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Refractory Pain, Existential Suffering, and Palliative Care: Releasing an Unbearable Lightness of Being

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ARTICLE

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

George P. Smith, II*

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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This Article is dedicated to Edmund D. Pellegrino, M.D., John Carroll Professor Emeritus at the Georgetown University Medical Center and former Chairman of the President’s Council on Bioethics, a most valued friend and mentor, for his guidance, inspiration, and support of my scholarship and work in Bioethics over the years.
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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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, often termed today as psychological distress or suffering, 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.” No doubt, Edvard Munch’s famous painting, “The Scream,” may well be taken as the most profound artistic

4 SØREN KIERKEGAARD, FEAR AND TREMBLING (1843); SØREN KIERKEGAARD THE SICKNESS UNTO DEATH (1849).
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. Indeed, it has been recognized as capturing an “intense state of anxiety and despair” where “loss of identity becomes death.” 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.”

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


\[8\] 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”:

\[
\begin{align*}
Pain \text{ has an Element of Blank;} \\
\text{It cannot recollect} \\
\text{When it began, or if there were} \\
\text{A day when it was not.} \\
\text{It has no future but itself,} \\
\text{Its infinite realms contain} \\
\text{Its past, enlightened to perceive} \\
\text{New Periods of pain.}
\end{align*}
\]


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 CYCLOPEDIC 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).


\[11\] 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. 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. 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.

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. 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.

From the very beginnings of the hospice movement, led by Dame Cicely Saunders of the United Kingdom in 1967, “total pain” management of physical, psychosocial and spiritual suffering was then—and is still today—the goal of hospice care. Palliating the whole person and offering compassionate care is central to hospice care. 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. In this regard, hospice care is an effort to counterbalance this irrational and inhumane compulsiveness and thereby “humanize medicine.”

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

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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).
18 Id. at 320.
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-

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. 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. 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. Yet, in order for a physician to engage in terminal sedation, he must not intend to end the life of his patient. 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. This is known as the doctrine of double effect, a well-established and nearly universally accepted principle of medical ethics and related law.

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.

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.

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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.\textsuperscript{36} Taxonomical confusion abounds when issues of self-determination are presented in end-stage illness.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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, \textit{The Case for Killing Granny: Re-thinking End-of-Life Care}, \textit{Newsweek}, Sept. 21, 2009, at 34, 39.


\textsuperscript{37} See George P. Smith, II, \textit{All’s Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?}, 22 \textit{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, \textit{Terminal Sedation: Pulling the Sheet Over Our Eyes}, 38 \textit{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, \textit{Rethinking Guidelines for the Use of Palliative Sedation}, 40 \textit{Hastings Center Rep.} 32 (May–June, 2010); see generally George P. Smith, II, \textit{Euphemistic Codes and Tell-Tale Hearts: Humane Assistance in End-of-Life Cases}, 10 \textit{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).


\textsuperscript{39} See Quill et al., \textit{supra} note 38, at 2103.
and legal concerns regarding the consequences of ordering its use, medical treatment of this nature is not readily available.  

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

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

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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.  

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.  

45 Physical Review, 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).


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 exists and is grounded in the essential right to refuse life-sustaining treatment.

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. 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.

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.

Interestingly, up to ninety percent of pain can be controlled by analgesics. 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. Indeed, previous

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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, Futility and the Principle of Medical Futility: Safeguarding Autonomy and the Prohibition Against Cruel and Unusual Punishment (1997) (on file with author) [hereinafter Smith, Futility and the Principle of Medical Futility].

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).


51 See Lynn, supra note 26, at 12.


54 Quill & Byock, supra note 52.
scholarship reported significant pain in as high as fifty percent of end-stage patients.\textsuperscript{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,\textsuperscript{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,\textsuperscript{57} which is tied to the notion that there is a human right to compassionate care in end-of-life illness\textsuperscript{58}—with suffering being seen, properly, to include physical \textit{and} psychological distress.\textsuperscript{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.

