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

George P Smith

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

George P. Smith, II*

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

“. . . adequate relief from severe and continuing pain is unusual in the modern hospital.” Eric Cassell²

“It hath often been said that it is not death, but dying which is terrible.” Henry Fielding³
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, or what today is often termed psychological distress or suffering, 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.

Without question, pain plays havoc with the human psyche and induces suffering which, having no meaning, can destroy. Indeed, denying “suffering is to trivialize another person's experience, to diminish its scope and lessen its significance.” Once it can be shown that there is a right to compassionate care—as this Article advocates—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. Central to the 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” 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
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.\textsuperscript{21} In this regard, hospice
care is an effort to counter balance this irrational and inhumane compulsiveness and thereby “
humanize medicine.”\textsuperscript{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.”\textsuperscript{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 in end-stage illness.24

Medical Futility and Terminal Sedation

It has been argued that death should never be sought or engineered as a “therapeutic option” to end suffering.25 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,26 thereby preventing as “comfortable” a death as possible,27 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 discomfort.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.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. 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. 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. This is known as the doctrine of double effect, a well-established and nearly universally accepted principle of medical ethics and related law.

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

Although physician assisted death is not to be considered a substantive liberty interest and a fundamental right, nor is palliative care seen as a "right" incorporated into a lofty constitutional principle, 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 and is grounded in the essential right to refuse life-sustaining treatment.

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

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.\textsuperscript{52}

Interestingly, up to ninety percent of pain can be controlled by analgesics.\textsuperscript{53} 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.\textsuperscript{54} Indeed, previous scholarship reported significant pain, among end-stage patients, to be as high as 50\%.\textsuperscript{55}

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\textsuperscript{,56} this Article advances the hypothesis that there is an inextricable component or commonality to evaluating and implementing each of these four actions designed to hasten a humane death: namely, common sense and compassion. In turn, this policy is rooted in the biomedical principle of beneficence\textsuperscript{57} which is tied to the notion that there is a human right to compassionate care in end-of-life illness\textsuperscript{58}—with suffering being seen, properly, to include physical \textit{and} psychological
distress. 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. 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.

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 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.

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
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. 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.
Recognizing that the physical and psychosocial etiology of chronic pain sufferers manifests itself by, among other conditions, depression, anxiety, fear, and even suicide,74 these three organizations defined pain recurring for a period of more than three months as chronic.75 Not only do studies also disclose the significant employment irregularities resulting from chronic pain sufferers76 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.77 That percentage for Americans translated into a raw figure of eight million. By 2030, it is expected this figure will double.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.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); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs—“adjuvants”—should be used. To maintain freedom from pain, drugs should be given ‘by the clock,’ that is every 3–6 hours, rather than ‘on demand.’ This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90% effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective."80
The President's Council on Bioethics concluded in 2005 that the basic standard for clinical decision making should be one which promotes the best patient care. 81 This must, obviously, be adjusted continually as patient's case history progresses. 82 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. 83

Psychological distress, or existential pain, is usually difficult to assess not only because it involves a substantial investment of physician time to determine or validate, but requires special training and contact with the families of patients. 84 There is a general aversion to proving a patient's emotional distress at end-of-life care. 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. 86 Because of these difficulties and uncertainties, the palliative management of existential pain has simply been neglected. 87

While no general “solutions” exist for meeting the existential needs of terminally ill patients, attempts to meet these needs require careful listening skills and defined lines of communication 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. 88 Even though a patient may have no absolute control 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 complete, 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 overriding fear: loss of human dignity, which brings with it a fear of being forced to become but a "passive bystander" to all of the normal functions of life. By acting to manage the dying process, which—for some—is viewed as too protracted and filled with growing and multiple functional losses, a level of control is thereby exerted over a process which is acknowledged to be "by and large, a messy business." And, sadly, this complicated and vexatious process for implementing the "new epidemiology of dying" almost assures that heroic procedures will be followed which do not promote or sustain quality so much as postpone death.

In approximately twenty-five percent of all terminally ill patients, depression and other mood disorders occur. Yet, interestingly, few receive pharmacological aid by anti-depressant prescriptions. As seen, the main obstacle to a more liberal response to these patients' needs
is 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 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 uncontrollable shakes).

