

ARTICLE

REFRACTORY PAIN, EXISTENTIAL SUFFERING, AND PALLIATIVE CARE: RELEASING AN UNBEARABLE LIGHTNESS OF BEING

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Since the beginning of the hospice movement in 1967, “total pain management” has been the declared goal of hospice care. Palliating the whole person’s physical, psychosocial, and spiritual states or conditions is central to managing the pain that induces suffering. At the end-stage of life, an inextricable component of the ethics of adjusted care requires recognition of a fundamental right to avoid cruel and unusual suffering from terminal illness. This Article urges wider consideration and use of terminal sedation, or sedation until death, as an efficacious palliative treatment and as a reasonable medical procedure in order to safeguard the “right” to a dignified death.

Once the state establishes a human right to avoid refractory pain of whatever nature in end-stage illness, a coordinate responsibility must be assumed by health care providers to make medical judgments consistent with preserving the best interests of a patient’s quality of life by alleviating suffering. The principle of medical futility is the preferred construct for implementing this professional responsibility.

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Rather than continue to be mired in the vexatious quagmire of the doctrine of double effect—all in an effort to “test” whether end-stage decisions by health care providers are licit or illicit—a relatively simple test of proportionality, or cost-benefit analysis, is proffered. Imbedded, necessarily, in this equation is the humane virtue of compassion, charity, mercy or agape.

Assertions of state interest in safeguarding public morality by restricting intimate associational freedoms to accelerate death in a terminal illness are suspicious, if, indeed, not invalid. No terminally ill individual suffering from either intractable somatic or non-somatic pain, or both, should be forced to continue living.

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“Dying is an integral part of life, as natural and predictable as being born.” Elisabeth Kübler-Ross¹

“[A]dequate relief for severe and continuing pain is unusual in the modern hospital.” Eric Cassell²

“[I]t hath been often said that it is not Death, but Dying which is terrible.” Henry Fielding³

INTRODUCTION

A. *Total Pain Management and Hospice Care*

The concept of existential pain has existed in various forms throughout mankind’s history. Long before Søren Kierkegaard first tackled the issue,⁴ often termed today as psychological distress or suffering,⁵ the reality of such a dimension of pain at death was perhaps first recorded when Jesus Christ, in contemplating his own death, stated, “I am deeply grieved, even to . . . death.”⁶ No doubt, Edvard Munch’s famous painting, “The Scream,” may well be taken as the most profound artistic

¹ ELISABETH KÜBLER-ROSS, *DEATH: THE FINAL STAGE OF GROWTH* 5 (Prentice Hall 1975) (1974).

² ERIC J. CASSELL, *THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE* 286 (2d ed. 2004).

³ HENRY FIELDING, *AMELIA* 109 (Martin C. Battestin ed., Wesleyan University Press 1983) (1751).

⁴ SØREN KIERKEGAARD, *FEAR AND TREMBLING* (1843); SØREN KIERKEGAARD *THE SICKNESS UNTO DEATH* (1849).

⁵ See ELAINE SCARRY, *THE BODY IN PAIN* 12 (1985).

⁶ *Mark* 14:34 (International Standard Version). Luke also records Jesus, prior to his crucifixion, expressing anxiety and distress for what he knows is to be his fate, when he asks, “Father, if thou be willing, remove this cup from me: nevertheless, not my will, but thine be done.” *Luke* 22:42 (King James).

depiction of existential suffering ever rendered in oil.⁷ Indeed, it has been recognized as capturing an “intense state of anxiety and despair” where “loss of identity becomes death.”⁸ While art confers an unmistakable visibility on distress in its varied complex forms, literature rarely captures it adequately, as there is no language for it—pain simply “resists verbal objectification.”⁹

Without question, pain plays havoc with the human psyche and induces suffering which, if lacking meaning, can destroy.¹⁰ Indeed, denying the impact of “suffering is to trivialize another person’s experience, to diminish its scope and lessen its significance.”¹¹ Once it can be shown that there is a right to compassionate care—as this Article advocates—

⁷ See Arthur G. Lipman, *The Scream by Edvard Munch: A Profound Portrayal of Existential Pain*, 19 J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY 1, 1–2 (2005); see generally REINHOLD HELLER, EDVARD MUNCH: THE SCREAM (John Fleming & Hugh Honour eds., 1973) (discussing the artistic attributes of Munch’s painting).

⁸ HELLER, *supra* note 7, at 90.

⁹ SCARRY, *supra* note 5, at 12. Thomas Mann opined that within the body of literature, however, no piece is to be found which is not concerned with suffering of some permutation. See *id.* For Emily Dickinson, the most overwhelming of all bodily experiences was pain. She captured this feeling in a forty-one word poem entitled, “The Mystery of Pain”:

Pain has an Element of Blank;
It cannot recollect
When it began, or if there were
A day when it was not.
It has no future but itself,
Its infinite realms contain
Its past, enlightened to perceive
New Periods of pain.

EMILY DICKINSON, *THE COLLECTED POEMS OF EMILY DICKINSON* 16 (Barnes & Noble Classics Series, 2003) (1890).

The courts view pain and suffering as inseparable although the concepts are, in fact, different. Acute pain—as a manifestation of a medical problem or disease—subsides usually within one month to six as part of the healing process. Pain may also be classified as chronic or within a collateral category of a chronic pain syndrome—with both of these types having long lasting and residual psychological structural defects different from acute episodes of pain. MARSHALL S. SHAPO, *PRINCIPLES OF TORT LAW* 419–20 (2003).

In the practice of medicine, pain—of which there are fifty-eight types—is defined as “an unpleasant sensory and emotional experience arising from actual or potential tissue damage or described in terms of such damage.” *TABER’S CYCLOPEDIA OF MEDICAL DICTIONARY* 1487, 1487–91 (19th ed. 2001). Psychogenic pain is used to describe mental pain—as opposed to pain of an organic nature. *Id.* at 1491. Suffering, being subjective, cannot be measured but must be referenced to the whole person. Accordingly, suffering is defined as a “state of severe distress associated with events that threaten the intactness of [the] person.” CASSELL, *supra* note 2, at 276, 312. Pain affects the body and is more properly addressed by physicians. Yet, a shared responsibility exists between physicians and other caregivers to control both the pain and suffering of those who are dying. Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*, 306 *NEW ENG. J. MED.* 639 (1982).

¹⁰ See Richard B. Gunderman, *Is Suffering the Enemy?*, 32 *HASTINGS CTR. REP.* 40, 43 (2002); see generally DAVID B. MORRIS, *THE CULTURE OF PAIN* (1991) (describing historical and artistic portrayals that depict the magnitude of human pain and suffering).

¹¹ Gunderman, *supra* note 10, at 43–44.

accepting and validating this new right will, necessarily, trigger a coordinating duty to make judgments relative to one's quality of life in order to assess the extent of one's suffering. In a very real way, then, a right of compassionate care will embrace and incorporate this collateral duty to prevent suffering.¹² An ethic requiring "a provision for competent care" is central to enforcing a right to compassionate care for terminal illness at the end-stage of life.¹³ This ethic adjusts to a patient's on-going medical needs as their illness progresses, and in doing so, meets the fundamental goal of medicine: to relieve suffering.¹⁴

Although existential pain has been defined as suffering "with no clear connections to physical pain," it has also been recognized as suffering which can in fact be expressed as physical pain.¹⁵ Existential pain is seen today as a significant clinical factor which may either reinforce existing physical pain or even be the root cause of it.¹⁶

From the very beginnings of the hospice movement, led by Dame Cicely Saunders of the United Kingdom in 1967,¹⁷ "total pain" management of physical, psychosocial and spiritual suffering was then—and is still today—the goal of hospice care.¹⁸ Palliating the whole person and offering compassionate care¹⁹ is central to hospice care.²⁰ Viewed as such, palliative care presents an alternative not only to assisted suicide and active, voluntary euthanasia, but to the compulsiveness of some health care providers who forever press active "curative" care and treatments when they are medically inappropriate or *contra* indicated.²¹ In this regard, hospice care is an effort to counterbalance this irrational and inhumane compulsiveness and thereby "humanize medicine."²²

Palliative care is defined by the World Health Organization (WHO) as care that "improves the quality of life for patients and families who

¹² See Lois L. Shepherd, *Sophie's Choice: Medical and Legal Responses to Suffering*, 72 NOTRE DAME L. REV. 103, 146 (1996) [hereinafter Shepherd, *Sophie's Choice*].

¹³ *Id.* at 138.

¹⁴ See CASSELL, *supra* note 2, at 291.

¹⁵ Peter Strang et al., *Existential Pain—an Entity, or Provocation, or a Challenge?*, 27 J. PAIN & SYMPTOM MGMT. 241 (Mar. 2004). In addition to Kierkegaard, Jaspers, Sartre and Heidegger are recognized as the major philosophers leading the philosophical movement of existentialism. See generally MARTIN HEIDEGGER, *BEING AND TIME* (1962) (describing Heidegger's philosophical views on such issues as Being, temporality, and death).

¹⁶ See Strang et al., *supra* note 15, at 241.

¹⁷ See Cicely Saunders, *Hospice*, 1 MORTALITY 317, 317, 329 (1996).

¹⁸ *Id.* at 320.

¹⁹ See *HOSPICE: THE LIVING IDEA* (Cicely Saunders et al. eds., 1981) [hereinafter *HOSPICE*]; see also Paul Torrens, *Achievement, Failure and the Future: Hospice Analysed*, in *HOSPICE: THE LIVING IDEA* 187, 187–94 (Cicely Saunders et al. eds., 1981).

²⁰ *Id.*

²¹ See *HOSPICE CARE ON THE INTERNATIONAL SCENE* 11 (Dame Cicely Saunders & Robert Kastenbaum eds., 1997).

²² See *id.* at 7; see also Torrens, *supra* note 19, at 188–90.

face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life, and bereavement.”²³ Palliating the whole person, then, requires medicine to attend more fully to the phenomenon of existential pain. For this to be efficacious, health care decision makers must regularly reassess patient treatment goals in order to not only learn how their patients define and experience suffering, but the patients’ thresholds for tolerating various sources of distress. These thresholds are seen as being informed by a patient’s personality, which has, in turn, been shaped by life experiences and attitudes toward death management and quality of life in end-stage illness.²⁴

B. *Medical Futility and Terminal Sedation*

This Article asserts that palliative care should include an unencumbered option of respite, or what is also termed, terminal sedation, as a compassionate response to suffering. Leon R. Kass has argued that death should never be sought or engineered as a “therapeutic option” to end suffering.²⁵ Yet, prolonged life-sustaining treatments often impose undue burdens or serve as futile roadblocks to one in the medically validated end-stage of life,²⁶ thereby preventing as “comfortable” a death as possible.²⁷ Accordingly, in fulfilling their ethical mandate to prevent pain and suffering, health care providers should standardize a protocol which allows them—with patient or family approval or when a patient is unconscious and without proxy decision maker—to take those reasona-

²³ *Palliative Care*, WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/en> (last visited Feb. 25, 2011); see also Jan Stjernsward, *The International Hospice Movement from the Perspective of The World Health Organization*, in *HOSPICE CARE ON THE INTERNATIONAL SCENE* 21 (Cicely Saunders & Robert Kastenbaum eds. 1997).

²⁴ See Martin J. Fegg et al., *Personal Values and Individual Quality of Life in Palliative Care Patients*, 30 *J. PAIN & SYMPTOM MGMT.* 154 (2005); Helene Stacks et al., *Why Now? Timing and Circumstances of Hastened Deaths*, 30 *J. PAIN & SYMPTOM MGMT.* 215, 225 (2005).

²⁵ Leon R. Kass, *Lingering Longer: Who Will Care?*, *WASH. POST*, Sept. 29, 2005, at A23.

²⁶ See JOANNE LYNN, *SICK TO DEATH AND NOT GOING TO TAKE IT ANYMORE!* 12 (2004).

²⁷ *Id.*; see Len Doyal, *Dignity in Dying Should Include the Legalization of Non-Voluntary Euthanasia*, 1 *CLINICAL ETHICS* 65 (2006) (arguing under a best interests test, that it is beneficial and compassionate to end the suffering of incompetent patients experiencing intractable physical and emotional suffering from terminal illness with abbreviated life expectancy and unable to either conceptualize or, for that matter, demand assistance in ending life); see also Nigel Bunyan, *I Helped Patients Die, Says Murder Case G.P.*, *DAILY TELEGRAPH*, June 19, 2010, at 1 (reporting on a seventy-five year-old physician, Dr. Harold Martin, who admitted hastening the death of three patients—for whom he had been charged with murder and was acquitted subsequently; he also admitted later that he had given fatal doses of painkillers to elderly and terminally ill patients, and in two cases without patient consent, acting as such, out of “Christian compassion” to limit suffering); see generally DAVID B. MORRIS, *THE CULTURE OF PAIN* (1991) (discussing the history of medical developments and attitudes toward treating pain).

ble steps to relieve unremitting pain and discomfort.²⁸ The thesis of this Article is that law and medicine must agree on set standards or protocols which allow for the use of terminal sedation as an efficacious and compassionate practice for the end-stage treatment of patients.

Existing medicolegal and ethical norms allow, in limited circumstances, the terminal sedation of a dying patient.²⁹ It is acceptable and even compassionate to sedate a patient in terminal distress when this action is taken to either “produce unconsciousness before extubation,” to relieve physical suffering when standard palliative care does not abate refractory symptoms, and *possibly* when nonphysical suffering is sought to be relieved.³⁰ Yet, in order for a physician to engage in terminal sedation, he must not intend to end the life of his patient.³¹ Rather, if a patient dies from high dosages of sedating medications, a physician must give medication with the intent to relieve pain rather than cause death—although death is a foreseeable risk.³² This is known as the doctrine of double effect, a well-established and nearly universally accepted principle of medical ethics and related law.³³

Troublesome as the doctrine of double effect is as a construct for discerning physician intent, the American Medical Association—through its Council on Ethics and Judicial Affairs—still clings to the doctrine as determinative in justifying the use of terminal sedation.³⁴

This Article proposes that, rather than have medico-legal decision-making mired, compulsively, in efforts to discern and validate positive subjective intentions for use of terminal sedation by a physician, a medical decision is made—based on accepted medical judgment—by weighing the costs of treatment directly against its benefits.³⁵

²⁸ See *infra* notes 189–200.

²⁹ See Norman L. Cantor & George C. Thomas, III, *The Legal Bounds of Physician Conduct Hastening Death*, 48 *BUFF. L. REV.* 83, 139 (2000).

³⁰ Glenys Williams, *The Principle of Double Effect and Terminal Sedation*, 9 *MED. L. REV.* 41, 42 (2001).

³¹ See generally T.A. CAVANAUGH, *DOUBLE-EFFECT REASONING: DOING GOOD AND AVOIDING EVIL* (2006) (describing the necessary elements within the principle of double effect); Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 *J. L. MED. & ETHICS* 182 (2001) (observing the differences in developing attitudes toward end-of-life treatment after *In re Quinlan*, which held in 1976 that a competent patient may reject life-saving medical treatment).

³² Victor Cellarius, *Terminal Sedation and the Imminence Condition*, 34 *J. MED. ETHICS* 69 (2008).

³³ See Joseph M. Boyle, Jr., *Toward Understanding the Principle of Double Effect*, 90 *ETHICS* 527 (1980) [hereinafter Boyle, *Toward Understanding the Principle of Double Effect*].

³⁴ See *infra* note 203 and accompanying text.

³⁵ See *infra* notes 52–53 and accompanying text. It is within the last two years of life that most medicine is used for Americans with chronic illness (diabetes, cancer, heart disease) who require hospital care. Robert Pear, *Researchers Find Huge Variations in End-of-Life Treatment*, *N.Y. TIMES*, April 7, 2008, at 17. As a consequence of this statistic, almost a third

C. *Common Sense and Compassion*

Wider acceptance and use of terminal sedation as a valid method of palliative treatment presents an important opportunity to more fully understand the issues of managing death. It also provides an equal opportunity for viewing this medical procedure as a compromise to the equally vexatious issue of physician-assisted suicide.³⁶ Taxonomical confusion abounds when issues of self-determination are presented in end-stage illness.³⁷ There is also, oftentimes, a tragic absence of explicit policies which enunciate clearly the extent to which care may be provided to the terminally ill.³⁸

The voluntary cessation of nutrition and hydration and the use of terminal sedation are acknowledged as legal and accepted widely in hospice care management.³⁹ Because of an absence of clear protocols for the administration of terminal sedation, and attendant moral objections

of Medicare monies expended go to patients in their last two years. Evan Thomas, *The Case for Killing Granny: Re-thinking End-of-Life Care*, NEWSWEEK, Sept. 21, 2009, at 34, 39.

³⁶ See Rob McStay, *Terminal Sedation: Palliative Care for Intractable Pain*, *Post Glucksberg and Quill*, 29 AM. J.L. & MED. 45 (2003); see generally George P. Smith, II, *Terminal Sedation as Palliative Care: Revalidating a Right to a Good Death*, 7 CAMBRIDGE Q. HEALTHCARE ETHICS 382 (1998) (advocating terminal sedation as a means to treat end-of-life suffering) [hereinafter Smith, *Terminal Sedation*].

³⁷ See George P. Smith, II, *All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?*, 22 U.C. DAVIS L. REV. 275, 283, 418–19 (1989). Indeed, the terms “palliative sedation,” “continuous deep sedation,” and “primary deep continuous sedation,” are all used interchangeably, with terminal sedation and are seen as euphemisms which mask the reality of finality which is inherent when terminal sedation is administered. “Death over days” is seen as feeling “more natural” than physician assisted suicide. Margaret P. Battin, *Terminal Sedation: Pulling the Sheet Over Our Eyes*, 38 HASTINGS CTR. REP. 27, 28 (2008). Once a terminal prognosis has been given, a concern then arises as to whether sedation should be administered within hours or days of death. There is no standard time-frame protocol. If sedation is administered within two weeks or less, typically the patient dies from the underlying disease rather than the sedation. Jeffrey T. Berger, *Rethinking Guidelines for the Use of Palliative Sedation*, 40 HASTINGS CENTER REP. 32 (May–June, 2010); see generally George P. Smith, II, *Euphemistic Codes and Tell-Tale Hearts: Humane Assistance in End-of-Life Cases*, 10 HEALTH MATRIX, J. L.-MED. 175 (2000) (urging hospitals to respect a patient’s Do Not Resuscitate order and honor their requests for treatment, or lack thereof).

³⁸ See Timothy E. Quill et al., *Palliative Options of Last Resort: A Comparison of Voluntarily Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia*, 278 J. AM. MED. ASS’N. 2099, 2104 (1997). In 2008, the Council on Ethical and Judicial Affairs of the American Medical Association issued a report entitled, *Sedation to Unconsciousness in End-of-Life Cases*, which hoped to bring clarity to this area of concern. Council on Ethical and Judicial Affairs, *Sedation to Unconsciousness in End-of-Life Cases*, AM. MED. ASS’N (2008), available at <http://www.ama-assn.org/ama1/pub/upload/mm/code-medical-ethics/2201a.pdf>. Many of the Council’s conclusions have been termed “naive.” See Battin, *supra* note 37. For a more complete analysis of the Council’s Report, see *infra* notes 203–18 and accompanying text.

³⁹ See Quill et al., *supra* note 38, at 2103.

and legal concerns regarding the consequences of ordering its use, medical treatment of this nature is not readily available.⁴⁰

Although illegal in all states but Oregon⁴¹ and Washington,⁴² physician-assisted suicide is difficult to prosecute successfully when requested by a competent and informed patient.⁴³ Voluntary euthanasia is also illegal in most states and, if uncovered, likely to be prosecuted.⁴⁴ Because of this legal situation, a vast underground flourishes, which assists not only in the practice of physician-assisted suicide but in voluntary euthanasia.⁴⁵

Although physician-assisted death is not considered a substantive liberty interest and a fundamental right,⁴⁶ just as palliative care is not seen as a *right* incorporated into a lofty constitutional principle,⁴⁷ this Article argues that both actions coalesce into actuating a right to be free

⁴⁰ *Id.* Elucidating on what he terms “the last options” for dealing with refractory pain not managed effectively by traditional palliative care, Dr. Quill makes pointed observations: aggressive pain management achieved by the use of opiates, proportional to their need to manage pain, is valid—even though there is an awareness (without purposeful intent) that death will be hastened; withdrawing or withholding of life sustaining therapies is a legal right for a competent patient to exercise; a voluntary decision by such a competent patient to cease nutrition and hydration is a valid treatment option but be an informed division to the degree that the patient understands the act of dying may take up to two weeks and physician support is essential; finally, in rare cases where none of these three medical options are considered reasonable, a disproportionate use of a sedative may be allowed to induce unconsciousness and abate pain. Timothy E. Quill, *Physician-Assisted Death in the United States: Are the Existing ‘Last Resorts’ Enough?*, 38 HASTINGS CTR. REP. 17 (Sept.–Oct. 2008) [hereinafter Quill, *Physician-Assisted Death*]. While reliable statistics on the use of these options are difficult to obtain and validate, one sets the use of sedation to unconsciousness anywhere from no deaths, less than one percent, to half of all deaths. *Id.* at 20.

⁴¹ OR. REV. STAT. ANN. §§ 127.800 (West 2003).

⁴² WASH. REV. CODE ANN. Ch. 70,245 (West 2010). The Supreme Court of Montana ruled on December 31, 2009, that—under the Rights of the Terminally Ill Act (MONT. CODE ANN. §§ 50–9–101 to –206 (1991))—competent, terminally ill patients can request physician assistance in obtaining a prescription for a lethal dose of medicine to be self-administered; and further the Act shields physicians from civil or criminal liability for any such acts of assistance. *See Baxter v. State*, 2009 Mont. LEXIS 695 (Dec. 31, 2009); *infra* note 316.

⁴³ WASH. REV. CODE ANN. Ch. 70,245 (West 2009); Quill et al., *supra* note 38, at 2103. *But see* Susan R. Martyn & Henry J. Bourguignon, *Physician-Assisted Suicide: The Lethal Flaws of the Ninth and Second Circuit Decisions* 85 CAL. L. REV. 371, 405 (1997) (questioning whether deep, or terminal, sedation is the same as physician assisted suicide).

⁴⁴ Quill et al., *supra* note 38, at 2104. Voluntary euthanasia occurs in those cases where a clearly competent person makes a voluntary and enduring request to be helped to end his life. *Voluntary Euthanasia*, STANFORD ENCYCLOPEDIA OF PHIL. <http://plato.stanford.edu/entries/euthanasia-voluntary> (last visited Oct. 27, 2010).

⁴⁵ Quill et al., *supra* note 38, at 2104; *see generally* ROGER S. MAGNUSSON, ANGELS OF DEATH: EXPLAINING THE EUTHANASIA UNDERGROUND (2002) (discussing doctors’ and patients’ views on, and the sometimes-tacit approval of, assisted dying, particularly with regard to HIV patients).

⁴⁶ *Washington v. Glucksberg*, 521 U.S. 702, 710 (1997).