\section*{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-

\begin{itemize}
\item \textsuperscript{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).
\item \textsuperscript{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).
\item \textsuperscript{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).
\item \textsuperscript{58} DAVID C. THOMASMA & GLENN C. GRABER, EUTHANASIA: TOWARD AN ETHICAL SOCIAL POLICY 192 (1991).
\item \textsuperscript{59} McStay, supra note 36, at 46; see Greg A. Sachs, Dying from Dementia, 361 NEW ENG. J. MED. 1595 (2009).
\end{itemize}
patible with the principle of adjusted care\textsuperscript{60} for all medical treatment, and a reasoned and compassionate response to managing medically futile cases.\textsuperscript{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.\textsuperscript{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,\textsuperscript{63} and—more recently—Switzerland\textsuperscript{64} have allowed compassionate medical assistance in those

\textsuperscript{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, \textit{The Spectrum of Medical Care: Curative, Rehabilitative and Palliative}, 279 J. Am. Med. Ass’n. 20 (1998); Sidney Wanzer et al., \textit{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 always 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, \textit{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.

\textsuperscript{61} Smith, \textit{Futility and the Principle of Medical Futility}, supra note 50, at 38; see generally Lauren Shaiova, \textit{Case Presentation: \textquotesingle\textquotesingle Terminal Sedation\textquotesingle\textquotesingle 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).

\textsuperscript{62} See John Griffiths, Helen Weyers & Maurice Adams, \textit{Euthanasia and Law in Europe} 45 (2008); Mary Warnock & Elisabeth Macdonald, \textit{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.

\textsuperscript{63} Grif\textit{fiths 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, \textit{Euthanasia Deaths on The Rise in Holland}, Sunday Telegraph, June 20, 2010, at 17.

\textsuperscript{64} Jacob M. Appel, \textit{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).


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.

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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 Exit 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. 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.

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, these three organizations defined chronic pain as pain recurring for a period of more than three months. 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, 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. That percentage for Americans translates into a raw figure of eight million. By 2030, this figure is expected to double.

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.

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:

73 Id.
74 Id. at 86.
75 Id. at 88.
76 Id. at 89.
77 Id. at 88.
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.”

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. This standard obviously must be continually adjusted as a patient’s case history progresses, 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.

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

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81 PRESIDENT’S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 217 (2005), available at http://bioethics.georgetown.edu/pceh/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 CASELL, 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.\textsuperscript{86} Because of these difficulties and uncertainties, the palliative management of existential pain has been largely neglected.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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 needs\textsuperscript{90}—a more complete, compassionate, and realistic approach to managing terminal illness and end-stage suffering would be implemented.\textsuperscript{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,\textsuperscript{92} to futile and unbearable suffering, and avoidance of humiliation.\textsuperscript{93} All of these conditions conduce to one overriding fear: loss of human dignity,\textsuperscript{94} which brings with it a fear of being forced to become but a “passive bystander” to all of the normal functions of life.\textsuperscript{95} By managing the dying process, which—for some—is viewed as too pro-

\textsuperscript{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.
\textsuperscript{87} Agrawal & Emmanuel, supra note 84.
\textsuperscript{88} Ingrid Bolmsjö et al., Meeting Existential Needs in Palliative Care—Who, When, and Why?, 18 J. PALLIATIVE CARE 185 (2002).
\textsuperscript{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).
\textsuperscript{90} See Hospice, supra note 19; Saunders, supra note 21, at 320.
\textsuperscript{91} Breitbart et al., supra note 89, at 371.
\textsuperscript{92} Stacks et al., supra note 24, at 216.
\textsuperscript{94} Humphry, supra note 53, at 135–36.
\textsuperscript{95} Gunderman, supra note 10, at 40, 42.
tracted and filled with growing and multiple functional losses, the patient can exert some level of control over a process which is acknowledged to be “by and large, a messy business.” Sadly, this complicated and vexatious process for implementing the “new epidemiology of dying” almost assures that health care providers will follow heroic procedures which do not promote or sustain quality so much as postpone death.

In approximately twenty-five percent of all terminally ill patients, depression and other mood disorders occur. Yet, interestingly, few receive pharmacological aid through anti-depressant prescriptions. 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. The components of both of these syndromes are often vague, imprecise, and difficult to evaluate. Commonly, when patients are obsessed with feelings of worthlessness, lose their ability and desire to interact socially, and—in deed—lose their sense of hope, they are properly assessed as suffering from clinical depression and should be given whatever dosage of analgesia is deemed necessary to alleviate that condition—because pharmacotherapy is ultimately the principal tool for symptom control.