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

**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. Seen as a “useful category of existential distress in which meaningless predominates and from which profound hopelessness and desire to die may result,” this syndrome, if not supported satisfactorily by pharmacological therapy, should render such a demoralized patient incompetent to make medical decisions.

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. 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}

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.\textsuperscript{122} By that time, one out of five Americans will have attained the age of sixty-five or older.\textsuperscript{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.\textsuperscript{124} The potential use of both hospice and palliative care for these Americans staggers the imagination.\textsuperscript{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
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.

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.

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

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.

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 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 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.  

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. 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 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 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.”

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—infect 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 “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.
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.\textsuperscript{167} Today, hospital management policies regarding the determination of medical futility are grounded normally in a “consultative consensus building approach.”\textsuperscript{168} Yet, interestingly, ten states have adopted the Uniform Health Care Decisions Act\textsuperscript{169} 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.\textsuperscript{170} Any such refusal of medical care may be grounded on the determination by the attending physician that the care would be “ineffective”\textsuperscript{171} contrary to generally accepted “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.

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.
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." And, the extent or degree of charity or compassion shown—from a standard of health care delivery and law—should, in turn, be framed by the doctrine of medical futility or adjusted care. 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.” Indeed, to continue treatment of futile medical conditions can be understood as violating the primary principle of traditional medical ethics: Beneficence.

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.” Often the sedation is intermittent and has been termed “respite” or “twilight sleep” 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. Others argue 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.

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.”\textsuperscript{186} The logic of this policy is found—very directly—in a straightforward application of cost/benefit analysis.\textsuperscript{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\textsuperscript{188}—or moribund\textsuperscript{189}—; have a current Do Not Resuscitate order listed in their medical records; have exhausted all palliative treatments for anxiety, delirium or depression;\textsuperscript{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 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 re-assessment 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 presents evidence of suffering (\textit{e.g.}, restlessness, grimaces or withdraws from stimuli)\textsuperscript{195} or discomfort (\textit{e.g.}, displays a furrowed brow or develops hypertension).\textsuperscript{196} Establishing in advance of the actual sedation a classification scale could also go far toward alleviating inconsistencies 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.\textsuperscript{197} When lower doses are ineffective to provide symptomatic relief, then—and only then—should dosages be increased.\textsuperscript{198} 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.\textsuperscript{199}

**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.\textsuperscript{200} 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 be obtained from the patient or the patient's designated health care surrogate; 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;” 5). Physician-patient discussions are held which consider the plan for sedation, its length of administration (intermittent or constant) and the expectations of treatment; 6). A process of implementation is coordinated which monitors the appropriateness of care during the sedation; 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;” 8). The intentional use of palliative sedation to “cause a patient's death” is never allowed.

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 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 patient, should be determinative.\textsuperscript{220}
The principle of double effect—sometimes also stated to be either a doctrine or rule—is grounded in Roman Catholic philosophy and moral theology. 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. 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. 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.”

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 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.227

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.228

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 grounded on a moral justification.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.”230 Yet, the fact remains in palliative management, society imposes moral and legal responsibility on care givers for both omissions as well as actions.231

In cases of artificial hydration—when a moral distinction is drawn between the withholding of treatment and the withdrawal of it232—greater blame may be given to the act of withdrawing treatment than withholding it.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.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 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}

**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 would be unusual for a doctor to admit such a course of conduct.\textsuperscript{239} 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.\textsuperscript{240} 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.\textsuperscript{241}
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 accepted at face value as an honest professional judgment. 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. Rather, these individuals, together with some patients and their families, are blind-sided by the myth (quite often spread by the media) that analgesics (e.g., barbiturates more directly than opioids) are “nothing more than a polite way to kill the patient.”

**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. 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.
ethicists, there is simply no clear line between efforts to relieve refractory systems and hastening 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.

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. 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.

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. This legal standard 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.

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 consequence, 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.\(^{255}\) Sadly, there is a mistaken perception that death is always hastened by the aggressive administration of pain management.\(^{256}\)

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.”\(^{257}\)

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 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 *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 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.