⁴⁷ *McStay*, *supra* note 36, at 60. *But see* Robert A. Burt, *The Supreme Court Speaks—Not Assisted Suicide but a Constitutional Right to Palliative Care*, 337 NEW ENG. J. MED. 1234 (1997).

from intolerable and unmanageable pain and suffering—a right which the U.S. Supreme Court has said exists⁴⁸ and is grounded in the essential right to refuse life-sustaining treatment.⁴⁹

Rather than continue to be overwhelmed with vexatious and often contrived issues, what should be uppermost is—in cases of intractable end-stage terminal suffering—a rational approach to legal decision making.⁵⁰ This approach should be guided by what, clinically, is judged to be in the best interests of the patient in order to maintain his dignity and comfort and promote a standard of beneficence during his final days.⁵¹

Perfect solutions for clinical dilemmas do not exist, nor can medicine sanitize death. When pain is refractory and unremitting, suffering follows despite efforts to palliate a patient's medical condition; terminal sedation and the voluntary refusal of nutrition and hydration although “imperfect,” are valid courses of action to follow and have the ultimate effect of enhancing patient autonomy.⁵²

Interestingly, up to ninety percent of pain can be controlled by analgesics.⁵³ Yet, for the fifteen to thirty-five percent of hospice care patients who suffer severe pain during their last week of life (with twenty-five percent experiencing unbearable shortness of breath), the ninety percent statistical success is unimpressive.⁵⁴ Indeed, previous

⁴⁸ McStay, *supra* note 36, at 60. See *Vacco v. Quill*, 521 U.S. 793 (1997); George J. Annas, *The Bell Tolls for a Constitutional Right to Physician-Assisted Suicide*, 33 *NEW ENG. J. MED.* 1098, 1102 (Oct. 9, 1997) (observing that five members of the *Vacco* Court “seem to think there is something akin to a ‘right not to suffer’ at least when death is imminent,” and when palliative care is provided by physicians whose primary intention is to relieve suffering); GEORGE P. SMITH, II, *FINAL EXITS: SAFEGUARDING SELF-DETERMINATION AND THE RIGHT TO BE FREE FROM CRUEL AND UNUSUAL PUNISHMENT* (1997) (on file with author) [hereinafter SMITH, *FINAL EXITS*].

⁴⁹ *Cruzan v. Mo. Dep't. of Health*, 497 U.S. 261 at 286–87 (1990); see also McStay, *supra* note 36, at 49. The Supreme Court has not given clear criteria for deciding when a right qualifies as a liberty interest. Accordingly, the right to die with assistance is best decided by state legislatures, prosecutors' offices, hospitals and private homes; for it is within these fora that the right is best tested and, when needed, acknowledged as legitimate. It should be remembered that even though there may be no constitutional foundation for a right to commit an act, this—alone—does not mean that, morally, the act is itself improper. Cass Sunstein, *The Right to Die*, 106 *YALE L. J.* 1123, 1156–57 n.151 (1997).

⁵⁰ George P. Smith, II, *Futility and the Principle of Medical Futility: Safeguarding Autonomy and the Prohibition Against Cruel and Unusual Punishment*, 12 *J. CONTEMP. HEALTH L. & POL'Y* 1 (1996) [hereinafter Smith, *Futility and the Principle of Medical Futility*].

⁵¹ See LYNN, *supra* note 26, at 12.

⁵² Timothy E. Quill & Ira R. Byock, *Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids*, 132 *ANNALS OF INTERNAL MED.* 408, 413 (2000).

⁵³ DEREK HUMPHRY, *FINAL EXITS* 134 (1991).

⁵⁴ Quill & Byock, *supra* note 52.

scholarship reported significant pain in as high as fifty percent of end-stage patients.⁵⁵

Rather than investigate the linguistic, moral, and philosophical ambiguities inherent in the voluntary cessation of nutrition and hydration, terminal sedation, physician-assisted suicides, and voluntary active euthanasia,⁵⁶ this Article advances the hypothesis that there is an inextricable component or commonality to evaluating and implementing each of these four actions designed to hasten a humane death: namely, common sense and compassion. This policy is rooted in the biomedical principle of beneficence,⁵⁷ which is tied to the notion that there is a human right to compassionate care in end-of-life illness⁵⁸—with suffering being seen, properly, to include physical *and* psychological distress.⁵⁹ The proper or controlling inquiry to be made with any of these four actions is, quite simply, whether these procedures are consistent with sound medical practice and thus whether it is in the best medical interests of the patients to relieve either end-stage physical or mental suffering, or both. Stated otherwise, the overarching strategic issue and, indeed, the conclusion to be reached is, to the extent to which any of these courses of action is a proportional response to patient suffering, they should be viewed legally and medically as proper acts of compassion and efficacious forms of relieving intractable end-stage pain and suffering.

D. Codifying Clinical Epidemiologies

With enlightened clinical policies or protocols setting forth standards for the use of terminal or respite sedation as a proportional response to the suffering associated with end-stage illness, palliative care will lose the shackles of being bound unnecessarily to the principle of double effect, and thereby broaden its focus and application. Rather than question the integrity of terminal sedation, its wider acceptance is com-

⁵⁵ See Quill et al., *supra* note 38, at n.1, 5, 7; see also Editorial, *Attending to Psychological Symptom and Palliative Care*, 20 J. CLINICAL ONCOLOGY 624 (Feb. 2001) (concluding more than one-third of dying patients are depressed).

⁵⁶ See Quill et al., *supra* note 38; McStay, *supra* note 36; see also Lynn A. Jansen & Daniel P. Sulmasy, *Sedation, Alimentation, Hydration, and Equivocation: Careful Conversation About Care at the End of Life*, 136 ANNALS OF INTERNAL MED. 845 (2002).

⁵⁷ See Albert R. Jonsen, *A History of Bioethics and Discipline and Discourse*, in BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS, AND PRACTICE 3–22 (Nancy C. Jecker, Albert R. Jonsen & Robert A. Pearlman eds. 2007); see also JOHN FLETCHER, *SITUATION ETHICS: THE NEW MORALITY* (1966); John Fletcher, *Love is The Only Measure*, 83 COMMONWEALTH 427 (1966).

⁵⁸ DAVID C. THOMASMA & GLENN C. GRABER, *EUTHANASIA: TOWARD AN ETHICAL SOCIAL POLICY* 192 (1991).

⁵⁹ McStay, *supra* note 36, at 46; see Greg A. Sachs, *Dying from Dementia*, 361 NEW ENG. J. MED. 1595 (2009).

patible with the principle of adjusted care⁶⁰ for all medical treatment, and a reasoned and compassionate response to managing medically futile cases.⁶¹

Once terminal sedation is more widely accepted and used as a valid medical procedure within the sound tenets of palliative care and made more readily available to alleviate distress in end-stage illness, the next step in broadening the impact of terminal sedation is to evaluate its validity in cases of nonterminal psychiatric illness.⁶² It is not within the scope of analysis of this Article to investigate this issue in depth. It is, however, important to make several observations that might well shape the course of impending policy debates in order to resolve this issue. Indeed, the proper laws for structuring normative standards must continue to be explored, debated, and subsequently refined over the succeeding years.

E. *European Approaches to Psychogenic Pain*

Interestingly, Belgium, the Netherlands,⁶³ and—more recently—Switzerland⁶⁴ have allowed compassionate medical assistance in those

⁶⁰ See THOMASMA & GRABER, *supra* note 58, at 129. Adjusted care is care adjusted, or suitable, to the progression of a medical condition. Thus, palliative care would come at the end-stage of a terminal illness while curative and rehabilitative care would be primary care at the onset of illness. See M. Sapir, *The Spectrum of Medical Care: Curative, Rehabilitative and Palliative*, 279 J. AM. MED. ASS'N. 20 (1998); Sidney Wanzer et al., *The Physician's Responsibility Toward Hopelessly Ill Patients: A Second Look*, 320 NEW ENG. J. MED. 844 (1989). Continually adjusted care is essential to a compassionate and common sense approach to the management of pain and suffering often encountered in the dying process. Care of this nature often strikes a balance in favor of pain relief—even though a potential exists for hastening death—rather than the mere prolongation of life which is in its end-stage. THOMASMA & GRABER, *supra* note 58, at 129. In a very real way, this standard of care complements the Principle of Double Effect. See Boyle, *Toward Understanding the Principle of Double Effect*, *supra* note 33; Cellarius, *supra* note 32; Quill et al., *supra* note 38, at 2101; *supra* notes 222–27.

⁶¹ Smith, *Futility and the Principle of Medical Futility*, *supra* note 50, at 38; see generally Lauren Shaiova, *Case Presentation: "Terminal Sedation" and Existential Distress*, 16 J. PAIN & SYMPTOM MGMT. 463 (1998) (describing a case study where a patient's pain management resulted in effective quadriplegia, and terminal sedation provided a way to calm her psychological distress).

⁶² See JOHN GRIFFITHS, HELEN WEYERS & MAURICE ADAMS, *EUTHANASIA AND LAW IN EUROPE* 45 (2008); MARY WARNOCK & ELISABETH MACDONALD, *EASEFUL DEATH: IS THERE A CASE FOR ASSISTED DYING?* 21–34 (2008). In cases of advanced or end-stage dementia, the prognosis should be properly seen as terminal and, thus, treated only with palliative care. Sachs, *supra* note 59, at 1596.

⁶³ GRIFFITHS ET AL., *supra* note 62, at 51, 275. In 2009, recent statistics showed that the number of people in Holland electing euthanasia was 2,636, or a thirteenn percent increase from 2,331 cases reported in 2008. Simon Caldwell, *Euthanasia Deaths on The Rise in Holland*, SUNDAY TELEGRAPH, June 20, 2010, at 17.

⁶⁴ Jacob M. Appel, *A Suicide Right for the Mentally Ill: A Swiss Case Opens the Debate*, 37 HASTINGS CTR. REP. 21 (May–June, 2007). On November 3, 2006, the Swiss Federal Supreme Court issued a ruling under which for the first time, assisted suicide is to be available to psychiatric patients and others with mental illness who suffer from “incurable, permanent, severe psychological disturbances” as well as to those with severe, long-term mental illness

cases where nonterminal patients have endured a constant (or permanent) level of mental suffering which qualifies as a chronic mental illness (e.g., manic/depressive or bipolar disorder) after years of “debilitating anxiety” or even possibly the “agonies of rheumatoid arthritis.”⁶⁵ In 1995, the Royal Dutch Medical Association determined that no valid distinction is to be drawn between physical and mental suffering.⁶⁶ Yet, the Association cautioned that in making medical evaluations of non-somatic illnesses, great care and caution should be exercised in assessing both the gravity and the depth of hopelessness consequential to the primary medical condition.⁶⁷

Any policy developed from a right to rational self-determination and thus, individual best interests, is also linked—inextricably—to the responsibility of the medical profession to minimize suffering—with the true extent being defined by each patient. The doctrine of medical futility would have to be reshaped in order to accommodate assistance at this

who have made “rational” and “well considered” decisions to end their lives in order to avoid further suffering. *Id.* at 21 n.4.

On February 25, 2010, the British, Crown Prosecution Service issued a document entitled, Policy for Prosecutors in Respect of Cases of Encouraging Assisting Suicide. See generally Director of Public Prosecutions, Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, CROWN PROSECUTION SERVICE, http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html [hereinafter CROWN PROSECUTION SERVICE]. Attempting to resolve moral ambiguities in cases of assisted suicide and mercy killings, the guidelines nonetheless fail to address not only the condition or degree of suffering the person requesting the suicide is experiencing nor do they address the situation in which a patient is neither terminally ill nor disabled but is suffering from severe depression or psychological distress. *See id.*

The guidelines do not change the law prohibiting assisted suicide. *See id.* Rather, they provide guidance on which cases are likely to be prosecuted. *See id.* They attempt to distinguish between “compassionate support” for which there would be a less likelihood of prosecution from cases of “malicious encouragement” which would be prosecuted. *See id.* For an analysis of the guidelines and the extent of their application, see Suzanne Ost, *The De-Medicalisation of Assisted Dying: Is a Less Medicalised Model The Way Forward?* 18 MEDICAL L. REV. 497, 510–11 (2010) [hereinafter Ost, *De-Medicalisation of Assisted Dying*].

The first case investigation under these guidelines involved a seventy-nine year-old physician, Dr. Michael Irwin, who provided death management assistance to some twelve patients. Although sufficient evidence was presented which could have provided a conviction under the Suicide Act of 1961, it was determined that the public interest would not be served by prosecuting a senior physician who claimed that he acted with compassion—consistent with the standards set under the assistance with suicide guidelines. Martin Beckford, *‘Dr. Death’ Ruled Too Old for Face Trial*, DAILY TELEGRAPH, June 26, 2010, at 4; *see also* Martin Beckford, *What the Law Says: Guidelines after The Purdy Case*, DAILY TELEGRAPH, June 26, 2010, at 4; Aidan O’Neill, *Assisted Suicide in the U.K.: From Crime to Right?*, 40 HASTINGS CTR. REP. (Inside back cover, unpaginated) (May–June, 2010).

⁶⁵ Appel, *supra* note 64, at 21; *see* Joachim Cohen et al., *European Public Acceptance of Euthanasia: Socio-demographic and Cultural Factors Assisted with the Acceptance of Euthanasia in 33 European Countries*, 63 SOC. SCI. & MED. 743 (2006).

⁶⁶ MARGARET OTLOWSKI, VOLUNTARY EUTHANASIA AND THE COMMON LAW 408, 409 (1997).

⁶⁷ *Id.*

level, since chronic mental illness is viewed today as totally separate from a medical condition diagnosed as futile and resulting in death.⁶⁸

Two primary concerns in any reevaluation of the feasibility of redefining the use and limits of palliative care for nonterminal psychological distress are the likelihood of cure from the mental illness and the competence of a mentally imbalanced patient to make a rational decision in seeking humane assistance to hasten death.⁶⁹ While agreements on time frames of affliction for the full range of mental illnesses might be helpful in determining nonterminal psychiatric illnesses that would qualify for terminal assistance, it remains arguable whether a patient diagnosed with a serious mental illness could ever be considered sufficiently competent to make a decision to hasten death. If new humane protocols for addressing the needs of those suffering from chronic psychotic distress are not forthcoming, those afflicted with mental illness will remain condemned to a form of lifetime incarceration where there is no palliative care.⁷⁰

In the final analysis, the determinative question to be posited is “not whether unbearable suffering is ever a justification for suicide but whether it can ever justify the provision of assistance for someone else who might not be able to bring it off unaided.”⁷¹ The bulwark of valid normative action must be seen as anchored to the principle of compassion.

⁶⁸ See Appel, *supra* note 64. While there is presently no consensus for palliative sedation to unconsciousness (PSU) when there is a primary level of existential suffering, it has been suggested by one physician that where “severe existential pain” is exhibited “for which all available and reasonable effective treatments are unacceptable to the patient,” PSU should be recognized as a valid medical option. Berger, *supra* note 37, at 32.

⁶⁹ See Appel, *supra* note 64. Additional concerns in determining the competency of an individual to make rational decisions of this nature would include whether consideration of this “final” alternative is of an impulsive nature; whether the decision is congruent with the actual personal values of the distressed patient; and the extent to which there is any form of coercion being extended upon the patient to decide one way or another. An assessment of the level of hopelessness associated with the medical condition at issue would also need to be evaluated. See JAMES L. WERTH, JR., RATIONAL SUICIDE? IMPLICATIONS FOR MENTAL HEALTH PROFESSIONALS 63–65 (1996).

⁷⁰ WARNOCK & MACDONALD, *supra* note 62, at 33, 34.

⁷¹ *Id.* at 30. See THOMASMA & GRAEBER, *supra* note 58, at 193 (arguing that there should be a level of social responsibility to aid those enduring pain and suffering at death). David H. Smith calls for the creation of supportive communities to be responsive to the needs of the dying. See GEORGE P. SMITH, II, FINAL CHOICES: AUTONOMY IN HEALTH CARE DECISIONS (1989); see also AP Leader of Assisted Suicide Group Defends Work in Interview, D.C. EXAMINER, Mar. 18, 2009, at 18 (reporting that the former President of the Final Exist Network—charged with violating Georgia’s assisted suicide law—argued that competent individuals suffering from medical conditions, such as a painful neurological condition accompanied by breathing lapses, have a right to be guided and assisted in ending their lives).

I. THE PARAMETERS OF PAIN

Led by the WHO, the International Association for the Study of Pain and its European Federation for Pain Study, a Global Day Against Pain was observed in October, 2004, in Geneva, Switzerland.⁷² This event marked an intensified effort to establish the relief of pain as a basic, fundamental human right and the recognition of chronic pain as a transnational health care issue.⁷³

Recognizing that the physical and psychosocial etiology of chronic pain sufferers manifests itself through a variety of conditions, including depression, anxiety, fear, and even suicide,⁷⁴ these three organizations defined chronic pain as pain recurring for a period of more than three months.⁷⁵ The broad nature of this definition finds support in both European and American studies. Not only do these studies disclose the significant employment irregularities resulting from chronic pain sufferers,⁷⁶ but surveys of households in Europe and the United States revealed that thirty-six percent of Europeans may be classified as chronic pain sufferers, and in America, forty-three percent of all households had members in chronic pain.⁷⁷ That percentage for Americans translates into a raw figure of eight million. By 2030, this figure is expected to double.⁷⁸

Within this demographic is another projection that, if accurate, presages even greater stress on health care resources for the elderly and underscores the ultimate need for a system attuned to the needs of long-term end-of-life care. If, indeed, the over-65 population in the United States will rise more than seventy percent between 2010 and 2030, while payroll taxes for those within the general population rise, as predicted, less than four percent, it is clear that planning efforts must be undertaken presently in order to meet these systematic needs.⁷⁹

Several organizations have made attempts to plan for the needs of end-of-life patients. The WHO has developed a three-step "ladder" for cancer pain relief. In summary, it states:

⁷² Arthur G. Lipman, *Pain as a Human Right: The 2004 Global Day Against Pain*, 19 J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY 85, 85 (2005).

⁷³ *Id.*

⁷⁴ *Id.* at 86.

⁷⁵ *Id.* at 88.

⁷⁶ *Id.* at 89.

⁷⁷ *Id.* at 88.

⁷⁸ BRUCE JENNINGS, ET AL., ACCESS TO HOSPICE CARE: EXPANDING BOUNDARIES, OVERCOMING BOUNDARIES, HASTINGS CTR., (2003), at S50, available at http://www.thehastingscenter.org/uploadedFiles/Publications/Special_Reports/access_hospice_care.pdf.

⁷⁹ *Id.* It is estimated that in order to support Medicare and Medicaid program costs, payroll taxes must rise four percent. *Id.*

If pain occurs, there should be prompt oral administration of drugs in the following order: nonopioids (aspirin and paracetamol); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs—“adjuvants”—should be used. To maintain freedom from pain, drugs should be given ‘by the clock,’ that is every 3—6 hours, rather than ‘on demand.’ This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90% effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective.”⁸⁰

The President’s Council on Bioethics concluded in 2005 that the basic standard for clinical decision-making should be one which promotes the best patient care.⁸¹ This standard obviously must be continually adjusted as a patient’s case history progresses,⁸² and to promote patient care anchored in mercy, compassion, beneficence, and loving charity—care which recognizes that relief of pain is the most universal moral obligation that a physician must uphold and that there is, indeed, a right not to suffer.⁸³

Psychological distress, or existential pain, however, is usually difficult to assess because evaluation requires special training and continual contact with the patients’ families.⁸⁴ There is a general societal aversion to the obstacles faced in proving a patient’s emotional distress at end-of-life care.⁸⁵ Distinguishing between depression and psychological morbidity is difficult because the sympathology of disrupted sleeping pat-

⁸⁰ WHO’s *Pain Ladder*, WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/painladder/en/index.html> (last visited Nov. 8, 2010).

⁸¹ PRESIDENT’S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 217 (2005), available at http://bioethics.georgetown.edu/pcbe/reports/taking_care/. Best patient care is adjusted to the developing medical needs of the patient. Essential to the standard of best care is acceptance of the “intrinsic dignity of persons” which, in turn, mandates that the goal of providing care must be to enhance total patient well being (somatic and non-somatic) and, at the end of life demonstrate beneficence, compassion, or charity in managing pain and suffering. DAVID C. THOMASMA, HUMAN LIFE IN THE BALANCE 165, 184 (1990); see CASSELL, *supra* note 2; EDMUND D. PELLEGRINO & DAVID C. THOMASMA, FOR THE PATIENT’S OWN GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE (1988); see also THOMASMA & GRAEBER, *supra* note 58, for a discussion of the principle of adjusted care.

⁸² THOMASMA & GRAEBER, *supra* note 58, at 129.

⁸³ *Id.* at 192, 194 (quoting Dr. Edmund D. Pellegrino).

⁸⁴ Manish Agrawal & Ezekial J. Emmanuel, *Attending to Psychologic Symptoms and Palliative Care*, 20 J. CLINICAL ONCOLOGY 624 (Feb. 1, 2001).

⁸⁵ *Id.*; see generally Paul Arnstein et al., *Self Efficacy as a Mediator of The Relationship between Pain Intensity, Disability and Depression in Chronic Pain Patients*, 80 PAIN 483 (1999) (calling for further research after conducting a study which showed a possible connection between chronic pain and low self efficacy—doubts about one’s own abilities).

terns, loss of energy, and lack of appetite are not exclusive response mechanisms to psychological distress, but appear in cancer and other terminal illnesses as well.⁸⁶ Because of these difficulties and uncertainties, the palliative management of existential pain has been largely neglected.⁸⁷

While no general “solutions” exist for meeting the existential needs of terminally ill patients, attempts to meet these needs require careful listening skills and defined lines of communication between health care providers, patients, affected families, and proxy or surrogate decision-makers. Valid existential concerns are often obscured during palliative care treatment.⁸⁸ Even though a patient may have no absolute control over the wide and varied spectra of suffering, the patient still has freedom to choose what attitude is taken toward that suffering.⁸⁹ By extending end-of-life care to include psychiatric, psychological, existential and spiritual issues—consistent with the WHO’s definition of palliative care and its goal of addressing total patient needs⁹⁰—a more complete, compassionate, and realistic approach to managing terminal illness and end-stage suffering would be implemented.⁹¹

A. *Assessing Existential Suffering*

The desire to hasten death arises because of a number of conditions: inadequate pain management, psychological conditions ranging from depression and hopelessness, to fears of loss of autonomy and physical functioning,⁹² to futile and unbearable suffering, and avoidance of humiliation.⁹³ All of these conditions conduce to one overriding fear: loss of human dignity,⁹⁴ which brings with it a fear of being forced to become but a “passive bystander” to all of the normal functions of life.⁹⁵ By managing the dying process, which—for some—is viewed as too pro-

⁸⁶ Put simply, the dying “do not have the luxury of clearly separating their physical suffering from their psychological, spiritual, an existential suffering.” Quill & Battin, *infra* note 328, at 332; *see also* Agrawal & Emmanuel, *supra* note 84.