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 Sherwen 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 Intractable 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. In some faith communities, cultural efforts are expended in order to view suffering—physically and mentally—as a positive, reinforcing value. Merely accepting suffering as authentic, however, does not mean that it is also meaningful. It remains for the physician to ascertain and then listen carefully to the spiritual parameters within each patient’s character in an attempt to treat those seriously ill as “whole persons.”

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. 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).

Palliative sedation therapy is thus defined as “the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness.” When patient suffering—physical or existential—becomes refractory to standard palliative therapies, the human...
compassionate and merciful response is to offer terminal sedation.\textsuperscript{115} This approach to medical treatment may be seen as consistent with sound principles of adjusted care.

\textbf{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.\textsuperscript{116} Seen as a “useful category of existential distress in which meaningless predominates and . . . profound hopelessness and [a] desire to die may result,”\textsuperscript{117} this syndrome, if not treated satisfactorily with pharmacological therapy, should render such a demoralized patient incompetent to make medical decisions.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{121}

\begin{itemize}
  \item \textsuperscript{115} Rousseau, \textit{supra} note 112; P.C. Rousseau, \textit{Dying and Terminal Sedation}, 7 CLIN. GERIATRICS 19, 19 (1999).
  \item \textsuperscript{116} David W. Kissane, \textit{The Contribution of Demoralization to End of Life Decisionmaking}, 34 HASTINGS CTR. REP. 21, 24 (2004).
  \item \textsuperscript{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.” \textit{Id.} at 23, 24.
  \item \textsuperscript{118} \textit{Id.} at 29.
  \item \textsuperscript{119} RONALD A. LINDSAY, \textit{FUTURE BIOETHICS: OVERCOMING TABOOS, MYTHS AND DOGMAS} 111 (2008).
  \item \textsuperscript{120} \textit{Id.} at 112.
  \item \textsuperscript{121} See THOMASMA & GRABER, \textit{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.
\end{itemize}
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. 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. The potential use of both hospice and palliative care for these Americans staggers the imagination.

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. 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.” This then allows the patient to decide, essentially, which of several terminal events will end his life. Understandably, some patients will not be willing, or psychologically capable, of entering into such a discussion. In those situations, the health care decisionmakers must attempt to discern the patient’s wishes by evaluating his “total good or best interests.” 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.

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 benefits—in other words, whether the treatment is worse than the end-stage disease itself.


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).


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. 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. 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.

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. 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.

Nevertheless, because of prevailing requirements to forego disease-directed therapy before being allowed hospice care, most Americans die without the benefit of palliative care. “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. 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.”

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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
close 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.\footnote{Kenen, \textit{supra} note 134.}

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.\footnote{Quill, \textit{Physician-Assisted Death, supra} note 40, at 17.} 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.\footnote{See \textit{id.} at 18.} It is hoped that this classification will serve as a
catalyst for advancing greater opportunities for expanded training and
service in palliative medicine.\footnote{See \textit{id.}}

\section{III. Shaping the Principle of Medical Futility}

\subsection{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.\footnote{See \textit{Ronald A. Lindsay, Future Bioethics: Overcoming Taboos, Myths, and Dogmas} 52–53 (2008).} When juxtaposed with quality of life, the religious view complicates and,
its 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.\footnote{\textit{Id.; see Robert Young, Medically Assisted Death}, 29–43 (2007).} Instead of one principle or concern dominating the
other, both approaches should be used in evaluating a patient’s medical
prognosis and placing “hope”\footnote{Adrienne M. Martin, \textit{Hope and Exploitation}, 38 Hastings Ctr. Rep. 49 (2008).} 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 a uniform standard, it can be tested by a sense of compas-
son 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
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

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


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. Ref. 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.  

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.  Accordingly, the principle of medical futility comes into play in those clinical cases where: a cure is physically impossible; the treatment is non-beneficial or unlikely to be beneficial; and in those cases where treatment, while plausible, has yet to be validated.  

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.  

Admitting the existence of futile treatment negates the primary obligation of health care professionals to “do no harm.”  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.  Administering CPR when there is no medically reasonable chance that a distressed patient will re-

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153 Id.  
154 Smith, *Futility and the Principle of Medical Futility*, supra note 50.  
158 Smith, *Euphemistic Codes*, supra note 37.
cover from the underlying illness amounts to physical torture. According to physicians, they 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.

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. 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.”