**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 *raison d'etre* 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 terminal illness may sometime outweigh the harm of shortening life through use of respite or terminal sedation, the principle becomes superfluous to palliative management.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.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."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.²⁷¹

**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 competent patient's request for assistance in dying. 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*281 and *Washington v. Glucksberg*282—although it invoked double effect reasoning—no moral arguments for accepting the rule or principle of double effect were proffered by the Court.283 It has been suggested, however, that what the court did here was to lay a foundation for recognizing a constitutional right to adequate pain relief from dying.284 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.286 This rule was formulated as is seen as a right of refusal grounded in Due Process clause protections by the U.S. Supreme Court in 1997 in *Washington v. Glucksberg*.287 Previously, in the 1990 case of
Cruzan v. Dir., Missouri Dept. of Health, writing for the majority, Chief Justice Rhenquist “assumed” that there 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 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.296

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.297

**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 2001.298 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.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 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.”300 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 pain—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." Reserved only for those cases of the “most severe, intractable suffering at the very end of life," 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.

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. 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 medical assistance in the dying process.310

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.311 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.312 The principle of medical futility, as seen, has 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.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,314 state courts—save one in Montana315 have neither found a right to physician assisted suicide within their state constitutions nor have state legislatures, other than in Oregon316 and Washington,317 legalized this type of action318 in the years following the Supreme Court's decision in Washington et al., v. Glucksberg et al.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 physician assisted dying.320 Indeed, since 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.321

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,”322 extends arguably to the very time and manner of one's death,323 it has been asserted, logically, that this fundamental right should not be limited necessarily to the terminally ill324 and the “seriously ill or impaired who are suffering or in pain.”325 Indeed, others have expressed concern that if this right is recognized nationally, it will most assuredly be asserted indiscriminately to the “seriously ill or impaired who are suffering in pain”326 and not invoked on behalf of the terminally ill.327

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 months328 or six months.329 Three specific scenarios have been posited as being dangerous because of the “open-ended” or limitless nature of present evaluations of terminal illness:330 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.331

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, 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 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.\(^{346}\)
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.”348 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.349 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.350 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 confrontation of their own mortality when caring for a dying patient.”351 Because of this situation, patient avoidance—unintentional though it may be—only serves to heighten patient fears of impending death.352

Because of these concerns and inadequacies among physicians, more often than not, issues of existential care are left to the nursing staff.353 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.\textsuperscript{354}

\textbf{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\textsuperscript{355}—it is well to reconsider its pre-eminence in complex cases of refractory 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.\textsuperscript{356} 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 \textit{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.\textsuperscript{357} Honoring, or, indeed, acknowledging such a right then becomes an act of “responsible benevolence”\textsuperscript{358} and is seen properly as complementing the duty to undertake actions which benefit the dying patient.\textsuperscript{359} The duty to relieve pain is acknowledged as the “least disputed and most universal of the moral obligations of the physician.”\textsuperscript{360} 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
refrain from causing pain or suffering but—as well—relieve it.

**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. 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. 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. 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.” Indeed, care or
compassion must be recognized as a universal moral principle which is vital to the very
fabric of social justice.

Within every adjudication, it has been suggested that neutral principles of law, or those
standards which transcend the instant case, should operate. Perhaps these principles or
standards are to be found within the very principle of equity; and from equity flows arguably,
mercy, sympathy, compassion, humaneness or love. 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. Arthur Schopenhauer, the German philosopher, maintained that compassion “is the real basis of all voluntary justice.” Accordingly, for an action to have moral value, it must derive from compassion.

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. Mercy is oftentimes used synonymously with compassion or benevolence. 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 called for the law to be empathetic which is used often, interchangeably, with love, altruism and sympathy.

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. 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.\textsuperscript{387} Indeed, empathetic discourse may well be seen as either irrelevant or merely
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
common sense”\textsuperscript{392} in assuring patient dignity or quality of life is preserved throughout all
palliative care treatments.\textsuperscript{393}

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.\textsuperscript{394} Accordingly, a benefits to burdens/risk calculus should be
utilized to assess the utility of one medical treatment over another.\textsuperscript{395} Anchoring such an
evaluation should be the doctrine of medical futility which acknowledges the practical limits of
medical treatment in all cases.\textsuperscript{396}

While compassion is experienced and evaluated subjectively,\textsuperscript{397} it need not stigmatize a
valid legal theory.\textsuperscript{398} 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 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 suffering as either despair, feelings of helplessness an isolation or a basic loss of self respect. And, as seen, a right not to suffer must be acknowledged, 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” or a “sense of shared humanity.”
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 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 “academic reasoning.”\textsuperscript{418}

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.”