⁸⁷ Agrawal & Emmanuel, *supra* note 84.

⁸⁸ Ingrid Bolmsjö et al., *Meeting Existential Needs in Palliative Care—Who, When, and Why?*, 18 J. PALLIATIVE CARE 185 (2002).

⁸⁹ William Breitbart, Christopher Gibson, Shannon Poppito & Amy Berg, *Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality*, 49 CAN. J. PSYCHIATRY 336 (June, 2004); *see also* GEORGE P. SMITH, II, FINAL CHOICES: AUTONOMY IN HEALTH CARE DECISIONS (1989).

⁹⁰ *See* HOSPICE, *supra* note 19; SAUNDERS, *supra* note 21, at 320.

⁹¹ Breitbart et al., *supra* note 89, at 371.

⁹² Stacks et al., *supra* note 24, at 216.

⁹³ Gerrit Van der Wal & Robert J. M. Dillman, *Euthanasia in the Netherlands*, 308 BR. MED. J. 1346 (1994).

⁹⁴ HUMPHRY, *supra* note 53, at 135–36.

⁹⁵ Gunderman, *supra* note 10, at 40, 42.

tracted and filled with growing and multiple functional losses,⁹⁶ the patient can exert some level of control over a process which is acknowledged to be “by and large, a messy business.”⁹⁷ Sadly, this complicated and vexatious process for implementing the “new epidemiology of dying”⁹⁸ almost assures that health care providers will follow heroic procedures which do not promote or sustain quality so much as postpone death.⁹⁹

In approximately twenty-five percent of all terminally ill patients, depression and other mood disorders occur.¹⁰⁰ Yet, interestingly, few receive pharmacological aid through anti-depressant prescriptions.¹⁰¹ As this Article shows, the main obstacle to a more liberal response to these patients’ needs is the lack of clarity in determining when a distressed, terminal patient is suffering from clinical depression or, instead, exhibiting a “normal grief response” to the dying process.¹⁰² The components of both of these syndromes are often vague, imprecise, and difficult to evaluate.¹⁰³ Commonly, when patients are obsessed with feelings of worthlessness, lose their ability and desire to interact socially, and—indeed—lose their sense of hope, they are properly assessed as suffering from clinical depression¹⁰⁴ and should be given whatever dosage of analgesis is deemed necessary to alleviate that condition—because pharmacotherapy is ultimately the principal tool for symptom control.¹⁰⁵

Another drawback to accurate and prompt evaluations of psychological distress or existential suffering is often the inability of a physician or palliative care management team to understand patient views about suffering. As a spiritual phenomenon, suffering is often accepted in Christian communities as a meaningful and authentic community response to

⁹⁶ Stacks, *supra* note 24, at 216.

⁹⁷ SHERWIN B. NUTLAND, *HOW WE DIE: REFLECTIONS ON LIFE’S FINAL CHAPTER* 142 (1994).

⁹⁸ *Id.* at 12.

⁹⁹ LYNN, *supra* note 26, at 164–65.

¹⁰⁰ Karel E. Miller, Stephen M. Adams & Martha M. Miller, *Antidepressant Medication Use in Palliative Care*, 23 *AM. J. HOSPICE & PALLIATIVE MED.* 127 (No. 2, Mar.-April 2006).

¹⁰¹ *Id.* Some other earlier studies have, however, shown that a number of terminally ill cancer patients have—indeed—received sedation for psychological or mental agonies. Tatsuya Morita et al., *Terminal Sedation for Existential Distress*, 17 *AM. J. HOSPICE AND PALLIATIVE CARE* 189, nn.4, 6–8. A 1996 study done of experts on sedation in the U.K. and America found that in twenty-two percent of cases evaluated, sedation was administered because of patient “anguish” and in sixteen percent of cases, it was undertaken because of the “emotional, psychological [or] spiritual distress” of those patients. Susan Chater et al., *Sedation for Intracetable Distress in the Dying—a Survey of Experts*, 12 *PALLIATIVE MED.* 255 (1998).

¹⁰² Miller et al., *supra* note 100.

¹⁰³ *Id.*

¹⁰⁴ *Id.* at 128.

¹⁰⁵ Lipman, *supra* note 7, at 2.

Jesus Christ's own suffering.¹⁰⁶ In some faith communities, cultural efforts are expended in order to view suffering—physically and mentally—as a positive, reinforcing value.¹⁰⁷ Merely accepting suffering as authentic, however, does not mean that it is also meaningful.¹⁰⁸ It remains for the physician to ascertain and then listen carefully to the spiritual parameters within each patient's character¹⁰⁹ in an attempt to treat those seriously ill as “whole persons.”¹¹⁰ In this way, the therapy is truly patient-centered.¹¹¹

Refractory existential suffering—or those symptoms which defy adequate control despite all efforts to provide relief—is difficult to distinguish during the end stages of life from physical distress.¹¹² Those additional refractory symptoms most commonly reported as requiring palliative sedation are: various degrees of agitation, restlessness or distress, confusion, respiratory distress, pain, and myoclonus (e.g., severe twitching, jerking or uncontrollable shakes).¹¹³

Palliative sedation therapy is thus defined as “the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness.”¹¹⁴ When patient suffering—physical or existential—becomes refractory to standard palliative therapies, the human,

¹⁰⁶ Stan Van Hooft, *The Meanings of Suffering*, 28 HASTINGS CTR. REP. 13 (1998); see CASSELL, *supra* note 2, at 42–44; STANLEY HAURWAS, GOD, MEDICINE, AND SUFFERING, chs. II, III (1990); see also SHAPO, *supra* note 9 (discussing the legal position in assessing pain and suffering).

¹⁰⁷ Van Hooft, *supra* note 106, at 14.

¹⁰⁸ *Id.* at 15.

¹⁰⁹ See Seth M. Holmes et al., *Screening the Soul: Communication Regarding Spiritual Concerns Among Primary Care Physicians and Seriously Ill Patients Approaching the End of Life*, 23 AM. J. HOSPICE & PALLIATIVE MED. 25, 30 (2006).

¹¹⁰ Alton Hart, Jr. et al., *Hospice Patients' Attitudes Regarding Spiritual Discussion with Their Donors*, 20 AM J. HOSP. PALLIATIVE CARE 135 (2003).

¹¹¹ Holmes et al., *supra* note 109, at 30; see generally A. B. Astro & Daniel P. Sulmasy, *Spirituality and The Patient-Physician Relationship*, 291 J. AM. MED. ASS'N. 2884 (2004) (describing studies that focused on the importance and effects of faith and spirituality in cancer patients).

¹¹² Paul Rousseau, *Existential Suffering and Palliative Sedation: A Brief Commentary with a Proposal for Clinical Guidelines*, 18 AM. J. HOSPICE & PALLIATIVE 151 (2001); see James Halenbeck, *Terminal Sedation for Intractable Distress: Not Slow Euthanasia but a Prompt Response to Suffering*, 171 WESTERN J. MED. 222 (Oct. 1999).

¹¹³ Bernard Lo & Gordon Rubenfeld, *Palliative Sedation in Dying Patients: “We Turn to It When Everything Else Hasn't Worked”*, 294 J. AM. MED. ASS'N. 1810, 1811 (2005); see generally Joseph W. Shega et al., *Patients Dying with Dementia: Experience at the End of Life and Impact on Hospice Care*, 35 J. PAIN SYMPTOM MGMT. 499 (2008) (conducting a study that showed patients with dementia who enroll in hospice programs may experience better end-of-life care, though certain “nontreatable” symptoms still persist and cause the majority of distress for patients).

¹¹⁴ Tatsuya Morita et al., *Definition of Sedation for Symptom Relief: A Systematic Literature Review and a Proposal For Operational Criteria*, 24 J. PAIN SYMPTOM MGMT. 447 (2002).

compassionate and merciful response is to offer terminal sedation.¹¹⁵ This approach to medical treatment may be seen as consistent with sound principles of adjusted care.

B. Demoralization

It has been suggested that—in the clinical setting of hospice or palliative care—a unique diagnostic category, termed the “demoralization syndrome,” is becoming more recognizable and should be refined and classified as a cognitive disorder.¹¹⁶ Seen as a “useful category of existential distress in which meaningless predominates and . . . profound hopelessness and [a] desire to die may result,”¹¹⁷ this syndrome, if not treated satisfactorily with pharmacological therapy, should render such a demoralized patient incompetent to make medical decisions.¹¹⁸

Yet, interestingly, there is no conclusive empirical evidence to support an all too popular conclusion that depression so impairs judgment as to prevent one from competently disapproving of the initiation or cessation of medical treatment.¹¹⁹ Sadly, this depression argument would appear to be a ruse to obstruct and even prevent end-of-life decision-making on the grounds of moral repugnancy to alternative or surrogate health care providers.¹²⁰

If—and when—the demoralization syndrome is accepted by diagnosticians as a cognitive disorder, it would then remain for physicians to respond with compassion and caring in remediating this medical condition. If deemed proper, under the overarching principle of medical futility, physicians should consider the reasonableness of alleviating this pathological mental state in the end-stage patient by administering terminal sedation. Such a course of treatment would be consistent with the central obligation of all physicians to alleviate pain and suffering—here, mental suffering—and to assure the dying patient’s dignity and best interests.¹²¹

¹¹⁵ Rousseau, *supra* note 112; P.C. Rousseau, *Dying and Terminal Sedation*, 7 CLIN. GERIATRICS 19, 19 (1999).

¹¹⁶ David W. Kissane, *The Contribution of Demoralization to End of Life Decisionmaking*, 34 HASTINGS CTR. REP. 21, 24 (2004).

¹¹⁷ *Id.* at 23. While anxiety and depression are viewed as “expressions of morality”—thereby making them “synonymous with suffering (and) existential distress,” demoralization may occur “independently of depression.” *Id.* at 23, 24.

¹¹⁸ *Id.* at 29.

¹¹⁹ RONALD A. LINDSAY, *FUTURE BIOETHICS: OVERCOMING TABOOS, MYTHS AND DOGMAS* 111 (2008).

¹²⁰ *Id.* at 112.

¹²¹ See THOMASMA & GRABER, *supra* note 58, at 192, 194 (quoting Dr. Edmund D. Pellegrino). All too often those suffering with dementia in the end-stage of life receive an array of aggressive therapies from forced tube feeding to hospitalization for pneumonia—all of which are not only of limited benefit but inconsistent with sound standards of palliative management.

II. BROADENING THE BOUNDARIES OF HOSPICE AND PALLIATIVE CARE

Over the next twenty years, the projected population of Americans at least sixty-five years-old will more than double from thirty-four million in 1997 to over sixty-nine million in 2030.¹²² For baby boomers, one in nine may expect to reach the age of ninety; and by the year 2040, the amount of Americans over the age of eighty-five will be nearly four times that of those in 2003.¹²³ The potential use of both hospice and palliative care for these Americans staggers the imagination.¹²⁴

Very often, palliative care practice seeks to manage incurable illness in “the least unpleasant course,” allowing a patient to die from their incurable illness in the least traumatic manner.¹²⁵ For a competent patient to exercise their autonomy and be sufficiently informed to determine the course of his medical treatment or non-treatment, they must have an admittedly “gruesome discussion about ways of dying.”¹²⁶ This then allows the patient to decide, essentially, which of several terminal events will end his life.¹²⁷ Understandably, some patients will not be willing, or psychologically capable, of entering into such a discussion.¹²⁸ In those situations, the health care decisionmakers must attempt to discern the patient’s wishes by evaluating his “total good or best interests.”¹²⁹ The challenge here is that if the patient is not informed, he cannot formulate or evaluate ideas which promote his best interests as death approaches.¹³⁰

When forced to determine whether to offer life-prolonging and life-sustaining treatments to terminally ill autonomous patients, health care decisionmakers should evaluate whether treatment measures are physiologically futile and whether the intrinsic burdens and risks of such measures are overwhelmingly greater than their benefits¹³¹—in other words, whether the treatment is worse than the end-stage disease itself.

Susan L. Mitchell et al., *The Clinical Course of Advanced Dementia*, 361 *NEW ENG. J. MED.* 1529, 1535 (Oct. 15, 2009).

¹²² JENNINGS ET AL., *supra* note 78, at S3.

¹²³ *Id.*

¹²⁴ *Id.* Current statistics show five million Americans are afflicted with dementia and more than thirteen million are projected to be diagnosed by 2050. Mitchell et al., *supra* note 121, at 1536; *see generally* JONATHAN HERRING, *MEDICAL LAW AND ETHICS* 506–07 (2d ed. 2008) (calling for an expansion of palliative care options); Susan L. Mitchell et al., *Hospice Care for Patients with Dementia*, 34 *J. PAIN & SYMPTOM MGMT.* 7 (2007) (evaluating the quality of care in hospices for patients with dementia).

¹²⁵ FIONA RANDALL & ROBIN S. DOWNIE, *PALLIATIVE CARE ETHICS: A GOOD COMPANION* 117 (1996).

¹²⁶ *Id.* at 118.

¹²⁷ *Id.* at 117.

¹²⁸ *Id.* at 118.

¹²⁹ *Id.*

¹³⁰ *Id.* at 119.

¹³¹ *Id.*

Normally, actual hospice care precludes curative treatment in end-of-life terminal illnesses.¹³² More contemporary thinking and policy, while acknowledging the primary goal of hospice care to provide comfort, symptom management and alleviate pain, should not preclude actual treatment.¹³³ Traditionally, interdisciplinary palliative care teams of nurses, social workers, residents, and geriatricians devote a major part of their work to maintaining a standard of qualitative living for patients with terminal illness. Often, a continuum of adjusted care is created, from the initial diagnosis through the end-stage of illness.¹³⁴

The last ten years have produced a distinct change in the actual scope of hospice care, which is expanding to embrace patients who are terminally ill and suffering from diseases other than cancer (e.g., dementia, chronic lung disease, and congestive heart failure) and provide palliative supplements for those patients who are terminally ill and confined to nursing homes.¹³⁵ In fact, approximately one-third of hospitals in the United States are now offering some form of inpatient palliative care which is not limited to life expectancy of six months or less.¹³⁶

Nevertheless, because of prevailing requirements to forego disease-directed therapy before being allowed hospice care, most Americans die without the benefit of palliative care.¹³⁷ “Bridge programs” are being experimented with, however, in some hospices, which actually allow patients to continue active treatment therapies that are deemed important to the patient and have some limited potential for helping manage end-stage illness.¹³⁸ In the final analysis, the better-reasoned view is to consider palliative care and hospice care “an integral part of all health care” and not as “care of last resort.”¹³⁹

¹³² Sandra L. Ragan, Elaine Wittenberg & Harry T. Hall, *The Communication of Palliative Care for the Elderly Cancer Patient*, 15 HEALTH COMM. 219 (2003).

¹³³ *Id.*

¹³⁴ Joanne Kenen, *A New Focus on Easing the Pain: Palliative Care Helps the Very Ill. It May Also Keep Costs Down*, WASH. POST, July 3, 2007, at F1.

¹³⁵ Quill, *Physician-Assisted Death*, *supra* note 40, at 18.

¹³⁶ Kenen, *supra* note 134, at F1.

¹³⁷ Quill, *Physician-Assisted Death*, *supra* note 40, at 18. While approximately seventy percent of Americans wish to die at home, about half die in hospitals; and although hospice or palliative care is available to those suffering from terminal illness, practically, most get only a few weeks of this care. Thomas, *supra* note 35, at 40.

¹³⁸ Quill, *Physician-Assisted Death*, *supra* note 40.

¹³⁹ Jennings et al., *supra* note 122, at S9. A recent report by the Lien Foundation on end-of-life care in forty countries found Britain topping the list with Australia placing second and the United States placing third. Rankings were given based on three factors: life expectancy, hospice availability, and access to painkillers. Because of a policy by health insurers that payment for palliative care will only be covered when a patient relinquishes curative treatments upon entering hospice, the United States did not score well on this assessment factor. See *Grim Reapings: The Quality of Death*, THE ECONOMIST, July 17, 2010, at 54.

The degree of care and level of sustainable qualitative living at the end-of-life depends on disease prognosis. Some prognoses are poor, others terminal. While metastatic cancer is terminal, end-stage liver disease, severe emphysema, and congestive heart failure are often seen as worse prognoses, as to time, than cancer. A diagnosis of kidney disease is often seen as an appropriate time to develop strategies for end-stage care.¹⁴⁰

It has been said that “the palliative care movement has come of age,” especially with the recent action of the American Board of Medical Specialties certifying this palliative care as a subspecialty.¹⁴¹ Even with these remarkable advances in expanded care and board certification of the field, there are gaps in providing adequate education and training in basic palliative management and a shortage of skilled clinicians in this board-certified field.¹⁴² It is hoped that this classification will serve as a catalyst for advancing greater opportunities for expanded training and service in palliative medicine.¹⁴³

III. SHAPING THE PRINCIPLE OF MEDICAL FUTILITY

A. *Quality of Life, Sanctity of Creation*

All too frequently, when sanctity of life is embraced as a religious or moral construct, it becomes impervious to rational argument.¹⁴⁴ When juxtaposed with quality of life, the religious view complicates and, it is argued, often trumps secular arguments viewing the standard of quality of life as the more rational construct for decision-making in end-stage illness.¹⁴⁵ Instead of one principle or concern dominating the other, both approaches should be used in evaluating a patient’s medical prognosis and placing “hope”¹⁴⁶ for recovery within a proper, realistic context consistent with patient values.

While quality of life varies from person to person and, thus, cannot be bound by one uniform standard, it can be tested by a sense of compassion or mercy. If a terminal patient is experiencing great physical pain or mental suffering, it makes sense that medically-approved actions must be undertaken to alleviate that suffering. Failure to act accordingly is surely an affront to the very notion of human dignity. Ambiguous and subtle

¹⁴⁰ Kenen, *supra* note 134.

¹⁴¹ Quill, *Physician-Assisted Death*, *supra* note 40, at 17.

¹⁴² *See id.* at 18.

¹⁴³ *See id.*

¹⁴⁴ *See* RONALD A. LINDSAY, *FUTURE BIOETHICS: OVERCOMING TABOOS, MYTHS, AND DOGMAS* 52–53 (2008).

¹⁴⁵ *Id.*; *see* ROBERT YOUNG, *MEDICALLY ASSISTED DEATH*, 29–43 (2007).

¹⁴⁶ Adrienne M. Martin, *Hope and Exploitation*, 38 *HASTINGS CTR. REP.* 49 (2008).

philosophical refinements serve no practical purpose and defy not only the medical principle of futility, but compassion and mercy.¹⁴⁷

Rather than analyze and “test” supposed levels of the patient’s intent in the management of end-stage illness, it is reasonable to isolate the standard of proportionality from the “traditional” test of double effect and simply weigh the costs and benefits of following a course of action.¹⁴⁸ Accordingly, if a decision to discontinue care is in proportion to the “quality” of life remaining for a terminal patient, that decision should be recognized as not only rational, but efficacious and humane. Anchored at the fulcrum of the cost-benefit test of proportionality is the principle of medical futility, which is supported and complemented by the principle of compassion and the cardinal principle of beneficence. If the present system were redesigned as this Article urges, a new approach to managing ethical issues in end-of-life care will avoid the taxonomical ambiguity seen in the classical principle of double effect.

B. *Clinical Applications*

In 1974, Richard A. McCormick, S.J., suggested a basic medical approach to determine when life is no longer meaningful, consistent with the American Medical Association’s 1974 policy on the issue.¹⁴⁹ For Fr. McCormick, when there is irrefutable evidence that biological death is imminent, no extraordinary measures should be undertaken to sustain life.¹⁵⁰ Fr. McCormick believed that evidence was met when an individual patient’s condition “negat[es] any truly human—i.e., relational—potential relationships.”¹⁵¹

Recognizing that this standard of relational capacity is not subject to mathematical precision, Fr. McCormick urged the medical profession to agree on concrete categories or presumptive symptoms to aid in reaching this judgment.¹⁵² When maintenance of life means the prolongation of pain, with little or no chance of a real or sustainable level of qualitative recovery or rehabilitation, there is really no opportunity to grasp or seek

¹⁴⁷ Edmund D. Pellegrino, *Decision at The End of Life: The Use and Abuse of The Concept of Family*, in *THE DIGNITY OF THE DYING PERSON* 231 (Juan De Dios Vial Correa & Elio Segreccia eds., 2000) (1999) [hereinafter Pellegrino, *Decision at The End of Life*].

¹⁴⁸ *Id.* (observing that a disproportionate treatment is synonymous with futility); see Pellegrino, *Decision at The End of Life*, *supra* note 147.

¹⁴⁹ Richard A. McCormick, *To Save or Let Die: The Dilemma of Modern Medicine* 229 J. AM. MED. ASS’N. 172 (1974).

¹⁵⁰ *Id.*

¹⁵¹ *Id.* Dr. Joseph Fletcher suggested a number of factors could be used to test whether one’s medical state is consistent with common indicators of personhood. The pivotal factor is whether the at-risk patient has a functioning cortex. Joseph Fletcher, *A Tentative Profile of Man*, 2 HASTINGS CTR. REP. 1 (Nov. 1972).

¹⁵² McCormick, *supra* note 149.

the overall meaning of life or “relational-potential.” At this point, any treatment should be recognized as futile and cease accordingly.¹⁵³

Today, Fr. McCormick’s analytical approach is absorbed within the principle of medical futility. Although Fr. McCormick abjured quality of life indices in determining when life should be maintained or allowed to end, it is argued here that the indicia, when shaped by standards of mercy, compassion, love or humanism, should be seen as an integral part of medical futility.¹⁵⁴ Accordingly, the principle of medical futility comes into play in those clinical cases where: a cure is physiologically impossible; the treatment is non-beneficial or unlikely to be beneficial; and in those cases where treatment, while plausible, has yet to be validated.¹⁵⁵

An alternative approach to defining futility concludes that no obligation exists to either offer treatment or maintain existing treatment. Thus, when an intervention—even a life-sustaining one—which is verified by contemporary clinical experience and medical knowledge, holds no reasonable promise for effecting recovery, imposes burdensome consequences “grossly disproportionate” to any expected benefit, has no efficacious value in mitigating patient discomfort, or serves only to artificially delay death “by sustaining, supplanting or restoring a vital function,” then no obligation exists to either offer for it, or, for that matter, maintain it.¹⁵⁶

Admitting the existence of futile treatment negates the primary obligation of health care professionals to “do no harm.”¹⁵⁷ When a physician prescribes a modality of treatment knowing that it is futile, he is exposing the patient to needless additional risks associated with the treatment, including infection or other adverse reactions. Even if futile treatment does not affect the patient adversely, the mere exposure to risk is cruel. Moreover, some interventions—such as cardiopulmonary resuscitation (CPR)—inflict severe physical trauma.¹⁵⁸ Administering CPR when there is no medically reasonable chance that a distressed patient will re-

¹⁵³ *Id.*

¹⁵⁴ Smith, *Futility and the Principle of Medical Futility*, *supra* note 50.

