

<sup>&</sup>lt;sup>369</sup> *Id.* at 1001. Emanuel refers to "[t]he myth of separation[,] . . . the notion that we can separate physician-assisted suicide from euthanasia." *Id.* at 984 n.4. He adds that "[a]lthough this distinction can be made conceptually, in practical terms it is extremely difficult." *Id.* 

<sup>370</sup> Id. at 1001.

<sup>371</sup> Groenewoud et al., supra note 245, at 555.

<sup>372</sup> Id. at 555-56.

<sup>&</sup>lt;sup>373</sup> Emanuel, *supra* note 319, at 1002.

<sup>374</sup> Id. at 1003.

<sup>375</sup> Id.

rather than illuminates."<sup>376</sup> David Orentlicher argues that the "bright-line" separation between withdrawal of treatment and euthanasia/assisted suicide is equally untenable.<sup>377</sup> When a patient refuses life-sustaining treatment, he does so because he no longer wishes to live.<sup>378</sup> When a physician acts to discontinue that treatment, she is facilitating an "intent to die."<sup>379</sup> When a doctor, at the patient's request, places him under terminal sedation, the patient will most likely refuse food and water.<sup>380</sup> The combination of medically induced coma and withdrawal of nutrition and hydration will inevitably result in death and therefore constitutes euthanasia.<sup>381</sup> If a patient may legally refuse treatment and cannot be forced to remain alive, whether because of intolerable suffering or because he has made a competent, reasoned decision to end his life, "we are left with an argument that does not distinguish between treatment withdrawal and euthanasia/assisted suicide."<sup>382</sup>

On the other hand, Robert Burt maintains that this distinction, though illogical, prevents us from becoming tolerant of actions that are "socially dangerous." Preserving the myth of separation is "in the service of promoting conscious awareness of moral discomfort." At first, this view seems reasonable. A little moral discomfort can go a long way in preventing a holocaust. Yet, a morality that rests on highly impeachable logic is easily attacked and easily overcome. Truly unsettling are distinctions promoting superficial or minimal compliance with arbitrary rules. Physicians may escape with their ethics and reputations intact. But whether the difference between treatment withdrawal and euthanasia is clear, patients are left with the less philosophical chore of dying.

In his concurring opinion in *Glucksberg*, Justice Souter cautioned against the recognition of unenumerated rights which effectively displace "the legislative ordering of things." Emanuel interprets this to mean that, rather than "declare the existence of such unenumerated rights," the Supreme Court should "ratify a social process that creates and accepts these rights." Moral dicta such as "doctors must not kill" and invocations of the sanctity of life do little to unravel the complexity of the assisted-dying debate. As Ronald Dworkin observed, "the crucial question is not whether to respect the sanctity of life, but

<sup>376</sup> Channick, supra note 128, at 619.

<sup>377</sup> Orentlicher, supra note 324, at 846.

<sup>&</sup>lt;sup>378</sup> *Id.* 

<sup>&</sup>lt;sup>379</sup> Id.

<sup>380</sup> Id. at 855.

<sup>&</sup>lt;sup>381</sup> *Id.* at 855-56.

<sup>382</sup> Id. at 846.

<sup>383</sup> Burt, *supra* note 325, at S12,

<sup>&</sup>lt;sup>384</sup> Id.

<sup>&</sup>lt;sup>385</sup> Washington v. Glucksberg, 521 U.S. 702, 788-89 (1997) (Souter, J., concurring).

<sup>&</sup>lt;sup>386</sup> Emanuel, *supra* note 319, at 994.

which decision best respects it." Sound public policy relies on experimentation and the testing of various assumptions. The resolution of assisted-dying issues will evolve, not from slogans or unsubstantiated beliefs, but from "a new paradigm of bioethics," based on empiricism and facts. 388 Improving and studying palliative and end-of-life care is the first step, along with proper diagnosis and treatment of depression in the seriously ill. As we learn more about the process of dying, we are better able to evaluate the boundaries of treatment and to recognize that, in some cases, assisted-dying may well be the most humane response. With so much yet to know, we must ask ourselves whether, in a compassionate society, the seemingly cold and peremptory practices the Oregon statute risks engendering are the best we can do. It may be impossible to effectively legislate and regulate assisted dying. Even the most painstakingly crafted safeguards, approved by the courts and the medical profession, do not guarantee adherence. 389 The Dutch experience has taught us that safeguards are often violated and, due to physician underreporting, it is difficult to ascertain the frequency and extent of those violations.<sup>390</sup>

Leon Kass abjures the legalization of euthanasia, "[f]or the choice for death is not one option among many, but an option to end all options." Given the gross inadequacy of medical care for the dying, the rush to assisted suicide and euthanasia does seem precipitate. But, for some time now, doctors have been engaged in furthering the process of dying, through pain medications that hasten death, as well as by terminal sedation. Moreover, as many as seventy percent of hospital deaths result from the decision to withdraw or withhold treatment. Reporting and documentation of medical decisions to terminate treatment or hasten death would provide valuable data on actual, current end-

<sup>&</sup>lt;sup>387</sup> Ronald Dworkin, *Life is Sacred: That's the Easy Part, in Arguing Euthanasia, supra* note 74, at 250.

