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

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George P. Smith, II*

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

“. . . adequate relief from severe and continuing pain is 
unusual in the modern hospital.” Eric Cassell

“It hath often been said that it is not death, but dying 
which is terrible.” Henry Fielding

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was affiliated as a Visiting Fellow at The Centre for The Study of Religion and Politics, 
University of St. Andrews, Scotland, and subsequently as a Visiting Scholar at The Institute of 
Society, Ethics and The Life Sciences at The Hastings Center, the George Washington University 
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(2d ed. 2004).

3 HENRY FIELDING, AMELIA, bk iii, vol. 4 (1751).
Abstract

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, psycho-social, and spiritual states or conditions are central to managing pain which induces suffering. At the end-stage of life, an inextricable component of an 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 efficacious palliative treatment and as a reasonable medical procedure in order to safeguard a “right” to a dignified death.

Once a human right to avoid refractory pain of whatever nature in end-stage illness is established by the state, a co-ordinate 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.

Rather than continuing 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 to safeguard public morality by restricting intimate associational freedoms to accelerate death in a terminal illness, are suspicious if indeed, not invalid. No individual should be forced to live when, in a futile medical condition, he or she is suffering from intractable somatic and/or non somatic pain.
I.

INTRODUCTION AND OVERVIEW

Total Pain Management and Hospice Care

Long before Soren Kierkegaard first tackled the issue of existential pain, the concept and reality of such a dimension or level of pain at death was perhaps first recorded in the Bible when Jesus, in contemplating his own death, stated, “I am deeply grieved, even to death.” No doubt, Edvard Munch’s artistic depiction of “The Scream” may well be taken as the most profound artistic 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—this, because pain “resists verbal objectification” as there is no language for it.

\[4 \text{ SOREN KIERKEGAARD, FEAR AND TREMBLING (1843), THE SICKNESS UNTO DEATH (1849).}\]

\[5 \text{ See ELAINE SCARRY, THE BODY IN PAIN 12 (1985).}\]

\[6 \text{ MARK 14:34.}\]

And, Luke records Jesus, prior to his crucifixion, expressing his anxiety and distress of what he knows is to be his future, when he asks, “Father, if thou be willing, remove this cup from me; nevertheless, not my will, but thine be done.” LUKE 22:42.


\[8 \text{ SCARRY, supra note 5 at 12.}\]

\[9 \text{ REINHOLD HELLER, THE SCREAM (1973).}\]
Without question, pain plays havoc with the human psyche and induces suffering which, having no meaning, can destroy.\textsuperscript{10} Indeed, denying “suffering is to trivialize another person’s experience, to diminish its scope and lessen its significance.”\textsuperscript{11} Once it can be shown that there is a right to compassionate care—as this Article advocates—accepting and validating this new right would, perforce, trigger a co-ordinating duty to make judgments relative to quality of life in order to assess the extent of one’s suffering. In a very real way, then, a right of compassionate care would embrace and incorporate this collateral duty to prevent suffering.\textsuperscript{12}

Central to the 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. \textit{Id.}

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 58 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 (19\textsuperscript{th} ed. 2001). Psychogenic pain is used to describe mental—as opposed to pain of an organic nature. \textit{Id.} 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, \textit{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, \textit{The Nature of Suffering and The Goals of Medicine}, 306 NEW ENG. J. MED. 639 (Mar. 18, 1982).


\textsuperscript{11} Gunderman, \textit{id.}

\textsuperscript{12} Lois L. Shepherd, \textit{Sophie’s Choice: Medical and Legal Responses to Suffering}, 72 NOTRE
enforcement of a right to compassionate care for terminal illness at the end-stage of life, them, is
acceptance of an ethic of care which requires a “provision for competent care”\textsuperscript{13} which is
adjusted to on-going medical needs as a patient’s illness progresses and which, thereby, meets the
fundamental goal of medicine which is to relieve suffering.\textsuperscript{14}

Although existential pain has been defined as suffering “with no clear connections to
physical pain,” it has also been recognized as suffering which can in fact be expressed as
physical pain.\textsuperscript{15} It is seen further as a significant clinical factor which may either reinforce
existing physical pain or be the root cause of physical pain.\textsuperscript{16}

From the very beginnings of the hospice movement in the United Kingdom led by Dame
Cicely Saunders in 1967,\textsuperscript{17} “total pain” management of physical, psycho-social and spiritual
suffering was then—and is today—the goal of hospice care.\textsuperscript{18} Palliating the whole person and
offering compassionate care\textsuperscript{19} is central to hospice care.\textsuperscript{20} Viewed as such, palliative care

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\textsuperscript{13} Id. at 138.
\textsuperscript{14} CASSELL, \textit{supra} note 2 at 291.
\textsuperscript{15} P. Strang, S. Strand \textit{et al.}, \textit{Existential Pain—an Entity, or Provocation, or a Challenge?}, 27 J.

In addition to Kierkegaard, Jaspers, Sartre and Heidegger are recognized as the major
philosophers leading the philosophical movement of existentialism. \textit{See generally} MARTIN
\textsuperscript{16} Strang \textit{et al.}, \textit{id}.
\textsuperscript{17} Cicely Saunders, \textit{Hospice}, 1 MORTALITY 317 (1996).
\textsuperscript{18} Id. at 320.
\textsuperscript{19} \textit{See} HOSPICE: THE LIVING IDEA, (Cicely Saunders, Dorothy H. Summers & Neville
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.\(^\text{21}\) In this regard, hospice care is an effort to counter balance this irrational and inhumane compulsiveness and thereby “humanize medicine.”\(^\text{22}\)

Palliative care is care which does not effect a cure and is defined by the World Health Organization as that care which “improves the quality of life for patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psycho-social support from diagnosis to the end of life and bereavement.”\(^\text{23}\) Palliating the whole person, then, requires medicine to attend more fully to the phenomenon of existential pain. For this to be efficacious, regular re-assessments of patient treatment goals must be undertaken. From these communications, the health care decision makers will not only learn directly from their patient how they define and experience suffering but their 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

\(^\text{20}\) Id.

\(^\text{21}\) HOSPICE CARE ON THE INTERNATIONAL SCENE at 11 (Ciceley Saunders & Robert Kastenbaum eds. (1997)).

\(^\text{22}\) Id. at 7; supra note 19.


See also Jan Stjernsward, ch. 2, The International Hospice Movement from The Perspective of The World Health Organization in HOSPICE CARE ON THE INTERNATIONAL SCENE (Ciceley Saunders & Robert Kastenbaum eds. 1997).
Medical Futility and Terminal Sedation

It has been argued that death should never be sought or engineered as a “therapeutic option” to end suffering. Yet, when the prolongation of life-sustaining treatments impose undue burdens or serve as futile roadblocks to one in the medically validated end-stage of life, thereby preventing as “comfortable” a death as possible, palliative care—it is asserted in this Article—should include an unencumbered option of respite or, what is also termed, terminal sedation as a compassionate response to such situations. Accordingly, fulfilling the 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 reasonable steps to relieve unremitting pain and suffering.5


26 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/or emotional suffering from terminal illness with abbreviated life expectancy and unable to either conceptualize or, for that matter, demand assistance in ending life).

discomfort.\textsuperscript{28}

The thesis of this Article is that law and medicine must agree on set standards or protocols which allow for—without professional censure or legal retribution—the use of terminal sedation as an efficacious and compassionate practice for end-stage treatment of patients.

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

\begin{thebibliography}{99}
\bibitem{28} See infra notes 188–99.
\bibitem{29} Norman L. Cantor & George C. Thomas, III, \textit{The Legal Bounds of Physician Conduct Hastening Death} 48 BUFF. L. REV. 83, 139 (2000).
\bibitem{32} Victor Cellarius, \textit{Terminal Sedation and The Imminence Condition}, 34 J. MED. ETHICS 69 (2008).
\bibitem{33} Joseph M. Boyle, Jr., \textit{Toward Understanding The Principle of Double Effect}, 90 ETHICS 527
\end{thebibliography}
Troublesome as the doctrine of double effect is as a construct for discerning physician intent, notably, 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. What is submitted in this Article is that rather than being mired, compulsively, in efforts to discern and validate positive subjective intentions for use of terminal sedation by a physician, a decision is made which—based on sound and accepted medical judgment—weighs directly the costs versus the benefits of treatments in this manner.

Common Sense and Compassion

Wider acceptance and use of terminal sedation as a valid method of palliative treatment presents an important opportunity for a fuller understanding of the issues of managing death and an equal opportunity for viewing this medical procedure as a compromise to the equally vexatious issue of physician-assisted suicide. Taxonomical confusion abounds when issues of

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34 See infra note 202 and accompanying text.

35 See infra notes 52–3 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 of Medicare monies expended go to patients in their last two years. Evan Thomas, The Case for Killing Granny: Re-thinking End-of-Life Care, NEWSWEEK, Sept. 21, 2009, at 34, 39.


See generally George P. Smith, II, Terminal Sedation as Palliative Care: Revalidating a Right to a Good Death, 7 CAMBRIDGE Q. HEALTHCARE ETHICS 382 (1998).
self-determination are presented in end-stage illness. As well, there is an often tragic absence of explicit policies which enunciate clearly the extent to which care may be provided to the terminally ill.

The voluntary cessation of nutrition and hydration and the use of terminal sedation are acknowledged as legal and accepted widely in hospice care management. Because of an absence of clear protocols on its administration as well as moral objections to its use and legal concerns of the consequences of ordering its use, terminal sedation is not readily available.


Indeed, the terms “palliative sedation,” “continuous deep sedation,” and “primary deep continuous sedation,” are all used interchangeably, with terminal sedation and are seen as euphemisms which mask the reality of finality which is inherent when terminal sedation is administered. “Death over days” is seen as feeling “more natural” than physician assisted suicide. Margaret P. Battin, *Terminal Sedation: Pulling the Sheet Over Our Eyes*, 38 HASTINGS CENTER RPT. 27, 28 (2008).


In 2008, the Council on Ethical and Judicial Affairs of the American Medical Association issued a report entitled, “Sedation to Unconsciousness in End-of-Life Cases,” which was hoped would bring clarity to this area of concern. CEJA Report 5-A-08. Many of the Council’s conclusions have been termed “naive.” See Battin, *supra* note at 37.

For a more complete analysis of the Council’s Report, see *infra* notes 202–13 and accompanying text.

39 Quill *et al.*, *id.* at 2103.

40 *Id.*
Although illegal in all states but Oregon,\(^{41}\) and Washington,\(^{42}\) physician assisted suicide is difficult to prosecute successfully when requested by a competent and informed patient.\(^{43}\)

Voluntary euthanasia is also illegal and, if uncovered, likely to be prosecuted.\(^{44}\) Because of this

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

\(^{41}\) ORE. REV. STAT. ANN. §127.800 et seq. (2003).

\(^{42}\) REV. CODE WASH. ANN. Ch. 70,245 (2009).

The Supreme Court of Montana ruled on December 31, 2009, that—under the Rights of The Terminally Ill Act (MT. 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 infra* note 315, Baxter v. Montana, DA 09–0051, 2009 MT. 449.

\(^{43}\) Quill *et al.*, *supra* note 38 at 2103; REV. CODE WASH. ANN. Ch. 70,245 (2009).


\(^{44}\) 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. STANFORD ENCYCLOPEDIA OF PHILOSOPHY. *See* http://plato.stanford.edu/entries/euthanasia-voluntary/.
legal situation, a vast underground flourishes which assists not only in the practice of physician assisted suicide but voluntary euthanasia.\footnote{Id.}

Although physician assisted death is not to be considered a substantive liberty interest and a fundamental right,\footnote{Washington v. Glucksberg, 521 U.S. 702, 710 (1997).} nor is palliative care seen as a “right” incorporated into a lofty constitutional principle,\footnote{McStay, \textit{supra} note 36 at 60.} it is argued here that both actions coalesce into actuating a right to be free from intolerable and unmanageable pain and suffering—a right which the U.S. Supreme Court has said exists\footnote{McStay, \textit{supra} note 36 at 49.} and is grounded in the essential right to refuse life-sustaining treatment.\footnote{Cruzan v. Dir., Missouri Dept. of Health, 497 U.S. 261 at 286–87.}

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

\footnote{See generally ROGER S. MAGNUSSON, ANGELS OF DEATH: EXPLAINING THE EUTHANASIA UNDERGROUND (2002).}

\footnote{But see Robert A. Burt, \textit{The Supreme Court Speaks—Not Assisted Suicide but a Constitutional Right to Palliative Care}, 337 NEW ENG. J. MED. 1234 (1997).}

\footnote{See Vacco v. Quill, 521 U.S. 793 (1997); George P. Smith, II, \textit{Monograph, Final Exits: Safeguarding Self-Determination and The Right to be Free from Cruel and Unusual Punishment} (1997); George J. Annas, \textit{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).}

\footnote{See also McStay, \textit{supra} note 36 at 49.}
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, 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 follow despite efforts to palliate a patient’s medical condition, although “imperfect,” terminal sedation and the voluntary refusal of nutrition and hydration 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 hospice care patients who suffer severe pain during the last week of life which is set in a range from 5%—35% (with 25% experiencing unbearable shortness of breath), the 90% statistical success is unimpressive. Indeed, previous scholarship reported significant pain, among end-stage patients, to be as high as 50%.

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51 See JOANNE LYNN SICK TO DEATH—AND NOT GOING TO TAKE IT ANYMORE! 12 (2004).

52 Timothy E. Quill & Ira R. Byock, Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids, 132 ANNALS INTERN. MED. 408, 413 (Mar. 7, 2000).


54 Quill & Byock, supra note 52.

55 See Quill, Lo & Brock, supra note 38 at n’s 1, 5, 7.

See also Editorial, Attending to Psychological Symptom and Palliative Care, 20 J. CLINICAL
Rather than investigating, the linguistic, moral, and philosophical ambiguities as well as the awkward consequences inherent with the voluntary cessation of nutrition and hydration, terminal sedation, physician-assisted suicides and voluntary active euthanasia,\(^\text{56}\) 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. In turn, this policy is rooted in the biomedical principle of beneficence\(^\text{57}\) which is tied to the notion that there is a human right to compassionate care in end-of-life illness\(^\text{58}\)—with suffering being seen, properly, to include physical and psychological distress.\(^\text{59}\) 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 are in the best medical interests of the patients to relieve end-stage physical and/or mental suffering.