¹⁵⁵ Lawrence J. Schneiderman & Nancy Jecker, *Futility in Practice*, 153 *ARCH. INTERN. MED.* 437, 440 (1993).

¹⁵⁶ Lance K. Stell, *Stopping Treatment on the Grounds of Futility: A Role for Institutional Policy*, 11 *ST. LOUIS U. PUB. L. REV.* 481, 495 (1992). Any request that medical therapy be offered to patients who would have less than a one percent chance of success should be deemed unreasonable and, thus, futile. Lawrence F. Schneiderman, Nancy S. Jecker & Albert R. Jonsen, *Medical Futility: Its Meaning and Ethical Implications*, in *BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS, AND PRACTICE* 408, 412 (Nancy S. Jecker, Albert R. Jonsen & Robert A. Pearlman eds. 2d ed. 2007).

¹⁵⁷ John L. Paris et al., *Physician’s Refusal of Requested Treatment: The Case of Baby L*, 322 *NEW ENG. J. MED.* 112, 1014 (1990).

¹⁵⁸ Smith, *Euphemistic Codes*, *supra* note 37.

cover from the underlying illness amounts to physical torture.¹⁵⁹ Accordingly, physicians should be under a duty to cease performing futile treatments because, by doing so, they are inflicting cruel and unusual punishment on their patients and their respective families.¹⁶⁰

Dr. Edmund D. Pellegrino, former Chairman of the President's Council on Bioethics, suggests that the primary goal in dealing with cases of futility is achieving for the patient a level of "total good." This goal is realized when a carefully calibrated balance is struck between three criteria: the effectiveness, benefits, and burdens of treatment reached within a cooperative "alliance" between the treating physician and the patient or his surrogate decisionmaker.¹⁶¹ For Dr. Pellegrino, futility is not an isolated, empirical yes or no test. Rather, each judgment of futility takes all aspects of patient's total life experience into account—physical, mental, and spiritual preferences together with their life goals. As such, each judgment "demands prudential assessment for a particular person in a particular experience of illness and within a particular metaphysical and theological context."¹⁶²

Closely, if not inextricably related to the doctrine of medical futility, is the principle of proportionality. Under this principle, there is no obligation to provide a specific treatment when overuse or underuse would create an unreasonable burden inflicting a disproportionate amount of harm or suffering to any realistic benefit derived from the treatment.¹⁶³ Often presented as a cost-benefit theory, the factors used in the balancing test under this principle are not uniformly quantified.¹⁶⁴ In an effort to bring structure to this contentious issue, Dr. Pellegrino suggests "disproportionate" use is—simply— futile medical care.¹⁶⁵

¹⁵⁹ *Id.*

¹⁶⁰ Smith, *Futility and the Principle of Medical Futility*, *supra* note 48.

¹⁶¹ Pellegrino, *Decision at The End of Life*, *supra* note 147, at 227.

¹⁶² *Id.* at 240.

¹⁶³ Margaret A. Somerville, *The Song of Death: The Lyrics of Euthanasia*, 9 J. CONTEMP. HEALTH L. & POL'Y 1, 62 (1993).

¹⁶⁴ TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 228–34 (3d ed. 1989).

¹⁶⁵ Pellegrino, *Decision at The End of Life*, *supra* note 147, at 229. For medical treatments seen as "extraordinary" and excessively burdensome, the Roman Catholic Church in 1957, through Pope Pius XII, concluded such can licitly be withdrawn. *Id.* at 219. And, in 1980, the Declaration on Euthanasia was issued by the Sacred Congregation for the Doctrine of the Faith which sought to amplify the policy for testing when medical treatment is disproportionate to the benefit conferred by it. *Id.* at 229. Accordingly, the Congregation suggests the type of treatment and its complexity be compared (or balanced) against the result to be expected from its use while considering the state of the ill person, his physician and their moral resources. *Id.*

C. *Model Legislative Guidance*

All too often, the clinical application of these substantive medical norms to aid in decision-making remains beyond the understanding of patients, their health proxies, and patients' families.¹⁶⁶ Today, hospital policies regarding the determination of medical futility are usually grounded in a "consultative consensus-building approach."¹⁶⁷ Yet, interestingly, nine states have adopted the Uniform Health Care Decisions Act¹⁶⁸ and gone on record as stating that there must be a point of closure or finality in end-of-life care-giving where consultation must yield eventually to decisive action.¹⁶⁹ Under this Act, there is no "absolute" obligation on the provider's part to honor a health care surrogate's demand for the initiation or continuation of care.¹⁷⁰ Medical care may be refused if the attending physician determines that care would be "ineffective"¹⁷¹ and contrary to generally accepted "health care standards,"¹⁷² or in violation of "conscience."¹⁷³ This model legislation is a bold step forward in bringing much-needed clarity and finality to an area of decision-making that is inherently clouded with emotional stress.

D. *Sedation-Hastened Death*

When aggressive medications used to control severe intractable symptoms such as dyspnea, pain, myoclonus, vomiting, delirium, anxiety, or agitation are unsuccessful and the symptoms remain severe, sedation for a dying patient's intractable distress is proper.¹⁷⁴ There is widespread disagreement, however, on the propriety of using sedatives when the patient is suffering from psychological or emotional distress

¹⁶⁶ One study discovered that conflicts arose in seventy-eight percent of cases where issues of limiting life-sustaining medical treatment were in play and normally involved a demand of health care providers to provide care when a decision was made that such action was either inappropriate or futile. Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure*, 22 OHIO ST. J. ON DISP. RESOL. 1, 4 n. 13 (2007).

¹⁶⁷ Sandra H. Johnson et al., *Legal and Institutional Policy Responses to Medical Futility*, 30 J. HEALTH & HOSP. L. 21, 31 (1997).

¹⁶⁸ Unif. Health Care Decisions Act §§ 1–19, 9 U.L.A. 93 (1993).

¹⁶⁹ See Johnson, *supra* note 168, at 34 (suggesting that if conflicts regarding medical futility remain unresolved after using a consultative, consensus-building approach, medical futility policies must designate a decision-maker and institute a process for decisively resolving the conflict); Unif. Health Care Decisions Act at §§ 1–19 (providing for the creation of advance health-care directives to authorize an agent or surrogate to make health care decisions for an individual).

¹⁷⁰ See Unif. Health Care Decisions Act, *supra* note 168, at Prefatory Note ¶ 7.

¹⁷¹ *Id.* § 13(d).

¹⁷² *Id.* §§ 7(f), 13(d).

¹⁷³ *Id.* § 7(e).

¹⁷⁴ Eric L. Krakauer et al., *Sedation for Intractable Distress of a Dying Patient: Acute Palliative Care and The Principle of Double Effect*, 5 THE ONCOLOGIST 53 (2000).

instead of physical pain.¹⁷⁵ This Article postulates that, instead of separating the somatic from the non-somatic in assessing and evaluating a course of proper medical treatment for end-stage illness, charity should be the “final principle and ultimate virtue of care for the dying.”¹⁷⁶ The extent or degree of charity or compassion shown—from a standard of health care delivery and law—should, in turn, be framed by the doctrine of medical futility¹⁷⁷ or adjusted care.¹⁷⁸ To continue treatment which is medically futile would be morally wrong, for it “would deny the fact of human finitude and impose unnecessary effort, expense, and emotional trauma on the patient and on others.”¹⁷⁹ Indeed, to continue treatment of futile medical conditions can be understood as violating beneficence—the primary principle of traditional medical ethics.¹⁸⁰

Autonomous patients may request sedation in order to abate severe distress manifested by unrelieved pain, restlessness, or mental anguish.¹⁸¹ Here, the intent of the physician administering the sedation is to alleviate the distress by either “decreasing mental anguish or lessening the patient’s awareness of it.”¹⁸² Often, sedation is intermittent and has been termed “respite”¹⁸³ or “twilight sleep”¹⁸⁴ leading to the concern by some that it is but a euphemism for euthanasia, especially when the procedure is used for non-autonomous patients.¹⁸⁵ Others argue that the degree or extent of sedation is tied to the level of patient distress—with the sole purpose of alleviating the distress.¹⁸⁶

While there is a significant risk that life may well be shortened by the use of sedatives in both the case of the terminally ill autonomous patient and the non-autonomous patient suffering medical distress, the generally accepted policy is that when all other “traditional” efforts at pain management are ineffective, “the great benefits of alleviating such suffering by sedation . . . outweigh the harm entailed in the risk of short-

¹⁷⁵ *Id.*; see also RANDALL & DOWNIE, *supra* note 125, at 154–55.

¹⁷⁶ Pellegrino, *Decision at The End of Life*, *supra* note 147, at 241.

¹⁷⁷ Smith, *Futility and the Principle of Medical Futility*, *supra* note 50.

¹⁷⁸ See Smith, *Terminal Sedation*, *supra* note 36, at 383.

¹⁷⁹ Pellegrino, *Decision at The End of Life*, *supra* note 147, at 235.

¹⁸⁰ *Id.* at 223. When a patient is in end-stage illness, yet not in peril of immediate death, efforts to sedate “toward death” are seen, by some as unethical. See, e.g., Daniel P. Sulmasy, *The Use and Abuse of The Principle of Double Effect*, 3 CLIN. PULMONARY MED. 86 (1996).

¹⁸¹ RANDALL & DOWNIE, *supra* note 125, at 72.

¹⁸² Quill & Byock, *supra* note 52, at 409.

¹⁸³ Williams, *supra* note 30, at 49.

¹⁸⁴ *Id.*

¹⁸⁵ *Id.*; see also RANDALL & DOWNIE, *supra* note 125, at 72. Another less troubling euphemism for terminal sedation is sedation-hastened death.

¹⁸⁶ *Id.*

ening life.”¹⁸⁷ The logic of this policy is found directly in a straightforward application of cost-benefit analysis.¹⁸⁸

E. A Protocol for Palliative Sedation of Existential Pain

In order for palliative, or “terminal” sedation to be administered, an eight-step process needs to be followed. Patients presenting symptoms should: (1) be diagnosed as being terminally ill¹⁸⁹ or moribund,¹⁹⁰ (2) have a current “Do Not Resuscitate” order listed in their medical records, (3) have exhausted all palliative treatments for anxiety, delirium, or depression,¹⁹¹ (4) receive a psychological evaluation by a qualified clinician together with a similar spiritual assessment by a member of the clergy of any issues which may be particular to the needs of a patient,¹⁹² (5) participate in a candid discussion with their physician and family regarding the costs versus the benefits of a course of palliative sedation, (6) subsequent to this discussion, have signed an informed consent to the therapy, on the part of the patient or his surrogate decisionmaker, and (7) give consideration to whether a trial of respite sedation should first be undertaken before the deep sedation.¹⁹³ With respite sedation, a sedative is ordered for a predetermined time frame—for example twenty-four to forty-eight hours—with a downward titration of the sedative occurring until the patient is restored to consciousness.¹⁹⁴ The eighth and final step in this model protocol requires an unequivocal dosage policy to be established and forbids increasing the level of sedative unless the patient awakens or otherwise presents evidence of suffering (e.g., restlessness, grimaces or withdraws from stimuli)¹⁹⁵ or discomfort (e.g., displays a furrowed brow or develops hypertension).¹⁹⁶

The significant value to this suggested eight-step protocol is that it provides both a chance for the patient’s family and health care team to reassess his condition, and may even ease or cease the distress which initiated the request for continuous sedation entirely. When trials of respite sedation are inconclusive or fail, all parties to the plan for full palliative sedation should be advised that death may not occur for days or even weeks.¹⁹⁷

¹⁸⁷ *Id.*

¹⁸⁸ *Id.*; see also Williams, *supra* note 30, at 41.

¹⁸⁹ Rousseau, *supra* note 112, at 152.

¹⁹⁰ Lo & Rubinfeld, *supra* note 113, at 1812.

¹⁹¹ Rousseau, *supra* note 112, at 152.

¹⁹² *Id.* at 153.

¹⁹³ *Id.*

¹⁹⁴ *Id.*; see Quill & Byock, *supra* note 52, at 413 tbl.2 (2000).

¹⁹⁵ Rousseau, *supra* note 112, at 153.

¹⁹⁶ Lo & Rubinfeld, *supra* note 113, at 1813.

¹⁹⁷ Rousseau, *supra* note 112, at 153.

Establishing a classification scale in advance of the actual sedation could also go far toward alleviating inconsistencies in treatment. Thus, for cancer patients, “primary continuous deep sedation for delirium” could be ordered, and for patients with dyspnea caused by lung cancer, “secondary continuous mild sedation” could be ordered.¹⁹⁸ When lower doses are unable to provide symptomatic relief, then—and only then—should dosages be increased.¹⁹⁹ To neglect establishing a policy of this type could well give rise to an impression or allegation that the attending physician was hastening death and had embraced euthanasia or physician-assisted suicide by exceeding the bounds of medically efficacious therapy through palliative sedation.²⁰⁰

F. *Public Misconceptions*

In popular culture, the use of barbiturates as a legitimate component of palliative care has developed a negative connotation because its administration has been closely associated with, not only euthanasia as practiced in the Netherlands, but also a method to perform capital punishment and as a means to effect physician-assisted suicide.²⁰¹ Their use can, however, be justified easily under the principle of double effect because barbiturates provide effective comfort for those at the end stages of life.²⁰² A simple standard of compassion and adjusted care can serve as a guide for pharmacological uses of barbiturates.

G. *A Noble Effort Toward Clarification?*

A 2008 report by the American Medical Association’s Council on Ethical and Judicial Affairs and dealing with the subject of sedation to unconsciousness in end-of-life care,²⁰³ reaches a number of pertinent conclusions: (1) “The use of sedation in palliative care is not ethically

¹⁹⁸ Morita et al., *supra* note 114, at 452.

¹⁹⁹ Lo & Rubinfeld, *supra* note 113, at 1812.

²⁰⁰ Rousseau, *supra* note 112, at 153. An alternative five step protocol for the administration of terminal sedation as palliative care requires five conditions be met before its administration: severe suffering (even though standard palliative care has been provided); no therapeutic options are seen as effective within disease prognosis; survival is severely limited; an explicit desire for sedation has been made by the at-risk patient, and—finally—respite is effected by intermittent or mild sedation and not continuous. Morita et al., *supra* note 101; *see* Quill & Byock, *supra* note 52, at 411 tbl.1; *see also* Berger, *supra* note 37, at 36 (providing listing of guidelines for acceptable usage of PSU); Ann Alpers & Bernard Lo, *The Supreme Court Addresses Physician-Assisted Suicide: Can Its Rulings Improve Palliative Care?*, 8 ARCH. FAM. MED. 200, 203 (1999).

²⁰¹ Krakauer et al., *supra* note 174, at 57.

²⁰² *Id.* at 56–57.

²⁰³ MARK A. LEVINE, AMERICAN MEDICAL ASS’N REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (CEJA), SEDATION TO UNCONSCIOUSNESS IN END-OF-LIFE CARE, CEJA REPORT 5-A-08, at 6 (2008) [hereinafter CEJA REPORT].

controversial”;²⁰⁴ (2) sedating to unconsciousness is a valid option of medical treatment for those who are “terminally ill” and have “clinical symptoms” which are “unresponsive to aggressive, symptom-specific treatments”;²⁰⁵ (3) before sedating to unconsciousness, informed consent must be obtained from the patient or the patient’s designated health care surrogate;²⁰⁶ (4) consultation with “a multi disciplinary team”—including a palliative care specialist—should be undertaken in order to determine whether this form of sedation is presently viewed as “appropriate”;²⁰⁷ (5) physicians should discuss the plan for sedation with their patients, including the expected results and length of treatment;²⁰⁸ (6) implementation should include monitoring the appropriateness of care during the sedation;²⁰⁹ (7) issues of existential pain should not be addressed through the use of palliative sedation, but rather “by providing the patient with needed social support”;²¹⁰ and (8) the intentional use of palliative sedation to “cause a patient’s death” should be prohibited.²¹¹

Although this Report makes a noble effort to clarify and even “resolve” inherent difficulties and imprecision surrounding the administration of palliative sedation, there remains a fatal flaw—its continued reliance on “intention” as the paramount guide for determining when opiate and sedative use is seen as palliative and not a means of either euthanasia or physician-assisted suicide.²¹² The Report embraces the doctrine of double effect as the tool to test whether proper intent is shown in pharmacologic therapies.²¹³ Although recognizing proportionality as a “central tenet of the principle of double effect,”²¹⁴ the Report tries—unsuccessfully and “naively”²¹⁵—to gauge intent and measure proportionality by dosage uses.²¹⁶ Accordingly, when there are continuous infusions or repeated dosages, these actions may be seen as “indicators of proportionate palliative sedation.”²¹⁷ Contrariwise, “one large dose or rapidly accelerating doses . . . may signify lack of knowledge or an inappropriate intention to hasten death.”²¹⁸ The Report neglects an alterna-

²⁰⁴ *Id.* at 6.

²⁰⁵ *Id.*

²⁰⁶ *Id.*

²⁰⁷ *Id.* at 6–7.

²⁰⁸ CEJA REPORT, at 7.

²⁰⁹ *Id.*

²¹⁰ *Id.*

²¹¹ *Id.*

²¹² *Id.* at 4.

²¹³ *Id.* at 5.

²¹⁴ CEJA REPORT, at 5.

²¹⁵ Battin, *supra* note 37, at 29.

²¹⁶ CEJA REPORT, *supra* note 203, at 5.

²¹⁷ *Id.*

²¹⁸ *Id.*

tive explanation for repeated doses and infusions: that such dosage patterns are little more than a “clever attempt to cover one’s tracks.”²¹⁹

This Article argues that instead of shackling humane patient care in end-of-life cases to the ambiguous doctrine of double effect, a more efficacious test for medical propriety would be whether the benefits of pharmacologic therapies, based on sound medical judgment, outweigh the costs of not applying the therapies.²²⁰ A rational, common-sense decision-making process, bereft of uncertainties and focused on what actions are beneficent and in the best interests of the terminal patient, should be determinative.²²¹

IV. DOUBLE EFFECT—TRADITIONAL AND CONTEMPORARY PERSPECTIVES

The principle of double effect—sometimes also stated as a doctrine or rule—is grounded in Roman Catholic philosophy and moral theology.²²² It proposes to structure specific guidelines to aid in determining when it is ethically permissible to pursue a course of action to achieve a good end—notwithstanding the full understanding the negative or bad results that will flow from the initiating conduct.²²³ Over time, philosophers and ethicists have embraced this principle as having a profound relevance in assessing complex cases of health care ethics either in their classical application or by implication.²²⁴ Indeed, it is contended that the principle has “improved care of the dying, and forms a common ground for competing notions of good care for the dying.”²²⁵

Four conditions must be met for the conduct of the actor to be acknowledged as ethically permissible: the nature of the action must be good or morally neutral and, thus, not prohibited; a good effect or consequence must be intended to flow from the action, and not a bad or evil consequence; the good or positive result must not be used as a direct casual consequence of the evil result; and the good or positive result must be proportionate to any evil result.²²⁶ When all four conditions are met, the personal conduct of the agent being evaluated is held to be ethi-

²¹⁹ Battin, *supra* note 37, at 29.

²²⁰ See *infra* Part IV notes and accompanying text.

²²¹ *Id.*

²²² Timothy E. Quill et al., *The Rule of Double Effect—A Critique of Its Role in End-of-Life Decision Making*, 337 NEW ENG. J. MED. 1768, 1768 (1997).

²²³ *Id.*

²²⁴ RANDALL & DOWNIE, *supra* note 125, at 73.

²²⁵ BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 10–11 (6th ed. 2008).

²²⁶ Quill et al., *supra* note 222.

cally permissible—this, even though an undesirable or “bad” result occurs.²²⁷

A. *Moral Distinctions or Subtleties*

In palliative care management, a moral distinction has all too often been recognized by some between the act of withdrawing treatment and withholding treatment.²²⁸ Accordingly, it has been asserted that actions incur a greater degree of legal accountability or responsibility than omissions.²²⁹ The decision to make an act or an omission, however, does not mean that its efficacy is grounded on a moral justification.²³⁰ Rather, any such justification for treatment should be based primarily “on whether the care given or not given is appropriate to the patient’s wishes [and] physical condition” together with “certainty of [medical] progress.”²³¹ The fact remains, however, that in palliative management, society imposes moral and legal responsibility on caregivers for both actions as well as omissions.²³²

This conundrum proves challenging for physicians to overcome. In cases of artificial hydration²³³—greater blame may be given to the act of withdrawing treatment than withholding it.²³⁴ Physicians may become reluctant—if not unwilling—to commence such medically appropriate treatment in order to avoid having to stop it whenever it becomes inap-

²²⁷ *Id.* Standing alone, without being tethered to the second condition, the undergirding policy supporting the principle of double effect is to be seen as validating ethically the use of medication in controlling pain—even when death may result. THOMASMA, *HUMAN LIFE IN THE BALANCE*, *supra* note 81, at 176. The doctrine of double effect is ordinarily presumed to apply *only* to doctors because it is presumed that only doctors administer the medication to their patients. Since, at the end-stage of life, more and more medical care and decision-making is delegated to palliative care specialists and allied health professionals, it is arguable that these individuals should be able to assert a defense of necessity. Accordingly, they could assert that the administration of lethal pain medications had been delegated legally to them and that their use was compatible with maintaining the best interests of dying patients to be free of unremitting and existential pain. IAN KERRIDGE ET AL., *ETHICS AND LAW FOR THE HEALTH PROFESSIONS* 653 (3d ed. 2009).

²²⁸ RANDALL & DOWNIE *supra* note 125, at 74; *see also* GEORGE P. SMITH, II, *LEGAL AND HEALTH CARE ETHICS FOR THE ELDERLY* 111–19 (1996).

²²⁹ RANDALL & DOWNIE, *supra* note 125, at 74.

²³⁰ *Id.*

²³¹ *Id.*; *see generally* James L. Bernat, *Chronic Disorders of Consciousness*, 367 *THE LANCET* 1181 (April 8, 2006) (arguing that physicians should “reliably establish[]” how a patient in a persistent vegetative state wished to be treated and then either treat aggressively or withhold treatment based on those wishes); Laine & Davidoff, *Patient-Centered Medicine: A Professional Evolution*, 275 *J. AM. MED. ASS’N.* 152 (1996) (arguing that American medicine is shifting towards patient-centered care).

²³² RANDALL & DOWNIE, *supra* note 125, at 74.