<sup>&</sup>lt;sup>388</sup> Channick, supra note 128, at 612; see also Susan M. Wolf, Pragmatism in the Face of Death: The Role of Facts in the Assisted Suicide Debate, 82 Minn. L. Rev. 1063, 1100 (1998) (The assisted suicide debate requires a larger discussion that has not yet occurred on the role of data and empiricism in the constitutional and policy questions. In the absence of that discussion, the debate too often veers into ungrounded abstraction. But the data tell an important story. They show that patients need not choose between agony and assisted suicide; numerous techniques for pain relief and palliative care are available, including sedation to unconsciousness. When patients do seek assisted suicide, it is usually because untreated depression or inadequate pain relief drives them. These patients are not independent agents freely choosing an uncoerced option, as in a commercial transaction. And termination of life-sustaining treatment, high-dose pain relief, and sedation to unconsciousness are distinct practices with significant therapeutic uses, each one distinguishable from assisted suicide.)

<sup>&</sup>lt;sup>389</sup> Emanuel, *supra* note 319, at 1011.

<sup>&</sup>lt;sup>390</sup> Id. at 1009, 1011.

<sup>&</sup>lt;sup>391</sup> Leon R. Kass, *Death with Dignity and the Sanctity of Life*, in Arguing Euthanasia, supra note 74, at 232.

<sup>&</sup>lt;sup>392</sup> N.Y. TASK FORCE, supra note 35, at 147.

of-life practices. These mechanisms would further assist in the development of ethics and guidelines in care for the dying, including determining those circumstances where euthanasia might be appropriate. It is time to penetrate the veil of calculated ambiguity and subterfuge preventing forthright discussion of these issues.<sup>393</sup> The threat of criminal prosecution is diminished when factual distinctions between euthanasia and withholding treatment are so difficult to prove. It is also unlikely that prosecutors and judges would want to assume the unenviable role of second-guessing the decisions of trained, competent professionals who routinely care for the dying and gravely ill.

Emanuel estimates that, of the 2.32 million Americans who die each year, there are 5,000 to 25,000 people who suffer unendurable pain and would choose physician-assisted suicide or euthanasia as a means of ending this pain. That these individuals might benefit from life-ending procedures does not obviate the urgent necessity of improving palliative care for all of us. That this group is comparatively small also calls into question the wisdom of a broad, legislative response. Donald McKinney's observation that assisted dying is best envisioned as a "private act" seems far more apt and persuasive than partisan arguments about legalization. The decision to end one's life is profoundly personal and properly resides within a secure, knowledgeable and unhindered doctor-patient relationship. 396

In an era when life-prolonging measures "force some patients to outlive their deaths," we require physicians to be more than staunch defenders of life. Medicine is essentially "a pastoral art, especially when a good physician, like a good shepherd," helps to guide the patient through illness and, when the time comes, from life into death. Undoubtedly, one risk of tolerating euthanasia is that the practice will expand to include an ever-widening array of candidates. While this risk should not be underestimated, it seems arbitrary and even heartless to exclude all but the terminally ill from the prospect of release. Terribly injured victims of accidents and war, and sufferers of degenerative diseases such as ALS might also wish for a permanent end to their ordeal. To categorically deny them relief implies that we are somehow qualified to judge the merits of their claims.

Assisted dying, however humanely practiced, is the taking of life. We cling to life, even in the most unimaginable circumstances. Indeed, A. Alvarez has

<sup>&</sup>lt;sup>393</sup> Ouill, *supra* note 96, at 203.

<sup>&</sup>lt;sup>394</sup> Emanuel, *supra* note 319, at 1008.

<sup>&</sup>lt;sup>395</sup> N.Y. TASK FORCE, *supra* note 35, at 102-103.

<sup>&</sup>lt;sup>396</sup> See Jackson, supra note 87, at 149 ("What is wanted is a commitment by physicians to a process of engaging patients regarding antemortem care issues, not a reliance on a 'one-shot' conversation that leaves a vaguely worded document tucked deep in the recesses of the patient's clinic record.").

<sup>&</sup>lt;sup>397</sup> Vaux, *supra* note 93, at 2141.

<sup>&</sup>lt;sup>398</sup> *Id.* at 2141; *see* Jackson, *supra* note 87, at 152 ("When all else is done, comfort the dying.").

written that the best counterargument to suicide "is life itself:"399

You pause and attend: the heart beats in you chest, outside the trees are thick with new leaves, a swallow dips over them, the light moves, people are going about their business.<sup>400</sup>

For those for whom life is no longer enough, who are weak and exhausted, immobilized and imprisoned in their bodies, longing for a death that is tantalizingly out of reach, one can only hope that they find their good shepherds.

#### VI. CONCLUSION

We have much more to learn about the care of the ill and the dying and about compassion in all of its contexts. Without more research and analysis, we cannot yet condemn or discard any practice that may help to alleviate suffering. Zealous devotion to the sanctity of life is not, and perhaps never has been, the cardinal rule in end-of-life care. Palliative treatment for the dying and severely ill is an emerging specialty. We must allow it to evolve unhampered by extremist sentiment and discredited notions of legal entitlement.

Yet, officially sanctioned assisted dying in the Netherlands and Oregon has produced mixed and problematic results. Until the medical profession willingly accepts an unambiguous role in end-of-life ethics and policy, legislative solutions will continue to be incremental, partially informed and perhaps even injurious to the dying.

<sup>&</sup>lt;sup>399</sup> ALVAREZ, supra note 11, at 152.

<sup>&</sup>lt;sup>400</sup> *Id*.