ONCOLOGY 624 (Feb. 2001) (concluding more than one-third of dying patients are depressed).

\(^{56}\) See Quill, Lo & Brock, \textit{supra} note 38; McStay, \textit{supra} note 36.

\textit{See also} Lynn A. Jansen & Daniel P. Sulmasy, \textit{Sedation, Alimentation, Hydration, and Equivocation: Careful Conversation about Care at the End of Life}, 136 \textit{ANNALS INTERN. MED.} 845 (2002).


\textit{See also} John Fletcher, \textit{Love is The Only Measure}, 83 \textit{COMMONWEALTH} 427 (1966); JOHN FLETCHER; \textit{SITUATION ETHICS: THE NEW MORALITY} (1966), \textit{infra} note 384.

\(^{58}\) \textsc{David C. Thomasma} & \textsc{Glenn C. Graber}, \textit{Euthanasia: Toward an Ethical Social Policy} 192 \textit{passim} (1991).

\(^{59}\) McStay, \textit{supra} note 36 at 46.

Stated otherwise, the overarching strategic issue and—indeed—the conclusion to be reached is 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.

**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 complex spectrum of pain and suffering associated with end-stage illness, palliative care will then have a broadened focus or sphere of application and not be shackled rigidly to being shaped or controlled unnecessarily by the principle of double effect. Rather than question the integrity of terminal sedation, its wider acceptance is compatible with the principle of adjusted care for all medical treatment and, as well, both a reasoned and compassionate response to managing medically futile cases.\(^{60}\)

\(^{60}\) 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 Sidney Wanzer, Daniel Federman *et al.*, *The Physician’s Responsibility Toward Hopelessly Ill Patients: A Second Look*, 320 NEW ENG. J. MED. 844 (Mar. 30, 1989); Sapir, *infra* note 312.

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 & Graeber, *id.* at 129. In a very real way, this standard of care complements the Principle of Double Effect. See Cellarius, *supra* note 32; Boyle, *supra* note 33; Quill *et al.*, *supra* note 38 at 2101 *passim* and *supra* notes 221–26.

\(^{61}\) Smith, *supra* note 50.

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Once terminal sedation is accepted and used more widely as a valid medical procedure within the sounds tenets of palliative care and made, accordingly, more readily available to alleviate psychological distress in end-stage illness, the next step is broadening the clinical outreach of terminal sedation is to evaluate the validity for use in cases of non-terminal psychiatric illness. 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 which might well shape the course of policy debate as it must eventually be shaped in order to resolve this issue. Indeed, the proper laws for structuring normative standards must continue to be explored, then debated, and subsequently refined over the succeeding years.

**European Approaches to Psychogenic Pain**

Interestingly, Belgium, the Netherlands, and—more recently—Switzerland have


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.

63 GRIFFITHS et al., *id.*, at 51 passim, 275 passim.


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

Any policy which might well emerge from analysis of a right of 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 level since chronic mental illness is simply viewed today as totally different from a medical condition diagnosed as futile which results in death.

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65 Id.


67 Id.

68 Appel, supra note 64.
Two other concerns are uppermost in any re-evaluation of the feasibility of redefining the use and limits of palliative care for non-terminal psychological distress: the likelihood of cure from the mental illness and the competence of a mentally imbalanced patient to make a rational decision to seek humane assistance in hastening death. While agreements on time frames of affliction for the full range of mental illnesses might be helpful in shaping contemporary clinical epidemiologies for use in determining non-terminal psychiatric illness that would qualify for terminal assistance, it remains arguable whether a patient diagnosed with a serious mental illness or, for example, having intermittent psychotic episodes, 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 incarceration for life where there is no palliative care.

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.” The bulwark of

69 Id.

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. 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.
valid normative action must be seen as being anchored to the principle of compassion.

II.

THE PARAMETERS OF PAIN

Led by the World Health Organization, 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.\textsuperscript{72} This event marked an intensified effort to establish the relief of pain as a basic, fundamental human right and the recognition of chronic pain as a trans-national healthcare issue.\textsuperscript{73}

Recognizing that the physical and psychosocial etiology of chronic pain sufferers manifests itself by, among other conditions, depression, anxiety, fear, and even suicide,\textsuperscript{74} these

\textit{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. \textit{See SMITH, infra} note 440 at ch. 5.

\textit{See AP Leader of Assisted Suicide Group Defends Work in Interview,} THE D.C. EXAMINER, Mar. 18, 2009, at 18 (where the former President of the Final Exist Network—charged with violating Georgia’s assisted suicide law—argues those 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).


\textsuperscript{73} \textit{Id.}

\textsuperscript{74} \textit{Id.} at 86.
three organizations defined pain recurring for a period of more than three months as chronic.\textsuperscript{75} Not only do studies also disclose the significant employment irregularities resulting from chronic pain sufferers\textsuperscript{76} but surveys of households in Europe and the United States, it revealed 36\% of Europeans may be classified as chronic pain sufferers; and in America, 43\% of all households had members in chronic pain.\textsuperscript{77} That percentage for Americans translated into a raw figure of eight million. By 2030, it is expected this figure will double.\textsuperscript{78}

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

The WHO has developed a three-step “ladder” for cancer pain relief. In summary, it states:

If pain occurs, there should be prompt oral administration of drugs in the following order: nonopioids (aspirin and paracetamol);

\textsuperscript{75} Id. at 88.

\textsuperscript{76} Id. at 89.

\textsuperscript{77} Id. at 88.

\textsuperscript{78} 33 HASTINGS CENTER RPT., Special Supplement, Access to Hospice Care: Expanding Boundaries, Overcoming Boundaries, Mar./April 2003 at S 50.

\textsuperscript{79} Id.

It is estimated that in order to support Medicare and Medicaid program costs, payroll taxes must meet four percent. Id.
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 must, obviously, be adjusted continually as patient’s case history progresses. And, furthermore, it is care anchored in mercy, compassion, beneficence, or loving charity and 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, is usually difficult to assess not only because it


81 President’s Council on Bioethics, TAKING CARE: ETHICAL CARE GIVING IN OUR AGING SOCIETY 217 (2005).

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 EDMUND D. PELLEGRINO & DAVID C. THOMASMA, FOR THE PATIENT’S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE chs. 2, 5 (1988); Cassell, supra note 9.

See also THOMASMA & GRAEBER supra note 60 for a discussion of the principle of adjusted care.

82 THOMASMA & GRABER, supra note 58 at 129.

83 Id. at 192, 194 (quoting Dr. Edmund D. Pellegrino).
involves a substantial investment of physician time to determine or validate, but requires special training and contact with the families of patients.\textsuperscript{84} There is a general aversion to proving a patient’s emotional distress at end-of-life care.\textsuperscript{85} Distinguishing between depression and psychologic morbidity is difficult as well because the sympathology of disrupted sleeping patterns, loss of energy and of appetite are response mechanisms to cancer and to other terminal illness and not just clear symptoms of deep psychological distress.\textsuperscript{86} Because of these difficulties and uncertainties, the palliative management of existential pain has simply been 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 among health care providers, patients, affected families and proxy or surrogate decisionmakers. Valid existential concerns are, oftentimes, obscured and not brought into clear focus during palliative care treatment.\textsuperscript{88} Even though a patient may have no absolute control

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

\textsuperscript{85} Id.

\textit{See generally} Paul Arnstein, Margaret Cahill, Carol Lynn Mandle \textit{et al.}, Self Efficacy as a Mediator of The Relationship between Pain Intensity, Disability and Depression in Chronic Pain Patients, 80 PAIN 483 (1999).

\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, \textit{infra} note 327, \textit{Excellent Palliative Care as The Standard, Physician Assisted Dying as a Last Resort}, at 323 in PHYSICIAN-ASSISTED DYING; (Timothy E. Quill & Margaret P. Battin eds. 2004); Agrawal & Emmanuel, \textit{supra} note 84.

\textsuperscript{87} Agrawal & Emmanuel, \textit{supra} note 84.

\end{footnotesize}
over the wide and varied spectra of suffering, there is still freedom for a patient to choose what attitude is taken toward that suffering. 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—a more compleat, compassionate, and realistic approach to managing terminal illness and end-stage suffering would be implemented.

**Assessing Existential Suffering**

Interest in hastened death arises because a number of conditions exist: inadequate pain management, psychological conditions ranging from depression and hopelessness to fears of loss of control, autonomy, and physical functioning, to futile and unbearable suffering, as well as avoidance of humiliation. All of these conditions conduce to one over-riding fear: loss of human dignity, which brings with it a fear of being forced to become but a “passive bystander”

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See also DAVID H. SMITH, infra note 440 at ch. 5.

90 Saunders, *supra* note 17 at 320; SAUNDERS *et al.*, *supra* note 19.

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

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


94 HUMPHRY *supra* note 53 at 135–36.
to all of the normal functions of life.\textsuperscript{95} By acting to manage the dying process, which—for some—is viewed as too protracted and filled with growing and multiple functional losses,\textsuperscript{96} a level of control is thereby exerted over a process which is acknowledged to be “by and large, a messy business.”\textsuperscript{97} And, sadly, this complicated and vexatious process for implementing the “new epidemiology of dying”\textsuperscript{98} almost assures that heroic procedures will be followed which do not promote or sustain quality so much as postpone death.\textsuperscript{99}

In approximately twenty-five percent of all terminally ill patients, depression and other mood disorders occur.\textsuperscript{100} Yet, interestingly, few receive pharmacological aid by anti-depressant prescriptions.\textsuperscript{101} As seen, the main obstacle to a more liberal response to these patients’ needs is

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\textsuperscript{95} Richard B. Gunderman, \textit{Is Suffering the Enemy?}, 32 HASTINGS CENTER RPT. 40, 42 (Mar.-April 2002).

\textsuperscript{96} Stacks, \textit{supra} note 24 at 216.

\textsuperscript{97} SHERWIN B. NULAND, \textit{HOW WE DIE: REFLECTIONS ON LIFE’S FINAL CHAPTER} 142 (1994).

\textsuperscript{98} \textit{Id.} at 12.

\textsuperscript{99} LYNN, \textit{supra} note 26 at 164–65.

\textsuperscript{100} Karel E. Miller, Stephen M. Adams & Martha M. Miller, \textit{Anti depressant Medication Use in Palliative Care}, 23 AM. J. HOSPICE & PALLIATIVE MED. 127 (No. 2, Mar.-April 2006).

\textsuperscript{101} \textit{Id.}
\end{footnotesize}
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the lack of clarity in determining where a distressed, terminal patient is suffering from clinical depression or, is, instead, exhibiting a “normal grief response” to the dying process. The components of both of these syndromes is often vague, imprecise and quite difficult to evaluate. Commonly, when patients are obsessed with feelings of worthlessness, lose their ability and desire to interact socially, and—indeed—lose their sense of hope, they are properly assessed as suffering from clinical depression and should be given whatever drug dosage deemed necessary to alleviate that condition—this, because pharmacotherapy is ultimately the principal tool for symptom control.

Another drawback to accurate and prompt evaluations of psychological distress or existential suffering is, as observed, often the inability of a physician or palliative care management team to understand patient views about suffering. As a spiritual phenomena, suffering is often accepted as a meaningful and authentic community response to Christ’s own suffering. In some faith communities, cultural efforts are expended in order to view

102 Miller, et al., supra note 100.
103 Id.
104 Id. at 128.
105 Lipman, supra note 7 at 2.

See also SHAPO, supra note 9 (discussion of the legal position in assessing pain and suffering).

See generally CASSELL, supra note 2; STANLEY HAUERWAS, GOD, MEDICINE AND SUFFERING, chs. II, III (1990).
suffering—physically and mentally—as a positive, re-enforcing value. Yet, merely because there is an acceptance of suffering as being authentic does not mean that suffering is, thus, 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.” In this way, the therapy is truly patient centered.

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

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107 Van Hooft, id. at 14.

108 Id. at 15.

109 Seth M. Holmes, Michael W. Rabow, Suzzane L. Dibble, Screening the Soul: Communication regarding Spiritual Concerns Among Primary Care Physicians and Seriously Ill Patients Approaching the End of Life, 23 AM. J. HOSPICE & PALLIATIVE MED. 25, 30 (2006).


111 Holmes et al., supra note 109.


uncontrollable shakes).\textsuperscript{113}

Palliative sedation therapy is, thus, defined as “the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness.”\textsuperscript{114} 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{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 from which profound hopelessness and desire to die may result,”\textsuperscript{117} this syndrome, if not supported satisfactorily by pharmacological

\begin{itemize}
\item \textsuperscript{113} Bernard Lo & Gordon Rubenfeld, \textit{Palliative Sedation in Dying Patients: ‘We Turn to it When Everything Else Hasn’t Worked’}, 294 JAMA 1810, 1811 (Oct. 12, 2005).
\item \textsuperscript{115} Rousseau, \textit{supra} note 112; P.C. Rousseau, \textit{Dying and Terminal Sedation}, 7 CLIN. GERIATRICS 19 (1999).
\item \textsuperscript{116} David W. Kissane, \textit{The Contribution of Demoralization to End of Life Decisionmaking}, 34 HASTINGS CENTER RPT. 21, 24 (July-Aug., 2004).
\item \textsuperscript{117} \textit{Id.} at 23.
\end{itemize}
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 making a competent decision to disapprove the initiation or cessation of medical treatment.\textsuperscript{119} Sadly, this “depression argument” would appear to be but a ruse to both obstruct and even prevent end-of-life decision making on grounds of moral repugnancy to alternative or surrogate health care providers.\textsuperscript{120}

If and when the demoralization syndrome is accepted as a cognitive disorder, it would then remain for physicians to respond with compassion and with humaneness in remediating this medical condition. Accordingly, if deemed proper, medically, 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 dignity and safeguard the best interests of the dying.\textsuperscript{121}

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.

\textsuperscript{118} \textit{Id.} at 29.