²³³ *Id.*

²³⁴ *Id.*; *see* CALLAHAN, *infra* note 327 (concluding that actions which withdraw nutrition and hydration are morally legitimate).

appropriate. The effect of this action may well result in undertreating at-risk patients.²³⁵

Another defensive response by physicians to the effort to chart a moral distinction between the withholding and the withdrawal of treatment—which makes this putative moral distinction, itself, neither logical nor helpful—is seen in physician conduct which manifests itself in an unwillingness “to stop life-prolonging treatment when it is no longer appropriate because this constitutes a withdrawal of treatment which is seen as potentially blameworthy[,] particularly as it may contribute to the patient’s death.”²³⁶ This may result in overtreatment of at-risk patients.²³⁷

B. *Competing Clinical Intentions*

Inasmuch as the doctrine of double effect analyzes two consequences flowing from an action and seeks to place a “substantive moral judgment” on one action (and its consequences) over another,²³⁸ the doctrine presents itself as a muddled template lacking any objective certainty for decision-making.²³⁹ Utilizing this doctrine in both British and American courts requires a particularly astute pool of jurors who can ascertain whether a physician’s intent was to either relieve suffering or cause death in the administration of pain relief. For the doctrine to be effective in aiding judicial decision-making, a physician must admit that he administered lethal treatment with the primary intent of causing death. The criminal consequences of such a forthright admission, make its occurrence unlikely.²⁴⁰ Indeed, it would be common for a physician to have multiple intentions, or considerations in managing the treatment of intractable pain that would likely result in death to the patient.²⁴¹ The competing intentions and the complexity of distinguishing between them thus prove exceedingly problematic for the “positive consequence” requirement of double effect. While legal terms such as “intention” and “foresight” may appear to be neutral in a moral sense, they actually “relate to inherently moral issues” and invite ill-advised subjective moral judgments.²⁴²

²³⁵ RANDALL & DOWNIE *supra* note 125, at 74.

²³⁶ *Id.*

²³⁷ *Id.*

²³⁸ Suzanne Ost, *Euthanasia and The Defense of Necessity: Advocating a More Appropriate Legal Response*, in *THE CRIMINAL JUSTICE SYSTEM AND HEALTH CARE LAW* 103 (Charles A. Erin & Suzanne Ost eds. 2007) [hereinafter Ost, *Euthanasia and The Defense of Necessity*].

²³⁹ *Id.* at 103, 104.

²⁴⁰ *Id.* at 105.

²⁴¹ Lo & Rubinfeld, *supra* note 113, at 1813.

²⁴² Ost, *Euthanasia and The Defense of Necessity*, *supra* note 238, at 103; see Lo & Rubinfeld, *supra* note 113, at 1810 (questioning whether dosage size is determinative of intent); Timothy E. Quill, *The Ambiguity of Clinical Intentions* 329 *NEW ENG. J. MED.* 1039

The medical community asserts that the use of sedatives is not intended to hasten death.²⁴³ Even though it is foreseeable that death will occur sooner rather than later with the use of terminal sedation, the fact that physicians maintain that the practice is medically justifiable should be taken as conclusive.²⁴⁴ Were this proposition accepted, then no need would exist to question the applicability of the principle of double effect. Yet, this “assurance” or “conclusion” is not accepted at face value as an honest professional judgment.²⁴⁵ While many in the medical field support the notion that sedatives do not hasten death, other caregivers see it as but a “fig leaf” for euthanasia.²⁴⁶ These dissenters, along with some patients and their families, are blinded by the myth (often spread by the media) that analgesics such as barbiturates are “nothing more than a polite way to kill the patient.”²⁴⁷

C. *Justifying Double Effect for Palliative Sedation*

The central element for justifying palliative sedation under the principle of double effect is found in the moral distinction drawn between the intentions of the actor-physician and the unintended yet foreseeable consequences of their primary action. Taking the life of another is always morally impermissible, yet when this results from actions carrying foreseeable but unintended harm, it may be permissible when the action produces proportionate good.²⁴⁸ Put in context, even when a foreseen risk of hastened death is accepted, a physician may nonetheless order high doses of opioids and sedative in order to relieve a patient’s suffering.²⁴⁹ For ethicists, however, there is no clear line between efforts to relieve refractory systems and hastening death.²⁵⁰ The *manner* by which a physician declares his intention, is more determinative than what actions he takes under this doctrine. Ambiguity arises when physicians have admitted to dual intentions when administering large doses of opioids: intentions to both decrease suffering and hasten death, as seen in various studies.²⁵¹

Physician intent is irrelevant, however, when the validity of withdrawing nutrition and hydration is raised. There, the operative issue is

(1993) (suggesting proportionality of treatments is crucial to discerning clinical intent); Williams, *supra* note 30, at 46.

²⁴³ Williams, *supra* note 30, at 46.

²⁴⁴ *Id.*

²⁴⁵ *Id.*

²⁴⁶ *Id.*

²⁴⁷ *Id.*

²⁴⁸ See Quill et al., *supra* note 38, at 2101; see also SHAI J. LAVI, THE MODERN ART OF DYING 129–34 (2005); SMITH, *supra* note 89, at 101–09

²⁴⁹ Lo & Rubinfeld, *supra* note 113, at 1812.

²⁵⁰ *Id.* at 1813; see Meisel, *infra* note 328.

²⁵¹ *Id.*; see LAVI, *supra* note 248, at 129–34.

whether it is within the individual patient's "liberty interest" in making this decision.²⁵²

Regardless of whether clinical reality supports the concept of total patient autonomy on this issue, the legal precedent places this decision ultimately with the patient Legally, a physician's intent is irrelevant with respect to a patient's refusal or request for the withdrawal of a life-sustaining medical intervention. A physician's intent becomes a legal factor only when the physician takes an active, interventionist measure that could cause a patient's death.²⁵³

It is well-established that legal liability is imposed upon those who cause injury to another and foresaw or should have foreseen the consequences of their actions.²⁵⁴ This legal standard is considerably broader than the principle of double effect, which limits liability for unintentional consequences. As such, the principle of double effect may well be at odds with the standards of modern jurisprudence. Those who disagree with this principle may also reject the idea that it is morally wrong to cause or hasten the death of a moribund or terminally ill patient.²⁵⁵

Given these inherent weaknesses in the principle of double effect, it would be more efficacious to reformulate the justification for palliative sedation by examining proportionality rather than intention. Under proportionality, compassion and patient preferences are determinative. Proportionality allows for a balancing of the guidelines, thus avoiding the oftentimes conflicting ethical obligations to both relieve patient suffering and not act with the intention of causing death. Thus, if a physician believes it is more compassionate to relieve refractory symptoms than to prolong a life filled with physical torment, the physician may, as guided by patient preferences, administer palliative sedation within the bounds of good medical practice.²⁵⁶ Sadly, there is a mistaken perception that death is always hastened by the aggressive administration of pain management.²⁵⁷

²⁵² McStay, *supra* note 36, at 60.

²⁵³ *Id.*

²⁵⁴ DAN B. DOBBS, *THE LAW OF TORTS* 334 (2000); *see* W. PAGE KEETON ET AL., *PROSSER AND KEETON ON THE LAW OF TORTS* 169, 290, 303 (W. Page Keeton, Dan B. Dobbs, Robert E. Keeton & David G. Owen eds., 5th ed. 1984).

²⁵⁵ Lo & Rubinfeld, *supra* note 113, at 1813.

²⁵⁶ *Id.*; *see* Joseph Boyle, *Enriching Proportionality Through Christian Narrative in Bioethics: The Decisive Development in Richard McCormick's Moral Theory?*, 24 *CHRISTIAN BIOETHICS* 302, 304, 306–08 (2008) [hereinafter Boyle, *Enriching Proportionality*] (analyzing proportionality as a method "for justifying moral norms and judgments in the light of basic goods").

²⁵⁷ FURROW ET AL., *supra* note 225, at 10.

British courts have, over time, allowed physicians to take palliative measures despite their incidental effect of shortening life. Their justification is expressed in a moral concept that acknowledges that physicians may limit suffering even though they may not put an immediate end to a patient's life. This focus on helping, rather than killing, may prove to be an invaluable psychological construct for the physician as well as the courts. While a physician may be fully aware of the consequences of his actions of increasing dosages of diamorphine for a patient, he need not describe the act nor be socially compelled to view it as "an act of killing."²⁵⁸ The nuanced complexities of double effect are essentially subsumed under this concept. This restatement is inextricably tied to the principles of compassion and mercy, and emphasizes proportionality, and the mandate to avoid suffering. This reformulation would go far to present a new contemporary construct for decision-making by avoiding the quicksands of the "traditional" approach used by the principle of double effect.

D. *Dosage and Titration*

Perhaps the most valid indicator of a physician's intent is the act of titrating analgesics to effect patient comfort without intending to hasten patient death. If analgesis (e.g., barbiturates, opioids) as titrated to effect patient comfort, without intending to hasten patient death, this action—in and of itself—is perhaps the most valid indicator of a physician's intent and of particular importance in "validating" actions under the doctrine of double effect.²⁵⁹ One of the rather predictable side effects of using opiates for pain relief is that sedation occurs.²⁶⁰ Non-sedating agents are, of course, preferred but not always effective.²⁶¹ In administering sedation for refractory pain, a physician should initially seek symptom relief by administering the lowest dosage²⁶²—one which neither suppresses respiration nor leads to respiratory distress.²⁶³ Dosage that provides no possibility for symptom relief *without* patient death could be termed properly as active euthanasia.²⁶⁴ When lower dosages are ineffective, increased dosages are permissible,²⁶⁵ but they should be justified by clear

²⁵⁸ Alexander McCall Smith, *Euthanasia: The Strengths of The Middle Ground*, 7 *MED. L. REV.* 195, 206–07 (1999).

²⁵⁹ Eric L. Krakauer et al., *Sedation for Intractable Distress of a Dying Patient: Acute Palliative Care and the Principle of Double Effect*, 5 *THE ONCOLOGIST* 53, 59 (2000).

²⁶⁰ *Id.*

²⁶¹ *Id.*

²⁶² *Id.*

²⁶³ Lo & Rubenfeld, *supra* note 113, at 1812.

²⁶⁴ *Id.*; see LAVI, *supra* note 248.

²⁶⁵ *Id.* For the conscious patient, reports of continued pain, displays of agitation, restlessness and confusion and either respiratory distress or myoclonus, would be grounds for dosage increases. For the unconscious patient, unable to report levels of distress, it remains for health

criteria or clinical indications such as documentation in the patient records and charts.²⁶⁶

Direct medical actions of this nature most usually occur when sudden or severe patient distress urge acute palliative care.²⁶⁷ This distress can manifest itself in the form of pain or other physical symptoms, as well as psychological distress in the form of severe anxiety or agitated delirium.²⁶⁸ As observed, the administration of the necessary analgesis in order to give effective comfort and relief, such as opioids and benzodiazepines, often are accompanied by significant side effects that must be anticipated, managed, and explained to a patient and their family.

E. Challenging Traditional Applications

Those who reject the rigid classical application of the principle of double effect assert that it lacks both efficacy and utility in palliative care. If released from the principle's *raison d'être*—to provide an absolute safeguard against the intentional shortening of life, and instead, recognizing that the benefits of relieving medical distress in cases of terminal illness through use of respite or terminal sedation may outweigh any associated harms, the principle becomes superfluous to palliative management.²⁶⁹ Indeed, adopting such a contemporary and humane policy would eliminate altogether the complex and finely-nuanced arguments which seek to distinguish between intending and foreseeing the effects of one's actions.²⁷⁰ Restructured as such, the principle of double effect would become a common sense approach to medicolegal and ethical decision-making in "accordance with the moral intuitions of most people."²⁷¹ Moreover, reformulating this template for decision-making and elevating compassion and proportionality to controlling values

care providers to access levels of discomfort (*e.g.*, furrowed brow, tachypnea and other symptomatology associated with suffering). *Id.* at 1811, 1813.

²⁶⁶ *Id.* at 1813. Efforts of the American Medical Association Council on Ethical and Judicial Affairs to "clarify" the medically proper uses for palliative sedation, and specifically dosage distinctions have been termed "naïve in the extreme." Battin, *supra* note 37, at 29. The Council's effort to infer physician intent from the pattern of practice in dosage states, "one large dose" or "rapidly accelerated doses of morphine may signify a bad intention (seeking to cause death) while "repeated doses or continuous infusions are benign." CEJA REPORT, *supra* note 203, at 5. Prof. Battin argues convincingly that "repeated dosage and continuous infusions" could well be taken as "a clever attempt to cover one's tracks." Battin, *supra* note 37, at 29.

²⁶⁷ Krakauer et al., *supra* note 259, at 60.

²⁶⁸ *Id.*

²⁶⁹ RANDALL & DOWNIE, *supra* note 125, at 73.

²⁷⁰ *Id.*

²⁷¹ *Id.*; see Boyle, *Enriching Proportionalism*, *supra* note 256, at 307 (discussing how, under proportionalism, not only are moral absolutes rejected, but also the traditional doctrine of double effect).

would constitute a bold reaffirmation of beneficence, charity, compassion, and mercy as the policies behind such action.²⁷²

F. *The Defense of Necessity*

In 1958, Glanville Williams proposed that the law should recognize a medical excuse in cases where pain is so severe that its alleviation can only be achieved by administering a lethal dose of drugs.²⁷³ This excuse would rest “upon the doctrine of necessity, there being at this juncture no way of relieving pain without ending life.”²⁷⁴ Accordingly, a physician could assert this defense to a charge of euthanasia or murder by showing that, by evaluating all circumstances surrounding a patient’s condition (and not focusing exclusively on a physician’s intent),²⁷⁵ he acted in a good faith effort to alleviate the severe or unbearable suffering of a patient,²⁷⁶ with a reasonable belief that the actions were a proportionate response to the patient’s medical condition.²⁷⁷ Factored into the validity of this legal defense would be another highly relevant factor: the extent and frequency of a competent patient’s request for assistance in dying.²⁷⁸ In a very real way, then, the defense of necessity is grounded in compassion.

²⁷² See Timothy E. Quill, *The Ambiguity of Clinical Institutions* 329 N. ENG. J. MED. 1039 (1993) (arguing that proportionality should be the central focus for evaluating decisions of this nature).

²⁷³ GLANVILLE WILLIAMS, *THE SANCTITY OF LIFE IN THE CRIMINAL LAW* 286–88 (1958). If there is “no way of relieving pain without ending life,” the defense of necessity should be allowed. *Id.* Yet, when other pain management therapies are available and effective, this defense would not be available to physicians nor would it be allowed when evidence established lethal drugs were administered which had “no analgesic or sedative effect.” KERRIDGE ET AL., *supra* note 227, at 652. The defense of necessity has been available as a valid defense to murder in the U.K. since 2000. *Id.* (citing Re A [2000] 4 All ER 961, 1051 (Brooke LJ); R v Latimer [2001] 193 DLR (4th) 577, 596); see Boyle, *Enriching Proportionalism*, *supra* note 256, at 306 (detailing how—under proportionalism—goods are commensurated so that a person deliberating rationally, intuitively, or by differential feelings, in order to make a reasonable judgment, seeks to promote a greater proportion of good over bad; or, alternatively, “when the situation is bad, a lesser proportion of bad over good—the lesser evil”—is sought).

²⁷⁴ *Id.* at 288.

²⁷⁵ Ost, *Euthanasia and The Defense of Necessity*, *supra* note 238, at 115–16.

²⁷⁶ *Id.* “A common sense notion of medical duty” to respond in end-stage care is not only established but validated, clinically, from either quantitative or qualitative evaluations of medical futility. Schneiderman et al., *supra* note 156, at 409; see CROWN PROSECUTION SERVICE, *supra* note 64.

²⁷⁷ Ost, *Euthanasia and The Defense of Necessity*, *supra* note 238, at 115–16; CROWN PROSECUTION SERVICE, *supra* note 64.

²⁷⁸ Ost, *Euthanasia and The Defense of Necessity*, *supra* note 238, at 116. The three elements of the defense of necessity could be established by utilizing the reasoning of the doctrine of double effect. Accordingly, when it could be established that a physician’s actions were undertaken in response to a patient’s intractable pain (and not to accelerate death) for which there was no reasonable alternative course of treatment and that this action was in turn “proportionate to the risk of a lengthy and painful dying process,” the defense should be allowed. KERRIDGE ET AL., *supra* note 227, at 652.

G. *Judicial Guideposts*

Law and “legal arguments do not settle moral questions,” and it is a truism “that all that is legal is not moral, and . . . all that is moral is not necessarily legal.”²⁷⁹ Consequently, the extent to which arguments over the legal definition and use of assisted suicide or euthanasia have any moral weight depends on the extent to which they are “morally persuasive.”²⁸⁰ Ultimately, any legal debate in this area will prove faulty by failing to address the moral complexities inherent in any discussion of hastened death.²⁸¹

When the U.S. Supreme Court had an opportunity to advance a moral argument for accepting the rule of double effect in 1997, in *Vacco v. Quill*²⁸² and *Washington v. Glucksberg*,²⁸³ the Court proffered no moral arguments for accepting such reasoning.²⁸⁴ It has been suggested, however, that the Court did lay a foundation for recognizing a constitutional right to adequate pain relief when dying.²⁸⁵ Within such a “right” to receive care and avoid suffering in dying exists the coordinate right to receive terminal sedation when deemed reasonable by either a competent patient or a properly designated surrogate decisionmaker. In cases of incompetency, this right would be exercised by an attending health care provider who determines this course of conduct is humane, compassionate, and in the best interest of the patient. This would be consistent with

²⁷⁹ Daniel P. Sulmasy & Edmund D. Pellegrino, *The Rule of Double Effect: Clearing Up The Double Talk*, 159 ARCH. INTERNAL MED. 545 (1999).

²⁸⁰ *Id.* at 548.

²⁸¹ *Id.* But see Edward Rabin, *Assisted Suicide, Morality, and Law: Why Prohibiting Assisted Suicide Violates The Establishment Clause*, 63 VAND. L. REV. 763, 773–78, 791, 797, 810–11 (2010) (asserting that since existing laws prohibiting assisted suicide have derived—historically—from a Christian morality of higher purpose and, thus, favor and indeed coerce a particular religious morality, these laws are violative of the Establishment Clause of the Constitution; instead, laws should reflect a standard of self-fulfillment which in turn would allow pursuit of values for a satisfying life which do not harm others).

Another rather novel idea for limiting prosecutions for physician assisted death can be found in the policy of desuetude—a notion, while not having explicit support by the U.S. Supreme Court—is a procedural due process claim which allows an exemption from prosecution under laws which have been enacted many years ago, and may not be “relevant” therefore with current public policies on the controlling issue, and are—further—also enforced sporadically. Thus, the central argument would be those laws imposing liability for assisting others in committing suicide were enacted during a time when physician assisted suicide was, because of the emerging state of developing medical technologies and the then nascent awareness of palliative treatment, not simply relevant and, accordingly, should be, as criminal statutes construed narrowly. Sunstein, *supra* note 49, at 1156–57 n.151.

²⁸² *Vacco v. Quill*, 521 U.S. 793 (1997).

²⁸³ *Washington v. Glucksberg*, 521 U.S. 702 (1997).

²⁸⁴ Sulmasy & Pellegrino, *supra* note 279, at 548. But see Marc Spindelman, *Death, Dying and Domination*, 106 MICH. L. REV. 1641 at 1661, n.60 (concluding that *Glucksberg* constitutionalized the principle of double-effect).

²⁸⁵ Burt, *supra* note 47.

a physician's commitment to embrace the "ethics of compassionate response."²⁸⁶

H. *Withdrawal of Nutrition and Hydration*

Artificial nutrition and hydration are properly viewed as medical treatment, and may be legally withdrawn if a medical professional deems their continuation as inconsistent with safeguarding the best interests of a patient.²⁸⁷ The U.S. Supreme Court first assumed the existence of a right to refuse nutrition and hydration in the 1990 case, *Cruzan v. Dir., Missouri Dept. of Health*.²⁸⁸ The Court "inferred" this right of refusal from a constitutionally-protected liberty interest grounded in the Due Process Clause and the doctrine of informed consent.²⁸⁹ In the 1997 decision *Washington v. Glucksberg*, the Court used the Due Process Clause to broaden this rule into a right to refuse medical treatment.²⁹⁰

In 1997, the U.S. Supreme Court again sharpened a necessary distinction between the withdrawal of life sustaining treatment and physician-assisted suicide in *Vacco v. Quill*.²⁹¹ Crucial to this distinction was an understanding that while a patient will be killed if he actively ingests a lethal dose of medication, an underlying disease pathology is the cause of death for one who refuses life-sustaining treatment (e.g., nutrition and hydration).²⁹²

In its effort to draw a clear distinction between the withdrawal of life sustaining treatment considered by a patient to be "futile or degrading"²⁹³ and physician-assisted suicide where "the patient be made dead,"²⁹⁴ the Court placed heavy emphasis upon the importance of intent as determinative, tacitly approving terminal sedation. The Court concluded that when evaluating the propriety of "induc[ing] barbiturate

²⁸⁶ ALBERT R. JONSEN, *THE NEW MEDICINE AND THE OLD ETHICS* 49 (1990). In cases of incompetency, the physician has a special fiduciary-type "obligation to act as a steward of the patient's moral right to have his or her wishes fulfilled." While not a type of moral warrant for a physician to impose a personal set of values or make the advancement of a medical good the controlling principle, neither does this act of "beneficence-in-trust" mean that a physician submit "slavishly and uncritically to decisions made by a surrogate." Instead, "the obligation of that stewardship is to clarify, validate and enhance the patient's will to the extent possible." PELLEGRINO & THOMASMA, *supra* note 81, at 162.

²⁸⁷ *Washington v. Glucksberg*, 521 U.S. at 736–37 (O'Connor, J. concurring); *see generally* Lois L. Shepherd, *Dignity and Autonomy After Washington v. Glucksberg*, *An Essay About Abortion Death and Dignity*, 7 CORNELL J.L. & PUB. POL'Y 431 (1998) (exploring the notion that our current perception of dignity as linked to autonomy is flawed, and that the concept of dignity needs to be expanded separately).

²⁸⁸ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 279 (1990).

²⁸⁹ *Id.* at 270.

²⁹⁰ *Id.* at 720–23.

²⁹¹ *Vacco v. Quill*, 521 U.S. 793, 801 (1997).

²⁹² *Id.* at 801.

²⁹³ Smith, *Futility and the Principle of Medical Futility*, *supra* note 50.

²⁹⁴ *Vacco v. Quill*, 521 U.S. at 801–02.

coma and then star[ving] [a patient] to death,” medical professionals may administer palliative care, including a decision to refuse the continuation of life-sustaining treatment, which may “have the foreseen but unintended ‘double effect’ of hastening the patient’s death.”²⁹⁵ Justice Sandra Day O’Connor, writing a strong and eloquent concurring opinion in both *Glucksberg* and *Quill* endorsing the use of terminal sedation in palliative care,²⁹⁶ concluded that while the Constitution did not grant any generalized right to “commit suicide,” there was a liberty interest in having mentally competent persons control the manner of their deaths.²⁹⁷

The trio of *Cruzan*, *Quill*, and *Glucksberg* did not directly address the legality of terminal sedation as a final strategy for dealing with refractory pain. The use of terminal sedation as an integral part of palliative care and management was, nonetheless, implicitly endorsed by the Court.²⁹⁸

I. Clarifying Standards for Sedation, Alimentation, and Hydration

In 2006, the American Academy of Hospice and Palliative Medicine (AAHPM) issued a new position statement on artificial nutrition and hydration (ANH) in end-of-life care, replacing its earlier statement on the

²⁹⁵ *Id.* at 807 n.11.