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. Often presented as a cost-benefit theory, the factors used in the balancing test under this principle are not uniformly quantified. In an effort to bring structure to this contentious issue, Dr. Pellegrino suggests “disproportionate” use is—simply—futile medical care.

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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.
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.
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.
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 & Rubenfeld, 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 & Rubenfeld, 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. When lower doses are unable to provide symptomatic relief, then—and only then—should dosages be increased. 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.

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. 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. 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 reaches a number of pertinent conclusions: (1) “The use of sedation in palliative care is not ethically

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198 Morita et al., supra note 114, at 452.
199 Lo & Rubenfeld, 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.
223 Id.
224 RANDALL & DOWNIE, supra note 125, at 73.
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 170. 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).
propriate. 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.


\(^{239}\) Id. at 103, 104.

\(^{240}\) Id. at 105.

\(^{241}\) Lo & Rubenfeld, supra note 113, at 1813.

\(^{242}\) Ost, Euthanasia and The Defense of Necessity, supra note 238, at 103; see Lo & Rubenfeld, 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.”\textsuperscript{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.”\textsuperscript{247}

\section*{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.\textsuperscript{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.\textsuperscript{249} For ethicists, however, there is no clear line between efforts to relieve refractory systems and hastening death.\textsuperscript{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.\textsuperscript{251}

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

\begin{itemize}
\item \textsuperscript{243} Williams, \textit{supra} note 30, at 46.
\item \textsuperscript{244} \textit{Id.}
\item \textsuperscript{245} \textit{Id.}
\item \textsuperscript{246} \textit{Id.}
\item \textsuperscript{247} \textit{Id.}
\item \textsuperscript{248} See Quill et al., \textit{supra} note 38, at 2101; see also Shai J. Lavi, The Modern Art of Dying 129–34 (2005); Smith, \textit{supra} note 89, at 101–09
\item \textsuperscript{249} Lo & Rubenfeld, \textit{supra} note 113, at 1812.
\item \textsuperscript{250} \textit{Id.} at 1813; see Meisel, \textit{infra} note 328.
\item \textsuperscript{251} \textit{Id.; see} Lavi, \textit{supra} note 248, at 129–34.
\end{itemize}
whether it is within the individual patient’s “liberty interest” in making this decision.\footnote{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.\footnote{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.\footnote{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.\footnote{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.\footnote{256} Sadly, there is a mistaken perception that death is always hastened by the aggressive administration of pain management.\footnote{257}

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.” 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. One of the rather predictable side effects of using opiates for pain relief is that sedation occurs. Non-sedating agents are, of course, preferred but not always effective. In administering sedation for refractory pain, a physician should initially seek symptom relief by administering the lowest dosage—one which neither suppresses respiration nor leads to respiratory distress. Dosage that provides no possibility for symptom relief without patient death could be termed properly as active euthanasia. When lower dosages are ineffective, increased dosages are permissible, but they should be justified by clear

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 analgesia 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 symptomatologies 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 “naive 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 & DONWHEY, 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 absolute 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.\textsuperscript{272}

\textbf{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.\textsuperscript{273} This excuse would rest “upon the doctrine of necessity, there being at this juncture no way of relieving pain without ending life.”\textsuperscript{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),\textsuperscript{275} he acted in a good faith effort to alleviate the severe or unbearable suffering of a patient,\textsuperscript{276} with a reasonable belief that the actions were a proportionate response to the patient’s medical condition.\textsuperscript{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.\textsuperscript{278} In a very real way, then, the defense of necessity is grounded in compassion.

\textsuperscript{272} See Timothy E. Quill, \textit{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).


\textsuperscript{274} 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, \textit{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).

\textsuperscript{275} Ost, \textit{Euthanasia and The Defense of Necessity}, supra note 238, at 115–16.

\textsuperscript{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., \textit{supra} note 156, at 409; see CROWN PROSECUTION SERVICE, supra note 64.

\textsuperscript{277} Ost, \textit{Euthanasia and The Defense of Necessity}, supra note 238, at 115–16; CROWN PROSECUTION SERVICE, supra note 64.

\textsuperscript{278} Ost, \textit{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 physicians 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

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.

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.”

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. 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. 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. 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.

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. 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).

In its effort to draw a clear distinction between the withdrawal of life sustaining treatment considered by a patient to be “futile or degrading” and physician-assisted suicide where “the patient be made dead,” 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 “inducing barbiturate

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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.”