\textsuperscript{119} RONALD A. LINDSAY, FUTURE BIOETHICS: OVERCOMING TABOOS, MYTHS AND DOGMAS 111 (2008).

\textsuperscript{120} \textit{Id.} at 112.

\textsuperscript{121} THOMASMA & GRABER, \textit{supra} note 58 at 192, 194 (quoting Dr. Edmund D. Pellegrino).

All too often those in the end-stage of life and suffering with dementia, receive an array of aggressive therapies from forced tube feeding to hospitalization for pneumonia—all of which are
III.

BROADENING THE BOUNDARIES OF HOSPICE AND PALLIATIVE CARE

Over the next thirty years, the projected population of seniors in the United States will more than double—rising from thirty-four million in 1997 to, by 2030, over sixty-nine million.122 By that time, one out of five Americans will have attained the age of sixty-five or older.123 For baby boomers, one in nine may expect to reach the age of ninety; and by the year 2040, those Americans over the age of eighty-five will have reached nearly four times that of those in 2003.124 The potential use of both hospice and palliative care for these Americans staggers the imagination.125

Very often, palliative care practice seeks to manage incurable illness in “the least unpleasant course” and thereby allow a patient to die from their incurable illness in a manner not only of limited benefit but inconsistent with sound standards of palliative management. Susan L. Mitchell, Joan M. Teno, Dan K. Kiely et al., The Clinical Course of Advanced Dementia, 361 NEW ENG. J. MED. 1529, 1535 (Oct. 15, 2009).

122 Bruce Jennings, True Rynders et al., Access to Hospice Care: Expanding Boundaries, Overcoming Barriers, 33 HASTINGS CENTER RPT. S3 (Special Supplement) (2003).

123 Id.

124 Id.

125 Id.

Current statistics show 5 million Americans are afflicted with dementia and more than 13 million are projected to be diagnosed by 2050. Mitchell et al., supra note 121 at 1536.

See generally Susan L. Mitchell, Dan K. Kiely, S.C. Miller et al., Hospice Care for Patients with Dementia. 34 J. PAIN SYMPTOM MGT. 7 (2007).

which is the least traumatic. In order for a competent patient to exercise his autonomy and be informed sufficiently to determine the course of his medical treatment or non treatment, an admittedly “gruesome discussion about ways of dying” must follow; for, 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 situations of this nature, the health care decision makers must attempt to discern the patient wishes by evaluating the patient’s “total good or best interests.” The challenge here is that if the patient is not informed, he cannot have a basis for formulating and evaluating ideas which promote his own best interests as he approaches his death.

When forced to determine whether to offer life-prolonging and life-sustaining treatments to terminally ill autonomous patients, health care decision makers should be guided by an evaluation of whether treatment measures are physiologically futile and the intrinsic burdens and risks they raise are overwhelmingly greater than their benefits; or, in other words, is the treatment worse than the end-stage disease itself.

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127 Id. at 118.

128 Id. at 117.

129 Id. at 118.

130 Id.

131 Id. at 119.

132 Id.
Normally, actual hospice care precludes curative treatment in end-of-life or terminal illness. More contemporary thinking and policy, while acknowledging the primary goal of hospice care to provide comfort, symptom management and alleviation of pain, should not preclude actual treatment. Traditionally, inter-disciplinary 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. Oftentimes, a continuum of adjusted care is created from the initial diagnosis through the end-stage of illness.

A distinct change in the actual scope of hospice care has been seen over the last ten years which is beginning to embrace patients who are terminally ill and suffering with diseases other than cancer (e.g., dementia, chronic lung disease and congestive heart failure) and—as well—to provide palliative supplements for those patients who are terminally ill and confined to nursing homes. In fact, presently approximately one-third of hospitals in the United States are offering some form of inpatient palliative care which is not limited to life expectancy of six months or less.

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134 Id.

135 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.

136 Quill, supra note 40 at 18.

137 Kenen supra, note 135.
Nevertheless, because of prevailing requirements to forego disease-directed therapy before being allowed hospice care, most Americans die without benefit of it. \(^{138}\) “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 of some limited potential for helping manage end-stage illness. \(^{139}\) In the final analysis, the better reasoned view is to consider palliative care and hospice care as “an integral part of all health care” and not as “care of last resort.” \(^{140}\)

The degree of care and level of sustainable qualitative living 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 seen as conditions having limited rates of survival and often worse prognoses, as to time, than cancer. With a diagnosis of kidney disease, more often than not, this is seen as an appropriate time to develop strategies for end-stage care. \(^{141}\)

It has been said that “the palliative care movement has come of age”—especially with the recent status of this care being certified as a sub specialty by the American Board of Medical

\(^{138}\) Quill, supra note 125.

While approximately 70% 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.

\(^{139}\) Quill, supra note 125.

\(^{140}\) Jennings et al., supra note 122 at S9.

\(^{141}\) Kenen, supra note 135.
Specialties. Even with these remarkable advances in expanded care and board certification of the field, there are not only gaps in providing adequate education and training in basic palliative management together but a shortage of skilled clinicians in this board-certified field. Yet, it is hoped that this classification will serve as a catalyst for advancing greater opportunities for expanded training and service in palliative medicine.

IV.

SHAPING THE PRINCIPLE OF MEDICAL FUTILITY

Quality of Life, Sanctity of Creation

All too frequently, when sanctity of life is embraced as a religious or moral construct, it then becomes impervious to rational argument. When juxtaposed with quality of life, the religious view complicates and, it is argued, often trumps common sense and humane policy making which favors the standard of quality of life as the more rational construct for decision making in end stage illness. Instead of one principle or concern dominating the other, both should be used in evaluating a patient’s medical prognosis and placing “hope” for recovery

142 Quill, supra note 40 at 17.
143 Id. at 18.
144 Id.
146 Id.
147 See ROBERT YOUNG, MEDICALLY ASSISTED DEATH ch. 3 (2007).
within a proper, realistic context—all consistent with, as such, patient values.

While it may be acknowledged that quality of life varies from person to person and, thus, cannot be set by one uniform standard, it can be tested by a sense of compassion or mercy. If a terminal patient is suffering greatly—physically or mentally—it makes common 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. No practical purpose is served by becoming mired in ambiguous and subtle philosophical refinements which defy not only the medical principle of futility but compassion and mercy as well.148

Rather than analyze and “test” supposed levels of intent in the management of end-stage illness, it is reasonable to simply isolate the standard of proportionality from the “traditional” principle or test of double effect and assess the patient costs of following a course of action with the benefits from such action.149 Accordingly, if a decision to terminate care is in proportion to the amount of “quality” remaining in a case where the patient is in a terminal condition, that decision should be recognized as not only rational but efficacious and humane. Anchored at the fulcrum of 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 redesigned or re-calibrated as urged here, a new contemporary approach to


149 Id. (observing disproportionate is synonymous with futility).

See Pellegrino infra note 166.
managing ethical issues in end-of-life care will be effected and one that is freed of taxonomical ambiguity as is seen in the classical principle of double effect.

Clinical Applications

In 1974, Richard A. McCormick, S.J., suggested a basic medical approach, consistent with the American Medical Association’s 1974 policy on the issue, to determine when life is no longer meaningful. For Fr. McCormick, when there is irrefutable evidence that biological death is imminent, no extraordinary measures should be undertaken to sustain life. That evidence was to be tested by a state of condition for the individual patient where there is a “negation of any truly human—i.e., relational—potential” or relationships.

Recognizing that this standard of relational capacity is not subject to precise mathematical deduction, Fr. McCormick urged the medical profession to agree on concrete categories or presumptive symptoms to aid in reaching this judgment. 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 overall

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151 *Id.*

152 *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 CENTER RPT. 1 (Nov. 1972).

meaning of life or “relational-potential.” At this point, such actions should be recognized as being futile and cease.  

Today, Fr. McCormick’s analytical approach is absorbed within the doctrine or principle of medical futility. Although McCormick abjured quality of life indices for 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, are indeed to be seen as an integral part of the clinical use of medical futility. Accordingly, the principle of medical futility comes into play in those clinical cases where: a cure is physiologically impossible; the treatment is non beneficial or unlikely to be beneficial; and in those cases where treatment, while plausible, has yet to be validated.

An alternative approach to defining futility concludes that when an intervention—including those seen as life-sustaining—which: verified by contemporary clinical experience and medical knowledge, holds no reasonable promise for effecting recovery; impose burdensome consequences “grossly disproportionate” to any expected benefit; have no efficacious value in mitigating patient discomfort; and serve, consequently, as but an artifice for death “by sustaining, supplanting or restoring a vital function, no obligation exists to either offer such treatment or, for that matter, maintain it.”

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154 McCormick, id.

155 Smith, supra note at 50.


Admitting 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—needlessly—the patient to additional risks associated with the treatment such as 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 CPR—inflict severe physical trauma. Administering CPR when there is no medically reasonable chance that a distressed patient will recover from the underlying illness amounts to physical torture. Accordingly, physicians should be under a duty not to administer futile treatments because, by doing so, they are indeed inflicting cruel and unusual punishment on their patients and their 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, in turn, then, is realized when a carefully calibrated balance is struck between three criteria: effectiveness, benefit and burden reached, co-operatively, within an

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Any request that medical therapy be offered to patients who would have less than a one percent chance of success should be deemed unreasonable and, thus, futile. Lawrence F. Schneiderman, Nancy S. Jecker & Albert R. Jonsen, Medical Futility: Its Meaning and Ethical Implications in BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS AND PRACTICE at 408, 412 (Nancy S. Jecker, Albert R. Jonsen & Robert A. Pearlman eds., 2d 2007).


159 Smith, Euphemistic Codes, supra note 37.

160 Id.

161 Smith, supra note 48.
“alliance” between the treating physician, the patient or his surrogate decision maker. For Dr. Pellegrino, futility is not an isolated, empirical yes/no test. Rather, each judgment of futility takes all aspects of patient’s total life experience into account—physical, mental, spiritual preferences together with 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. Accordingly, under this principle, there is no obligation to provide a specific treatment when overuse or underuse of it create an unreasonable burden where the harm or suffering inflicted by such treatment is disproportionate to any realistic benefit derived from it. Often presented as a cost/benefit theory, the factors used—however—in specific applications to effect 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—medical care which, under prevailing standards of medicine, is futile.

162 Pellegrino, supra note 148 at 227.

163 Id. at 240.


166 Pellegrino, supra note 148 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. Pellegrino, 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
Model Legislative Guidance

All too often, the clinical application of these substantive medical norms to aid in decision making remain under and beyond the understanding of patients, their health proxies and their families. Today, hospital management policies regarding the determination of medical futility are grounded normally in a “consultative consensus building approach.” Yet, interestingly, ten states have adopted the Uniform Health Care Decisions Act and thereby have gone on record that there must be a point of closure or finality in end-of-life care giving where consultation must yield eventually to decisive action. 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. Any such refusal of medical care may be grounded on the determination by the attending physician that the care would be “ineffective” contrary to generally accepted medical treatment is disproportionate to the benefit conferred by it. Pellegrino, 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.

167 One study discovered that conflicts arose in 78% of cases where issues of limiting life-sustaining medical treatment were in play and normally involved a demand of healthcare providers to provide care when a decision was made that such action was either inappropriate or futile. Thaddeus M. Pope & Ellen A. Wallmas, Mediation at The End of Life: Getting Beyond The Limits of The Talking Cure, 22 OHIO STATE J. DISPUTE RESOLUTION, 1, 4 at n. 13 (2007).


170 Id. Prefatory Note ¶ 7.

171 Id., § 13(d).
“health care standards”\textsuperscript{172} or be in violation of “conscience.”\textsuperscript{173} This model legislation is a bold step forward in bringing much needed clarity and finality to an area of decision making clouded inherently with emotional stress.

\textbf{Sedation Hastened Death}

When, despite aggressive efforts to control severe intractable symptoms, such as dyspnea, pain or myoclonus, vomiting, delirium, anxiety or agitation, sedating medications do not achieve success and the symptoms remain severe, the sedation for intractable distress of such a dying patient is proper.\textsuperscript{174} There is wide disagreement, however, on the propriety of using this when the patient is suffering from psychological or emotional distress and not physical pain.\textsuperscript{175} Yet, it is the position of this Article 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.”\textsuperscript{176} And, the extent or degree of charity or compassion shown—from a standard of health care delivery and law—

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\textsuperscript{172} \textit{Id.}, §§ 7(f) & 13(d).
\textsuperscript{173} \textit{Id.}, § 7(e).
\textsuperscript{175} \textit{Id.}
\textsuperscript{176} See also RANDALL & DOWNIE, \textit{supra} note 126 at 155.
\end{flushright}

\textsuperscript{176} Pellegrino, \textit{supra} note 148 at 241.
should, in turn, be framed by the doctrine of medical futility\textsuperscript{177} or adjusted care.\textsuperscript{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.”\textsuperscript{179} Indeed, to continue treatment of futile medical conditions can be understood as violating the primary principle of traditional medical ethics: Beneficence.\textsuperscript{180}

Autonomous patients may request sedation in order to abate severe distress manifested by unrelieved pain, restlessness or mental anguish. 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.”\textsuperscript{181} Often the sedation is intermittent and has been termed “respite”\textsuperscript{182} or “twilight sleep”\textsuperscript{183} leading to the concern by some that it is, again, but a euphemism for euthanasia especially when the procedure is used for non autonomous patients.\textsuperscript{184} Others argue

\textsuperscript{177} \textit{Smith, supra} note 50.

\textsuperscript{178} \textit{See Smith, Terminal Sedation, supra} note 36 at 383.

\textsuperscript{179} \textit{Pellegrino, supra} note 148 at 235.

\textsuperscript{180} \textit{Id.} at 223.

\textsuperscript{181} Quill & Byock \textit{supra} note 52 at 409.

\textsuperscript{182} Williams, \textit{supra} note 30 at 49.

\textsuperscript{183} \textit{Id.}

\textsuperscript{184} RANDALL & DOWNIE, \textit{supra} note 126 at 72; Williams \textit{id}.