**VIII. CONCLUSIONS**

Patient values must always be viewed as the base line for developing and pursuing patient centered palliative care for terminal illness. Best patient care, then, is adjusted—of necessity—to a patient's changing medical condition. Palliative care provides adjusted care by endeavoring to relieve end-stage suffering of all kinds—physical and psychological. If this is seen or recognized as a right to relief from suffering, as the European Federation for Pain Study advocates, 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.” Accordingly, both law and medicine
must set standards or protocols which allow for the wider adoption and use of terminal sedation as an efficacious and humane practice for end-stage care of patients in hospice. Efforts to both accept, and then adopt, a protocol for specifically determining medical futility will be enhanced and legitimized by a wider adoption of the Uniform Health Care Decisions Act. The works of the American Academy of Palliative Medicine to develop, and thereby structure, standards for regulating nutrition and hydration in palliative management, together with the American Medical Association's guidance on when, clinically and ethically, it is proper to sedate to unconsciousness, 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 and by Morita and Quill. 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.

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
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 medical practice" applicable within each medical case presented.

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. 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. In 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 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 strengthens 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 and terminal sedation, 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. 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—first and foremost—this is but a clinical judgment and not an encompassing moral evaluation or principle on the “worthlessness” of a life. 462 Whether the operable normative standard for policy making be termed *agape*, 463 charity, 464 compassion, 465 love, 466 or mercy, 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*.” 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 on both patient and other affected parties. 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. 470

It has been argued persuasively that while the state may declare a legitimate interest in
morality, 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” grounded as such in “expressive association or in intimate
association” 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.”

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

The conclusion of The New York State Task Force on Life and the Law in its 1997
supplemental report to When Death is Sought, serves not only as an aspirational call to action but
also as a telling indictment of the tragic state of health care delivery at the end-of-life.

“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.\textsuperscript{482}

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\textsuperscript{483} and Washington\textsuperscript{484} and in parts of Europe, notably, the Netherlands, Belgium and Switzerland\textsuperscript{485}—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.\textsuperscript{486} 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 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} 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.”\textsuperscript{492}
ENDNOTES

*. Professor of Law, The Catholic University of America, Washington, D.C.

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Additional research and writing continued throughout the Summer of 2008, when I was a Visiting Fellow at The Faraday Institute of St. Edmund's College, University of Cambridge, and at the Faculty of Law at the Australian National University in Canberra as well as at The University of Sydney's Centre for Health Governance, Law and Ethics. A “final” draft of the Article was completed during the Summer of 2009, when I was a Visiting Scholar at the Notre Dame University Center for Ethics and Culture, and at The Center for Biomedical Ethics and Humanities at the University of Virginia School of Medicine. Revisions to this draft continued throughout the remainder of the year.

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3. HENRY FIELDING, AMELIA, bk iii, vol. 4 (1751).
4. SOREN KIERKEGAARD, FEAR AND TREMBLING (1843), THE SICKNESS UNTO DEATH (1849).
6. 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. HELLER, id. at 90.
9. SCARRY, supra note 5 at 12.

Thomas Mann opined that within the body of literature, however, no piece is to be found which is not concerned with suffering of some permutation. 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,
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 th ed. 2001). Psychogenic pain is used to describe mental—as opposed to pain of an organic nature. 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, supra note 2 at 276, 312. Pain affects the body and is more properly addressed by physicians. Yet, a shared responsibility exists between physicians and other caregivers to control both the pain and suffering of those who are dying. Eric J. Cassell, The Nature of Suffering and The Goals of Medicine, 306 NEW ENG. J. MED. 639 (Mar. 18, 1982).


11. Gunderman, id.


13. Id. at 138.

14. CASSELL, supra note 2 at 291.

In addition to Kierkegaard, Jaspers, Sartre and Heidegger are recognized as the major philosophers leading the philosophical movement of existentialism. See generally MARTIN HEIDEGGER, BEING AND TIME (1962).

16. Strang et al., id.


18. Id. at 320.


20. Id.

21. HOSPICE CARE ON THE INTERNATIONAL SCENE at 11 (Ciceley Saunders & Robert Kastenbaum eds. (1997)).

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).