288 Id. at 270.
289 Id. at 720–23.
290 Id. at 720–23.
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.”

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, 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.

The trio of Cruzan, Quill, and Glucksburg 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.

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.
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 Ilits eds. 2004).
issue in 2001. 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. 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.” 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. 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. 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, these efforts “can be ethically withheld or withdrawn.”

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 pain—the AAHPM’s Statement on Palliative Sedation, issued in 2006, is clear that

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.
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-

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308 Id.
309 Id.
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
sessed a patient by determining whether their condition is curative, rehabilitative, or palliative. 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. Consistent with the lack of national cognizance of a right or liberty interest to seek assistance from a physician in ending one’s life, no state courts—save one in Montana—have found a right to physician-assisted suicide within their state constitutions. Similarly, no state legislatures, other than in Oregon and Washington, have legalized this type of action in the post-*Glucksberg* era.

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. 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.

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.*


318 WASH. REV. CODE ANN. ch. 70.245 (West 2009).

319 Kamisar, supra note 312, at 1467.


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,” extends to the very time and manner of one’s death, this fundamental right, arguably, should not be limited to the terminally ill and the “seriously ill or impaired who are suffering or in pain.” 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, but also those who are “seriously ill or impaired . . . enduring pain or suffering.”

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 months or six months. Three particular scenarios have been posited as being dangerous because of the “open-ended” or limitless nature of present evaluations of terminal illness: (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.

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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 Tammso 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).
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.\textsuperscript{333}

\footnotesize{\textsuperscript{333} See Adrienne M. Martin, \textit{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* and *Eisenstadt v. Baird* 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. In *Lawrence*, the Court determined that sexual intimacy among same-sex couples was a freedom not limited by any spatial bounds. 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.” Moreover, the Court recognized that people are entitled to “dignity as free persons.” Over time, it may even be possible that decisions post-*Lawrence* may find a fundamental right to physician-assisted suicide within the Constitution. For the “foreseeable future,” however, the *Glucksberg* rule remains.

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.” Linked with this right of self-determination is the equally important right to beneficent treatment that advances the best interests of the distressed. These two rights are fundamental to any and all decisions regarding health care treatment. 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-

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334 381 U.S. 479 (1965).
335 405 U.S. 438 (1972).
337 *Id.*
338 *Id.* at 564–65.
339 *Id.*
341 *Id.*
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.\textsuperscript{345}

\textbf{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.\textsuperscript{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.\textsuperscript{347}

\textbf{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.\textsuperscript{348} “Caring indubitably incorporates empathy,”\textsuperscript{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.\textsuperscript{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.\textsuperscript{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

\textsuperscript{346} Furrow \textit{et al.}, supra note 225, at 43.
\textsuperscript{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_painActs.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).
\textsuperscript{349} Id.
\textsuperscript{350} Id. at 225.
\textsuperscript{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." Because of this situation, patient avoidance, even when unintentional, only serves to heighten patient fears of impending death.

Because of these concerns and inadequacies among physicians, issues of existential care are more often than not left to the nursing staff. 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.

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-malfeasance, and distributive justice. 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. 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. Acknowledging such a right then becomes an act of “responsible benevolence” and is seen properly as complementing the duty to undertake

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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 Houtpen & David Hendrikx, 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. The duty to relieve pain is acknowledged as the “least disputed and most universal of the moral obligations of the physician.” 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, and demands that efforts not only refrain from causing pain or suffering, but also work to relieve it.

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. Consequently, there “has been a deformation of both the private ethic care and the very public ethic of legal justice.” 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.” 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.” Indeed, care or compassion must be recognized as a universal moral principle that is vital to the very fabric of social justice.

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


375 See id.


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.


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
issues arise that test the validity of a principle’s application within the context of a given situation or norm of conduct.\textsuperscript{390} Scholars assert that “the morally good person is not just principled, but also compassionate.”\textsuperscript{391} The “morally good person” exhibits both “practical wisdom”\textsuperscript{392} and “simple common sense”\textsuperscript{393} in preserving a patient’s dignity or quality of life throughout all palliative care treatments.\textsuperscript{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.\textsuperscript{395} Accordingly, physicians should perform a risk calculus that weighs the benefits and burdens to assess the utility of various medical treatments.\textsuperscript{396} In all cases, the doctrine of medical futility should anchor these evaluations by acknowledging the practical limits of medical treatment.\textsuperscript{397}