Another less troubling euphemism for terminal sedation is sedation hastened death.
that the degree or extent of sedation used is tied to the level of patient distress—with the sole purpose being that of alleviating the distress.\footnote{185}

Both in the case of the terminally ill autonomous patient and the non-autonomous patient suffering medical distress, even though there is a significant risk that life may well be shortened, 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 shortening life.”\footnote{186} The logic of this policy is found—very directly—in a straight forward application of cost/benefit analysis.\footnote{187}

**A Protocol for Palliative Sedation of Existential Pain**

In order for palliative, or “terminal sedation” to be administered, patients presenting should:  be diagnosed as being terminally ill\footnote{188}—or moribund\footnote{189}—; have a current Do Not Resuscitate order listed in their medical records; have exhausted all palliative treatments for anxiety, delirium or depression;\footnote{190} received a psychological evaluation by a qualified clinician together with a similar assessment of spiritual issues, which may be particular to the needs of a

\footnote{185} *Id.*

\footnote{186} *Id.*

\footnote{187} *Id.*

\footnote{188} Rosseau, *supra* note 112 at 152.

\footnote{189} Bernard Lo & Gordon Rubenfeld, *supra* note 113 at 1812.

\footnote{190} Rosseau, *supra* note 112 at 152.
patient, by either a member of the clergy or other qualified clinician;\textsuperscript{191} participate in a candid discussion with their physician and/or family regarding the costs versus the benefits of a course of palliative sedation; and, subsequent to this discussion, an informed consent to the therapy should be obtained, again, from the patient or his surrogate decision maker; finally, consideration should be given to whether a trial of respite sedation should first be undertaken before the deep sedation.\textsuperscript{192} With respite sedation, a sedative is ordered for a pre-determined time frame—for example 24 to 48 hours, with a downward titration of the sedative occurring until the patient is restored to consciousness.\textsuperscript{193}

The significant value to this eight step suggested protocol is that not only may a reassessment be made of the patient’s condition by his family and health care team, but this course of action may ease or cease altogether the distress which initiated the request for continuous sedation and thereby resolve the need for additional sedation. 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.\textsuperscript{194}

The final step in this model protocol requires a dosage policy to be established which is unequivocal and forbids increase in the level of sedative unless the patient awakens or otherwise

\textsuperscript{191} Id. at 153.

\textsuperscript{192} Id. at 153.

\textsuperscript{193} Id.

\textsuperscript{194} Rosseau, supra note 112 at 153.

See Quill & Byock, supra note 52 at 413, Table 2, Medications Used for Terminal Sedation (2000).
presents evidence of suffering (e.g., restlessness, grimaces or withdraws from stimuli) or discomfort (e.g., displays a furrowed brow or develops hypertension). Establishing in advance of the actual sedation a classification scale could also go far toward alleviating inconsistences of 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 ineffective to provide symptomatic relief, then—and only then—should dosages be increased. To neglect the establishment of a policy of this type could well give rise to an impression or allegation that the attending physician was hastening death and had exceeded the bounds of a medically efficacious therapy in palliative sedation and thereby embrace euthanasia or physician-assisted suicide.

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195 *Id.*

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

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

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

199 Rosseau, *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, Table 1, Guidelines for Terminal Sedation and Voluntary Cessation of Eating and Drinking.

Public Misconceptions

Because, in popular conception, the administration of barbiturates has been very closely associated with euthanasia—especially in The Netherlands—and are, as well, used to perform capital punishment (and as a method for assisting suicide) in the United States and recommended for use in use of barbiturates in palliative care treatment has been seen as something akin to being unethical. Their use can, however, be justified easily under the principle of double effect—this, because simply their use provides effective comfort for those at the end stages of life. As well—and in further justification, as suggested, a simple standard of compassion and adjusted care can serve as a guide for pharmacological uses of barbiturates.

A Noble Effort Toward Clarification?

In a report of the American Medical Association’s Council on Ethical and Judicial Affairs released in 2008, dealing with the subject of sedation to unconsciousness in end-of-life care, a number of conclusions are reached: 1). “The use of sedation in palliative care is not ethically controversial;” 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;” 3). Before sedating to unconsciousness, informed consent must

200 Krakauer et al., supra note 174.
201 Id. at 56, 57.
203 Id. at 6.
204 Id.
be obtained from the patient or the patient’s designated health care surrogate;\textsuperscript{205} 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 viewed presently, based on past treatments, as “appropriate;”\textsuperscript{206} 5). Physician-patient discussions are held which consider the plan for sedation, its length of administration (intermittent or constant) and the expectations of treatment;\textsuperscript{207} 6). A process of implementation is coordinated which monitors the appropriateness of care during the sedation;\textsuperscript{208} 7). Addressing issues of existential pain should not be deemed appropriate through the use of palliative sedation. Rather, existential suffering should be addressed “by providing the patient with needed social support;”\textsuperscript{209} and 8). The intentional use of palliative sedation to “cause a patient’s death” is never allowed.\textsuperscript{210}

While this Report may be seen as a noble effort to clarify and even “resolve” inherent difficulties and imprecision surrounding the administration of palliative sedation, there remains a fatal flaw in the Report: that is, its continued reliance on “intention” as the paramount guide or construct for determining when opiate and sedative use is palliative and not to be seen as either euthanasia or physician assisted suicide.\textsuperscript{211} The Report embraces the doctrine of double effect as

\textsuperscript{205} Id.  
\textsuperscript{206} Id. at 6, 7.  
\textsuperscript{207} Id. at 7.  
\textsuperscript{208} Id. at 7.  
\textsuperscript{209} Id. at 7.  
\textsuperscript{210} Id. at 7.  
\textsuperscript{211} Id. at 4.
the tool to test whether proper intent is shown in pharmacologic therapies.\textsuperscript{212} Although recognizing proportionality as a “central tenent of the principle of double effect,” the Report\textsuperscript{213} tries—unsuccessfully—and “naively”\textsuperscript{214}—to gauge intent and measure proportionality by dosage uses.\textsuperscript{215} Accordingly, when there are continuous infusions or repeated dosages, these actions may be seen as “indicators of proportionate palliative sedation.”\textsuperscript{216} Contrariwise, “one large dose or rapidly accelerating doses . . . may signify lack of knowledge or an inappropriate intention to hasten death.”\textsuperscript{217} An alternative explanation for repeated doses and infusions might well be that such dosage patterns are little more than a “clever attempt to cover one’s tracks.”\textsuperscript{218}

It is argued subsequently in this Article that instead of miring and indeed shackling humane patient care in end-of-life cases to the ambiguous doctrine of double effect, a more efficacious test for determining the medical propriety of pharmacologic therapies should be whether their benefits, based on sound medical judgment, simply outweigh the costs of not applying the therapies.\textsuperscript{219} 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

\textsuperscript{212} Id. at 5.
\textsuperscript{213} Id. at 5.
\textsuperscript{214} Battin, supra note 37 at 29.
\textsuperscript{215} CEJA Report, supra note 202 at 5.
\textsuperscript{216} Id.
\textsuperscript{217} Id.
\textsuperscript{218} Battin, supra note 37 at 29.
\textsuperscript{219} See infra Part V notes and accompanying text.
patient, should be determinative. \textsuperscript{220}

V. \textbf{DOUBLE EFFECT—TRADITIONAL AND CONTEMPORARY PERSPECTIVES}

The principle of double effect—sometimes also stated to be either a doctrine or rule—is grounded in Roman Catholic philosophy and moral theology. \textsuperscript{221} It proposes to structure specific guidelines to aid in determining when, ethically, it is permissible to pursue a course of action to achieve a good end—notwithstanding the full understanding that negative or bad results will, as well, flow from the initiating conduct. \textsuperscript{222} The coverage and application of the principle has, over time, been embraced by philosophers and ethicists as having a profound relevance to assessing complex cases of health care ethics either in its classical application or by implication. \textsuperscript{223} 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.” \textsuperscript{224}

For the conduct of the actor to be acknowledged as ethically permissible, four conditions must be met: 1) The nature of the action must be good or morally neutral and, thus, not prohibited; 2) A good effect or consequences must be intended to flow from the action, and not a

\textsuperscript{220} Id.
\textsuperscript{222} Id.
\textsuperscript{223} RANDALL & DOWNIE supra note 126 at 73.
\textsuperscript{224} BARRY R. FURROW, THOMAS L. GREANERY, SANDRA H. JOHNSON, TIMOTHY S. JOST & ROBERT L. SCHWARTZ, BIOETHICS: HEALTH CARE LAW AND ETHICS 10 (6\textsuperscript{th} ed. 2008).
bad or evil consequence; 3). The good or positive result must not be used as a direct casual consequence of the evil result and 4). The good or positive result must be proportionate to any evil result. When all four conditions are met, the personal conduct of the agent being evaluated is held to be ethically permissible—this, even though an undesirable or “bad” result occurs.

Moral Distinctions or Subtleties

In palliative care management, a moral distinction has all too often been recognized by some between an act of withdrawing treatment and withholding treatment—an omission. And, accordingly, because of this ambiguous viewpoint, it is asserted that a greater degree of accountability or responsibility must be assumed—legally—for the consequences of an individual’s actions rather than his omissions.

Subtle complexities infuse this “distinction” because in the event a decision which leads to either an act or an omission is made does not necessarily, ipso facto, mean that its efficacy is

225 Quill et al., supra note 221.

226 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, supra note 81 at 176.

227 RANDALL & DOWNIE supra note 126 at 74.

See also GEORGE P. SMITH, II, LEGAL AND HEALTHCARE FOR THE ELDERLY, infra note 447 at 111–19.

228 RANDALL & DOWNIE, supra note 126 at 74.
grounded on a moral justification.\textsuperscript{229} 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.”\textsuperscript{230} Yet, the fact remains in palliative management, society imposes moral and legal responsibility on care givers for both omissions as well as actions.\textsuperscript{231}

In cases of artificial hydration—when a moral distinction is drawn between the withholding of treatment and the withdrawal of it\textsuperscript{232}—greater blame may be given to the act of withdrawing treatment than withholding it.\textsuperscript{233} When cases of type present, physicians become reluctant—if not unwilling—to commence treatment, even though medically appropriate, in order to avoid stopping it when it becomes subsequently inappropriate. The effect of this action may well result in under treating at-risk patients.\textsuperscript{234}

Another defensive response by physicians to the effort to chart a moral distinction between the withholding and withdrawal of treatment—which makes this putative moral

\begin{itemize}
  \item \textsuperscript{229} Id.
  \item \textsuperscript{230} Id.
  \item \textsuperscript{231} RANDALL & DOWNIE \textit{supra} note 126 at 74.
  \item \textsuperscript{232} Id.
  \item \textsuperscript{233} Id.
  \item See CALLAHAN, \textit{infra} note 326 where it is concluded that actions which withdraw nutrition and hydration are morally legitimate.
  \item \textsuperscript{234} RANDALL & DOWNIE \textit{supra} note 126 at 74.
\end{itemize}
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.”\textsuperscript{235} The end result when physician conduct of this nature occurs is that overtreatment may be the norm.\textsuperscript{236}

\textbf{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 the content of the intention of one action (and its consequences) as opposed to the other action,\textsuperscript{237} the doctrine presents itself as a muddled template bereft of objective certainty for decision making.\textsuperscript{238}

Utilizing this doctrine in 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 an efficacious tool for judicial decision making, a physician is required to admit he administered lethal treatment with the primary intent to cause death. Given the criminal consequences of such a forthright admission, it

\textsuperscript{235} Id.

\textsuperscript{236} Id.


\textsuperscript{238} Id. at 103, 104.
would be unusual for a doctor to admit such a course of conduct. Indeed, it would be common for a physician to have more than one intention, an awareness, or consideration that death will most likely occur from actions undertaken primarily to manage intractable pain. Because of this duality of competing or cross intents and the complexity of distinguishing between them, the requirement under the principle of double effect that a positive consequence be intended is exceedingly problematic. While legal terms such as intention and foresight appear to be neutral in a moral sense, in point of fact, they “relate to inherently moral issues” and perforce dictate ill-advised subjective moral judgments.

The medical community asserts that the use of sedatives is not intended to hasten death. Even though it is foreseen—as in cases of end-stage illness—that death will most certainly occur sooner than later with the use of terminal sedation, the fact that physicians maintain the practice is medically justifiable should be taken as conclusive. And, were this proposition to be accepted, then, no valid need to question the application of the principle of double effect could be allowed. Yet, the fact remains, this “assurance” or “conclusion” is not

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239 Id. at 105.

240 Lo & Rubenfield, supra note 113 at 1813.

241 Ost, supra note 237 at 103.

See Lo & Rubenfield, supra note 113 at 1810 (questioning whether dosage size is determinative of intent); Timothy E. Quill, The Ambiguity of Clinical Intentions 329 N. ENG. J. MED. 1039 (1993) (suggesting proportionality of treatments is crucial to discerning clinical intent). Williams supra note 30 at 46.

242 Williams supra note 30 at 46.

243 Id.
accepted at face value as an honest professional judgment.\textsuperscript{244} Even within the ranks of the medical profession, itself, although the principle is supported by most physicians and nurses, other care givers see it as but a “fig leaf” for euthanasia.\textsuperscript{245} Rather, these individuals, together with some patients and their families, are blind-sided by the myth (quite often spread by the media) that analgesics (\emph{e.g.}, barbiturates more directly than opioids) are “nothing more than a polite way to kill the patient.”\textsuperscript{246}

\textbf{Justifying Double Effect for Palliative Sedation}

The central element for a justification of palliative sedation under the principle of double effect is to be found in the moral distinction drawn between the intentions of an actor, or physician, and the unintended—yet foreseen—consequences of the primary action. Taking the life of another is always, thus, morally impermissible; yet such actions which are foreseeable, but unintentional, may be permissible when the action produces proportionate good.\textsuperscript{247} Put in context, then, 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 patient suffering.\textsuperscript{248} For ethicists, there is simply no clear line between efforts to relieve refractory systems and hastening

\begin{itemize}
  \item \textsuperscript{244} Id.
  \item \textsuperscript{245} Id.
  \item \textsuperscript{246} Id.
  \item \textsuperscript{247} See Quill, \textit{et al.}, supra note 38 at 2101 \textit{passim}.
  \item \textsuperscript{248} Lo & Rubenfeld \textit{supra} note 113 at 1812.
\end{itemize}
death. The manner by which a physician declares his intention, thus, is more determinative than what actions he takes under this doctrine. Ambiguity arises when physicians have, in various studies, admitted to double intentions when they administered large doses of opioids: intentions to both decrease suffering and hasten death.250

Physician intent is irrelevant when the validity of a withdrawal of nutrition and hydration is raised; for, the operative issue is whether an individual patient is within his “liberty interest” in making this decision.251

“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.”252

In contemporary society, legal liability is imposed upon those who foresee or should have foreseen the consequences of their actions which cause injury to another.253 This legal standard

249 Id. at 1813.

See Meisel, infra note 327, Physician-Assisted Suicide.