²⁹⁶ She was joined by Justice Ginsberg and, in part, by Justice Breyer. *Washington v. Glucksberg*, 521 U.S. 702, 736–37.

²⁹⁷ *Id.* at 736.

²⁹⁸ McStay, *supra* note 36, at 53. On August 1, 2007, The Congregation for The Doctrine of Faith published, with approval, *Responses to Certain Questions of The U.S. Conference of Catholic Bishops* which acknowledges in principle, that nutrition and hydration are both “an ordinary and proportionate means of preserving life” and “therefore obligatory.” Similarly, for patients in a permanent vegetative state, who are being maintained artificially with nutrition and hydration, there can be no discontinuance of this care even when a medical judgment is made that patient consciousness will never occur. FURROW ET AL., *supra* note 225, at 310–11. The authority and force of this means of policymaking has been questioned when other, more established vehicles for setting policy are available. *Id.* at 310–11 (referencing John Hardt & Kevin O’Rourke, *Nutrition and Hydration: The Congregation for the Doctrine of Faith, In Perspective*, 88 HEALTH PROGRESS 1 (2007)). *But see* U.S. Bishops’ Pro-Life Committee, *Nutrition and Hydration: Moral and Pastoral Reflections*, in *BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS, AND PRACTICE*, *supra* note 156, at 417, 419 (showing where, under Moral Principles (5), the Committee concluded in 1996: “In the final stage of dying one is not obliged to prolong the life of a patient by every possible means: ‘When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.’”). *See also* ARTIFICIAL NUTRITION AND HYDRATION AND THE PERMANENTLY UNCONSCIOUS PATIENT: THE CATHOLIC DEBATE (Ronald P. Hamel & James J. Walter eds. 2007); Alan Sanders, *The Clinical Reality of Artificial Nutrition and Hydration for Patients at The End of Life*, 9 NAT’L CATH. BIOETHICS Q. 293 (2009); *see generally* RELIGIOUS PERSPECTIVES IN BIOETHICS 1–20 (John F. Peppin, Mark J. Cherry & Ana Iltis eds. 2004).

issue in 2001.²⁹⁹ While recognizing that artificial nutrition and hydration were developed to accommodate acutely ill patients and provide short-term care, the AAHPM also acknowledged current data that suggested these procedures neither prolong life nor prevent suffering.³⁰⁰ Since patients in end-stage illnesses often lose their capacity to eat and drink, the ethical issue thus becomes whether patients, their families, or caregivers should have the right at all to request the provision or withholding of nutrition, alimentation, and hydration to those with no prospects of rehabilitation or recovery.

The AAHPM concluded that ANH should always be recognized as medical therapy and should be evaluated by balancing its costs and benefits (or benefits and burdens) “in light of the patient’s goals of care and clinical circumstances.”³⁰¹ While acknowledging that ANH has symbolic value and importance for some patients and their families, the AAHPM prefers that lines of communication be maintained among health care providers who not only deal with fears of starvation by afflicted patients and their families, but with clarifications of the clinical conditions which come with end-stage illness.³⁰² More specifically, patient information should be provided explaining that an individual’s inability to both eat and drink are a part of the “normal” process of dying.³⁰³ Accordingly, when efforts at ANH are not advancing a patient’s goals nor seen as consistent with sound clinical standards of practice, and thus are futile,³⁰⁴ these efforts “can be ethically withheld or withdrawn.”³⁰⁵

While there are reports that suggest the use of terminal sedation is now endorsed by many hospices—with some hospices inducing coma through an added morphine drip to address unremitting pain³⁰⁶—the AAHPM’s Statement on Palliative Sedation, issued in 2006, is clear that

²⁹⁹ *Statement on Artificial Nutrition and Hydration Near the End of Life*, AM. ACAD. OF HOSPICE AND PALLIATIVE MED., <http://www.aahpm.org/positions/default/nutrition.html>, (last visited Oct. 14, 2007) [hereinafter *Position Statement*].

³⁰⁰ *Id.*; see DANIEL CALLAHAN, *THE TROUBLED DREAM OF LIFE*, 80–82 (2000) (observing that artificial nutrition and hydration were originally for short-term treatments for post surgical patients but, over the years, have been transformed into Basic Care rather than regarded as treatment—this, in spite of the fact that the process of dying is recognized as being accompanied by the inability to take food and water).

³⁰¹ *Position Statement*, *supra* note 299.

³⁰² *Id.*

³⁰³ *Id.*

³⁰⁴ *Id.*

³⁰⁵ Charlotte F. Allen, *Back Off!, I’m Not Dead Yet!*, WASH. POST, Oct. 14, 2007, at B1; *Position Statement*, *supra* note 299.

³⁰⁶ See generally Balfour Mount, *Morphine Drips, Terminal Sedation, and Slow Euthanasia: Definitions and Facts, Not Anecdotes*, 12 J. PALLIATIVE CARE 31 (1996) (arguing that a morphine drip is merely a euphemism for slow euthanasia and incompatible with the principle of double-effect and palliative care).

palliative sedation must be “proportionate to the patient’s level of distress.”³⁰⁷ Reserved only for those cases of the “most severe, intractable suffering at the very end of life,”³⁰⁸ palliative sedation to unconsciousness is supported ethically and legally when three conditions are met: the intent of the clinician is to relieve a patient’s suffering, the degree of sedation administered is proportionate to the severity of that suffering, and the patient or the patient’s surrogate decision-maker provide an informed patient consent that is consistent with the patient’s treatment goals and personal values.³⁰⁹

This bold and compassionate action by the AAHPM is designed to educate the public to the validity of accepting physician-assisted death under certain medically futile conditions by integrating palliative care and its philosophies into a standard of appropriate care for the terminally ill.³¹⁰ By changing the taxonomy of the act itself from the traditional “Physician-Assisted Suicide” (PAS) to “Physician-Assisted Death” (PAD), the AAHPM is attempting to recast the debate as a discussion over the legality of receiving medical assistance in the dying process.³¹¹

V. PHYSICIAN-ASSISTED SUICIDE OR EUTHANASIA: ENDURING EPHEMERAL DISTINCTIONS?

As a matter of principle, it is difficult to find and defend present distinctions between physician assisted suicide and euthanasia.³¹² Instead of falling into a taxonomical quagmire, physicians traditionally as-

³⁰⁷ *Statement on Palliative Sedation*, AM. ACAD. OF HOSPICE AND PALLIATIVE MED., <http://www.aahpm.org/positions/default/sedation.html> (last visited Oct. 14, 2007).

³⁰⁸ *Id.*

³⁰⁹ *Id.*

³¹⁰ *Physician-Assisted Death*, AM. ACAD. OF HOSPICE AND PALLIATIVE MED., <http://www.aahpm.org/positions/default/suicide.html> (last visited Oct. 14, 2008); see generally Smith, *Terminal Sedation*, *supra* note 36 (advocating greater acceptance of assisted dying in certain circumstances).

³¹¹ See Smith, *All’s Well That Ends Well*, *supra* note 37 (arguing for a taxonomical change in terminology which accepts and uses enlightened self-determination or assisted rational suicide rather than assisted suicide).

³¹² Yale Kamisar, *Foreword: Can Glucksberg Survive Lawrence? Another Look at The End of Life and Personal Autonomy*, 106 MICH. L. REV. 1453, 1474 (2008); see RICHARD A. POSNER, *AGING AND OLD AGE* 235–45 (1995) (maintaining that there should be a right to assisted suicide); see also Charles H. Baron et al., *A Model State Act to Authorize and Regulate Physician Assisted Suicide*, 33 HARV. J. ON LEGIS. 1, 10 (1996). Interestingly, in *Vacco*, the Supreme Court found no legal relevance between the classic distinctions between either active or passive euthanasia or, as well, between “the provision of artificial fluids and nutrition and other medical interventions.” Annas, *supra* note 48, at 1099. What was, however, seen as determinative by the court was causation and physician intent in prescribing or in administering medications which have a direct or even indirect role in hastening death. *Id.* The New York State Task Force on Life and the Law, in issuing its 1997 supplement to its 1994 report, *When Death is Sought*, concluded that valid distinctions between assisted suicide, the refusal of treatment, and the administration of high opioid dosages for refractory pain were essential for coherent policies in end-of-life medical care and that the latter two treatments should in no

sess a patient by determining whether their condition is curative, rehabilitative, or palliative.³¹³ The principle of medical futility has been most helpful in making a medical assessment; through its use and implementation, physicians have clear markers and protocols for non-treatment.³¹⁴ Consistent with the lack of national cognizance of a right or liberty interest to seek assistance from a physician in ending one's life,³¹⁵ no state courts—save one in Montana³¹⁶—have found a right to physician-assisted suicide within their state constitutions. Similarly, no state legislatures, other than in Oregon³¹⁷ and Washington,³¹⁸ have legalized this type of action³¹⁹ in the post-*Glucksberg* era.³²⁰

Rather than continue efforts to find meaningful distinctions between suicide and assisted suicide, a clearer strategy would be to structure dialogue around references to aid in dying or physician-assisted dying.³²¹ Indeed, since *Glucksberg* recognized terminal or palliative sedation, the essence of assisted suicide has not been germane to any discussion of end-of-life care.³²²

way be considered an act of euthanasia. COMM. ON CARE AT THE END OF LIFE, INSTITUTE OF MEDICINE 12 (1997).

³¹³ See F. Fox *Predominance of the Curative Model of Medical Care: A Residual Program*, 278 J. AM. MED. ASS'N. 761 (1997); Sapir, *supra* note 60.

³¹⁴ Smith, *Futility and the Principle of Medical Futility*, *supra* note 50.

³¹⁵ Kamisar, *supra* note 312, at 1467.

³¹⁶ On December 5, 2008, a Montana District Court determined in the case of *Baxter v. Montana* that there is a fundamental right for the terminally ill to die with dignity; that the state law barring assisted suicide violates the right to privacy guaranteed by the state constitution and the provision that proclaims the dignity of the human being is inviolable. 2008 Mont. Dist. LEXIS 482, at *36 (Dec. 5, 2008). The decision was appealed, and in its ruling on this appeal on December 31, 2009, the Montana Supreme Court declined to declare a constitutional right to die with dignity. *Baxter v. State*, 2009 Mont. LEXIS 695 (Dec. 31, 2009). Rather, the court held that physicians aid in dying was not violating the stated legislation protecting the terminally ill nor against state public policy. *Id.*

³¹⁷ ORE. REV. STAT. §§ 127.800(12), 127.805 (2005).

³¹⁸ WASH. REV. CODE ANN. ch. 70,245 (West 2009).

³¹⁹ Kamisar, *supra* note 312, at 1467.

³²⁰ *Washington v. Glucksberg*, 521 U.S. 702 (1997).

³²¹ Kathryn L. Tucker, *In the Laboratory of the States: The Progress of Glucksberg's Invitation to States to Address End-of-Life Choices*, 106 MICH. L. REV. 1593 (2008).

³²² *Id.* at 1599 n.23 (noting the American Medical Association's brief *amicus curiae* in *Vacco* and *Glucksberg* which endorsed the proper medical use of palliative sedation). Writing for the majority in *Vacco*, Chief Justice Rehnquist recognizes that a state may allow palliative care for patients refusing unwanted medical treatment "which may have the foreseen but unintended 'double effect' of hastening . . . death." 521 U.S. 793, 808 n.11 (1997). *But see* David Orientleicher, *The Supreme Court and Terminal Sedation: Rejecting Suicide Embracing Euthanasia*, 24 HASTINGS CONST. L.Q. 947, 955–56 (1997) (concluding terminal sedation is a form of active, voluntary or slow euthanasia).

A. *The Scope of Personal Autonomy*

If personal autonomy, or “the right to define one’s own concept of existence” and “the mystery of human life,”³²³ extends to the very time and manner of one’s death,³²⁴ this fundamental right, arguably, should not be limited to the terminally ill³²⁵ and the “seriously ill or impaired who are suffering or in pain.”³²⁶ Indeed, others have expressed concern that if this right is recognized nationally, it will be asserted not only by those patients who are terminally ill,³²⁷ but also those who are “seriously ill or impaired . . . endur[ing] pain or suffering.”³²⁸

Specifically, concerns have been raised that the standard of terminal illness, in and of itself, is inadequate to measure certain medical conditions that exceed a diagnosis of life expectancy beyond, for example, the more “normal” period of three months³²⁹ or six months.³³⁰ Three particular scenarios have been posited as being dangerous because of the “open-ended” or limitless nature of present evaluations of terminal illness:³³¹ (1) where a patient might be suffering from Lou Gehrig’s disease, yet the patient is not diagnosed as fully suffering from the end-stage of the disease; (2) where a patient, afflicted with paralysis from the neck down can survive with palliative care for some twenty years; or, (3) where a patient is in the early stages of Alzheimer’s disease.³³²

³²³ Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 851 (1992).

³²⁴ Kamisar, *supra* note 312, at 1474.

³²⁵ *Id.* at 1459.

³²⁶ *Id.* at 1471, 1472.

³²⁷ *Id.* at 1473. For Yale Kamisar, the supreme value of human life always trumps an exercise of autonomy or self-determination designed, as such, to end life. Yet, interestingly, while he maintains that it is acceptable to honor a patient’s wish to end an intolerably burdensome existence by ceasing medical treatment deemed futile, Kamisar would deny assistance to that individual to end his life. YOUNG, *supra* note 145, at 57. While Kamisar maintains further that a “critical moral significance” is to be found between an act and an omission, others assert the “distinction” between acts and omissions and between killing and letting die has no moral significance at all. *Id.* at 56–58. Callahan also characterizes the withdrawal of artificial nutrition and hydration as morally legitimate. Daniel Callahan, *Terminal Sedation and The Artefactual Fallacy*, in *TERMINAL SEDATION: EUTHANASIA IN DISGUISE?* 93–102 (Torbjorn Tannsjo ed. 2004).

³²⁸ Kamisar, *supra* note 312, at 1473; see Dan W. Brock, *Voluntary Active Euthanasia*, 22 HASTINGS CTR. REP. 10, 14 (Mar.-April 1992). The right to forego medical treatment is recognized as “virtually absolute” and in no way limited to the terminally ill. 1 ALAN MEISEL, *THE RIGHT TO DIE* § 8.2 (2d ed. 1995).

³²⁹ Tucker, *supra* note 321, at 1610 n.90 (referencing the California Compassionate Choices Act introduced in 2007 which was not enacted into legislation).

³³⁰ ORE. REV. STAT. §§ 127.800 (12), 127.805 (2005).

³³¹ Kamisar, *supra* note 312, at 1472.

³³² *Id.* The case of Mrs. Janet Adkins is illustrative of a patient suffering from Alzheimer’s disease who—before succumbing to debilitating effects of the disease and thereby losing her competency—decided, with the support of her family, to seek assistance in committing suicide, in Michigan, with Dr. Jack Kevorkian. On June 4, 1990, with her death, Mrs. Adkins became the first publicly reported case in the United States of medically assisted sui-

In each of these hypotheticals, no rigid timeline can delineate a patient's personal standard of hopelessness. If an informed unilateral decision is made to end one's life in the early stages of Alzheimer's disease, before levels of incompetence and indignity occur, then surely that decision must be accepted. The principle of medical futility applies equally to all three scenarios because in each case, there are simply no available options for curative care or rehabilitation. Rather than be concerned with the misapplication of the terminal illness standard in these three specific cases, the opportunity to embrace individuals presenting these symptomologies should be guided by compassion and mercy because there is no hope of a qualitative recovery.³³³

cide. George P. Smith, II *Reviving the Swan, Extending the Curse of Methuselah, or Adhering to the Kevorkian Ethic?*, 2 CAMBRIDGE Q. HEALTHCARE ETHICS 49, 51 (1993).

Being an Alzheimer disease patient does not preclude that individual from being recognized, legally, as competent to make health care decisions regarding treatment or non-treatment if the decision-making is undertaken in the early onset stage of the disease before recognition is lost. ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 281 (1989); see WERTH, *supra* note 69, at 76; see generally Mitchell et al., *supra* note 121 (observing that patients with advanced dementia who were able to discuss the disease's prognosis with their health care proxies received less burdensome interventions than those whose proxies who did not understand the expected complications).

The double assisted suicide, on July 10, 2009, of the renowned musical conductor, Sir Edward Downes, 85, virtually blind, suffering from a loss of hearing and in psychological distress—although not in a terminal medical condition—and his wife, Lady Downes, 74, who was suffering from terminal cancer, has raised, anew, concerns that death is becoming a “lifestyle choice.” Both Sir Edward and his wife traveled to a private assisted suicide clinic in Zurich, Switzerland, called Dignitas. Of some 117 Britons who have availed themselves of Dignitas the past years, at least five were not—at the time of their deaths—considered to be in a terminal condition. Nick Allen & Caroline Gammell, *Conductor's Son Saw Parent's Die in Suicide Clinic*, DAILY TELEGRAPH, July 15, 2009, at 7; David Brown & Helen Nugent, ‘Together Forever’ Couple Raise New Suicide Fears, THE TIMES (London), July 15, 2009, at 1.

In a British case in 2004, *Local Authority v. Z, EWHC 2817 (Fam)*, the Court held a woman suffering from a terminal medical condition—cerebella ataxia—who wished to travel to Switzerland with the assistance of her husband to be euthanized, could not be enjoined from such a course of action. Although the Suicide Act of 1961 would, indeed, criminalize the actions of the woman's husband because they would aid or abet her illegal act of suicide, the law of suicide did not criminalize the conduct. The court concluded that although Parliament may criminalize an act, “it is not always in the public interest to prosecute in respect of it.” KERRIDGE ET AL., *supra* note 227, at 655–56.

Relative Assisted Suicide (RAS) and, more specifically, Relative Facilitating Suicide Abroad (RFASA), has the real potential to resolve the furor over physician-assisted death if it is accepted legislatively and judicially. Indeed, when British prosecutors have essentially given a relative exemption for assisting terminally ill family members, in some limited number of cases, they have advanced the de-medicalization of assisted dying and thereby relegated the role of the physician to that of determining the competency of the terminal, end-of-life person to request assistance in dying and providing a drug prescription to effect that purpose. Ost, *De-Medicalisation of Assisted Dying*, *supra* note 64, at 515–17, 533.

³³³ See Adrienne M. Martin, *Hope and Exploitation*, 38 HASTINGS CTR. REP. 49 (2008) (concluding hope should be viewed as a complex emotion which inputs value judgments and deliberative processes and—thus—should not be exploited to the point of being false or, at best, bereft of an accurate factual or scientific basis).

The U.S. Supreme Court's decisions in *Griswold v. Connecticut*³³⁴ and *Eisenstadt v. Baird*³³⁵ were foundational in recognizing a right to privacy from government intrusions. These decisions were crucial support in the Court's decision in *Lawrence v. Texas* in 2003, which held the Texas Homosexual Conduct law was an unconstitutional abridgment of the right to liberty under the Due Process Clause.³³⁶ In *Lawrence*, the Court determined that sexual intimacy among same-sex couples was a freedom not limited by any spatial bounds.³³⁷ Rather, the liberty of persons must be recognized inherently as "an autonomy of self that includes freedom of thought, belief, expression, and certain intimate conduct."³³⁸ Moreover, the Court recognized that people are entitled to "dignity as free persons."³³⁹ Over time, it may even be possible that decisions post-*Lawrence* may find a fundamental right to physician-assisted suicide within the Constitution.³⁴⁰ For the "foreseeable future," however, the *Glucksberg* rule remains.³⁴¹

B. *The Limits of State Interest*

Limits must be placed on the state's *parens patriae* powers to interfere with autonomous and informed decisions by citizens who wish to be relieved of their pain and suffering in futile medical conditions with no curative hope of rehabilitation or sustained qualitative existence, mentally or physically. Indeed, "there is a realm of personal liberty which the government may not enter."³⁴² Linked with this right of self-determination is the equally important right to beneficent treatment that advances the best interests of the distressed.³⁴³ These two rights are fundamental to any and all decisions regarding health care treatment.³⁴⁴ When considering terminally ill patients or those diagnosed with a futile medical condition, the state's general interest in protecting or even enforcing a continuance of life surely must be trumped by the right of self-

³³⁴ 381 U.S. 479 (1965).

³³⁵ 405 U.S. 438 (1972).

³³⁶ 539 U.S. 558 (2003).

³³⁷ *Id.*

³³⁸ *Id.* at 564–65.

³³⁹ *Id.*

³⁴⁰ Kamisar, *supra* note 312, at 1466.

³⁴¹ *Id.*

³⁴² *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833, 847 (1992).

³⁴³ See THOMASMA & GRABER, *supra* note 58.

³⁴⁴ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990). Artificial alimentation (e.g., nourishment) and hydration are not readily distinguishable "from other forms of medical treatment," and, as such, can be refused by a competent patient exercising his "liberty interest" in refusing such treatments. 497 U.S. at 287–88 (1990) (O'Connor, J., concurring).

determination to make one of life's most intimate, private decisions: when to die.³⁴⁵

C. *Resolving Ambiguity: Toward a Resolution—State Action*

The growing idea of integrating the issue of physician-assisted suicide or death with proper efforts to manage intractable pain may well prove to be the ideal construct for accepting and validating medical assistance in hastening death where it is deemed medically proper and humane.³⁴⁶ State statutes are being enacted which allow for the delivery of "adequate pain relief" and exempt this conduct from liability under both criminal law and state medical licensing guidelines, so long as the medical actions are "in accord with accepted guidelines" for relieving intractable pain.³⁴⁷

VI. SHAPING A CARING RESPONSE: A MEDICO-LEGAL CHALLENGE

Health care providers' role of caring may be seen as a moral obligation rooted in the time-honored principle of beneficence, the goal of which is to promote patient well-being.³⁴⁸ "Caring indubitably incorporates empathy,"³⁴⁹ but incorporating it into the management of the terminally ill is difficult. For the physician to convey to a patient that "I *could* be you," involves initiating a sympathetic response that may begin as early as during the taking of the patient history.³⁵⁰ During this process, a one-on-one relationship commences, which opens a line of communication between the treating physician and the patient. This, in turn, provides a mechanism for the physician to assess and identify the emotions the terminally ill patient is experiencing, the reason for the display of emotion, and a response to the patient which allows the patient to see that the physician has "connect[ed]" the emotion and its root cause.³⁵¹

A physician's empathetic response has the direct effect of assuring the patient that they will not be abandoned in their final days. For many

³⁴⁵ CALLAHAN, *supra* note 300, at 107–08 (1993); Erwin Chemerinsky, Washington v. Glucksberg Was Tragically Wrong, 106 MICH. L. REV. 1501 (2008).

³⁴⁶ FURROW ET AL., *supra* note 225, at 43.