While compassion is experienced and evaluated subjectively,\textsuperscript{398} it need not stigmatize a valid legal theory.\textsuperscript{399} In DeShaney \textit{v.} Winnebago County \textit{Dept. of Social Services},\textsuperscript{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.”\textsuperscript{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.”\textsuperscript{402}

Eschewing emotion as a dominant vector of force when seeking the truth in law,\textsuperscript{403} Justice Holmes urged that the reasoning behind a particular rule’s adoption “ought to be of paramount importance.”\textsuperscript{404} And,  

\textsuperscript{390} Randall & Downie, supra note 125, at 12–13.  
\textsuperscript{391} Id. at 13.  
\textsuperscript{392} Id. at 24.  
\textsuperscript{393} Id. at 73.  
\textsuperscript{394} Annette F. Street & David W. Kисsane, \textit{Constructions of Dignity in End-of-Life Care}, 17 J. Palliative Care 93, 95, 99 (2001); Randall & Downie, supra note 125, at 71.  
\textsuperscript{395} Randall & Downie, supra note 125.  
\textsuperscript{396} Id. at 116–18.  
\textsuperscript{397} Id.  
\textsuperscript{398} Zipursky, supra note 388, at 1142.  
\textsuperscript{399} Id. at 1147. See Lois L. Shepherd, \textit{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, \textit{Face to Face}].  
\textsuperscript{400} DeShaney \textit{v.} Winnebago County \textit{Dept. of Social Servs.}, 489 U.S. 189 (1988).  
\textsuperscript{401} 489 U.S. at 213 (Blackmun, J. dissenting).  
\textsuperscript{402} Id. at 213.  
\textsuperscript{404} Oliver Wendell Holmes, Jr., \textit{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.”

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. Therefore, a right not to suffer and a professional medical responsibility to validate this right must be acknowledged.

D. A Contemporary Model in Legal Decision-Making

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

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. 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.” 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.


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 See id. at 1030.


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. By adhering to legal formalism, moral judgments are avoided altogether. 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. If formalism is rejected, however, judicial deference can be given to “tradition and convention” as an imperfect means for discerning moral convictions or discovering shared ones.

The best model of judicial decision-making achieves a balance between logical reasoning and “critical morality.” As such, the courts must endeavor to apply a situation ethic rather than an unyielding and rigid normative standard, 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. 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.”

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.


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 Decision Making 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.\textsuperscript{424} The best patient care adjusts to a patient’s changing medical condition.\textsuperscript{425} Palliative care provides adjusted care by endeavoring to relieve physical and psychological end-stage suffering.\textsuperscript{426} If this is recognized as a right to relief from suffering,\textsuperscript{427} as the European Federation for Pain Study advocates,\textsuperscript{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.”\textsuperscript{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.\textsuperscript{430}

Efforts to both accept and adopt a protocol for specifically determining medical futility\textsuperscript{431} will be enhanced and legitimized by a wider adoption of the Uniform Health Care Decisions Act.\textsuperscript{432} The American Academy of Palliative Medicine has worked to develop standards for regulating nutrition and hydration in palliative management.\textsuperscript{433} The American Medical Association has also offered guidance on when, clinically and ethically, it is proper to sedate to unconsciousness.\textsuperscript{434} These policies are having a salutary effect on both codifying and normalizing proper medical care and procedures in end-of-life care. Rousseau,\textsuperscript{435} Morita,\textsuperscript{436} and Quill\textsuperscript{437} 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-

\begin{thebibliography}{99}
\bibitem{425} President’s Council on Bioethics, \textit{supra} note 81, at 217; see also Pellegrino & Thomasma, \textit{supra} note 81; Thomasma, \textit{Human Life in the Balance}, \textit{supra} note 81; Thomasma & Graber, \textit{supra} notes 58.
\bibitem{426} See \textit{supra} notes 17–23.
\bibitem{427} Thomasma & Graber, \textit{supra} note 58, at 192.
\bibitem{428} See \textit{supra} notes 72–80; see also Report of the Council on Ethical and Judicial Affairs, \textit{supra} notes 203–14.
\bibitem{429} Pellegrino, \textit{Decision at The End of Life}, \textit{supra} note 147.
\bibitem{430} See \textit{supra} notes 189–200 and accompanying text.
\bibitem{431} See, e.g., \textit{supra} notes 151–63.
\bibitem{432} See, e.g., \textit{supra} notes 169–74.
\bibitem{433} See, e.g., \textit{supra} notes 297–303.
\bibitem{434} See, e.g., \textit{supra} notes 203–11.
\bibitem{435} See, e.g., \textit{supra} notes 189–94.
\bibitem{436} See, e.g., \textit{supra} notes 101, 114, 200.
\bibitem{437} See, e.g., \textit{supra} notes 52, 194, 248.
\end{thebibliography}
stage care, these actions educate the public on the parameters of appropriate medical care and humane treatment for the terminally ill.\footnote{38}