250 Id.

See LAVI, supra note 247 at ch. 5.

251 McStay, supra note 36 at 60.

252 Id.


is, accordingly, broadened considerably from one which, under the principle of double effect, limits the liability for only unintended consequences and, thus, may well characterize the principle as inconsistent with the standards of modern jurisprudence. The additional assumption made under the principle that it is morally wrong to cause or to hasten a moribund or terminally ill patient’s death may also be rejected by those who disagree with this and become a reason for them to disregard the application of the principle altogether.\textsuperscript{254}

Given these inherent weaknesses of the principle of double effect, it would be more efficacious to reformulate the justification for palliative sedation by examining proportionality rather than affirming intention. Accordingly, under proportionality, compassion and patient preferences are determinative. Rather than deal with oftentimes conflicting ethical guidelines to relieve patient suffering yet not act in a way which causes death as a consequences, proportionality allows for a balancing of the guidelines. Thus if—for example—a physician believes it to be more compassionate to relieve refractory symptoms than to prolong life filled with physical torment for but a few hours, days, or a “few months,” then—guided, as well, by patient preferences for sedative amount, palliative sedation may be administered properly within the bounds of good medical practice.\textsuperscript{255} Sadly, there is a mistaken perception that death is always

\textsuperscript{254} Lo & Rubenfeld \textit{supra} note 113 at 1813.

\textsuperscript{255} \textit{Id.}

hastened by the aggressive administration of pain management.  

British courts have, over time, allowed palliative measures to be taken even though their incidental effect is to shorten life. The justification is to be found in a moral metaphor which acknowledges physicians may limit suffering even though they may not put an immediate end to a patient’s life. This metaphor of helping, rather than killing, may prove to be an invaluable psychological construct for the physician as well as an enlightened one for the courts. Under it, while a physician may know fully the consequences of his actions of increasing dosages of diamorphine for a patient, he need not describe the act, nor be required by society, to view it as “an act of killing.”

Rather than re-evaluate and test anew the principle of double effect by accepting/adopting this metaphor which is tied inextricably to the principle of compassion or mercy, the nuanced complexities of double effect are, essentially, subsumed under this metaphor. This restatement—together with major emphasis on proportionality, which in turn brings in the mandate to avoid suffering—would go far to present a new contemporary construct for decision making not mired in the quicksands of the “traditional” approach to testing with the principle of double effect applies.

**Dosage and Titration**

If medication (*e.g.*, barbiturates, opioids) are titrated to effect patient comfort, without

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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.\textsuperscript{258} One of the rather predictable side effects of using opiates for pain relief is that sedation occurs.\textsuperscript{259} Non sedating agents are, of course, preferred but not always effective.\textsuperscript{260}

In administering sedation for refractory pain, the goal of symptom relief should be sought initially by administering the lowest dosage\textsuperscript{261}—one which neither suppresses respiration nor leads to respiratory distress.\textsuperscript{262} Dosage which provides for no possibility for symptom relief \textit{without} patient death could be termed properly as active euthanasia.\textsuperscript{263} When lower dosages are ineffective, increased dosages are permissible.\textsuperscript{264} But, there should be clear criteria, or clinical

\begin{footnotesize}
\begin{enumerate}
\item \textit{Id.}
\item \textit{Id.}
\item \textit{Id.}
\item \textit{Id.}
\item \textit{Id.}
\item Lo & Gordon Rubenfeld, \textit{supra} note 113 at 1812.
\item \textit{Id.}
\item \textit{See} LAVI, \textit{supra} note 247.
\item \textit{Id.}
\end{enumerate}
\end{footnotesize}

For the conscious patient, reports of continued pain, displays of agitation, restlessness and confusion and/or respiratory distress or myoclonus, would be grounds for dosage increases. For the unconscious patient, unable to report levels of distress, it remains for health care providers to access levels of discomfort (\textit{e.g.}, furrowed brow, tachypnea and other symptomatologies associated with suffering). \textit{Id.} 1811, 1813.
indications, to justify increased levels of medication and this—in turn—should be documented in
the patient records and/or chart.\textsuperscript{265}

Direct medical actions of this nature most usually occur when acute palliative care is
made urgent because of sudden or severe patient distress\textsuperscript{266} owing to pain or other physical
symptoms as well as psychological distress in the form of severe anxiety or agitated delirium.\textsuperscript{267}
As observed, the administration of the necessary medications, such as opioids and
benzodiazepines, in order to give effective comfort and relief, often are accompanied by
significant side effects which must be anticipated and explained to a patient’s family and then
managed.

\textbf{Challenging Traditional Applications}

Those who reject the rigid classical application of the principle of double effect assert that
it is neither efficacious nor necessary in palliative care. If released from the principle’s \textit{raison d’
entre} to provide an absolute safeguard against the intentional shortening of life and, instead, a
position is that which recognizes that the benefits of relieving medical distress in cases of

\textsuperscript{265} \textit{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, \textit{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, \textit{supra} note 202 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, \textit{id.} note 37 at 29.

\textsuperscript{266} Krakauer, \textit{et al., supra} note 258 at 60.
terminal illness may sometime outweigh the harm of shortening life through use of respite or terminal sedation, the principle becomes superfluous to palliative management.\textsuperscript{268} Indeed, adoption of such a contemporary and humane policy would eliminate altogether the complex and finely nuanced arguments which seek to draw distinctions—sometimes hair splitting—between intending and foreseeing the effects of one’s actions.\textsuperscript{269} Restructured as such, the principle of double effect would become a common sense approach to medico-legal-ethical decision making and would—accordingly—appear to be in “accordance with the moral intuitions of most people.”\textsuperscript{270} Moreover, by reformulating this template for decision making and elevating compassion and proportionality to controlling values instead of merely seeking to prolong a life of suffering for those with end-stage illness by playing “shell games” of uncertainty and chance in determining the intentions of health care providers who are managing health care for those with terminal illness, a bold reaffirmation of beneficence, charity, compassion and mercy would be the controlling policies for action.\textsuperscript{271}

\textsuperscript{267} Id.

\textsuperscript{268} RANDALL & DOWNIE, supra note 126 at 73.

\textsuperscript{269} Id.

\textsuperscript{270} Id.

\textsuperscript{271} See Timothy E. Quill, The Ambiguity of Clinical Institutions 329 N. ENG. J. MED. 1039 (1993) (arguing that proportionality should be the central focus for evaluating decisions of this nature).
The Defense of Necessity

In 1958, Glanville Williams put forward the proposition that in cases where a pain is so severe that its alleviation can no longer be achieved other than by administration of a lethal dosage of drugs, a medical excuse should be recognized in law. This excuse, then, would rest “upon the doctrine of necessity, there being at this juncture no way of relieving pain without ending life.” Accordingly, under a contemporary gloss for this suggestion, 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), he acted in an effort to alleviate the severe or unbearable suffering of a patient. And, furthermore, that his actions were taken in good faith and with a reasonable belief that they were a proportionate response to the patient’s medical condition. Factored into the validity of this legal defense would be another highly relevant factor: the extent to which, and frequency of, a

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See Boyle, supra note 255 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).

273 Id. at 288.

274 Ost, supra note 237 at 115–116.

275 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, Jecker & Jonsen, supra note 156 at 409.

276 Ost, supra note 237 at 115–16.
In a very real way, recognizing the defense of necessity is grounded in compassion.

**Judicial Guideposts**

It is a given that moral questions are not settled by laws or legal arguments. And, it is truism that “all that is legal is not moral, and all that is moral is not necessarily legal.” Consequently, the extent to which legal arguments over the definition and use of assisted suicide or euthanasia have weighted morally is tied extricably to the extent to which they are “morally persuasive.” In this area of debate, it has been concluded that legal argumentation is faulty because it fails to address the moral complexities inherent in any discussion of hastened death.

When the United States Supreme Court had an opportunity to advance a moral argument for accepting the rule of double effect in 1997 in *Vacco v. Quill* and *Washington v. Glucksberg*—although it invoked double effect reasoning—no moral arguments for accepting the rule or principle of double effect were proffered by the Court. It has been suggested,

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277  *Id.* at 116.


279  *Id.* at 548.

280  *Id.*


283  Sulmasy & Pellegrino, *supra* note 278 at 548.

*But see* Marc Spindelman, *Death, Dying and Domination*, 106 MICH. L. REV. 1641 at 1661, 61.
however, that what the court did here was to lay a foundation for recognizing a constitutional
right to adequate pain relief from dying. And, within such a “right” to avoid suffering in
dying, and to receive care, is—it is argued here—the co-ordinate right to receive terminal
sedation when deemed reasonable by either a competent patient or a properly designated
surrogate decision maker. In cases of incompetency, this right would be exercised by an
attending health care provider who determines this course of conduct is humane and
compassionate and in the best interests of the patient. Action of this nature would be consistent
with a physician’s responsibility—and, indeed—commitment, to embrace the “ethics of
compassionate response.”

Withdrawal of Nutrition and Hydration

That artificial nutrition and hydration are properly viewed as medical treatment and may,
as such, be withdrawn if their continuation is evaluated as inconsistent with safeguarding the best
interests of a patient, is legally sound and a medically valid position. This rule was formulated
as is seen as a right of refusal grounded in Due Process clause protections by the U.S. Supreme
Missouri Dept. of Health, writing for the majority, Chief Justice Rhenquist “assumed” that there

n. 60 (concluding that Glucksberg constitutionalized the principle of double effect).

284 Burt, supra note 47.


is a right, of a competent person, to refuse nutrition and hydration. As such, this right of refusal is “inferred” from a constitutionally protected liberty interest—grounded in the doctrine of informed consent—for one to exercise their consent to refuse treatment.

It remained for the Court, again, in 1997 to sharpen a necessary distinction between the withdrawal of life sustaining treatment and physician assisted suicide. Crucial to this distinction is an understanding that while a patient who ingests a lethal dose of medication will, accordingly, be killed by such action, an underlying disease pathology will be the cause of death when one refuses life sustaining treatment (e.g., nutrition and hydration).

Going further 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 intention of the physician is to assure “that the patient be made dead,” the court placed heavy emphasis upon the importance of intent as determinative and in doing so gave tacit approval for the use of terminal sedation. Very decisively, the court concluded that when evaluating the propriety of “inducing barbiturate coma and then starving [a patient] to death,” palliative care may be administered which includes a decision to refuse the continuation of life-sustaining treatment which may in turn “have the foreseen but unintended ‘double effect’ of

\[^{288}\text{497 U.S. 261, 279 (1990).}\]
\[^{289}\text{497 U.S. at 270.}\]
\[^{290}\text{Vacco v. Quill, 521 U.S. 793, 801 (1997) (Stevens, J.).}\]
\[^{291}\text{Vacco v. Quill, 521 U.S. 793 at 801.}\]
\[^{292}\text{Smith, supra note 50.}\]
\[^{293}\text{Vacco v. Quill, 521 U.S. 793 at 801–02.}\]
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, however, a liberty interest in securing for mentally competent persons, experience great suffering, to control the manner in which their deaths occurred.

Evaluating *Cruzan*, *Quill* and *Glucksberg* as a unit, and being mindful that the issue of the legality of terminal sedation as a final strategy for dealing with refractory pain was not directly before the Court, the use of terminal sedation as an integral part of palliative care and management was—nonetheless—endorsed, implicitly, by the Court.

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294 Vacco v. Quill, 521 U.S. 793 at 807, n.11.


297 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 224 at 310–11.

The authority and force of this means of policy making has been questioned when other more established vehicles for setting policy in this are available. *Id.* at 311 referencing John Hardt & Kevin O’Rourke, *Nutrition and Hydration: The Congregation for the Doctrine of Faith, In Perspective*, 88 HEALTH PROGRESS 1 (2007). FURROW, et al., *id.* at 310–311.

*But see* U.S. Bishops’ Pro-Life Committee, Nutrition and Hydration: Moral and Pastoral Reflections in BIOETHICS: AN INTRODUCTION TO THE HISTORY METHODS AND
Clarifying Standards for Sedation, Alimentation and Hydration

In 2006, the American Academy of Hospice and Palliative Medicine issued a new position statement on artificial nutrition and hydration (ANH) in end-of-life care replacing, as such, its earlier statement on this issue in 2001.\textsuperscript{298} Recognizing that artificial nutrition and hydration were developed originally to accommodate patients acutely ill and thus provide short-term care, the Academy also acknowledged current data which suggests these procedures neither prolong life nor prevent suffering.\textsuperscript{299} Since patients in end-stage illnesses often lose both capacities to eat and drink, the ethical issue thus becomes whether—with no prospects for rehabilitation or recovery—nutrition or alimentation and hydration should be provided either

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PRACTICE, \textit{supra} note 157 at 417, 419, 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.’”


\textit{See generally} RELIGIOUS PERSPECTIVES IN BIOETHICS ch. 1 (John F. Peppin, Mark J. Cherry & Ana Itlis eds. 2004).


\textsuperscript{299} \textit{Id}.

\textit{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
upon request by patients, families or care givers or, contrariwise, be withheld.

The Academy concluded that ANH should always be recognized as medical therapy and, as such, 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 Academy’s position is that lines of communication be maintained among health care providers which deal not only in 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 which explains an individual’s inability to both eat and drink are but 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 futile—they “can be ethically withheld or withdrawn.”