³⁴⁷ *Id.* Indeed, some twenty-one states have these pain relief laws and seven states allow specifically for use of medical marijuana. For a complete listing of the state statutes, see *State Pain Relief Acts*, PAIN & L., http://www.painandthelaw.org/statutes/state_pain_acts.php (last visited Feb. 25, 2011). Interestingly, the federal government has been unsuccessful in enacting pain and relief legislation, which would allow the presumption of controlled substances in order to manage refractory pain. See Pain Relief Promotion Act, H.R. 2260, 106th Cong. (1999); Pain Relief Promotion Act of 1999, S. 1272, 106th Cong. (1999).

³⁴⁸ Paul Rousseau, *The Fears of Death and The Physician's Responsibility to Care for the Dying*, 18 AM. J. HOSP. & PALLIATIVE CARE 224 (July–Aug. 2001).

³⁴⁹ *Id.*

³⁵⁰ *Id.* at 225.

³⁵¹ *Id.*

physicians, however, non-abandonment is instinctively difficult to honor because of “the fear generated by confrontation of their own mortality when caring for a dying patient.”³⁵² Because of this situation, patient avoidance, even when unintentional, only serves to heighten patient fears of impending death.³⁵³

Because of these concerns and inadequacies among physicians, issues of existential care are more often than not left to the nursing staff.³⁵⁴ Even in the daily hospital bed environment, however, the nursing staff must possess a special level of sensitivity to understand patients’ indirect questions regarding the depth and severity of their distress over their terminal illness. Once understood, it typically falls upon the nurses to devise a procedure for providing empathetic support.³⁵⁵

A. *Alleviating Suffering*

Autonomy emerged in the twentieth century as the dominant or capstone principle in biomedical ethics, supporting and complementing the principles of beneficence, non-maleficence, and distributive justice.³⁵⁶ It has also played a dominant role in complex cases of refractory pain. Indeed, in cases where one’s quality of life is so severely diminished because of suffering, it is arguably necessary to reconfigure or enhance autonomy so that compassion becomes the operative bioethical principle in decision-making.³⁵⁷ In scenarios where end-of-life pain is intractable, efforts to address this condition and thereby assure a dignified death become a paramount state interest.

The goal of alleviating suffering, if acknowledged as a *right* to relief, imposes upon both the state and health care providers a coordinate responsibility to make prudential judgments that validate this right.³⁵⁸ Acknowledging such a right then becomes an act of “responsible benevolence”³⁵⁹ and is seen properly as complementing the duty to undertake

³⁵² *Id.*

³⁵³ *Id.*; see generally J. S. Felton, *Burnout as a Clinical Entity: Its Importance in Health Care Workers*, 48 OCCUP. HEALTH 237 (1998) (discussing the elements that lead to burnout among those workers in the health care field, as well as ways to prevent or counteract the effects of burnout).

³⁵⁴ Robert Hoatpen & David Hendriks, *Nurses and The Vicissitudes of Dealing with Euthanasia Questions in Terminal Palliative Care*, 10 NURSING ETHICS 377 (2003).

³⁵⁵ *Id.*

³⁵⁶ Jonsen, *supra* note 57; see generally GEORGE P. SMITH, II, *BIOETHICS AND THE LAW: MEDICAL, SOCIO-LOCAL AND PHILOSOPHICAL DIRECTIONS FOR A BRAVE NEW WORLD* (1993) (recognizing the three pillars of Autonomy, Beneficence, and Justice as vital to the modern understanding of bioethics).

³⁵⁷ Shepherd, *Sophie’s Choice*, *supra* note 12, at 106, 126.

³⁵⁸ *Id.* at 146.

³⁵⁹ LIEZL VAN ZYL, *DEATH AND COMPASSION: A VIRTUE-BASED APPROACH TO EUTHANASIA* 197 (2000).

actions that benefit the dying patient.³⁶⁰ The duty to relieve pain is acknowledged as the “least disputed and most universal of the moral obligations of the physician.”³⁶¹ End-of-life autonomy is actually fortified by, and through, this new right of compassion. Compassion, then, necessarily becomes the denominator in health care decisions for end-of-life care,³⁶² and demands that efforts not only refrain from causing pain or suffering, but also work to relieve it.³⁶³

B. *Legal Caring Responses in a Just Society*

American history shows rather remarkably that the capacity to care has often been seen as antithetical, rather than vital, to maintenance of a just society.³⁶⁴ Consequently, there “has been a deformation of both the private ethic care and the very public ethic of legal justice.”³⁶⁵ This, in turn, has meant that not only have the ideals and practices of justice been uncaring, but that the ideals and practices of care “have been unjust,” resulting in a “deflation of both values.”³⁶⁶ Rather than viewing caregiving as an emotional, morally arbitrary response, it should be properly accepted as an ethical activity “integral to development of a just society.”³⁶⁷ Indeed, care or compassion must be recognized as a universal moral principle³⁶⁸ that is vital to the very fabric of social justice.³⁶⁹

It has been suggested that within every adjudication, neutral principles of law, or those standards which transcend the instant case, should operate.³⁷⁰ Perhaps these principles or standards are to be found within the very principle of equity.³⁷¹ From this equity flows mercy, sympathy,

³⁶⁰ THOMASMA & GRABER, *supra* note 58.

³⁶¹ *Id.* at 194 (quoting Dr. Edmund D. Pellegrino).

³⁶² *Id.* at 126.

³⁶³ Margaret P. Battin, ENDING LIFE: ETHICS AND THE WAY WE DIE 90, 91 (2005).

³⁶⁴ ROBIN WEST, CARING FOR JUSTICE 7, 9 (1997); *see* MICHAEL FINE, A CARING SOCIETY? 52–74 (2007).

³⁶⁵ WEST, *supra* note 364, at 9; *see* JONATHAN HERRING, OLDER PEOPLE IN LAW AND SOCIETY 127 (2009).

³⁶⁶ WEST, *supra* note 364 at 9.

³⁶⁷ FINE, *supra* note 364, at 63; HERRING, *supra* note 365, at 125–27.

³⁶⁸ FINE, *supra* note 364, at 61; JONSEN, *supra* note 286, at 126.

³⁶⁹ *See generally* MARIAN BARNES, CARING AND SOCIAL JUSTICE (2006) (considering developments in care-giving and its relationship to social justice).

³⁷⁰ Herbert Wechsler, *Toward Neutral Principles of Law*, 73 HARV. L. REV. 1, 17, 29 (1959).

³⁷¹ *See generally* WILLIAM Q. DEFUNIACK, HANDBOOK ON MODERN EQUITY (2d ed. 1956) (discussing the requisite elements of equity in tort, property, and contract law); Garrard Glenn & Kenneth Redden, *Equity: A Visit to the Founding Fathers*, 31 VA. L. REV. 753, 756 (1945) (quoting Blackstone’s idea that “equity exists for corrections of situations wherein the law, by reason of its universality, is deficient.”).

compassion, humaneness, and love.³⁷² David Hume, the eighteenth-century British philosopher, opined that the basis for a system of justice and social solidarity was tied to expressions of natural sympathy for others.³⁷³ German philosopher Arthur Schopenhauer maintained that compassion “is the real basis of all voluntary justice.”³⁷⁴ Accordingly, for an action to have moral value, it must derive from compassion.³⁷⁵

Compassion is defined as an acknowledgment of another’s suffering which prompts a response to assist in alleviating the suffering, and is often regarded as the motivation for subsequent merciful acts.³⁷⁶ Mercy is oftentimes used synonymously with compassion or benevolence.³⁷⁷ Indeed, acts of this nature have been termed “responsible benevolence,”³⁷⁸ or “compassionate mercy.”³⁷⁹

For others, charity is seen as the ultimate value in caring for the dying;³⁸⁰ beneficence and benevolence may combine to become “loving charity.”³⁸¹ The elimination or management of suffering is so central to this attitude that it can well be seen as trumping the biomedical principle of autonomy.³⁸²

In contemporary society, it has been urged that sympathy and compassion must be integrated into the fabric of the law.³⁸³ A modern and principled rule of law, then, needs notions of decency and compassion within its sinews³⁸⁴ and does not have to conflict with a rule of love.³⁸⁵

³⁷² Equity is defined as not only “the quality of being equal or fair” but, “given in accordance with natural justice . . . something fair and right.” 5 OXFORD ENGLISH DICTIONARY 358 (2d ed. 1989).

³⁷³ Paul T. Menzel, *Justice and the Basic Structure of Health Care Systems* in MEDICINE AND SOC. JUST. 261, 262 (Rosamund Rhodes, Margaret P. Battin & Anita Silvers eds. 2002).

³⁷⁴ WILLIAM S. SAHAKIAN & MABEL LEWIS SAHAKIAN, IDEAS OF THE GREAT PHILOSOPHER 49 (1993).

³⁷⁵ See *id.*

³⁷⁶ Steven Tudor, *Modes of Mercy*, 28 AUSTRALIAN J. LEGAL PHIL. 79, 95 (2003); see also Guinan, *The Christian Origin of Medical Compassion*, 5 NAT’L CATHOLIC BIOETHICS Q. 21 (2005); Martha C. Nussbaum, *Compassion: The Basic Social Emotion*, 13 SOC. PHIL. & POL’Y 27 (1996).

³⁷⁷ Tudor, *supra* note 376, at 81.

³⁷⁸ VAN ZYL, *supra* note 359, at 197.

³⁷⁹ Battin, *supra* note 363, at 66; see also TIMOTHY E. QUILL, DEATH AND DIGNITY: MAKING CHOICES AND TAKING CHARGE 131 (1994).

³⁸⁰ Pellegrino, *Decision at the End of Life*, *supra* note 147.

³⁸¹ *Id.* at 225, 241.

³⁸² Shepherd, *Sophie’s Choice*, *supra* note 12, at 106, 119.

³⁸³ Laurence H. Tribe, *Revisiting the Rule of Law*, 64 N.Y.U. L. REV. 726, 729 (1989).

³⁸⁴ *Id.* at 731.

³⁸⁵ *Id.* at 729; see FLETCHER, *supra* note 57 (arguing that so long as one’s intention to act is anchored in love, the end result justifies the means). For Fletcher, the Situation Ethic is a variant or sub-set of moral ethics, which, in turn, holds that ethics are relative to culture, immediate circumstances and specific individual needs. See generally SAMUEL FLEISCHACKER, INTEGRITY AND MORAL RELATIVISM (1992) (taking a relativistic approach to a system of ethics, values, and morals); Hugh LaFollette, *The Truth in Ethical Relativism*, 22 J.

Others have called for the law to be empathetic, a term often used interchangeably with love, altruism, and sympathy.³⁸⁶

One of the inherent weaknesses of the rule of law has been said to be its all too often efforts to distance itself from human experience.³⁸⁷ A strong claim could be made that introducing human values or attitudes into the judicial process would conflict with the idea of judgment sustained by rational and objective argumentation, not feelings and emotions.³⁸⁸ Thus, empathetic discourse runs the risk of being seen as irrelevant and dismissed.³⁸⁹

C. Principles, Emotions, and The Holmesian Caveat

While principles provide the foundational framework for standards of normative conduct, feelings are important when individuals or discrete

SOC. PHIL. 146, 146–54 (eschewing routine application of existing moral rules and, instead, stressing that a “cultivated moral judgment” should be the normative standard of conduct).

³⁸⁶ Lynne N. Henderson, *Legality and Empathy*, 85 MICH. L. REV. 1574, 1579–82 (1987). For Adam Smith, the process of judging involves a lesson in learning the importance of impartiality by imagining how an impartial spectator would act in a particular situation. “Moral judgment is either approval or disapproval of an action. Judging is a complex matter and forms the last step in a process” relying upon the capacity of humans to sympathize—not show compassion but, in a neutral way—express empathy. GEOFF COCKFIELD, ANN FIRTH & JOHN LAURENT, NEW PERSPECTIVES ON ADAM SMITH’S “THE THEORY OF MORAL SENTIMENTS” 71 (2007); see RICHARD A. POSNER, HOW JUDGES THINK 117 (2008) (observing that an element of “good judgment” in judicial decision-making is “empathy” and “common sense”).

³⁸⁷ See generally JOHN NOONAN, PERSONS AND MASKS OF THE LAW (1976) (recasting the study of the law through a person-centric viewpoint, focusing on those affected by the law and its changes).

³⁸⁸ Benjamin Zipursky, *DeShaney and the Jurisprudence of Compassion*, 65 N.Y.U.L. REV. 1101, 1122 (1990). But see MARTIN L. HOFFMAN, EMPATHY AND MORAL DEVELOPMENT: IMPLICATIONS FOR CARING AND JUSTICE (2000).

³⁸⁹ Henderson, *supra* note 386, at 1588; see Dan Balz, *Empathy and Judicial Picks Rarely Mix on Capitol Hill*, WASH. POST, May 3, 2009, available at <http://www.washingtonpost.com/wp-dyn/content/article/2009/05/02/AR2009050202081.html> (observing Senator Graham’s concern that the “empathy test” for judicial appointments is “a dangerous road to go down”); Michael A. Fletcher, *Obama Names Judges to Appeals Court*, WASH. POST, Mar. 18, 2009, at A4 (reporting on Obama’s interest in getting judicial nominees who show “empathy” and a conservative advocacy group’s response that that such a quality “has nothing to do with a judge’s work of interpreting statutes and the Constitution” and, furthermore, does not set a clear focus on whom a judge should show empathy); Peter Slevin, *Obama Makes Empathy a Requirement for Court*, WASH. POST, May 13, 2009, at A3 (reporting on the President’s efforts to recruit judicial candidates to the federal bench who have a “capacity to understand others,” thereby renewing the concerns of some that such individuals would show sympathies for particular groups from the bench). But see Douglas W. Kmiec, *The Case for Empathy*, AMERICA, May 11, 2009, available at http://www.americamagazine.org/content/article.cfm?article_id=11649. See generally LOU AGOSTA, EMPATHY IN THE CONTEXT OF PHILOSOPHY (using philosophical methods to expose empathy as fundamental to the human community); FRANS DE WAAL, THE AGE OF EMPATHY (2009) (describing biological, psychological, and socio-cultural displays of empathy in humans); David R. Stros & Ryan W. Scott, Review Essay, *Navigating the New Politics of Judicial Appointments*, 102 NW. U. L. REV. 1869 (2008) (describing the heavily-politicized process of Supreme Court nominations and possible reforms by both the legislative and executive branches).

issues arise that test the validity of a principle's application within the context of a given situation or norm of conduct.³⁹⁰ Scholars assert that "the morally good person is not just principled, but also compassionate."³⁹¹ The "morally good person" exhibits both "practical wisdom"³⁹² and "simple common sense"³⁹³ in preserving a patient's dignity or quality of life throughout all palliative care treatments.³⁹⁴

The best way to assure this goal while managing a plan of adjusted palliative care is to embrace a test of medical utility in determining what end-stage options should be made available as treatment.³⁹⁵ Accordingly, physicians should perform a risk calculus that weighs the benefits and burdens to assess the utility of various medical treatments.³⁹⁶ In all cases, the doctrine of medical futility should anchor these evaluations by acknowledging the practical limits of medical treatment.³⁹⁷

While compassion is experienced and evaluated subjectively,³⁹⁸ it need not stigmatize a valid legal theory.³⁹⁹ In *DeShaney v. Winnebago County Dept. of Social Services*,⁴⁰⁰ Justice Blackmun addressed the importance of compassion in judicial analysis and interpretation by observing that "compassion need not be exiled from the province of judging."⁴⁰¹ He further stated that when a court removes "natural sympathy," it is unable to "recogniz[e] the facts of the case before it or the legal norms that should apply to those facts."⁴⁰²

Eschewing emotion as a dominant vector of force when seeking the truth in law,⁴⁰³ Justice Holmes urged that the reasoning behind a particular rule's adoption "ought to be of paramount importance."⁴⁰⁴ And,

³⁹⁰ RANDALL & DOWNIE, *supra* note 125, at 12–13.

³⁹¹ *Id.* at 13.

³⁹² *Id.* at 24.

³⁹³ *Id.* at 73.

³⁹⁴ Annette F. Street & David W. Kissane, *Constructions of Dignity in End-of-Life Care*, 17 J. PALLIATIVE CARE 93, 95, 99 (2001); RANDALL & DOWNIE, *supra* note 125, at 71.

³⁹⁵ RANDALL & DOWNIE, *supra* note 125.

³⁹⁶ *Id.* at 116–18.

³⁹⁷ *Id.*

³⁹⁸ Zipursky, *supra* note 388, at 1142.

³⁹⁹ *Id.* at 1147. See Lois L. Shepherd, *Face to Face: A Call for Radical Responsibility in Place of Compassion*, 77 ST. JOHN'S L. REV. 444 at 449, 457 (2003) (calling for a greater prominence for caring responses in law and a sense of "shared humanity") [Shepherd, *Face to Face*].

⁴⁰⁰ *DeShaney v. Winnebago County Dept. of Social Servs.*, 489 U.S. 189 (1988).

⁴⁰¹ 489 U.S. at 213 (Blackmun, J. dissenting).

⁴⁰² *Id.* at 213.

⁴⁰³ THE ESSENTIAL HOLMES: SELECTIONS FROM THE LETTERS, SPEECHES, JUDICIAL OPINIONS, AND OTHER WRITINGS OF OLIVER WENDELL HOLMES, JR. 119 (Richard A. Posner ed. 1992).

⁴⁰⁴ Oliver Wendell Holmes, Jr., *The Path of The Law*, 10 HARV. L. REV. 457 (1987); see RICHARD A. POSNER, *LAW, PRAGMATISM AND DEMOCRACY* 107 (2003) (arguing that ordinary people have little interest in complex policy and limited intellectual depth—with half of the population with I.Q.s of below 100).

when the reasons for structuring the rule have disappeared, it is improper to maintain the rule, simply due to “blind imitation of the past.”⁴⁰⁵

The reasons behind the prohibitions and restricted use of terminal sedation as a means of care in palliative treatment of patients in end-stage care need to be reevaluated and expanded to include care of patients suffering severe psychological distress. Suffering at the end of life may be physical, psychological, emotional, or existential, and may take form as despair, feelings of helplessness and isolation, or a basic loss of self-respect.⁴⁰⁶ Therefore, a right not to suffer and a professional medical responsibility to validate this right must be acknowledged.⁴⁰⁷

D. *A Contemporary Model in Legal Decision-Making*

The law should accord a greater “caring response”⁴⁰⁸ or a “sense of shared humanity”⁴⁰⁹ in its interpretation and application. These values are essential to sustaining the rule of law.⁴¹⁰ Often, though, values are challenged or perceived as being in conflict with “moralistic abstractions about liberty, equality and dignity.”⁴¹¹

Unquestionably, health care decisions concerning the maintenance of life and the hastening of death often pose complicated moral questions which are anchored in normative reasoning which may soon become irrelevant because of changing contemporary values.⁴¹² If moral reasoning is found to be ambiguous or ineffectual, courts will rely on “moral intuitions,” or “assumptions about intrinsic normative order” found implicitly “in the natural course of life.”⁴¹³ Analytical frameworks of this nature invite conflict because of non-verifiable subjective values—this, because determining normative assumptions which animate moral judgments is very difficult if not indiscernible.⁴¹⁴

⁴⁰⁵ Holmes, *supra* note 404, at 469; *see generally* MAGNUSSON, *supra* note 45; Stephen W. Smith, *Some Realism About End of Life: The Current Prohibition and the Euthanasia Underground*, 33 AM. J.L. & MED. 55 (2007) (arguing in favor of legalizing physician-assisted suicide and active voluntary euthanasia).

⁴⁰⁶ VAN ZYL, *supra* note 359, at 196.

⁴⁰⁷ THOMASMA & GRABER, *supra* note 58, at 192.

⁴⁰⁸ Shepherd, *Face to Face*, *supra* note 399, at 449.

⁴⁰⁹ *Id.* at 457.

⁴¹⁰ Neil S. Siegel, *The Virtue of Judicial Statesmanship*, 86 TEX. L. REV. 961, 971 (2008); *see generally* Kathryn Webb Bradley, *Knowing Law's Limits: Comments on "Forgiveness: Integral to Close Relationships and Inimical to Justice?"*, 16 VA. J. SOC. POL'Y & L. 322 (2009) (arguing that concepts such as forgiveness have only a limited purpose within the law, and that society is better off realizing the limitations of law in repairing emotional injuries).

⁴¹¹ Siegel, *supra* note 410, at 1030.

⁴¹² *See* Steven D. Smith, *De-Moralized: Glucksberg in the Malaise*, 106 MICH. L. REV. 1571, 1589 (2008).

⁴¹³ *See id.* at 1589–90.

⁴¹⁴ *See id.* at 1589.

In order to add greater precision to their analyses, courts can choose to embrace the philosophy of Holmes, which prizes logic over experience.⁴¹⁵ By adhering to legal formalism, moral judgments are avoided altogether⁴¹⁶ This is largely because there is an awareness that it is very difficult to safeguard and sustain social solidarity if purely emotional values are given weight during the processes of judicial decision-making.⁴¹⁷ If formalism is rejected, however, judicial deference can be given to “tradition and convention”⁴¹⁸ as an imperfect means for discerning moral convictions or discovering shared ones.⁴¹⁹

The best model of judicial decision-making achieves a balance between logical reasoning and “critical morality.”⁴²⁰ As such, the courts must endeavor to apply a situation ethic rather than an unyielding and rigid normative standard,⁴²¹ and then proceed to acknowledge love or *agape* as the controlling moral principle in all judicial decision-making. Stated otherwise, the judiciary should seek to interpret evolving social values while guided by compassion or humaneness.⁴²² These values and conditions will necessarily change with the facts of each case and, so too, will the pertinence of compassion and humaneness. The ultimate goal of judicial decision-making should be a “practical realization of the rule of law.”⁴²³

⁴¹⁵ See generally Holmes, *supra* note 403 (collecting various writings from the distinguished Supreme Court Justice that impart his philosophy on jurisprudence).

⁴¹⁶ Smith, *supra* note 412, at 1590.

⁴¹⁷ See generally Cass R. Sunstein, *Due Process Traditionalism*, 106 MICH. L. REV. 1543 (2008) (explaining arguments on behalf due process traditionalism and ultimately concluding that these arguments provide a tenuous defense of judicial decision-making); Siegel, *supra* note 410, at 979; see also WILLIAM F. SULLIVAN, *EYE OF THE HEART: KNOWING THE HUMAN GOOD IN THE EUTHANASIA DEBATE* 27–58 (2005).

⁴¹⁸ Smith, *supra* note 412, at 1590.

⁴¹⁹ *Id.*

⁴²⁰ *Id.* Judge Richard Posner suggests that by employing a type of reasoning termed, “cultural cognition,” which is considered “a valid[,] though flawed[,] sense of knowledge,” a judge is allowed to consider his personal vision of those policies important to him in order to advance his model of a good society. *Id.* “The personal, the emotional and the intuitive” are factors used in judicial making—with the intuitive being a real factor in appellate review. *Id.* at 116, 117.

⁴²¹ See generally FLETCHER, *supra* note 385 (arguing for a new approach to ethics grounded in love and married to an objective rationale of utility).

⁴²² Siegel, *supra* note 410, at 981.