26. JOANNE LYNN, SICK TO DEATH—AND NOT GOING TO TAKE IT ANYMORE! 12
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).


28. See infra notes 188–99.


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.


   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).


Suicide, and Voluntary Active Euthanasia, 278 JAMA 2099, 2104 (1997).

In 2008, the Council on Ethical and Judicial Affairs of the American Medical Association issued a report entitled, “Sedation to Unconsciousness in End-of-Life Cases,” which 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.

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.
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.

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.standford.edu/entries/euthanasia-voluntary/.

But see Robert A. Burt, The Supreme Court Speaks—Not Assisted Suicide but a Constitutional Right to Palliative Care, 337 NEW ENG. J. MED. 1234 (1997).
See Vacco v. Quill, 521 U.S. 793 (1997); George P. Smith, II, *Monograph, Final Exits: Safeguarding Self-Determination and The Right to be Free from Cruel and Unusual Punishment* (1997); George J. Annas, *The Bell Tolls for a Constitutional Right to Physician-Assisted Suicide*, 33 NEW ENG. J. MED. 1098, 1102 (Oct. 9, 1997) (observing that five members of the Vacco Court “seem to think there is something akin to a ‘right not to suffer’ at least when death is imminent,” and when palliative care is provided by physicians whose primary intention is to relieve suffering).

   See also McStay, supra note 36 at 49.


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

56. See Quill, Lo & Brock, supra note 38; McStay, supra note 36.

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

57. See Albert R. Jonsen, A History of Bioethics and Discipline and Discourse in BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS & PRACTICE 3–22 (Nancy C. Jecker,
See also John Fletcher, *Love is The Only Measure*, 83 COMMONWEALTH 427 (1966); JOHN FLETCHER; SITUATION ETHICS: THE NEW MORALITY (1966), *infra* note 384.


*See* Greg A. Sachs, *Dying from Dementia*, 361 NEW ENG. J. MED. 1595 (Oct. 15, 2009).

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.


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.

64. Jacob M. Appel, A Suicide Right for the Mentally Ill: A Swiss Case Opens the Debate, 37 HASTINGS CENTER RPT. 21 (May–June, 2007).

On November 3, 2006, the Swiss Federal Supreme Court issued a ruling under which for the first time, assisted suicide is to be available to psychiatric patients and others with mental illness who suffer from “incurable, permanent, severe psychological disturbances” as well as to those with severe, long-term mental illness who have made “rational” and “well considered” decisions to end their lives in order to avoid further suffering. Jacob M. Appel, id., at n. 4.

On February 25, 2010, the British Crown Prosecution Service issued a document entitled, Policy for Prosecutors in Respect of Cases of Encouraging Assisting Suicide. Attempting to resolve moral ambiguities in cases of assisted suicide and mercy killings, the guidelines nonetheless fail to address not only the condition or degree of suffering the person requesting the suicide is experiencing nor do they address the situation in which a patient is neither terminally ill nor
disabled but is suffering from severe depression or psychological distress.

The guidelines do not change the law prohibiting assisted suicide. Rather, they provide guidance on which cases are likely to be prosecuted. They attempt to distinguish between “compassionate support” for which there would be a less likelihood of prosecution from cases of “malicious encouragement” which would be prosecuted.


65. Appel, id.


67. Id.

68. Appel, supra note 64.

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?


70. WARNOCK & MacDONALD, supra note 62 at 33, 34.

71. Id. at 30.

See THOMASMA & GRAEBER, supra note 58 at 193 arguing that there should be a level of social responsibility to aid those enduring pain and suffering at death.

David H. Smith calls for the creation of supportive communities to be responsive to the needs of the dying. See SMITH, infra note 440 at ch. 5.

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).


73. Id.

74. Id. at 86.

75. Id. at 88.

76. Id. at 89.

77. Id. at 88.
It is estimated that in order to support Medicare and Medicaid program costs, payroll taxes must meet four percent. Id.


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 58 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).

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

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

86. Put simply, the dying “do not have the luxury of clearly separating their physical suffering from their psychological, spiritual, an existential suffering.” Quill & Battin, infra note 327, 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, supra note 84.

87. Agrawal & Emmanuel, supra note 84.


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.

96. Stacks, *supra* note 24 at 216.


98. *Id.* at 12.