While there are reports that the use of terminal sedation is now endorsed by many hospices—with some even inducing coma with an added morphine drip to address unremitting

by the inability to take food and water).

\[300\] Position Statement, supra note 298.

\[301\] Id.

\[302\] Id.

\[303\] Id.

\[304\] Id.

pain—\textsuperscript{305} the AAHPM’s Statement on Palliative Sedation, issued in 2006 and, thus, different from its earlier position in 2001, is clear that palliative sedation be “proportionate to the patient’s level of distress.”\textsuperscript{306} Reserved only for those cases of the “most severe, intractable suffering at the very end of life,”\textsuperscript{307} palliative sedation to a level of unconsciousness is supported ethically and legally when three conditions are met: 1). The intent of the clinician is to relieve a patient’s suffering; 2). The degree of sedation administered is proportionate to the severity of suffering being induced; and 3). Either an informed patient consent is obtained directly from the patient or his surrogate decision maker—all consistent, as such, with the patient’s treatment goals and personal values.\textsuperscript{308}

This bold and compassionate action by the Academy is designed to educate the public to the validity of—under certain end-stage medically futile conditions—accepting physician-assisted death by integrating palliative care and its undergirding philosophies into a standard of appropriate care for the terminally ill.\textsuperscript{309} By changing the taxonomical tone of analysis from the more traditional Physician-assisted Suicide (PAS) to Physician-assisted Death (PAD), the Academy is attempting to recast the very essence of the debate over the legality of receiving


\textsuperscript{307} \textit{Id.}

\textsuperscript{308} \textit{Id.}


\textit{See generally Smith, supra} note 36.
medical assistance in the dying process.  

VI.

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. Instead of falling into a taxonomical quagmire, it has been more traditional to assess—clinically—a patient’s condition by determining whether the condition is curative, rehabilitative, or palliative. The principle of medical futility, as seen, has

310 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).


See also Charles H. Baron et al., A Model State Act to Authorize and Regulate Physician Assisted Suicide, 33 HARV. J. LEGISLATION 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 supplemental report 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 way be considered an act of euthanasia. Committee on Care at The End of Life, Institute of Medicine 12 (1997).

312 See M. Sapir, The Spectrum of Medical Care: Curative, Rehabilitative and Palliative, 279
been most helpful, if not determinative, in making a medical assessment; for, by its use and implementation, physicians have clear markers, if not protocols, for non treatment.\textsuperscript{313} Consistent with the failure to find an emerging national cognizance to a right or liberty interest to enlist assistance from a physician in ending life,\textsuperscript{314} state courts—save one in Montana\textsuperscript{315} have neither found a right to physician assisted suicide within their state constitutions nor have state legislatures, other than in Oregon\textsuperscript{316} and Washington,\textsuperscript{317} legalized this type of action\textsuperscript{318} in the years following the Supreme Court’s decision in \textit{Washington et al., v. Glucksberg et al.}\textsuperscript{319}

Rather than continue efforts to find meaningful distinctions between suicide and assisted suicide, it is less confusing to structure a dialogue grounded in references to aid in dying or


\textsuperscript{313} Smith, \textit{supra} note 50.

\textsuperscript{314} Kamisar, \textit{supra} note 311 at 1467.

\textsuperscript{315} 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, on appeal to the state Supreme Court.

In its ruling on this appeal on December 31, 2009, the Montana Supreme Court declined to declare a constitutional right to die with dignity. Rather, the court held that physicians aid in dying was not violating the stated legislation protecting the terminally ill nor against state public policy.

\textsuperscript{316} ORE. REV. STAT. §§127.800(12), 127.805 (2005).

\textsuperscript{317} REV. CODE WASH. ANN., ch. 70.245 (2009).

\textsuperscript{318} Kamisar, \textit{supra} note 311 at 1467.

\textsuperscript{319} 521 U.S. 702 (1997).
physician assisted dying.\textsuperscript{320} Indeed, since \textit{Glucksberg}, the essence of assisted suicide is not really germane to any discussion of end of life care since the recognition of terminal or palliative sedation was validated there.\textsuperscript{321}

\textbf{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,”\textsuperscript{322} extends arguably to the very time and manner of one’s death,\textsuperscript{323} it has been asserted, logically, that this fundamental right should not be limited necessarily to the terminally ill\textsuperscript{324} and the “seriously ill or impaired who are suffering or in pain.”\textsuperscript{325} Indeed, others have expressed concern that if this right is recognized nationally, it will most assuredly be

\textsuperscript{320} Kathryn L. Tucker, \textit{In the Laboratory of the States: The Progress of Glucksberg’s Invitation to States to Address End-of-Life Choices}, 106 MICH. L. REV. 1593 (2008).

\textsuperscript{321} Tucker, \textit{id.} at 1599, n. 23 (noting the American Medical Association’s brief \textit{amicus curiae} in \textit{Vacco} and \textit{Glucksberg} which endorsed the proper medical use of palliative sedation).

Writing for the majority in \textit{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, \textit{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).


\textsuperscript{323} Kamisar, \textit{supra} note 311 at 1474.

\textsuperscript{324} \textit{Id.} at 1459.

\textsuperscript{325} \textit{Id.} at 1471, 1472.
asserted indiscriminately to the “seriously ill or impaired who are suffering in pain” and not invoked on behalf of the terminally ill.

Specifically, concerns have been raised that the standard of terminal illness in and of itself, is inadequate to measure certain medical conditions which exceed a diagnosis of life expectancy beyond, for example, the more “normal” period of three months or six months.

326 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 146 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. Young, id. at 56–58, ch. 6. 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? at ch. 9 (Torbjorn Tannsjo ed. 2004).

327 Id. at 1471, 1472.

See Dan W. Brock, Voluntary Active Euthanasia, 22 HASTINGS CENTER RPT. 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 at 470 (2d ed. 1995).

Since physicians have been permitted, legally, under the rubric of “forgoing life-sustaining treatment,” to end the lives of the terminally ill for over twenty-five years, it becomes “a major hypocrisy” to perpetuate distinctions among the various means used to hasten death. No real difference can be drawn truthfully between “actively hastening death” and “passively hastening death.” Alan Meisel, Physician-Assisted Suicide: Shifting the Focus from Means to Ends, at 283, 297 in PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE (Timothy E. Quill & Margaret P. Battin eds. 2004).

328 Tucker, supra note 320 at 1610, n. 90 referencing the California Compassionate Choices Act introduced in 2007 which was not enacted into legislation.

Three specific scenarios have been posited as being dangerous because of the “open-ended” or limitless nature of present evaluations of terminal illness: cases where patients might be suffering from Lou Gehrig’s disease yet not diagnosed fully as suffering from the end-stage of the disease; or, where a patient, afflicted with paralysis from the neck down, can survive with palliative care for some twenty years; or, finally, where a patient is in the early stages of Alzheimer’s disease.

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

Being an Alzheimer disease patient does not preclude that individual from being recognized, legally, as competent to make health care decisions regarding treatment or non treatment if the decisionmaking is undertaken in the early onset stage of the disease before recognition is lost. A.E. BUCHANAN & DON W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING 281 (1989). See WERTH, supra note 69 at 76.

The double assisted suicide, on July 10, 2009, of the renowned musical conductor, Sir Edward Downes, 85, virtually blind, suffering from a loss of hearing and in psychological distress—although not in a terminal medical condition—and his wife, Lady Downes, 74, who was suffering from terminal cancer, has raised, anew, concerns that death is becoming a “lifestyle choice.” Both Sir Edward and his wife traveled to a private assisted suicide clinic in Zurich, Switzerland, called Dignitas. Of some 117 Britons who have availed themselves of Dignitas the past years, at least 5 were not—at the time of their deaths—considered to be in a terminal condition. Nick Allen & Caroline Gammell, Conductor’s son saw parent’s die in suicide clinic, THE DAILY TELEGRAPH, July 15, 2009, at 7; David Brown & Helen Nugent, ‘Together Forever’ couple raise new suicide fears, THE TIMES (London), July 15, 2009, at 1.
In each of these hypotheticals, no rigid time-line can be imposed on 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 occurs, then—surely—that decision must be accepted. The principle of medical futility applies equally to all three scenarios because, put simply, there is neither curative care nor rehabilitation available. Rather than be concerned with the misapplication of the terminal illness standard in these three specific cases, the opportunity to embrace widely, with human compassion and mercy, individuals presenting with these sympathologies should be accepted as futile—for, there is no hope for a qualitative recovery.332

Foundational to the recognition of a “right” to privacy from governmental intrusions were the U.S. Supreme Court decisions in *Griswold v. Connecticut*333 and *Eistenstadt v. Baird*.334 These decisions became crucial to 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.335 Accordingly, the Court determined, sexual intimacy among same sex couples was a freedom not limited by any spatial bounds.336 Rather, the liberty of persons must be recognized inherently “an autonomy of self that includes freedom of thought,

332 *See* Adrienne M. Martin, *Hope and Exploitation*, 38 HASTINGS CENTER RPT. 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).

333 381 U.S. 479 (1965).


336 *Id.*
belief, expression, and certain intimate conduct.”337 People are entitled to “dignity as free persons.”338 It is posited that, over time, based on Lawrence, a fundamental right to physician assisted suicide may be found in the Constitution.339 For the “foreseeable future,” however, the Glucksberg rule remains.340

The Limits of State Interest

There must be limits to 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—which, as such, is the result of medical conditions which are properly evaluated as futile 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.”341 Linked with this right of self determination is the equally important right to beneficent treatment which advances the best interests of the distressed patient as determined by the patient, himself.342 These two rights are fundamental to any and all decisions regarding healthcare treatment.343 When considering

337 539 U.S. 558, 564–65.
338 Id.
339 Kamisar, supra note 311 at 1466.
340 Id.
342 See THOMASMA & GRABER, supra note 58 at ch. 2.

Artificial alimentation (e.g., nourishment) and hydration are not readily distinguishable “from
terminally ill patients or those diagnosed as having a futile medical condition, the state’s general interest in protecting—and in some cases enforcing a continuance of life which has little if any quality—surely must be qualified or trumped by the right of self-determination to make one of life’s most intimate, private decisions, namely death.344

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

The idea, and what appears to be a growing practice, of addressing the issue of physician assisted suicide or death by conjoining this practice with proper efforts to manage intractable pain may well prove to be the very construct for accepting, and later validating, medical assistance in hastening death in those cases where it is deemed medically proper and humane.345 State statutes are being enacted which allow for the delivery of “adequate pain relief” and exempt this conduct from liability, both under criminal law and/or state medical licensing guidelines; and so long as these medical actions are “in accord with accepted guidelines” for relieving intractable pain, they are deemed legitimate and lawful.346

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345 FURROW *et al.*, *supra* note 224 at 43.

346 *Id.*

Interestingly, 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: [http://www.painandthelaw.org/statutes/state_painActs.php](http://www.painandthelaw.org/statutes/state_painActs.php).
VII.

SHAPING A CARING RESPONSE: A MEDICO-LEGAL CHALLENGE

Caring, as a role and obligation for health care providers, may be seen as a moral
obligation rooted in the time-honored principle of beneficence whose goal is to promote patient
well-being. Considered as such, “caring indubitably incorporates empathy.” Incorporating it
into the management of the terminally ill is, however, difficult. For the physician to convey to a
patient that “I could be you,” involves a sympathetic response which—ideally—may be initiated
during the taking of the patient history. During this process, a one-on-one relationship may be
commenced which provides a mechanism for physician assessment and identification of the
emotion the terminally ill patient is experiencing, a determination of the reason for the display of
emotion and then a response to the patient which allows him, the patient, to see that a
“connection” has been made by the physician between the emotion and its root cause. A line of
communication is then opened.

Establishment of an empathetic response by the physician also has the direct effect of
assuring that the patient will not be abandoned in his final days. For many physicians, however,
non abandonment is difficult—instinctively—to honor because of “the fear generated by

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348 Id.

349 Id. at 225.

350 Id.
confrontation of their own mortality when caring for a dying patient.” Because of this situation, patient avoidance—unintentional though it may be—only serves to heighten patient fears of impending death. Because of these concerns and inadequacies among physicians, more often than not, issues of existential care are left to the nursing staff. And, even in the daily hospital bed environment, it takes a special level of sensitivity for the nursing staff to understand questions often raised indirectly by the patients regarding the depth and severity of their distress over their terminal illness. Once understood, it remains for the nurses to devise a procedure for providing empathetic support.