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?\footnote{39} 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 practice\footnote{40} and endeavoring to make a ‘value-consequent choice’ consistent with the patient’s values\footnote{41} and best interests.\footnote{42} Ultimately, reasonableness\footnote{43} and compassion\footnote{44} 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 analysis\footnote{45} which, in turn, are shaped by the “accepted standards of medical practice” applicable to each medical case presented.\footnote{46}

The doctrine of medical futility must bring into focus the popular notion within American society that there is a prescription available for every circumstance.\footnote{47} 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-

\footnote{38 See, e.g., supra notes 310–311; see Mitchell et al., supra note 121.}
\footnote{39 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.}
\footnote{40 Smith, supra note 248, at 109.}
\footnote{41 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.}
\footnote{42 Smith, supra note 89, at 109.}
\footnote{43 Smith, supra note 89, at 180.}
\footnote{44 See Pellegrino & Thomasma, supra note 81; supra notes 12, 388, 414–23.}
\footnote{45 See Barry R. Schaller, Understanding Bioethics and the Law 4 (2008) (using the term “ethinics” 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).}
\footnote{46 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).}
\footnote{47 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. 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 death or, alternatively, the “least worst death.”

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. This right of refusal is not a right to hasten death, but merely a right to resist unwanted physical invasions.

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

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).

\[\text{See Quill, supra note 379, at 51.}\]

\[\text{Margaret P. Battin, The Least Worst Death: Essays in Bioethics on the End of Life (1994); see generally Ira Byock, Dying Well: Peace and Possibilities at the End of Life (1997) (collecting testimonials and anecdotes about terminally ill patients finding love and reconciliation during the end-stage of life).}\]

\[\text{See Meisel, supra note 328; Annas, supra note 48, at 1102.}\]

\[\text{See Comm. on Care at the End of Life, 1997 Supplement, supra note 312, at 5.}\]
In 1990, Congress enacted the Patient Self-Determination Act, a bold step toward strengthening patient autonomy and the national validation of the right to refuse treatment. 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.

When the Uniform Health Care Decisions Act is considered, together with the successful efforts of some states to enact pain relief statutes, such as Oregon and Washington, and medical protocols for use of palliative care and terminal sedation, 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. 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 futility since this is fundamentally a clinical judgment, not an encompassing moral evaluation or principle on the “worthlessness” of a life.

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455 Id.
456 See supra notes 169–173 and accompanying text.
457 See supra note 547.
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*, charity, compassion, love, or mercy, 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.” 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. When physicians attempt to treat futile medical conditions, such actions are a total abnegation of one of the cardinal principles of medical ethics—beneficence.

It has been argued persuasively that while the state may declare a legitimate interest in morality, it cannot easily sacrifice “claims of associational autonomy” found in “expressive [or] intimate association” 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.”

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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).
473 Id. at 1936.
474 Id.
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. In Society’s central obligation is not to mandate one moral code over another but rather, to define and safeguard “the liberty of all” and promote social policies which address suffering with charity, compassion, and common sense. Inextricable to this societal obligation is recognition of a coordinate duty of health care providers “not to prolong dying.” This duty arguably coalesces with, and validates, the very principle of beneficence 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.

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.

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

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 Oregon and Washington and in parts of Europe, notably, the Netherlands, Belgium, and Switzerland. 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. 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 nonsomatic pain and suffering. Individuals must have the right to be free from the cruel and unusual punishment of being forced to live on despite futile medical conditions.

The slippery slope is, in reality, nothing more than the inescapable human condition. 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.” No safe plateau of moral security can ever be reached in this journey of life. Rather, painful dilemmas of choice are the rule rather than the exception. Perhaps, in

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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.
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).
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.