⁴²³ *Id.* at 979; see generally, George P. Smith, II, *Judicial Decisionmaking in the Age of Biotechnology*, 13 NOTRE DAME J.L. ETHICS & PUB. POL’Y 93 (1999) (calling for courts to consider the modern refinements of biotechnology in conjunction with social policy in shaping judicial decisions regarding bioethics).

CONCLUSION

Patient values must always be viewed as the baseline for developing and pursuing patient-centered palliative care for terminal illnesses.⁴²⁴ The best patient care adjusts to a patient's changing medical condition.⁴²⁵ Palliative care provides adjusted care by endeavoring to relieve physical and psychological end-stage suffering.⁴²⁶ If this is recognized as a right to relief from suffering,⁴²⁷ as the European Federation for Pain Study advocates,⁴²⁸ then health care providers and the state have a basic responsibility to establish policies designed to validate this right and follow a course of action which seeks to honor the wants and desires of patients for a dignified death. Indeed, there is a medical duty to act to benefit the dying patient, for relief of pain "is the least disputed and most universal of the moral obligations of the physician."⁴²⁹ Accordingly, both law and medicine must set standards or protocols that allow for the wider adoption and use of terminal sedation as an efficacious and humane practice for end-stage care of patients in hospice.⁴³⁰

Efforts to both accept and adopt a protocol for specifically determining medical futility⁴³¹ will be enhanced and legitimized by a wider adoption of the Uniform Health Care Decisions Act.⁴³² The American Academy of Palliative Medicine has worked to develop standards for regulating nutrition and hydration in palliative management.⁴³³ The American Medical Association has also offered guidance on when, clinically and ethically, it is proper to sedate to unconsciousness.⁴³⁴ These policies are having a salutary effect on both codifying and normalizing proper medical care and procedures in end-of-life care. Rousseau,⁴³⁵ Morita,⁴³⁶ and Quill⁴³⁷ have also shown significant gains in proposing a protocol for the administration of palliative or terminal sedation. In addition to providing a framework for principled decision-making in end-

⁴²⁴ Quill, *Physician-Assisted Death*, *supra* note 40, at 21.

⁴²⁵ PRESIDENT'S COUNCIL ON BIOETHICS, *supra* note 81, at 217; *see also* PELLEGRINO & THOMASMA, *supra* note 81; THOMASMA, HUMAN LIFE IN THE BALANCE, *supra* note 81; THOMASMA & GRABER, *supra* notes 58.

⁴²⁶ *See supra* notes 17–23.

⁴²⁷ THOMASMA & GRABER, *supra* note 58, at 192.

⁴²⁸ *See supra* notes 72–80; *see also* Report of the Council on Ethical and Judicial Affairs, *supra* notes 203–14.

⁴²⁹ Pellegrino, *Decision at The End of Life*, *supra* note 147.

⁴³⁰ *See supra* notes 189–200 and accompanying text.

⁴³¹ *See, e.g., supra* notes 151–63.

⁴³² *See, e.g., supra* notes 169–74.

⁴³³ *See, e.g., supra* notes 297–303.

⁴³⁴ *See, e.g., supra* notes 203–11.

⁴³⁵ *See, e.g., supra* notes 189–94.

⁴³⁶ *See, e.g., supra* notes 101, 114, 200.

⁴³⁷ *See, e.g., supra* notes 52, 194, 248.

stage care, these actions educate the public on the parameters of appropriate medical care and humane treatment for the terminally ill.⁴³⁸

Once a codified framework or template for end-of-life decision-making emerges, an informed dialogue can begin which addresses namely one question: is the terminally ill individual exercising rational thinking in his treatment decisions, which, in turn, validate self-determination or autonomy?⁴³⁹ If the answer is in the negative and the patient is deemed incompetent to make end-of-life decisions, the issue then becomes whether the health care provider is acting consistent with standard medical practice⁴⁴⁰ and endeavoring to make a “value-consequent choice” consistent with the patient’s values⁴⁴¹ and best interests.⁴⁴² Ultimately, reasonableness⁴⁴³ and compassion⁴⁴⁴ shape the parameters of a patient’s best medical interests. Reasonableness is not capable of a precise formulation, but—rather—is tied inextricably to fact-sensitive issues of proportionality or cost-benefit analysis⁴⁴⁵ which, in turn, are shaped by the “accepted standards of medical practice” applicable to each medical case presented.⁴⁴⁶

The doctrine of medical futility must bring into focus the popular notion within American society that there is a prescription available for every circumstance.⁴⁴⁷ Under this doctrine, when medical care is complemented by the test of proportionality imbedded in the principle of double-effect, the central question becomes whether the burdens of treat-

⁴³⁸ See, e.g., *supra* notes 310–311; see Mitchell et al., *supra* note 121.

⁴³⁹ SMITH, *supra* note 89, at 109. Indeed, a dominant concern in testing the extent to which the terminally ill patient is rational and competent to make health care decisions is the extent to which the decisions are consistent with the patient’s life values. WERTH, *supra* note 69.

⁴⁴⁰ SMITH, *supra* note 248, at 109.

⁴⁴¹ WERTH, *supra* note 69; see DAVID H. SMITH, PARTNERSHIP WITH THE DYING: WHERE MEDICINE AND MINISTRY SHOULD MEET 15–38, 83–106 (2005); THOMASMA, HUMAN LIFE IN THE BALANCE, *supra* note 81, at 169.

⁴⁴² SMITH, *supra* note 89, at 109.

⁴⁴³ SMITH, *supra* note 89, at 180.

⁴⁴⁴ See PELLEGRINO & THOMASMA, *supra* note 81; *supra* notes 12, 388, 414–23.

⁴⁴⁵ See BARRY R. SCHALLER, UNDERSTANDING BIOETHICS AND THE LAW 4 (2008) (using the term “ethnics” is used to describe the convergence of ethics and economics and recognition taken of the concern that opens acknowledgment of this convergence is oftentimes avoided for fear its recognition would in some way dehumanize the process of medical decision making); Boyle, *Enriching Proportionalism*, *supra* note 256 (discussing proportionalism as a consequentialist form of moral analysis where, in order to reach a moral judgment, all aspects of an action—including its side effects—are compared or balanced in terms of their ultimate effect on the human good).

⁴⁴⁶ SMITH, *supra* note 89, at 173–74; see Schneiderman et al., *supra* note 156 (discerning the doctrine of medical futility as the basis of common sense).

⁴⁴⁷ CALLAHAN, *supra* note 300, at 203–06; see generally Ost, *De-Medicalisation of Assisted Dying*, *supra* note 64 (weighing the benefits and burdens of de-medicalising assisted dying); Smith, *All’s Well That Ends Well*, *supra* note 37 (arguing for an approach to the dying process that respects the self-determined, rational wishes of a dying patient to end their life).

ment clearly outweigh its benefits to the patient and if it would be inhumane if continued.⁴⁴⁸ In cases where medical treatment is deemed futile, terminal sedation should function as part of end-stage total symptom management and validated as an integral part of palliative management and adjusted care.

Once end-stage, terminal suffering is managed more effectively, the law must abandon its reliance on the principle of double effect in determining whether assistance in ending a life is capital murder or euthanasia. Instead, the legal analysis of end-stage care should pivot on both the degree of necessity for providing compassionate assistance to dying patients and an assessment of the soundness of the medical judgment of the health care providers. The fundamental part of the end-of-life equation for making rational medical decisions must always be the patient's quest for a dignified death⁴⁴⁹ or, alternatively, the "least worst death."⁴⁵⁰

Rather than continue the quest to establish a constitutional right to assisted suicide, perhaps the time-honored right to refuse treatment should be seen as the cornerstone for building a more compassionate and enlightened ethics of understanding when managing end-of-life issues.⁴⁵¹ This right of refusal is not a right to hasten death, but merely a right to resist unwanted physical invasions.⁴⁵²

⁴⁴⁸ See *supra* notes 155–66 and accompanying text. For patients with advanced dementia, typical complications will include pneumonia, incontinence, limited verbal communication, eating difficulties and febrile episodes—all of which are correlated, directly, with mortality rates of six months. These distressing symptoms should be palliated rather than treated aggressively and, thus, inhumanely. Mitchell et al., *supra* note 121, at 1529; Sachs, *supra* note 59, at 1596.

For Callahan, testing the burdens and benefits of treatment modalities is tied ultimately to the principle of medical futility. Accordingly, when there is a significant likelihood that the end result of further treatment will either raise a strong probability of death, entail a very real probability of death that treatment will bring extended pain and suffering, extend a state of unconsciousness which is not curative or when available treatment—while promising an extension of life—increases greatly the near certainty of “a bad death,” then these forms of treatment are classified as medically futile and improper to undertake. CALLAHAN, *supra* note 300, at 201–02; see generally GEORGE P. SMITH, II, FAMILY VALUES AND THE NEW SOCIETY: DILEMMAS OF THE 21ST CENTURY, 217–46 (1998) (explaining various moral and religious frameworks for making end-of-life decisions); GEORGE P. SMITH, II, LEGAL AND HEALTH CARE ETHICS FOR THE ELDERLY, 55–68 (1996) (discussing advance directives that allow patients to prescribe situations in which continued care is undesirable).

⁴⁴⁹ QUILL, *supra* note 379, at 51.

⁴⁵⁰ MARGARET P. BATTIN, THE LEAST WORST DEATH: ESSAYS IN BIOETHICS ON THE END OF LIFE (1994); see generally IRA BYOCK, DYING WELL: PEACE AND POSSIBILITIES AT THE END OF LIFE (1997) (collecting testimonials and anecdotes about terminally ill patients finding love and reconciliation during the end-stage of life).

⁴⁵¹ See MEISEL, *supra* note 328; Annas, *supra* note 48, at 1102.

⁴⁵² See COMM. ON CARE AT THE END OF LIFE, 1997 Supplement, *supra* note 312, at 5.

In 1990, Congress enacted the Patient Self-Determination Act,⁴⁵³ a bold step toward strengthening patient autonomy and the national validation of the right to refuse treatment.⁴⁵⁴ This Act requires most hospitals, nursing homes, health agencies, and HMO's to advise newly-admitted patients of information regarding Advance Health Care Directives and their right to specify if they wish to either accept or refuse specific medical care.⁴⁵⁵

When the Uniform Health Care Decisions Act⁴⁵⁶ is considered, together with the successful efforts of some states to enact pain relief statutes,⁴⁵⁷ such as Oregon⁴⁵⁸ and Washington,⁴⁵⁹ and medical protocols for use of palliative care and terminal sedation,⁴⁶⁰ a powerful arsenal is in place that bolsters the framework for principled decision-making in end-of-life care. These weapons serve to protect and encourage sound, reasonable medical judgments and balance physician powers and protections with patient autonomy.

Utility comes into play after medical conditions are assessed and evaluated and a treatment prognosis is charted.⁴⁶¹ The principle of medical futility is tested within the bounds of utility on a case-by-case basis and determined to be either efficacious or invalid. Cost-benefit analysis of treatment benefits is central to a determination of medical futility⁴⁶² since this is fundamentally a clinical judgment, not an encompassing moral evaluation or principle on the "worthlessness" of a life.⁴⁶³

⁴⁵³ Patient Self-Determination Act, 42 U.S.C. §§ 1395cc(f), 1396a(w) (1994) (Medicare and Medicaid, respectively).

⁴⁵⁴ See Laurence P. Ulrich, *The Patient Self-Determination Act: Meeting the Challenges of Patient Care* 283 J. AM. MED. ASS'N. 2454 (2000).

⁴⁵⁵ *Id.*

⁴⁵⁶ See *supra* notes 169–173 and accompanying text.

⁴⁵⁷ See *supra* note 347.

⁴⁵⁸ ORE. REV. STAT. §§ 127.800 (12), 127.805 (2005).

⁴⁵⁹ WASH. REV. CODE ANN., ch. 70,245 (West 2009).

⁴⁶⁰ See, e.g., *supra* notes 299–305, for the suggestions of the American Academy of Palliative Medicine; *supra* notes 203–11, for the suggestions of the American Medical Association.

⁴⁶¹ See JONATHAN BARON, *AGAINST BIOETHICS*, 25–50 (2006) (stressing the ineluctable foundation of utilitarianism as the preferred basis for bioethical decision making); Smith, *Futility and the Principle of Medical Futility*, *supra* note 50.

⁴⁶² See generally Vijay N. Joish & Gary M. Oderda, *Cost Utility Analysis of Quality Adjusted Years*, 19 J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY 57 (2005) (providing an overview of cost-utility analysis as an assessment tool in determining the cost-effectiveness of a course of treatment). It has been suggested that any determination of futility must be a joint determination made, as such, by physician, patient and surrogate decision-maker, with the final determination endeavoring to strike a balance between three criteria: effectiveness, benefit, and burden—in achieving the patient's good. Pellegrino, *Decision at The End of Life*, *supra* note 147, at 227.

⁴⁶³ Pellegrino, *Decision at The End of Life*, *supra* note 147, at 220, 227; see generally Amir Halevy, *Medical Futility, Patient Autonomy, and Professional Integrity: Finding the Appropriate Balance*, 18 HEALTH MATRIX 261 (2008) (discussing the need for integrity in the medical profession to counterbalance patient requests for inappropriate medical treatment).

Whether the operable normative standard for policy-making is termed *agape*,⁴⁶⁴ charity,⁴⁶⁵ compassion,⁴⁶⁶ love,⁴⁶⁷ or mercy,⁴⁶⁸ the common unifying denominator in palliative care is a humane, morally responsible approach to dealing with intractable suffering at the end-stage of life.

Judicial decisionmakers, just as health care providers, must exercise good judgment. Good judgment is characterized as “an elusive . . . compound of *empathy*, modesty, maturity, a sense of proportion, balance, a recognition of human limitations, sanity, prudence, a sense of reality and *common sense*.”⁴⁶⁹ This elusive trait must be the norm when making medicolegal decisions, not the exception.

To initiate or continue medically futile treatment should be recognized as simply wrong; for, acting in such a manner not only denies the fact of human finitude, but it imposes unnecessary effort, expense, and emotional trauma on both the patient and other affected third parties.⁴⁷⁰ When physicians attempt to treat futile medical conditions, such actions are a total abnegation of one of the cardinal principles of medical ethics—beneficence.⁴⁷¹

It has been argued persuasively that while the state may declare a legitimate interest in morality,⁴⁷² it cannot easily sacrifice “claims of associational autonomy”⁴⁷³ found in “expressive [or] intimate association”⁴⁷⁴ in order to protect public morality. Accordingly, care must be taken by the state to eschew administrative, judicial, or legislative determinations that abridge “choices central to personal dignity and autonomy . . . central to the liberty protected by the Fourteenth Amendment.”⁴⁷⁵

⁴⁶⁴ Defined as a sense of Christian love, charity. 1 OXFORD ENGLISH DICTIONARY 243 (2d ed. 1998).

⁴⁶⁵ Defined as Christian love. 3 OXFORD ENGLISH DICTIONARY 42 (2d ed. 1998); see Pellegrino, *Decision at The End of Life*, *supra* note 147, at 241 (where charity is advanced as an attribute of end-of-life care and treatment).

⁴⁶⁶ Defined as pity. 3 OXFORD ENGLISH DICTIONARY 597 (2d ed. 1998).

⁴⁶⁷ Defined as benevolence. 4 OXFORD ENGLISH DICTIONARY 52 (2d ed. 1998); see Fletcher, *supra* note 57.

⁴⁶⁸ Defined as mercy, showing compassion or kindness. 9 OXFORD ENGLISH DICTIONARY 626 (2d ed. 1998).

⁴⁶⁹ POSNER, *supra* note 386, at 117 (emphasis added); see Schneiderman et al., *supra* note 156, at 409 (regarding the basis of common sense).

⁴⁷⁰ Pellegrino, *Decision at The End of Life*, *supra* note 147, at 233–35.

⁴⁷¹ *Id.* at 223; see generally PELLEGRINO & THOMASMA, *supra* note 81 (summarizing forms of euthanasia and suggesting legislative and public policy movements toward euthanasia).

⁴⁷² Laurence H. Tribe, *Lawrence v. Texas: The Fundamental Right That Dare Not Speak Its Name*, 117 HARV. L. REV. 1893, 1935–36 (2004).

⁴⁷³ *Id.* at 1936.

⁴⁷⁴ *Id.*

⁴⁷⁵ *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833, 851 (1992).

It is logical to assume that the right to compassionate care in end-stage illness is grounded in a liberty interest and cannot be unduly challenged or restricted by a state interest in judging the “morality” of autonomous actions designed to give purpose and promote dignity.⁴⁷⁶ Society’s central obligation is not to mandate one moral code over another but rather, to define and safeguard “the liberty of all”⁴⁷⁷ and promote social policies which address suffering with charity, compassion, and common sense.⁴⁷⁸ Inextricable to this societal obligation is recognition of a coordinate duty of health care providers “not to prolong dying.”⁴⁷⁹ This duty arguably coalesces with, and validates, the very principle of beneficence,⁴⁸⁰ and thereby shapes a new “right” of the terminally ill to be free from refractory pain and existential suffering at the end-stage of life.⁴⁸¹

The New York State Task Force on Life and the Law concludes its 1997 supplemental Report, *When Death is Sought*, with an aspirational call to action that serves as a telling indictment of the tragic state of health care delivery at the end-of-life stage:

The widespread public interest in physician-assisted suicide represent[s] a symptom of a much larger problem: our collective failure to respond adequately to the suffering that patients often experience at the end of life. Improving palliative care, and attending to the psychological, spiritual, and social need of dying patients, must be a critical national priority.⁴⁸²

Acceptance, or even approval, of the right of the terminally ill to receive assistance in ending their lives has grown in the United States, as

⁴⁷⁶ See *Lawrence v. Texas*, 539 U.S. 558, 573, 578 (2003).

⁴⁷⁷ *Casey*, 505 U.S. at 850. The right of privacy from governmental intrusions, expressed in *Griswold* and *Eisenstadt*, add to the strength of the liberty of associational expression found in *Lawrence*, in arguing for a right to die with dignity without unduly burdensome state interference. See *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Griswold v. Connecticut*, 381 U.S. 479 (1965).

⁴⁷⁸ THOMASMA, HUMAN LIFE IN THE BALANCE, *supra* note 81, at 195; SMITH, *supra* note 89, at 83–96.

⁴⁷⁹ THOMASMA, HUMAN LIFE IN THE BALANCE, *supra* note 81, at 195. This duty should be triggered when one is diagnosed as terminally ill, has made a determination (or executed an advance directive) that, because of medical conditions, life no longer has personal meaning or, when, even though no such decision has been made by the patient and there is no advance directive, there is nonetheless a medical realization that the terminal illness is “in its imminent phase.” THOMASMA, HUMAN LIFE IN THE BALANCE, *supra* note 81, at 194.

⁴⁸⁰ PELLEGRINO & THOMASMA, *supra* note 81.

⁴⁸¹ See Cassell, *The Nature of Suffering and the Goals of Medicine*, *supra* note 9; see also Berger, *supra* note 37, at 32.

⁴⁸² COMM. ON CARE AT THE END OF LIFE, *supra* note 312, at 12.

seen by the states of Oregon⁴⁸³ and Washington,⁴⁸⁴ and in parts of Europe, notably, the Netherlands, Belgium, and Switzerland.⁴⁸⁵ This acceptance should not be stymied by the fear that these actions will force society onto a slippery slope that ends in the unequivocal endorsement and unrestricted practice of active euthanasia.⁴⁸⁶ Rather than allowing fear to serve as an excuse for passivity or ineptitude, public policy and contemporary standards of normative conduct should be grounded in simple notions of compassionate dignity, beneficence, mercy, or charity in end-of-life decision-making. This conduct will lead ideally to the simple recognition of a human right to avoid intractable somatic and non-somatic pain and suffering. Individuals must have the right to be free from the cruel and unusual punishment⁴⁸⁷ of being forced to live on despite futile medical conditions.⁴⁸⁸

The slippery slope is, in reality, nothing more than the inescapable human condition.⁴⁸⁹ The common duty of man is but to “struggle along” in reaching a common destiny—a life struggle which is either “upwards or downwards, with very uncertain footing.”⁴⁹⁰ No safe plateau of moral security can ever be reached in this journey of life.⁴⁹¹ Rather, painful dilemmas of choice are the rule rather than the exception. Perhaps, in

⁴⁸³ ORE. REV. STAT. §§ 127.800(12), 127.805 (2005).

⁴⁸⁴ WASH. REV. CODE ANN., ch. 70,245 (West 2009); see *Baxter v. Montana*, 2008 Mont. Dist. LEXIS 482 (Dec. 5, 2008) (holding a statutory right to assistance in dying was recognized by the Montana Supreme Court in December, 2009); Kirk Johnson, *Ruling by Montana Supreme Court Bolsters Physician Assisted Suicide*, N.Y. TIMES, January 1, 2010, at A17.

⁴⁸⁵ GRIFFITHS ET AL., *supra* note 62.

⁴⁸⁶ See generally GEORGE P. SMITH, II, *THE LAST RIGHT: EUTHANASIA, SUICIDE OR SELF-DETERMINATION—ETHICAL, LEGAL AND PHILOSOPHICAL CONCERNS* (1999) (on file with author) (advocating an enlightened recognition of the right to die as one possibility in a spectrum of options for patient care, focusing on the patient’s reasoning for the action desired) [SMITH, *THE LAST RIGHT*].

⁴⁸⁷ See generally SMITH, *FINAL EXITS*, *supra* note 48.

⁴⁸⁸ See Smith, *All’s Well That Ends Well*, *supra* note 37. Finding a moral similarity between physician-assisted suicide and active euthanasia, it has been argued that fairness requires that if physician-assisted death is recognized legally, recognition must also be given to a variant of active euthanasia which allows a patient—unable physically to commit physician-assisted death or wishing to end his life by lethal injection but unable to self administer—to rely upon, legally, an attending physician to act accordingly to end his suffering. Nicholas Dixon, *On The Difference between Physician-Assisted Suicide and Active Euthanasia* 28 HASTINGS CTR. REP. 25 (1998).

⁴⁸⁹ GEORGE P. SMITH, II, *WHEN MERCY SEASONS JUSTICE* 21 (2007) (on file with author).

⁴⁹⁰ Minette Marin, *Opinion, An Acceptable Way to Arrange Our Death*, THE SUNDAY TIMES, May 14, 2006, at 18, available at <http://www.timesonline.co.uk/article/0,2088-2179494,00>.

⁴⁹¹ *Id.* Instead of being a rush toward moral oblivion, recognition of assisted dying may well “be a step uphill to a better society” where a greater opportunity for deeper moral development occurs and—consequently—fosters a more compassionate understanding of the end-stage of life. CHARLES F. MCKANN, *A TIME TO DIE: THE PLACE OF PHYSICIAN ASSISTANCE* 239, 240 (1999).

reality, the “goal of the human moral effort” should be simply “to keep seeing and drawing the line, and struggling to stay above it.”⁴⁹²

⁴⁹² Marrin, *supra* note 490.