Alleviating Suffering

While autonomy emerged in the 20th century as the dominant or capstone principle in biomedical ethics—supporting and complementing beneficence, non malfeasence, and distributive justice—it is well to reconsider its pre-eminence in complex cases of refractory

351 Id.

352 Id.


354 Id.

355 See Jonsen, *supra* note 57.

pain. Indeed, once cases are presented where one’s quality of life is so severe and diminished because of suffering, it is proper to advance an argument which necessitates a re-configuring or enhancement of autonomy so that compassion becomes the operative bioethical principle in decision making at this level. Accordingly, in case 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, requires action by the state and the health care providers and imposes upon them a co-ordinate responsibility to make prudential judgments which validate this right. Honoring, or, indeed, acknowledging such a right then becomes an act of “responsible benevolence” and is seen properly as complementing the duty to undertake actions which 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.” In reality, end-of-life autonomy is actually fortified by and through this new right of compassion. Of necessity, compassion then becomes the denominator in health care decisions for end-of-life care and directs that efforts should be undertaken which not only

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356 Shepherd, supra note 12 at 106, 126.
357 Id. at 146.
358 LIEZL VAN ZYL, DEATH AND COMPASSION: A VIRTUE BASED APPROACH TO EUTHANASIA 197 (2000).
359 THOMASMA & GRABER, supra note 58 at ch. 2.
360 Id. at 194 (quoting Dr. Edmund D. Pellegrino).
361 Id. at 126.
refrain from causing pain or suffering but—as well—relieve it.\footnote{362}{MARGARET P. BATTIN, ENDING LIFE: ETHICS AND THE WAY WE DIE 90, 91 (2005).}

**Legal Caring Responses in a Just Society**

American history shows rather remarkably that instead of being perceived as vital to maintenance of a just society, the capacity to care has been often seen as antithetical to it.\footnote{363}{ROBIN WEST, CARING FOR JUSTICE 7, 9 (1997).} As a consequence of this attitude, there “has been a deformation of both the private ethic care and the very public ethic of legal justice.”\footnote{364}{WEST, id. at 9.} This, in turn, has meant that not only have ideals and practices of justice been uncaring, but the ideals and practices of care “have been unjust” with a “deflation of both values” resulting.\footnote{365}{WEST, id. at 9.} Rather than viewing care giving as an emotional, morally arbitrary response, it should be more properly accepted as an ethical activity—with the beliefs and the values of care accepted as “integral to development of a just society.”\footnote{366}{FINE, supra note 362 at 63; HERRING, supra note 364 at 125–27.} Indeed, care or compassion must be recognized as a universal moral principle\footnote{367}{FINE, id. at 61; JONSEN, supra note 285 at 126.} which is vital to the very fabric of social justice.\footnote{368}{See generally MARIAN BARNES, CARING AND SOCIAL JUSTICE ch. 8 (2006).}
Within every adjudication, it has been suggested that neutral principles of law, or those standards which transcend the instant case, should operate.\(^{369}\) Perhaps these principles or standards are to be found within the very principle of equity;\(^{370}\) and from equity flows arguably, mercy, sympathy, compassion, humaneness or love.\(^{371}\) David Hume, an eighteenth British philosopher, opined that the basis for a system of justice and social solidarity was, in fact, tied to expressions of natural sympathy for others.\(^{372}\) Arthur Schopenhauer, the German philosopher, maintained that compassion “is the real basis of all voluntary justice.”\(^{373}\) Accordingly, for an action to have moral value, it must derive from compassion.\(^{374}\)

Defined as an acknowledgment of another’s suffering which prompts a response to assist in alleviating the suffering, compassion is often regarded as the motivation for subsequent merciful acts.\(^{375}\) Mercy is oftentimes used synonymously with compassion or benevolence.\(^{376}\)

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\(^{370}\) See generally WILLIAM Q. DeFUNIAK, HANDBOOK ON MODERN EQUITY, ch. 1 (2nd ed. 1956); Garrard Glenn & Kenneth Redden, *Equity: A Visit to the Founding Fathers*, 31 VA. L. REV. 753, 756 (1945) (quoting Blackstone’s idea that “equity exists for corrections of situations wherein the law, by reason of its universality, is deficient.”).

\(^{371}\) Equity is defined as not only “the quality of being equal or fair ...” but, “given in accordance with natural justice ... something fair and right.” V OXFORD ENGLISH DICTIONARY 358 (2nd ed. 1989).


\(^{373}\) WILLIAM S. SAHAKIAN & MABEL LEWIS SAHAKIAN, IDEAS OF THE GREAT PHILOSOPHER 49 (1993).

\(^{374}\) Id.

Indeed, acts of this nature have been termed “responsible benevolence,” or “compassionate mercy.”

For others, charity is seen as the ultimate value in caring for the dying; and they suggest beneficence and benevolence may combine, properly, to become “loving charity.” When there is suffering, its elimination or management is central and can well be seen as trumping the biomedical principle of autonomy.

Modernly, it has been urged that sympathy and compassion must be integrated into contemporary law. A modern and principled rule of law, then, needs notions of decency and compassion within its sinews and does not have to conflict with a rule of love. Others have


Tudor, *id.* at 81.

VAN ZYL, *supra* note 358 at 197.

BATTIN, *supra* note 362 at 66.

See also TIMOTHY E. QUILL, *DEATH AND DIGNITY: MAKING CHOICES AND TAKING CHARGE* 131 *passim* (1994).


*Id.* at 225, 241.


*Id.* at 731.

*Id.* at 729.

See JOSEPH FLETCHER, *SITUATION ETHICS: THE NEW MORALITY* (1966) (where the
called for the law to be empathetic which is used often, interchangeably, with love, altruism and sympathy.\cite{385}

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.\cite{386} Certainly by introducing human values or attitudes into the judicial process a strong claim could be made that they might well conflict with the ideal of judging which is sustained by rational and objective argumentation and not feelings and emotions.\cite{387} Indeed, empathetic discourse may well be seen as either irrelevant or merely

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argument is presented which holds 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 ethics are relative to culture, immediate circumstances and specific individual needs. \textit{See generally} SAMUEL FLEISCHACKER, INTEGRITY AND MORAL RELATIVISM (1992), HUGH LaFOLLETTE, THE TRUTH IN ETHICAL RELATIVISM (where an argument is advanced which eschews routine application of existing moral rules and stresses, instead, that a “cultivated moral judgment” should be the normative standard of conduct).


For Adam Smith, the process of judging involves a lesson in learning the importance of impartiality by imagining how an impartial spectator would act in a particular situation. “Moral judgment is either approval or disapproval of an action. Judging is a complex matter and forms the last step in a process” relying upon the capacity of humans to sympathize—not show compassion but, in a neutral way—express empathy. GEOFF COCKFIELD, ANN FIRTH & JOHN LAURENT, NEW PERSPECTIVES ON ADAM SMITH’s THE THEORY OF MORAL SENTIMENTS 71 (2007).

\textit{See} RICHARD A. POSNER, HOW JUDGES THINK 117 (2008) (observing that an element of “good judgment” in judicial decisionmaking is “empathy” and “common sense”).

\cite{386} \textit{See generally} JOHN NOONAN, PERSONS AND MASKS OF THE LAW (1976).


\textit{But see} MARTIN L. HOFFMAN, EMPATHY AND MORAL DEVELOPMENT: IMPLICATIONS FOR CARING AND JUSTICE (2000).
policy and, thus, dismissed.\textsuperscript{388}

**Principles, Emotions, and The Holmesian Caveat**

While principles provide the foundational framework for standards of normative conduct, feelings are important when individuals or micro issues arise which, in turn, test the extent to which principles are valid in their application within the context of a given situation or norm of conduct.\textsuperscript{389} It is asserted that “the morally good person is just not principled, but also compassionate.”\textsuperscript{390} As well, that person not only exhibits “practical wisdom”\textsuperscript{391} but “simple

\textsuperscript{388} Henderson, supra note 385 at 1588.

\textsuperscript{389} RANDALL & DOWNIE, supra note 126 at 12–13.

\textsuperscript{390} Id. at 13.

\textsuperscript{391} Id. at 24.
common sense” in assuring patient dignity or quality of life is preserved throughout all palliative care treatments.

The best way to assure this mandate or goal throughout cases of adjusted palliative care management is to embrace a test of medical utility in determining what end-stage options should be made available as treatment. Accordingly, a benefits to burdens/risk calculus should be utilized to assess the utility of one medical treatment over another. Anchoring such an evaluation should be the doctrine of medical futility which acknowledges the practical limits of medical treatment in all cases.

While compassion is experienced and evaluated subjectively, it need not stigmatize a valid legal theory. Indeed, in the case of De Shaney v. Winnebago County Dept. of Social Services et al., Justice Harry Blackmun, in dissent, addressed the importance of compassion in judicial analysis and interpretation by observing “...compassion need not be exiled from the

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392 Id. at 73.

393 Annette F. Street & David W. Kissane, Constructions of Dignity in End-of-Life Care, 17 J. PALLIATIVE CARE 93, 95, 99 (2001); RANDALL & DOWNIE, supra note 126 at 71.

394 RANDALL & DOWNIE, supra note 126 at ch. 11.

395 Id. at 116–118.

396 Id.

397 Zipursky, supra note 387 at 1142.

398 Id. at 1147.

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

province of judging.” He went further and stated that when “natural sympathy” is removed from a case by courts, they are thereby prevented “from recognizing the facts of the case before it or the legal norms that should apply to those facts.”

Eschewing emotion as a dominant vector of force in truth seeking in law, Oliver Wendell Holmes, Jr. urged that the reasoning behind a particular rule’s adoption “ought to be of paramount importance.” And, when the reasons for structuring the rule have disappeared, it is improper to maintain the rule, “from blind imitation of the past.”

Surely, 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, at minimum, re-evaluated and even expanded to include such care of patients suffering severe psychological distress in illnesses of this type. Suffering at the end of life may be manifested in different forms—in presenting with physical symptomology—of psychological, emotional and existential

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400 489 U.S. at 213.
401 489 U.S. at 213.
403 Oliver Wendell Holmes, Jr., The Path of The Law, 10 HARV. L. REV. 457 (1987).

See RICHARD A. POSNER, LAW, PRAGMATISM AND DEMOCRACY 107 (2003) (arguing ordinary people have little interest in complex policy and—with half of the population with I.Q’s of below 100—limited intellectual depth).
404 Id.

suffering as either despair, feelings of helplessness an isolation or a basic loss of self respect.\textsuperscript{405} And, as seen, a right not to suffer must be acknowledged,\textsuperscript{406} together with a professional responsibility among physicians to validate this right—to the extent that they can under sound medical practice—alleviate the suffering.

**A Contemporary Model in Legal Decisionmaking**

The law should accord a greater “caring response”\textsuperscript{407} or a “sense of shared humanity”\textsuperscript{408} in its interpretation and application. This value, and others of equal merit, are essential to sustaining the rule of law.\textsuperscript{409} Oftentimes, however, values are challenged or perceived as being in conflict with abstruse “moralistic abstractions about liberty, equality and dignity.”\textsuperscript{410}

Unquestionably, decisions in health care concerning the maintenance of life and the hastening of death often pose complicated moral questions which are anchored in normative reasoning which—in turn—may, or may not, be relevant or cogent because of changing

\textsuperscript{405} VAN ZYL, supra note 358 at 196.

\textsuperscript{406} THOMASMA & GRABER, supra note 58 at 192.

\textsuperscript{407} Shepherd, supra note 398 at 449.

\textsuperscript{408} Id. at 457.


\textsuperscript{410} Siegel, id. at 1030.
contemporary values.\textsuperscript{411} If moral reasoning is either ambiguous or ineffectual, courts will rely on “moral intuitions,” or “assumptions about intrinsic normative order” found implicitly “in the natural course of life.”\textsuperscript{412} 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.\textsuperscript{413}

In order to add order or greater precision in their analyses, courts can choose to embrace the philosophy of Holmes—as seen—which prizes logic over experience.\textsuperscript{414} By adhering to legal formalism, moral judgments are avoided altogether\textsuperscript{415}—this, in very large part because there is an awareness that it is very difficult to safeguard and sustain social solidarity if emotional values are given recognition in the processes of judicial decision making.\textsuperscript{416} If, however, formalism is rejected, judicial deference can then be given to “tradition and convention”\textsuperscript{417} as a construct for discerning moral convictions or discovering shared humanity instead of a rigid adherence to


\textsuperscript{412} Id. at 1589-90.

\textsuperscript{413} Id. at 1590.

\textsuperscript{414} Holmes, \textit{supra} note 402.

\textsuperscript{415} Smith, \textit{supra} note 411 at 1590.


\textsuperscript{417} Smith, \textit{supra} note 411 at 1590.
“academic reasoning.”

The best approach to or model for judicial decision making is one that achieves a balance between logical reasoning and, when appropriate, “critical morality” as opposed to traditional conventional morality. As such, the courts must endeavor to apply a situation ethic rather than an unyielding and rigid normative standard and to then proceed to acknowledge love or agape as the controlling moral principle in all judicial decision making. Stated otherwise, guided by compassion or humaneness, the judiciary should interpret ever evolving social values and the social conditions which shape those values. Of necessity, these values and conditions change with the facts of each case and, thus, so also does the extent to which compassion and humaneness are pertinent. The ultimate goal of judicial decision making should, in the final analysis, be a “practical realization of the rule of law.”

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418 Id.
419 Id.
420 See generally FLETCHER, supra note 384.
421 Siegel, supra note 409 at 981.
422 Id. at 979.

VIII.

CONCLUSIONS

Patient values must always be viewed as the base line for developing and pursuing patient centered palliative care for terminal illness.\(^{423}\) Best patient care, then, is adjusted—of necessity—to a patient’s changing medical condition.\(^{424}\) Palliative care provides adjusted care by endeavoring to relieve end-stage suffering of all kinds\(^{425}\)—physical and psychological. If this is seen or recognized as a right to relief from suffering,\(^{426}\) as the European Federation for Pain Study advocates,\(^{427}\) then health care providers and the state have a basic responsibility to establish policies designed to validate the right to avoid suffering 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.”\(^{428}\) Accordingly, both law and medicine must set standards or protocols which allow for the wider adoption and use of terminal sedation as an


\(^{424}\) PRESIDENT’s COUNCIL, *supra* note 81 at 217.

*See also* THOMASMA & GRABER, *supra* notes 58, 60; THOMASMA, *supra* note 81; PELLEGRINO & THOMASMA, *supra* note 81.

\(^{425}\) *See supra* notes 18–23.

\(^{426}\) THOMASMA & GRABER, *supra* note 58 at 192.


\(^{428}\) Pellegrino, *supra* note 148.
efficacious and humane practice for end-stage care of patients in hospice.\footnote{See supra note 188–99 and accompanying text.}

Efforts to both accept, and then adopt, a protocol for specifically determining medical futility\footnote{See e.g., supra notes 152–63.} will be enhanced and legitimized by a wider adoption of the Uniform Health Care Decisions Act.\footnote{See e.g., supra notes 169–73.} The works of the American Academy of Palliative Medicine to develop, and thereby structure, standards for regulating nutrition and hydration in palliative management,\footnote{See e.g., supra notes 296–302.} together with the American Medical Association’s guidance on when, clinically and ethically, it is proper to sedate to unconsciousness,\footnote{See e.g., supra notes 202–10.} are having a salutary effect on both codifying and—thus—stabilizing proper medical care and procedures in end-of-life care. Significant progress is also seen by Rosseau in proposing a protocol for the administration of palliative or terminal sedation\footnote{See e.g., supra notes 188–93.} and by Morita\footnote{See e.g., supra notes 101, 114, 199.} and Quill.\footnote{See e.g., supra notes 52, 193 (Table of Medications), 247.} In addition to providing a framework for principled decisionmaking in end-stage care, these actions serve to educate the public to the parameters of appropriate medical care and humane treatment for the terminally ill.\footnote{See e.g., supra 309–10.}

\footnote{See Mitchell et al., supra note 121.}
Once a new codified framework or template for decision making emerges, an informed dialogue can begin anew which addresses itself to one question: namely, is the terminally ill individual exercising rational thinking in his treatment decisions which, in turn, validate self-determination or autonomy? Alternatively, when he is deemed incompetent to make end-of-life decisions, the issue becomes whether the healthcare provider is not only acting consistent with standard medical practice, but is endeavoring to make a “value consequent choice”—consistent with the patient’s values and thus within the best interests of the terminal patient. Ultimately, determining the parameters of a patient’s best medical interests are shaped by policies of reasonableness and compassion. As seen, reasonableness is not capable of a precise formulation, but—rather—is tied inextricably to issues of proportionality or cost/benefit analysis which, in turn, must remain fact sensitive and shaped by the “accepted standards of

438 SMITH, supra note 247 at 109.

Indeed, a dominate 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.

439 Id., SMITH at 109.

440 WERTH, supra note 69.

See DAVID H. SMITH, PARTNERSHIP WITH THE DYING: WHERE MEDICINE ND MINISTRY SHOULD MEET chs. 2, 5 (2005); THOMASMA, supra note 227 at 169.

441 SMITH, supra note 247 at 109.

442 SMITH, supra note 247 at 180.

443 See supra notes 12, 387, 419–22.

See PELLEGRINO & THOMASMA, supra note 81.

medical practice” applicable within each medical case presented.\textsuperscript{445}

The popular notion within the American society that there is a required prescription to treat under all circumstances, needs to be re-evaluated and brought into contemporary focus through acceptance of the doctrine of medical futility.\textsuperscript{446} Under this recognized doctrine, as seen, when medical care is complemented by the test of proportionality imbedded presently in the principle of double effect, the central treatment question becomes whether the burdens of treatment clearly outweigh its benefits to the patient and would be inhumane if continued.\textsuperscript{447} In

(\textsuperscript{where “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).}

\textit{See Boyle, supra} notes 255, 270, 272 (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).

\textsuperscript{445} \textbf{SMITH, supra} note 247 at 173–74.

\textit{See Schöniderman, Jecker & Jonsen, supra} note 275 (discerning the doctrine of medical futility as the basis of common sense).

\textsuperscript{446} \textbf{CALLAHAN, supra} note 299 at 203–06.

\textit{See generally Smith, All’s Well That Ends Well, supra} note 37.

\textsuperscript{447} \textit{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, \textit{supra} note 121 at 1529; Sachs, \textit{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
those cases where medical treatment is seen as futile, terminal sedation should be recognized as but a part of end-stage total symptom management—and validated as an integral part of palliative management. Once end-stage, terminal suffering is managed more effectively, the law must change the legal taxonomy and reliance on the principle of double effect in testing whether assistance in ending life is capital murder or euthanasia. Instead, the degree of necessity for providing compassionate assistance to dying patients—together with an assessment of the soundness of the medical judgment of the health care providers rendering the assistance should be pivotal in legal analysis of end-stage care. Indeed, the central or fundamental part of the end-of-life equation for making rational medical decisions must always be seen as 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—in the final analysis—the time-honored right to refuse treatment should be seen as the corner stone for building a more compassionate and enlightened ethics of understanding in

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See generally IRA BYOCK, DYING WELL (1997).
managing end-of-life issues. This right of refusal is not a right to hasten death—but, rather, merely a right to resist physical invasions which are unwanted.

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

Again, when—additionally—the Uniform Health Care Decisions Act is considered—together with the successful efforts of some states to enact pain relief statutes—the Death with Dignity statutes of Oregon and Washington and medical protocols for use of palliative care

450 Annas, supra note 48 at 1102; MEISEL, supra note 327.


454 Id.

455 See supra notes 166–73 and accompanying text.

456 See supra note 346.


and terminal sedation,\textsuperscript{459} a powerful arsenal is in place to safeguard a framework for principled
decision making in end-of-life care. These weapons in the arsenal serve to protect and encourage
sound, reasonable medical judgments and—thus—in a very real way, balance physicians powers
and protections with patient rights of autonomy.

Utility, most assuredly, comes into play after medical conditions are assessed and
evaluated and a treatment prognosis is charted.\textsuperscript{460} It is within the boundaries of utility that the
principle of medical futility is indeed tested and determined to be efficacious or, as to a particular
case, invalid. Cost/benefit (or, simply proportional) analysis of treatment benefits is central to a
determination of medical futility since\textsuperscript{461}—first and foremost—this is but a clinical judgment and
not an encompassing moral evaluation or principle on the “worthlessness” of a life.\textsuperscript{462} Whether
the operable normative standard for policy making be termed \textit{agape},\textsuperscript{463} charity,\textsuperscript{464} compassion,\textsuperscript{465}

\textsuperscript{459} See e.g., supra notes 298–304 for the suggestions of the American Academy of Palliative
Medicine; supra note 202–210, for the suggestions of the American Medical Association.

\textsuperscript{460} See Smith supra note 50.

\textit{See} JONATHAN BARON, AGAINST BIOETHICS, ch. 3 (2006) (stressing the ineluctable
foundation of utilitarianism as the preferred basis for bioethical decision making).

\textsuperscript{461} See generally Vijay N. Joish & Gary M. Oderda, \textit{Cost Utility Analysis of Quality Adjusted
Years}, 19 J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY 57 (2005).

It has been suggested that any determination of futility must be a joint determination made, as
such, by physician, patient and surrogate decisionmaker, with the final determination endeavoring
to strike a balance between three criteria: effectiveness, benefit, and burden—in achieving the
patient’s good. Pellegrino, supra note 148 at 227.

\textsuperscript{462} Pellegrino \textit{id.} at 220, 227.

\textit{See generally} Amir Halevy, \textit{Medical Futility, Patient Autonomy, and Professional Integrity:

\textsuperscript{463} Defined as a sense of Christian love, charity. I OXFORD ENGLISH DICTIONARY 243 (2\textsuperscript{nd})
love,\textsuperscript{466} or mercy,\textsuperscript{467} the common or unifying denominator to palliative care is a humane, morally responsible approach to dealing with intractable suffering at the end-stage of life.

Good judgment is to be expected of judicial decisionmakers just as it is for healthcare providers. As a quality in reasoning, 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.”\textsuperscript{468} Elusive though such judgment may be to capture or own, sound, reasoned judgments in medico-legal decision making must be the norm and not the exception.

To initiate or continue with medical treatment which is determined to be medically futile should be recognized as simply wrong; for, acting in such a manner, not only denies the fact of human finitude but—additionally, it imposes unnecessary effort, expense and emotional trauma.

\begin{footnotesize}

\textsuperscript{464} Defined as Christian love. III OXFORD ENGLISH DICTIONARY 42 (2nd ed. 1998).

\textit{See} Pellegrino, supra note 148 at 241 (where charity is advanced as an attribute of end-of-life care and treatment).

\textsuperscript{465} Defined as pity. III OXFORD ENGLISH DICTIONARY 597 (2nd ed. 1998).

\textsuperscript{466} Defined as benevolence. IV OXFORD ENGLISH DICTIONARY 52 (2nd ed. 1998).

\textit{See} FLETCHER, FLEISCHACKER, & LaFOLLETTE, supra note 384.

\textit{See} Fletcher, supra note 57.

\textsuperscript{467} Defined as mercy, showing compassion or kindness. IX OXFORD ENGLISH DICTIONARY 626 (2nd ed. 1998).

\textsuperscript{468} POSNER, supra note 383 at 117. Emphasis added.

\textit{See} Schneiderman, Jecker & Jonsen, supra note 156 at 409 (regarding the basis of common sense).
\end{footnotesize}
on both patient and other affected parties.\textsuperscript{469} As well, when efforts to treat futile medical conditions are undertaken, such actions serve as a total abnegation of one of the cardinal principles of medical ethics—namely beneficence.\textsuperscript{470}

It has been argued persuasively that while the state may declare a legitimate interest in morality,\textsuperscript{471} for it to meet a heightened level of judicial scrutiny on review of such end-of-life declarations, it faces an increasingly difficult challenge to justify a decision to sacrifice “claims of associational freedom”\textsuperscript{472}—grounded as such in “expressive association or in intimate association”\textsuperscript{473}—in order to protect public morality. Accordingly, care must be taken by the state to eschew administrative, judicial, or legislative determinations which abridge “choices central to personal dignity and autonomy . . . central to the liberty protected by the Fourteenth Amendment.”\textsuperscript{474}

It is logical to assume that the right to compassionate care in end-stage illness is, indeed, grounded in a liberty interest and, thus, cannot be unduly challenged or restricted by a state interest in judging the “morality” of autonomous actions designed to give purpose and promote

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\textsuperscript{469} Pellegrino, \textit{supra} note 148 at 233–35.
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\textsuperscript{470} \textit{Id.} at 223.
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\textit{See generally} PELLEGRINO \& THOMASMA, \textit{supra} note 81.

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\textsuperscript{472} \textit{Id.} at 1936.
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\textsuperscript{473} \textit{Id.}
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dignity to the basic interest in liberty to die with dignity.\textsuperscript{475} Society’s central obligation is to refrain from mandating one moral code over another but, rather, to define and safeguard “the liberty of all”\textsuperscript{476} and promote social policies which address suffering with charity, compassion, and common sense.\textsuperscript{477} Inextricable to this societal obligation is recognition of a co-ordinate duty of health care providers “not to prolong dying.”\textsuperscript{478} This duty arguably coalesces with and, indeed, validates the very principle of beneficence,\textsuperscript{479} and—accordingly—shapes a new “right” of the terminally ill not to enhance pain and suffering at the end-stage of life.\textsuperscript{480}

The conclusion of The New York State Task Force on Life and the Law in its 1997 supplemental report to \textit{When Death is Sought}, serves not only as an aspirational call to action but

\begin{itemize}
\item \textsuperscript{475} See \textit{Lawrence v. Texas}, 539 U.S. 558, 573, 578 (2003).
\item \textsuperscript{476} Planned Parenthood of Southeastern Pa. v. Casey, 505 U.S. at 850.
\item \textsuperscript{477} The right of privacy from governmental intrusions, expressed in Griswold and Eisestadt, 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 \textit{Griswold v. Connecticut}, 381 U.S. 479 (1965); \textit{Eisenstadt v. Baird}, 405 U.S. 438 (1972).
\item \textsuperscript{478} \textit{Thomasma, Human Life}, \textit{supra} note 81 at 195; \textit{Smith}, ch. 5, \textit{supra} note 420.
\item \textsuperscript{479} \textit{Pelegrino & Thomasma}, \textit{supra} note 81.
\item \textsuperscript{480} See \textit{Cassell, The Nature of Suffering and The Goals of Medicine}, \textit{supra} note 9.
\end{itemize}
also as a telling indictment of the tragic state of health care delivery at the end-of-life.\footnote{Supra note 311, New York State Task Force 1997 Supplemental Report.}

“The widespread public interest in physician-assisted suicide represent 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.”\footnote{Id. at 12.}

Growing acceptance—or even approval of the right of the terminally ill to receive assistance in ending their lives—as is done in the United States, in the states of Oregon\footnote{ORE. REV. STAT. §§ 127.800 (12), 127.805 (2005).} and Washington,\footnote{REV. CODE WASH. ANN., ch. 70, 245 (2009).} and in parts of Europe, notably, the Netherlands, Belgium and Switzerland\footnote{See Baxter v. Montana, supra notes 42 and 315, where 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.}—should not be stymied by fear that these actions will force society, irretrievably, onto a slippery slope ending in the unequivocal endorsement and unrestricted practice of active euthanasia.\footnote{GRIFFITHS et al., supra note 62.}

Rather than fear being used 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-stage decisionmaking. This conduct will, ideally, then conduce to a simple recognition that there must be a human right to avoid

\footnote{See generally George P. Smith, II, Monograph, Euthanasia, Suicide or Self-Determination—Ethical, Legal and Philosophical Concerns (1999).}
intractable somatic and non-somatic pain and suffering and to be immune from cruel and unusual punishment\textsuperscript{487} by being forced to live when futile medical conditions present.\textsuperscript{488}

The slippery slope is, in reality, nothing more than the human condition and, as such, “we are already on it and unable to escape it.”\textsuperscript{489} The common duty of man is to but “struggle along” in reaching a common destiny—a life struggle which is either “upwards or downwards, with very uncertain footing.”\textsuperscript{490} No safe plateau of moral security is ever reached in this journey of life.\textsuperscript{491}

\textsuperscript{487} See generally Smith, Monograph, supra note 48.

\textsuperscript{488} 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 CENTER RPT. 25 (1998).

\textit{See} Doyal, supra note 27 arguing that autonomy should be de-emphasized as the operative principle in decision making and, instead, a standard of common dignity, mercy or best interests of the dying should be controlling. Accordingly, since competent patients suffering from a terminal illness can choose to refuse treatment, why “should it not be possible for clinicians, in partnership with families, to make similar decisions on behalf of those who cannot competently choose for themselves.” \textit{Id.}

\textit{See also} Len Doyal, Why Active and Physician-Assisted Suicide Should be Legalized, 323 BRIT. MED J. 1079 (2001).

THOMASMA & GRAEBER stress the notion that there should be a communitarian or societal obligation to relieve pain and suffering which exceeds the individual right to forego such. \textit{Supra} note 58 at 193.

\textit{See also} PELLIGRINO & THOMASMA, supra note 81.

\textsuperscript{489} George P. Smith, II, Monograph, When Mercy Seasons Justice 21 (2007).

\textsuperscript{490} \textit{Id.} at 21, n. 101 citing Minette Marrian, An Acceptable Way to Arrange our Death, http://www.timesonline.co.uk/article/0.2088-2179494.00.
Rather, painful dilemmas of choice are a given rather than the exception. Perhaps, in reality, the “goal of the human moral effort” should be simply “to keep seeing and drawing the line, and struggling to stay above it.”\footnote{Marrian, 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).

\footnote{Marrian, id.}